

Improving Outcomes by Recognizing and Responding to Fetal Alcohol Spectrum Disorders (FASD) in Individuals in Treatment

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Objectives

By the end of this training,
participants will be able to:

- ▶ Identify the estimated prevalence of FASD
- ▶ Describe structures of the brain that are commonly affected in individuals with an FASD
- ▶ List three reasons for the reluctance in identifying the impact of FASD in treatment
- ▶ Discuss two studies that highlight why approaches need to be modified for those with an FASD



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Fetal Alcohol Spectrum Disorders (FASD)

- ▶ FASD is a spectrum of disorders
- ▶ There is a wide range of intellectual capabilities in individuals with an FASD
- ▶ There is a wide range of disabilities due to prenatal alcohol exposure
- ▶ There is no way to predict how much alcohol will cause how much damage in any individual
- ▶ Across the spectrum of FASD there is brain damage
- ▶ FASD is a descriptive term in the U.S.



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Diagnostic Terms

- ▶ Fetal Alcohol Syndrome (FAS)
- ▶ Partial Fetal Alcohol Syndrome (pFAS)
- ▶ Alcohol Related Neurodevelopmental Disorder (ARND)
- ▶ Alcohol Related Birth Defects (ARBD)



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FASD in the DSM-5

- ▶ DSM 5
 - Neurodevelopmental Disorder Associated with Prenatal Alcohol Exposure 315.8 (F88)
 - Neurobehavioral Disorder Associated with Prenatal Alcohol Exposure (ND-PAE) (Section III)



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Incidence and Prevalence of FASD

- ▶ The range of FASD is more common than disorders such as Autism and Down Syndrome
 - Recent studies are identifying a prevalence of between 1.13% and 5% (1 in 88 to 1 in 20) with a weighted prevalence of between 3.11% and 9.85% (1 in 32 to 1 in 10) (May et al 2018)
 - Limitations in studies due to:
 - Consent issues
 - Population issues
 - Lack of documentation of prenatal exposure

Much higher in systems of care

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Importance of Preventing FASD: Facts to Consider

- ▶ 100% preventable
- ▶ No known safe amount of alcohol or safe time during pregnancy
- ▶ Of all drugs of abuse, alcohol causes the most serious neurobehavioral effects
- ▶ First weeks of fetal development are critical
- ▶ Close to 50% of pregnancies are unplanned
- ▶ Most women don't recognize pregnancy this early in fetal development

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Importance of Preventing FASD: Facts to Consider

- ▶ FASD can occur in any community
- ▶ 54% increase in national sales of alcohol for the week ending March 21, 2020 compared to 1 year earlier and online sales increased 262% from 2019
 - Neilson as reported in JAMA 2020
- ▶ Men have a role
 - Genetics
 - Epigenetics

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Importance of Preventing FASD: Available Tools

- ▶ There are three promising practices for the prevention of alcohol exposed pregnancies
 - CHOICES—a CDC funded program for non-pregnant women at risk
 - Screening and Brief Intervention
 - Parent-Child Assistance Program—a 3 year case management model for women at highest risk



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Brain Damage in FASD

- ▶ Prenatal alcohol exposure leading to an FASD causes brain damage
- ▶ Behaviors are often due to brain damage
- ▶ Behaviors often appear to be purposeful and willful when they are not
- ▶ Understanding the brain damage helps us understand the behaviors and develop appropriate interventions
 - Typical approaches such as evidence based practices will not be effective due to brain functioning



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Brain Structures Affected by Prenatal Alcohol Exposure

- ▶ **Basal ganglia, especially the caudate nucleus**
 - Cognition
 - Emotion
 - Motor activity
- ▶ **Corpus callosum**
 - Connects the two halves of the brain
 - May play a role in communication within the brain



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Brain Structures Affected by Prenatal Alcohol Exposure

- ▶ **Frontal lobes**
 - Control emotional responses and processing of humor
 - Control expressive language
 - Responsible for abstract thinking
 - Assign meanings to words
 - Control aggression
 - Are involved in processing information
 - Are involved in deciding how to act in a specific situation

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Brain Structures Affected by Prenatal Alcohol Exposure

- ▶ **Hippocampus**
 - Memory
 - Learning
 - Emotion
 - Aggression
- ▶ **Amygdala**
 - Fear
 - Stress and anxiety
 - Anger
 - Aggression



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MRI, MRS, and fMRI Study Findings Susan Astley (2009)

