Improving Outcomes for Families Impacted by Alcohol and Drugs: A National, State, and Local Perspective

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Developmental Disabilities (TOPDD)

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Fetal Alcohol Spectrum Disorders (FASD)

- Umbrella term for the range of effects that can occur with prenatal alcohol exposure
- Not a diagnosis
- Diagnostic terms include
 - Fetal alcohol syndrome
 - Partial fetal alcohol syndrome
 - Alcohol Related Neurodevelopmental Disorder
- ▶ DSM 5
 - Neurodevelopmental Disorder Associated with Prenatal Alcohol Exposure 315.8 (F88)
 - Neurobehavioral Disorder Associated with Prenatal Alcohol Exposure (Section III)

Incidence and Prevalence of FASD

- The range of FASD is more common than disorders such as Autism and Down Syndrome
 - Generally accepted incidence of FASD in North America has been 1 in 100 live births
 - Recent studies are identifying a prevalence of between 2% and 5% (1 in 50 to 1 in 20)
 - Much higher percentage in systems of care

Alcohol and Women

- All beverages with alcohol are harmful to the fetus
- \rightarrow A drink \neq a drink \neq a drink
 - All beer and wine do not have the same alcohol content
 - a typical drink is often more than a standard drink
- Kaskutas and Graves (2001) studied alcohol consumption in 321 pregnant women
 - When self selecting drinks, their estimated drink size was up to 307% greater than standard measures

Effects of Prenatal Crack/Cocaine Exposure (Ira Chasnoff)

- Decreased growth
- Vascular problems
- Increased risk of SIDS
- Withdrawal symptoms
- Hyperactivity
- Impulsivity
- Attention problems
- Cognitive delays
- Poor feeding and sleeping patterns

Long Range Impact of Crack-Cocaine on a Child (Ira Chasnoff)

- Early difficulties seem to resolve by age 6
- There are some increased difficulties in adolescents
 - Difficult to decipher whether it is due to the early exposure or to environmental factors or to concomitant alcohol use by the mother during pregnancy

Differences Between Prenatal Cocaine and Prenatal Alcohol Use

- Wayne State University: Burden, Jacobson, Dehaene, Dodge, Jacobson
- Examined the effects of alcohol and cocaine on mathematics skills
 - 261 14 year olds in Detroit
 - Looked at number sense and calculation skills
 - The more alcohol exposure, the poorer both number sense and calculation skills
 - No relationship found between prenatal cocaine exposure and either number sense or calculation

Possible Effects of Prenatal Marijuana Use

- Lower birth weight
- Nervous system changes
- Delayed learning
 - Dye 1997
- No gross fetal malformations noted
- Metabolites of THC freely cross the placenta
 - Schwartz 2002

Reported Malformations Possibly Associated with Prenatal Methamphetamine Exposure Derouf (2003)

- Cleft lip
- Cardiac defects
- Low birth weight
- Growth reduction
- Prematurity
- Stillbirth
- Cerebral hemorrhage
- **Tachycardia**

- Inability to tolerate stimulation
- Poor modulation of behavior
- Jitteriness
- Coordination problems

These findings have not yet been shown in controlled, blinded research

Adverse Consequences of In Utero Nicotine Exposure Derouf (2003)

- ↑ perinatal mortality/morbidity¹
- ↑ incidence of SIDS
- ▶ ↓ birth weight
- ↑ airway hyper-responsiveness
- Adverse cognitive-behavioral outcomes^{2,3}
- Neuro-teratogenicity in animal model⁴
- 1 Werler MM. Teratogen update: smoking and reproductive outcomes. *Teratology*. 1997;55: 382–388
- 2 Lassen K et al. Effects of maternal cigarette smoking during pregnancy on long-term physical and cognitive parameters of child development. Addict Behav. 1998;23: 635-653
- 3 Weitzman M et al. Maternal smoking and behavior problems of children. *Pediatrics.* 1999;104: 1312-1320
- 4 Slotkin TA. Fetal nicotine or cocaine exposure: which one is worse? *J Pharmacol Exp Ther.* 1998;285: 931–945

