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Recognizing Fetal Alcohol Spectrum Disorders (FASD) to Improve Outcomes

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Recognizing Fetal Alcohol Spectrum Disorders (FASD) to Improve Outcomes

continued

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Learning Outcomes

After this course, participants will be able to:

- List 3 brain structures affected by prenatal alcohol exposure.
- Identify the most recent prevalence rates for FASD in the U.S.
- Describe 3 approaches that can be helpful for someone with 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, from mild to severe
- There is no way to predict how much alcohol will cause how much damage in any individual
- There are many different ways that the disabilities of FASD are manifested

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FASD

- Behavior often appears to be purposeful
- Typical approaches to “difficult” behaviors often don’t work
- Many individuals with an FASD have other difficulties
 - One cannot categorically say that all behavior is due to the FASD
- Not all children prenatally exposed to alcohol have an FASD, but the spectrum of FASD causes brain damage

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Incidence and Prevalence of FASD

- Recent studies in the U.S. have found a prevalence of between 1.13% and 5%
- Weighted prevalence in these studies was 3.11% to 9.85% (1 in 32 to 1 in 10) (May et al 2018)
- 2013 estimates in Alberta are 1.4-4.4% (1 in 71 to 1 in 22) of the general population (Thanh 2014)
- The range of FASD is more common than disorders such as Autism and Down Syndrome

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Incidence and Prevalence of FASD

- Prevalence research is very limited
 - Methodology variance
 - Population variance
 - Consent
 - Adequate information for a diagnosis
- Much higher prevalence in systems of care e.g., special education, mental health services, early intervention services, corrections, vocational services, domestic violence programs
- Majority undiagnosed or misdiagnosed

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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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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 means re-examining our practices
- 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

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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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What to Expect from a Person with 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 FASD

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

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Language Issues in FASD

- Early language development often delayed
 - Early speech therapy is very helpful
- Often very verbal as adults
- Verbal receptive language is more impaired than verbal expressive language
- Verbal receptive language is the basis of most of our interactions with people

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Situations That Rely on Verbal Receptive Language Processing

- Parenting techniques
- Elementary and secondary education
- Child welfare
- Judicial system
- Treatment
 - Motivational interviewing
 - Cognitive behavioral therapy
 - Group therapy
 - AA/NA groups

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Issues in Addressing Behaviors

- We are a problem based society
- Many with FASD, as well as many with other disabilities that manifest behaviorally, those with substance use disorders, and those with mental illness have repeatedly heard what they do wrong throughout their lives
- They rarely hear what they do right

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Strengths of Persons With an FASD

- Friendly
- Likeable
- Verbal
- Helpful
- Caring
- Hard worker
- Creative
- Determined
- Have points of insight
- Good with younger children*
- Not malicious
- Every day is a new day

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Working with Families

- If a youth may have an FASD, it is essential to help families understand FASD and how best to approach the youth
 - Consistency is very important especially for these children
 - Understanding what is causing the behaviors is essential before responding
 - Recognizing FASD as a brain based disorder
 - Focus on strengths and abilities
 - Reduce the use of reward and consequence approaches
 - Be careful about physical restraint

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Working with Families

- If a family member has an FASD, the approach to them has to be modified
 - One step or direction at a time
 - A lot of consistency e.g., in appointments
 - Help in completing applications and getting to appointments on time
 - Repetition and support in achieving what is expected of them
 - Modeling
 - In vivo parenting approaches

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Strategies for Individuals with FASD

- Reduce stimuli in the environment
 - Their room
 - Treatment settings
 - Visuals
 - Sounds
- Use softer lighting and colors
 - Avoid fluorescent lights

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Strategies for Individuals with FASD

- Be consistent in appointment days and times, activities, and routines
 - For groups, appointments, meetings, 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 FASD

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

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Strategies for Individuals with FASD

- If consequences need to be used, they should be immediate, related to what occurred, and finished preferably within the same day
- **Any time you need to tell someone “you can’t” you must also say “but you can”**
- Avoid using a reward and consequence system
- Utilize a positive focused system instead

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Strategies for Individuals with 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

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Strategies for Individuals with FASD

- Be careful about using verbal instructions
- Use multiple senses (visual, auditory, tactile)
 - Break things down to one step at a time
 - Always check for **true** understanding
 - What does this rule mean? How would you follow this rule? How would you complete this?
- When a rule is broken, work with the person on how to help them remember the rule when they need it

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Final Thoughts to Keep in Mind

- Creativity is essential in the identification of services needed for the person with an FASD and his or her family
- Identifying and supporting strengths and validating accomplishments is essential
- Developing true collaborative relationships between agencies and systems is essential as FASD crosses every system of care

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Final Thoughts to Keep in Mind

- All programs interfacing with the person must be trained in FASD
- Correctly recognizing and addressing FASD (in terms of both prevention and treatment) can reduce long term costs and improve outcomes for the individual, family, agency, and system

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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 and family 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 **inter**dependence
- FASD is a human issue

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FASD Is a Human Issue

- It's essential to “really care”
- People with FASD and their families have great potential
- We need reminders of what has been accomplished
 - Especially when things are not going well
- Always remember that addressing FASD can be a matter of life or death
 - What you do concerning this issue can save lives!

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