- ▶ Those with prenatal alcohol exposure scored significantly poorer on the two-back test
 - The level of activation in the Dorsolateral Prefrontal Cortex was significantly less in those with an FASD
 - This is a measure of working memory
- ▶ Implications for working with those with an FASD

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Recent Animal Studies on Anxiety

Joanne Weinberg (2008)

- ▶ The body deals with stress and anxiety through the amygdala and the hypothalamus-pituitary-adrenal (HPA) axis
- ▶ Prenatal alcohol exposure affects the body's response to stress and anxiety
 - The HPA axis over-responds to minor stressors with an over-release of cortisol
- ▶ Implications for working with those with an FASD



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Rationale for Screening for FASD

- ▶ If we don't identify individuals with FASD, they often experience
 - Many moves as children
 - Repeated abuse and trauma
 - Failure in typical education, parenting, treatment, justice, vocational, and housing approaches
 - Think they are "bad" or "stupid"
 - High risk of being homeless, in jail, or dead
- ▶ The earlier we recognize FASD, the better the long term outcomes



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Rationale for Screening Caregivers

- ▶ If we do not recognize FASD in caregivers, they often
 - Are labeled as neglectful, uncaring, or sabotaging
 - Have children removed from their care
 - Fail to follow through with multiple instructions
 - Have parental rights terminated
- ▶ Woman may have another alcohol exposed pregnancy



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How Outcomes Can Be Improved by Recognizing an FASD

- ▶ The individual is seen as having a disability
- ▶ Frustration and anger are reduced by recognizing behavior is due to brain damage
- ▶ Abuse and trauma can be decreased or avoided
- ▶ Approaches can be modified
- ▶ Diagnoses can be questioned



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Screen for Identifying Individuals with a Possible FASD

- ▶ In response to requests from providers, we developed a screen to identify older adolescents and adults who may have an FASD
- ▶ Called the Life History Screen (LHS)
- ▶ Information on the screen was published in the International Journal of Alcohol and Drug Research
- ▶ There are 32 questions in 9 categories



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Challenges in Recognizing FASD

- ▶ Recognizing an FASD challenges the basic tenets of treatment and interactions with people
 - That people need to take responsibility for their actions
 - That people learn by experiencing the consequences of their actions
 - That people are in control of their behavior
 - That enabling and fostering dependency are to be avoided
 - A person has to learn to do things on her or his own because that's the real world



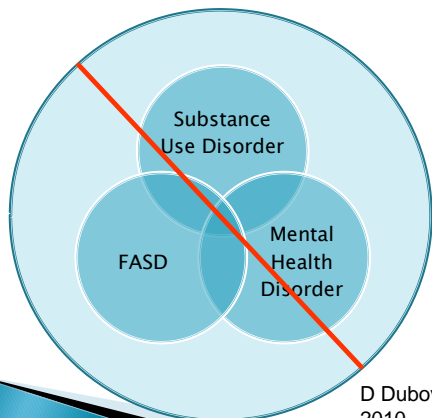
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Challenges in Recognizing FASD

- ▶ Our values and biases may come into play
 - About behaviors
 - About drinking during pregnancy
- ▶ It may bring up issues in our own lives
- ▶ It is easier to view the person as having the responsibility to change
- ▶ We think we need to treat everyone the same in order to be fair
- ▶ It means re-examining and changing our practices



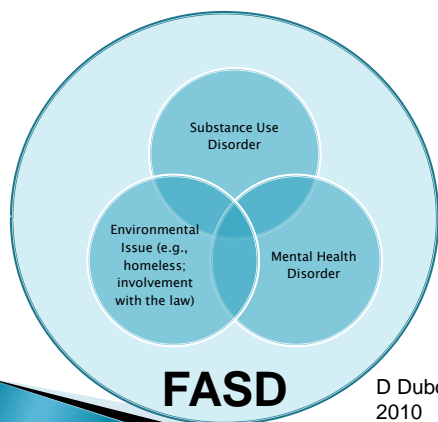
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2010



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D Dubovsky
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Common Misdiagnoses for Individuals with an FASD

- ▶ ADHD
- ▶ Oppositional Defiant Disorder
- ▶ Conduct Disorder
- ▶ Reactive Attachment Disorder
- ▶ Autism
- ▶ Bipolar Disorder
- ▶ Antisocial Personality Disorder
- ▶ Borderline Personality Disorder



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Comparing FASD, ADHD and ODD (D Dubovsky 2002)