Co-occurring Use of Drugs and Alcohol

- A significant proportion of individuals who use illegal drugs also use alcohol
- "Of all the substances of abuse (including cocaine, heroin, and marijuana), alcohol produces by far the most serious neurobehavioral effects in the fetus."
 - IOM Report to Congress, 1996

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
- ▶ 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
- Lacking that ability, we need to modify approaches
- If prenatal alcohol exposure is known, it is very important to document it

- A screen was developed called the Life History Screen
- Published in the International Journal of Alcohol and Drug Research
- There are 28 questions in the current version of the screen, broken down into 9 categories
- ▶ 11 of the questions are asked in the ASI

- 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 after a trusting relationship is formed with the person
- Some questions may need to be revisited once this relationship is formed
- The screen is not a diagnostic tool but an assessment tool
- The screen is not meant to be a burden but rather a guide for future work

- 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

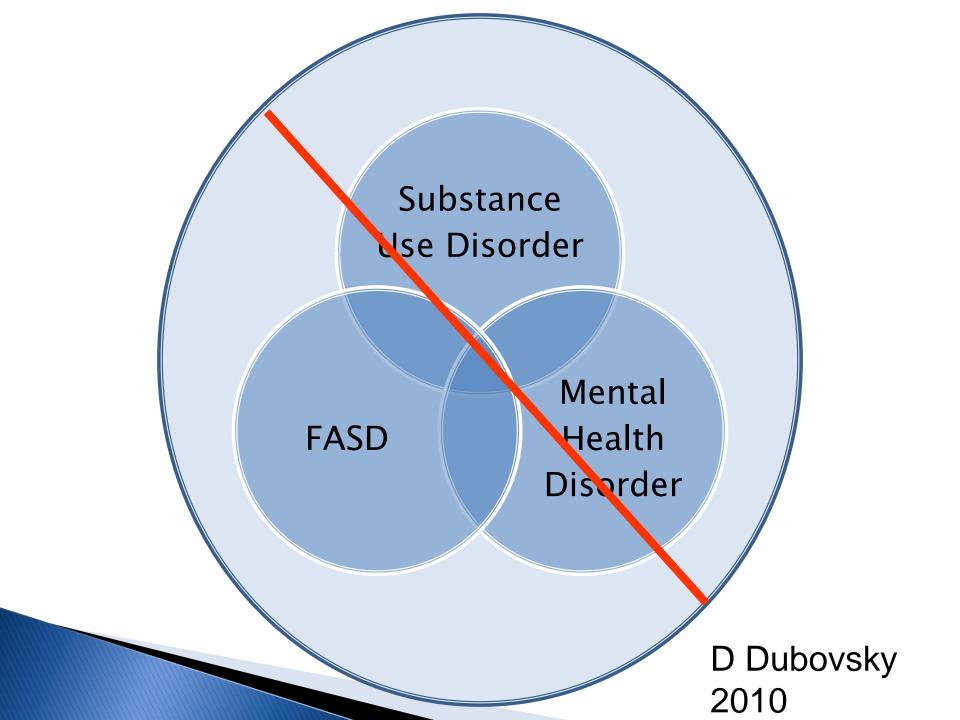
- There are two methods to screen positive:
 - A red flag response for each of the three key life history domains
 - A red flag response for two of the three key life history domains and a red flag response for at least two of the other six life history domains
- The cutoff scores for a positive screen are being tested

