Modifying FASD Prevention Strategies for Individuals with an FASD

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Fetal Alcohol Spectrum Disorder Prevention Project

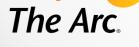
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How Outcomes Can Be Improved by Recognizing an FASD

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

Consequences of Not Recognizing an FASD in an Individual

- Many moves as children
- Abuse and Trauma
- Fail with typical education, parenting, treatment, justice, vocational, and housing approaches
 - If women fail in treatment, they are at risk for alcohol exposed pregnancies
- Think they are "bad" or "stupid"
- Risk of being homeless, in jail, or dead

Consequences of Not Recognizing an FASD in a Caregiver

- Labeled as neglectful, uncaring, or sabotaging
- Removal of their children from their care
- Fail to follow through with multiple instructions
- Parental rights are terminated
- Woman may have another alcohol exposed pregnancy

So How Do We Recognize Individuals Who May Have an FASD?

- There is no blood test or other simple test
- Diagnostic capacity for adults is limited
- A screen can be very helpful
- In the ideal world, a positive screen would lead to an assessment and diagnostic evaluation
- As diagnostic capacity is lacking in most parts of the country, we need to do a good assessment and modify approaches for those we suspect may have an FASD

- It is called the Life History Screen
- Published in the International Journal of Alcohol and Drug Research
- Aside from demographics, there are 28 questions in 9 categories
- The screen is meant to be a guide for modifications in approach
- The screen needs to be validated for sensitivity and specificity

- Categories:
 - Childhood History
 - Maternal Alcohol Use
 - Education
 - Criminal History
 - Substance Use
 - Employment and Income
 - Living Situation
 - Mental Health
 - Day to Day Behaviors

- The screen was not developed to ask all questions in order the first day the person comes into treatment
- Some questions will already have been asked, but not through the lens of whether this could be a person with an FASD
- Some questions may need to be asked or revisited after a trusting relationship has been formed

- There are three key life history domains that have been identified through use of the screen in treatment centers
 - Childhood history
 - Maternal alcohol use
 - Day-to-day behaviors

Childhood History Questions Grant, Whitney, Dubovsky (2011)

- Were you raised by someone other than your birth parents
- How many living situations did you have before the age of 18?



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Maternal Alcohol Use Questions Grant, Whitney, Dubovsky (2011)

- To your knowledge, did your mother ever drink alcohol that caused problems for her or others around her?
- Did she drink alcohol when you were young?
- Did your mother drink alcohol while she was pregnant with you?



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Day to Day Behaviors Grant, Whitney, Dubovsky (2011)

- Do you have trouble on a regular basis with any of the following:
 - Concentrating and paying attention?
 - Understanding what adults were telling you?
 - Remembering things?
 - Following rules and instructions?
 - Getting along with others without arguing or fighting?



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Day to Day Behaviors Grant, Whitney, Dubovsky (2011)

- Do you have trouble on a regular basis with any of the following:
 - Being on time?
 - Keeping enough money to last you throughout the month?
 - Doing things that later you wish you hadn't done?



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Day to Day Behaviors Grant, Whitney, Dubovsky (2011)

- Do you have trouble on a regular basis with any of the following:
 - Getting really upset at little things or what people have told you are little things?
 - Forgetting or missing appointments?
 - Being surprised when you are in trouble?



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Challenges in Recognizing FASD

- Recognizing an FASD challenges the basic tenets of all interactions
 - 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
- It may bring up issues in our own lives
- There may be concerns of relapse especially in discussing FASD with women in treatment

Strategies to Reduce the Incidence of Alcohol Exposed Pregnancies

- There are excellent prevention strategies that have been proven to be effective in reducing the risk of an alcohol exposed pregnancy
 - Screening and Brief Intervention
 - CHOICES
 - Parent-Child Assistance Program
- Although these approaches work with many women, they do not work with all

State of the Art Prevention in FASD

- Screening all women at risk for alcohol use
 - Ask specifically about alcohol use
 - Especially examine further if other drug use
 - Embed questions in general health screening
 - Ask questions in a manner that promotes honest responses
 - Ask open-ended questions and ask repeatedly
 - Be careful about how questions are asked
 - Be sure they are literal
- Identify women who may have an FASD and modify interventions to improve success

Issues in Prevention for Individuals with an FASD

- If a person is very literal in their thinking, they may respond differently to screening questions depending on how they are asked
- Individuals with an FASD have difficulty with verbal receptive language processing across the intellectual span

• Many prevention strategies rely on verbal processes

 Motivational interviewing relies on verbal processing and the individual making decisions on their own about their behavior

Challenges in Recognizing FASD

- We have to change our thinking and approaches
- Prevention and intervention strategies must be modified if a person has an FASD
- The modifications are based on an understanding of the brain damage caused by prenatal alcohol exposure

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

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 overrelease of cortisol
- Implications for working with those with an FASD

Brain Structures Affected by Prenatal Alcohol Exposure

- Basal ganglia, especially the caudate nucleus
 - Cognition
 - o **Emotion**
 - Motor activity

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

Brain Structures Affected by Prenatal Alcohol Exposure

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

Check Point...

QUESTIONS??