	FASD	ADHD	ODD
Behavior	Does not complete tasks		
Underlying cause for the behavior	<ul style="list-style-type: none"> •May or may not take in the information •Cannot recall the information when needed •Cannot remember what to do 	<ul style="list-style-type: none"> •Takes in the information •Can recall the information when needed •Gets distracted 	<ul style="list-style-type: none"> •Takes in the information •Can recall the information when needed •Chooses not to do what they are told
Interventions for the behavior	Provide one direction at a time	Limit stimuli and provide cues	Provide positive sense of control, limits, and consequences

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What to Expect from a Person with an FASD

- ▶ Friendly
- ▶ Talkative
- ▶ Strong desire to be liked
- ▶ Desire to be helpful
- ▶ Naïve and gullible
- ▶ May “get it” one day and not the next
- ▶ Older than their age in some ways and childlike in others



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What to Expect from a Person with an FASD

- ▶ Difficulty identifying dangerous people or situations
- ▶ Difficulty following multiple directions/rules
- ▶ Model the behavior of those around them
- ▶ Sleep disturbances
- ▶ Literal thinking



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Difficulties with Literal Thinking

- ▶ Do “exactly” as told
- ▶ Difficulty with predicting consequences
- ▶ Difficulty with the sense of time
- ▶ Difficulty with a sense of space
- ▶ Difficulty in reward/consequence systems
- ▶ Difficulty managing money
- ▶ Difficulty with sarcasm, joking, similes, metaphors, proverbs, idiomatic expressions



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Living with FASD

- ▶ Individuals with an FASD and their families often experience:
 - Constant anxiety
 - Frequent frustration
 - Depression from repeated “failures”
 - Isolation
 - Lack of predictability
 - Living in the moment
 - Ongoing loss and grief
 - Not feeling in control
 - Difficulty understanding the world
 - Difficulties in every day life

• Adapted from Alaska’s FASD 201 curriculum



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Language Issues in FASD

- ▶ Often very verbal as adults
- ▶ Verbal receptive language is more impaired than expressive language
- ▶ Verbal receptive language is the basis of most of our interactions with people
 - In every system of care
 - Especially evidence-based practices in treatment



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Issues in Substance Use Treatment for Those with an FASD

- ▶ Treatment is based on:
 - Verbal receptive language processing skills
 - Working memory
 - Abstract thinking
 - Learning from experiencing the consequences of one's actions
 - Taking responsibility for one's actions
 - Being willful in their behavior and choices
 - Being able to generalize from one situation to another



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Issues in Addressing Behaviors

- ▶ Many people think that if we find the right motivating factor, the person will do what we want them to
 - Not effective for many with an FASD
 - Results in them thinking they are "bad"
- ▶ We are a problem based society
- ▶ Professionals get paid for addressing problem behaviors
 - Meetings, policies, procedures, handbooks



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Issues in Addressing Behaviors

- ▶ Many people with FASD and other issues have never heard what they do right
- ▶ We need to shift our approach
- ▶ We need to incorporate a true strengths-based approach to everyone
- ▶ Identifying strengths and abilities needs to be foremost
- ▶ We need to move towards a positive focused system



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A Positive Focused System

- ▶ Utilize a true strengths-based approach
 - Identify strengths and abilities
 - Focus on building strengths and abilities
- ▶ Consistently tell the person what she or he does well and is good at
- ▶ Revise policies, procedures, and client handbooks to be more positively focused
- ▶ This does not mean ignoring challenging behaviors



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A Strengths Based Approach to Improving Outcomes

- 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 providers
- Identify strengths in the community
 - Include cultural strengths in the community



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Strategies for Individuals with an FASD

- Reduce stimuli in the environment
- Use softer lighting, colors, and sounds
 - Avoid fluorescent lights
- Utilize Occupational Therapy, Speech and Language, and Physical Therapy as needed
- Be consistent in routines
- Limit the number of rules
- Check for **true** understanding



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Strategies for Individuals with an FASD

- ▶ Be consistent in appointment days and times, activities, and routines
 - For groups, therapy appointments, probation appointments, meetings with child welfare, etc.
 - Limit staff changes whenever possible
 - Prepare the person for any changes in personnel or appointment times often
 - Work with the person to set reminders of when they have to leave for their appointments on their cell phone or other device



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Strategies for Individuals with an FASD

- Keep conversations short and review them
- Designate a point person for the person to go to whenever she has a question or a problem or does not know what to do
- Identify a mentor/role model
- Repeatedly role play situations the person may get into, modeling how you would like him or her to respond
- Much repetition due to damage to working memory