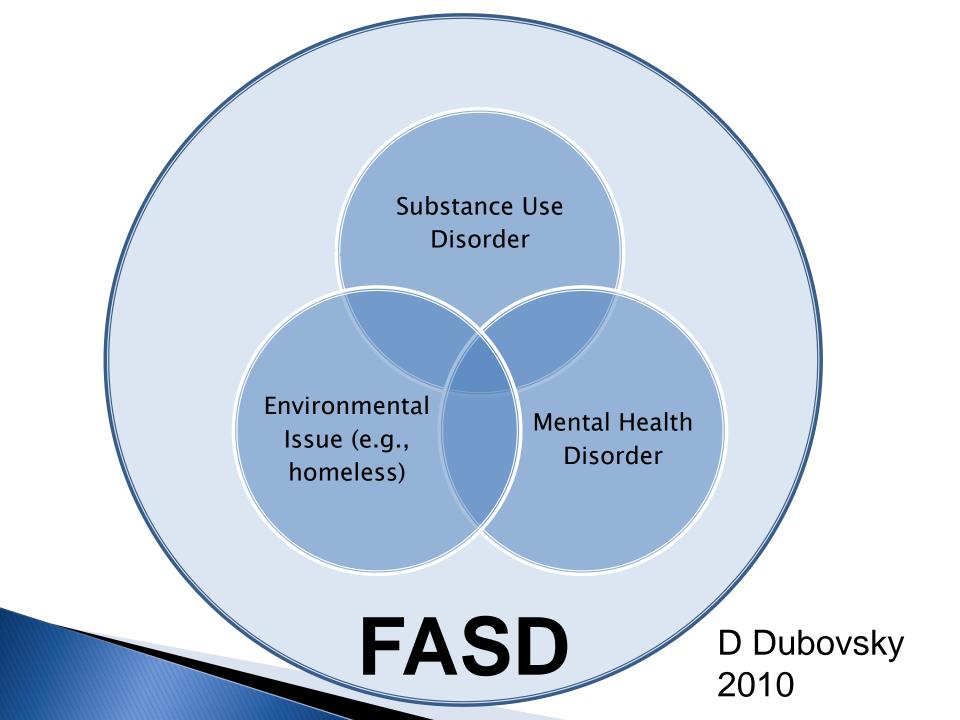
Challenges for Professionals in Recognizing FASD

- Recognizing an FASD challenges the basic tenets of treatment and 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 in treatment
- It may bring up issues in our own lives

Challenges for Professionals in Recognizing FASD

- People with an FASD are often challenging to work with
 - They repeat the same negative behavior
 - They are always surprised when in trouble
 - They appear to be non-compliant, uncooperative, resistant, manipulative, and unmotivated
- We have to change our thinking and approaches
- Treatment of co-occurring issues must be different if a person also has an FASD



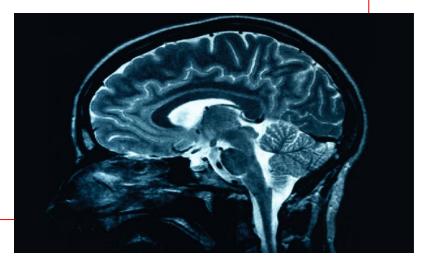


Fetal Alcohol Spectrum Disorders (FASD)

- Prenatal alcohol exposure leading to an FASD causes brain damage
- Behaviors often appear to be purposeful
- Behaviors are often due to brain damage
- Understanding the brain damage helps us understand the behaviors and develop appropriate interventions

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



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

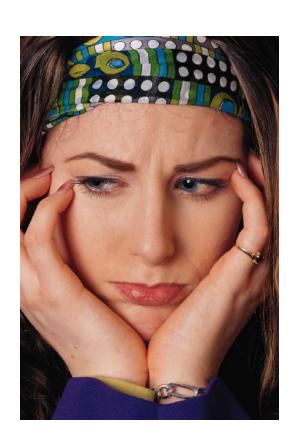
Brain Structures Affected by Prenatal Alcohol Exposure

Hippocampus

- Memory
- Learning
- Emotion
- Aggression

Amygdala

- Fear
- Stress and anxiety
- Anger
- Aggression



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

- Those with prenatal alcohol exposure scored significantly poorer on the twoback 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 over-release of cortisol
- Implications for working with those with an FASD

Language Issues in FASD

- Early language development often delayed
- 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

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

FASD and Sexually Transmitted Infections

- People with an FASD are at risk for HIV and sexually transmitted infections
 - Difficulty avoiding dangerous situations
 - Difficulty negotiating safe sex
 - Difficulty remembering to use safe sex techniques
- The approach to sex education and prevention and treatment of HIV and sexually transmitted infections must be different
 - Literal
 - Repeated
 - Role playing of situations the person might find him or herself in