Why Screening and Brief Intervention May Need to be Modified for Those with an FASD

- Screening questions may be misinterpreted by someone who is literal in her thinking
- Assessment of risk might not be accurate
- Brief intervention is verbally based
- The brief intervention is expected to change behavior
- It works with many women
- It does not work with all women

How Screening and Brief Intervention May Need to be Modified for Those with an FASD

- Screening questions to identify risk may need to be explained
 - E.g., how many drinks does it take for you to feel the effects; have others annoyed you by talking to you about your alcohol use
- Brief intervention may need to be much more directive
- More senses than verbal need to be utilized
- True understanding needs to be assessed

Why CHOICES May Need to be Modified for Those with an FASD

- CHOICES utilizes a motivational interviewing approach
 - Verbal approach
 - Once a week
 - The person is expected to take in the information and decide to change her behavior by increasing effective contraception, decreasing alcohol use, or both
- The woman is expected to keep a journal
- It is effective for approximately 67% of women in testing
- It is not effective for all women

How CHOICES May Need to be Modified for Those with an FASD

- More frequent, shorter sessions
- More active and directive
- More senses utilized
- The journal would be completed by the woman and facilitator together (or the woman and another individual)
- Motivational interviewing approach will often need to be modified

Why Motivational Interviewing Needs to be Modified for Someone with an FASD

- MI strategies utilize a verbal approach
 - Intact verbal receptive language processing skills are required
 - Verbal receptive language skills are often impaired in FASD
- The approach used in MI is a brief treatment approach
 - Brief interventions are often not effective in long term change for individuals with an FASD

Why Motivational Interviewing Needs to be Modified for Someone with an FASD

- The individual is expected to process information on his or her own between sessions
 - Due to difficulties in abstract thinking, processing information in the abstract is often difficult for someone with an FASD
- The individual is expected to move through the stages of change after the sessions are completed
 - For many individuals with an FASD, long term support is essential for behavior change

- Adjust the strategies
 - Talk about a typical day (or period in school or afternoon or weekend or bedtime):
 - What do you do?
 - What stresses (or difficulties) do you have?
 - When do you do this behavior?
 - How does it fit in to your life?
 - What happens when you do this?
 - This needs to be broken down taking into account the literal thinking of the individual

- Adjust the strategies
 - What are the good things and less good things about this behavior/action
 - Write it down
 - Be thorough
 - Ask questions such as: "what else is good about it?"
 - Review the list periodically
 - What has happened to you in the last week (or today or yesterday)?
 - How have you been since your last birthday?
 - What fun things or good things have happened
 - What not so good things have happened?

- Adjust the strategies
 - What do you want for yourself in the next week? The next year? When you are on your own?
 - Is there anything you want to change (or you hope gets better)?
 - Would your behavior get in the way of that plan?
 - If so, how?
 - If not, point out how it might?
 - Is there any way to not have that happen?

- Typically will need to be a longer process

 Not necessarily the brief treatment approach as developed
- The therapist needs to be much more active and directive
- Limit the receptive language skills needed
- Need a lot of review and repetition
- Use multiple senses
 - Write things down
 - Use visuals (E.g., videos, computer)

- Plan on more frequent, shorter sessions
- Need to ensure that the person gets to the sessions
- Do the work with the individual in the session rather than expecting the person to think about their situation outside of the session
- Frequently check understanding
- Use a lot of empathy
- Acknowledge successes
- Schedule follow up "booster" sessions

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 (that is safe and legal) and arrange to have the person do that regardless of behavior
- Create "chill out" spaces in each setting
- Use literal language
- Use person first language

Person First Language

- "He's a child with FAS" not "he's an FAS kid"
- "She is a woman with a substance use disorder" not "she's a substance abusing woman"
- A mother with FAS, not "an FAS mom"
- "He has schizophrenia" not "he is a schizophrenic"
- "Ms. Smith" not "mom"
- No one "is" FAS although a person may have FAS

Paradigm Shift

"We must move from viewing the individual as failing if s/he does not do well in a program to viewing the program as not providing what the individual needs in order to succeed."

–Dubovsky, 2000



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Final Thoughts to Keep in Mind

- Creativity and flexibility are essential in providing effective prevention strategies for women with an FASD
- Don't forget men in the prevention of alcohol exposed pregnancies
- Developing true collaborative relationships between agencies and systems is essential as FASD crosses every system of care

Final Thoughts to Keep in Mind

- 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
- By successfully intervening with women who have an FASD, we can reduce the incidence of alcohol exposed pregnancies

References

- Grant TM, Novick Brown N, Dubovsky D, Sparrow J, Ries R. "The Impact of Prenatal Alcohol Exposure on Addiction Treatment." Journal of Addiction Medicine 2013; 7(2) 87-95.
- Grant TM, Novick Brown N, Graham JC, Whitney N, Dubovsky D, Nelson LA. "Screening in treatment programs for Fetal Alcohol Spectrum Disorders that could affect therapeutic progress." International Journal of Alcohol and Drug Research 2013; 2(3) 37-49.

Resources

- SAMHSA FASD Center for Excellence: <u>fasdcenter.samhsa.gov</u>
- Centers for Disease Control and Prevention FAS Prevention Team: <u>www.cdc.gov/ncbddd/fas</u>
- National Institute on Alcohol Abuse and Alcoholism (NIAAA): <u>www.niaaa.nih.gov/</u>
- National Organization on Fetal Alcohol Syndrome (NOFAS): <u>www.nofas.org</u>
- These sites link to many other Web sites

Thank You!

Learn more about The Arc's FASD Prevention Project at:

www.thearc.org/FASD-Prevention-Project