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Strategies for Individuals with an FASD

- Consequences need to be immediate, related to what occurred, and brief
- **Any time you need to tell a person “you can’t” you must also say “but you can”**
- Avoid using a reward and consequence system
 - E.g., starting a sentence with “if” or “when”
- Use multiple senses
- Break things down to one step, direction, or rule at a time



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Strategies for Individuals with an FASD

- **Do not ignore negative attempts for attention**
- Plan carefully for group activities
 - Shorter group activities may be more useful
 - It may be helpful to have the person sit next to the teacher or other facilitator
 - Use senses other than verbal
 - Allow the person to take a break in the middle of group if necessary



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Strategies for Individuals with an FASD

- If you joke with the person, let him or her know you are joking
- Point out when others are joking with the person
- Teach the person to check out whether someone is kidding or serious if he or she doesn't “get it”



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Strategies for Individuals with an FASD

- Point out misinterpretations of words and actions when they occur
 - Especially in terms of body language and non-verbal cues
- Don't use weekly or monthly money allocations as a way for the person to learn responsibility if he or she routinely spends whatever money he or she has
- Simplify medication schedules



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Strategies for Individuals with an FASD

- Identify signs that the person is beginning to get stressed or anxious
- Identify one or two things that help the person calm down when s/he gets upset
- Talk with the person about the importance of using those techniques at the moment they are beginning to get upset
- This can reduce aggression and getting thrown out of programs
 - But everyone needs to support their doing this
- Plan warm handoffs for program changes



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Strategies for Individual With an FASD

- *Find something that the person likes to do and does well (that is safe and legal) and work to have the person do that regardless of behavior*
- **Be fair rather than equal**
- Use sign language
- Create "chill out" spaces in each setting
- Use literal language
- Use person first language



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Person First Language

- “He’s a person with FAS” not “he’s FAS”
- “She is a woman with a substance use disorder” not “she’s a substance abusing woman”
- “He is a child who has been adopted” not “he is an adopted child”
- “She has Autism” not “She is Autistic”
- “He has been in jail” not “He’s an ex-con”
- “He has an addiction” not “He is an addict”



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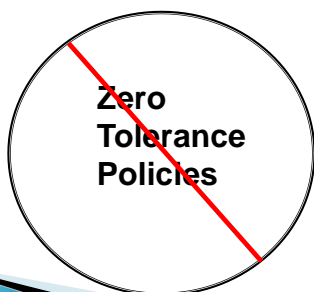
Strategies for AA/NA

- Limit the number of meetings per week
- Identify what meetings to attend
- Go to the same meetings on the same days each week
- Have someone be responsible for taking the person to each meeting for at least 6 months if necessary
- Discuss each meeting with the person
- Utilize open meetings if necessary



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Strategies for Individuals with an FASD





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Additional Interventions to Consider

- Art therapy
 - Identify creative talents of the individual
- Movement and dance therapy
- Cultural traditions and rituals
- Animal assisted therapy
- Exercise



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Final Thoughts to Keep in Mind

- ▶ The focus in FASD is on changing the environment rather than the person
- ▶ Creativity is essential in the identification of services needed
- ▶ Identifying and supporting strengths and validating accomplishments is essential
- ▶ All programs interfacing with the person must be trained in FASD
- ▶ Correctly addressing FASD can improve outcomes and reduce long term costs



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Final Thoughts to Keep in Mind

- ▶ We want to help people succeed
 - “Whatever it takes” is an important attitude
 - Ask the question “what does this person need in order to be successful (function at his or her best) and how do we help him or her achieve that
- ▶ We need to foster **interdependence**
- ▶ FASD is a human issue



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FASD Is a Human Issue

- ▶ It's essential to "really care"
- ▶ People with an FASD and their families have great potential
- ▶ We need reminders of what has been accomplished
 - Especially when things are not going well
- ▶ Recognizing and correctly addressing FASD is literally a matter of life or death
 - What you do can save lives!



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U.S. Resources

- ▶ Centers for Disease Control and Prevention FAS Prevention Team: www.cdc.gov/ncbddd/fas
- ▶ National Institute on Alcohol Abuse and Alcoholism (NIAAA): www.niaaa.nih.gov/
- ▶ National Organization on Fetal Alcohol Syndrome (NOFAS): www.nofas.org
- ▶ Proof Alliance: www.proofalliance.org
- ▶ UW: www.depts.washington.edu/fadu
- ▶ These sites link to many other Web sites



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