Suicide Risk Among Individuals with an FASD

Whitney and Dubovsky (2010)

- Literal thinking can lead to a higher risk for suicide
 - Language used in discussing deaths
- Community response to other suicides
- Wanting to "go along with the crowd"
- "If I kill myself, people will be upset"
- Inability to predict the consequence of death at the moment

Difficulties in Treatment for Individuals with an FASD

- Sporadic in keeping appointments
- Problems doing things on their own
- Consistently get into difficulty with others
- Viewed as manipulative, unmotivated and non-compliant
- Wander away, "fade out," "space out," and/or talk inappropriately in group
- Need a lot of one-to-one support
- Appear to be intrusive and rude
- Have the same issues week after week

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
 - E.g., cultural strengths in the community

Strengths of Persons With an FASD

Friendly

Likeable

Verbal

Helpful

Caring

Determined

Have points of insight

Good with younger children*

Not malicious

Every day is a new day

Hard worker

- Modifications are based on scientific knowledge of brain damage in FASD
- All modifications do not need to be used with every person
- The treatment team should identify the modifications to be implemented for a particular woman/family

- Modifications are broken down into broad areas of difficulty
 - Impaired executive functioning
 - Impaired ability to think abstractly
 - Impaired verbal receptive language processing
 - Difficulty reading and responding to social cues
 - Impaired working and short-term memory
 - Impaired coping skills
 - Impaired sensory integration

- 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

- Have short treatment sessions every day at the same time rather than once a week
- Be careful about verbal approaches
 - Use multiple senses
- Simplify and review routines, schedules, rules frequently
 - Check for true understanding
- Prepare the individual for changes in schedule

- 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 treatment buddy for the woman to 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

- Utilize a positive reinforcement system rather than a reward and consequence system
- If consequences need to be used, they should be immediate, related to what occurred, and over preferably within the same day
- Any time you need to tell someone "you can't" you must also say "but you can"

- Limit the number of plans and goals the person has
 - One overall integrated treatment plan is best
 - Provide a few steps at a time
 - Do not have more than 2 or 3 short term goals for the person to work on at any one time
- Plan carefully for groups
 - They may appear to be disinterested or rude
 - It may be helpful to have the person sit next to the facilitator in group
 - Verbal discussions can be overwhelming
 - They may need to calm down in the middle of group

- Use a calendar for daily planning with all appointments
 - Put appointment time and when to leave for appointment on the calendar
 - Identify carefully how the person will get to outside appointments
 - Set reminders for appointments
 - Place the calendar where it is easily seen regularly
 - Review the calendar with the person often as a support until she gets into the routine of looking at it

Use literal language

Do not use metaphors, similes, or idioms

 Do not use vague terms that could be misunderstood

Ensure the person understands what you are saying

If you joke with the person, let 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

- Evaluate the person's ability to manage money
 - Natural consequences often set the person up to be homeless
 - Consider a representative payee if necessary
- Evaluate the need for a guardian
- Complete forms and applications with the person
 - Go to appointments with the person when needed

- Do not only use verbal instructions and treatment approaches
 - 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 to

- Point out misinterpretations of words and actions when they occur
 - Especially in terms of reading words and actions of others
- Have the person carry a small notebook so that providers can write down appointments, instructions, etc.

- Identify signs that the person is beginning to get stressed or anxious
- Identify one or two things that help the person calm down when she gets upset
- Talk with the person about the importance of recognizing when she is beginning to get upset and doing what helps her calm down at that moment
- Point out when you see the woman starting to get upset and say "why don't you ..."

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

Other 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

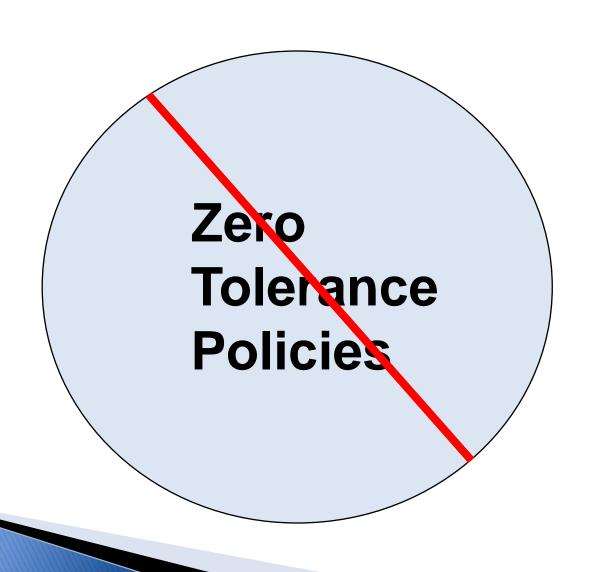
Person First Language

- "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

Other Strategies for Improving Outcomes for Persons With an FASD

- Set the person up to succeed
 - · The person with an FASD having a mentor
 - The person with an FASD being a mentor
 - May need to change the definition of success
- Provide in vivo parenting rather than parenting classes
- Model appropriate behaviors with the person
- Simplify medication schedules
- Ensure other systems understand FASD

Strategies for Improving Outcomes for Individuals with an FASD



Suicide Intervention/Prevention for Individuals with an FASD Adapted from Huggins, et al (2008)

- Standard suicide assessment protocols need to be modified
 - Instead of "How does the future look to you?" ask "What are you going to do tomorrow? Next week?"
 - Lethality of attempt ≠ level of intent to die
 - Obtain family/collateral input
- Be careful about words used regarding other suicides or deaths

Huggins, et al., 2008. Mental Health Aspects of Developmental Disabilities, 11(2) 1-9.

Suicide Intervention/Prevention Huggins, et al (2008)

- Intervene to reduce risk
 - > Address basic needs and increase stability
 - Treat depression
 - > Teach distraction techniques
 - > Remove lethal means
 - Increase social support
 - Monitor risk closely
 - > Build reasons for living
 - > Strengthen relationship between the woman and her support (e.g., case manager; therapist)
- Do not rely on suicide contracts

Huggins et al, 2008. Mental Health Aspects of Developmental Disabilities 11(2) 1-9.

Preparation for Life

- Evaluate ability to handle money
 - Consider representative payee if necessary
- Evaluate housing needs
 - What would be best for this person at this time
- Identify job desires and possibilities
 - Identify what is needed for employment success
 - Job coach possibility
- Identify specific support person and back up
 - Encourage checking with the support person whenever unsure of a situation or response

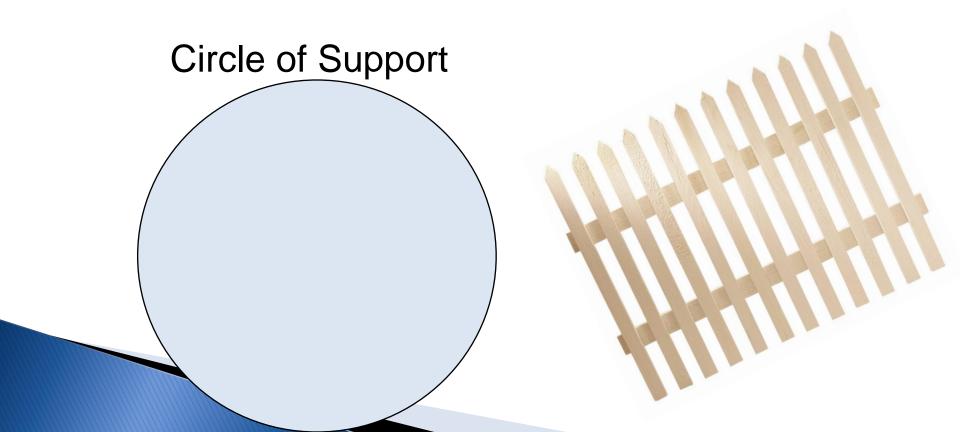
Preparation for Life

- Address parenting issues
- Evaluate mental health needs
 - Identify a treatment setting that understands FASD
- Arrange for warm handoffs
- Check in regularly with the person after leaving services
 - Reinforces that someone cares

Circle and Fence

N Whitney 2010

Who is helpful to you and who is someone who is not good for you (e.g., has gotten you in trouble or has encouraged you to do things you should not)



Additional Interventions to Consider

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

Voices of Women with an FASD

D. Rutman (2011)

- Women's needs
 - Affordable, safe and/or supported housing
 - Income
 - Mothering-related support
 - Greater availability of mental health and trauma-related services and counseling
 - Employment readiness, job search, and life skills

Voices of Women with an FASD D. Rutman (2011)

- Women's positive experiences
 - Readiness for change is crucial
 - Immediacy of support is necessary
 - Relational approach
 - Holistic, coordinated supports
 - One-to-one care from a skilled professional

Voices of Women with an FASD D. Rutman (2011)

- Women's positive experiences
 - Peer-based support
 - Linkages with FASD-related programs and organizations
 - Supportive housing
 - Flexibility in extending a program's duration and longer term programs
 - Support from family and/or partner

Final Thoughts to Keep in Mind

- Creativity is essential in the identification of services needed for the woman with an FASD and 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

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

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/her best) and how do we help him/her achieve that
- We need to foster interdependence
- FASD is a human issue

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
- Always remember that addressing FASD can be a matter of life or death
 - What you do concerning this issue can save lives!

References

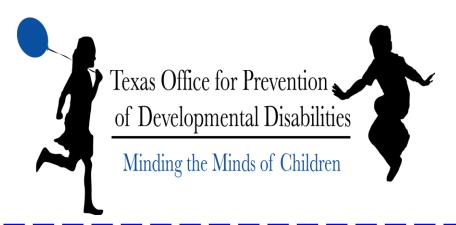
- Grant TM, Novick Brown N, Dubovsky D, Sparrow J, Ries R. "The Impact of Prenatal Alcohol Exposure on Addiction Treatment." Journal of Addiction Medicine 2013; 7(2) 87-95.
- Grant TM, Novick Brown N, Graham JC, Whitney N, Dubovsky D, Nelson LA. "Screening in treatment programs for Fetal Alcohol Spectrum 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: www.cdc.gov/ncbddd/fas
- National Institute on Alcohol Abuse and Alcoholism (NIAAA): www.niaaa.nih.gov/
- National Organization on Fetal Alcohol Syndrome (NOFAS): <u>www.nofas.org</u>
- These sites link to many other Web sites

State level perspective

Janet Sharkis Leah Davies, LMSW TOPDD



- Mission: Minimize the human and economic losses caused by preventable developmental disabilities
- Created in 1989 by the Texas Legislature.
- State agency administratively attached to HHSC.
- Overseen by an Executive Committee, appointed by the Governor, Lieutenant Governor, and Speaker of the House.
- Identified the need for a statewide approach to planning around FASD in 2010.

Texas FASD Collaborative

The Collaborative is a group of approximately 50 active members from diverse professional backgrounds: legal and judicial professionals, mental and behavioral health providers, policy makers, interventionists, educators, etc.

Primary focus is gathering data and educating professionals about FASD. FASD Steering Committee

Texas FASD Collaborative

Data workgroup:
Making the case for FASD in Texas

Education workgroup:

Targeting medical professionals and those who work directly with women of childbearing age

Promotion workgroup:

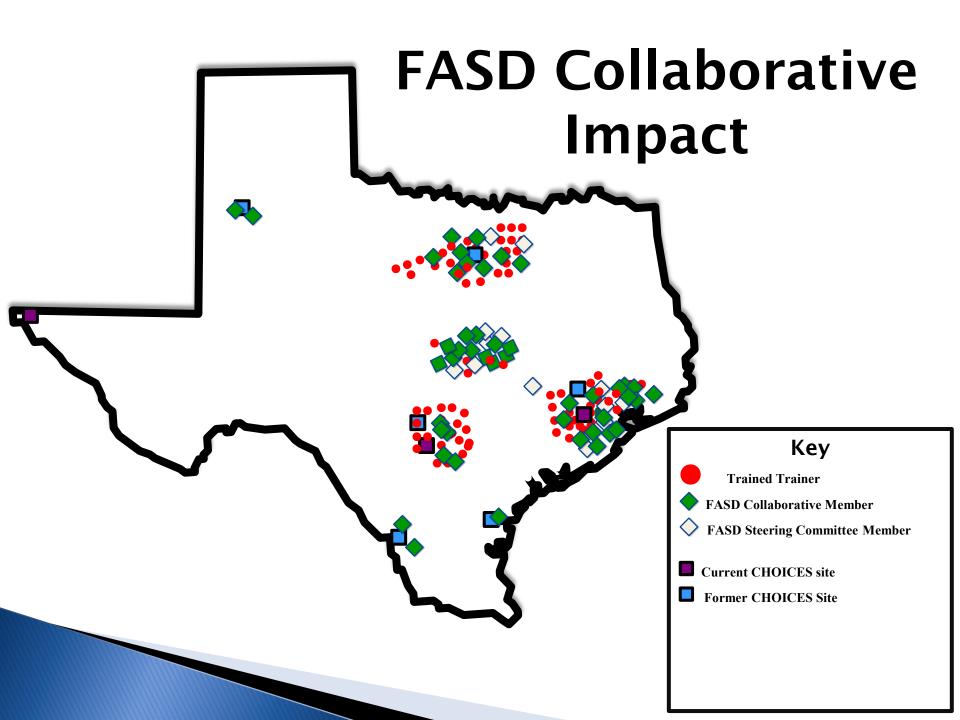
Getting the data and literature to the community and key stakeholders

Membership workgroup:

Identification, engagement, and retention of stakeholders

Highlights

- Project CHOICES
- Guthrie Card pilot
- ▶ 9/9 FASD Awareness Day events
- FASD Training of Trainers
- Modifications to Treatment efforts
- Education events for medical community
- MDT training for ITCs
- Hogg Foundation, Mental Health Policy Fellow



We would love your participation!



- Texas FASD Collaborative
- Medical Advisory Committee





Houston perspective



Nadine Scamp
Santa Maria Hostel



Santa Maria Hostel

The mission of Santa Maria is to empower women and their families to lead successful, productive, self-fulfilling lives

Santa Maria Hostel Programs

- Specialized intervention, treatment and recovery support services for women and women accompanied by their children
- One of the only residential substance use treatment programs that allows children to stay with the mother during treatment
- Parenting education, coaching and support to help mothers improve parenting skills
- Court liaison to prepare mother for and accompany mother to hearings, facilitate communication with CPS and courts
- Project CHOICES to educate mothers on alcohol use and pregnancy and to promote positive changes in related health behaviors
- Caring for Two Pregnant and Post Partum Intervention Program to provide individualized support, counseling and case management to atrisk families, including those involved with CPS
- Recovery support services including peer recovery coaching, housing, and alumni groups

FASD Screening and Modifications to Treatment Project

- Organization wide change process to implement an FASDinformed treatment center
- Change management team made up of employee stakeholders
- Identified process for screening, modifying treatment plans, and modifying program environment/structure
- Training for all staff, from receptionist to CEO
- Intensive training for direct care and clinical staff on treatment and program modifications



SMT Screen Results

- Screening from Feb-June 2014
- 166 women screened from all programs
- Of those, 46% had a positive screen for potential FASD
- For those in criminal justice programs, 62% had a positive screen



SMT Treatment Modifications - Staff

- 1. Teach staff how to recognize signs that the individual is becoming stressed, including how to intervene appropriately
- 2. Less clinical, more layman's terms
- 3. Checking in with the client on a daily basis
- 4. Model parenting skills
- 5. Incorporate more role play into sessions
- 6. Patience!



SMT Treatment Modifications - Clients

- 1. Have client repeat their understanding of instructions
- 2. Memory tools (calendars, white boards in rooms)
- 3. Teach individual to identify when he/she is getting upset and practice use of effective coping techniques
- 4. Model and have individual practice multiple relaxation techniques, retaining one or two strategies that are effective.
- 5. Help individual find extracurricular activities that are calming, fun, easy to access (arts, crafts, music, walking).



Conclusion

Success Stories - Jessica and Nina

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Questions/Thoughts



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