

A Method to Improve Outcomes in Treatment by Recognizing Fetal Alcohol Spectrum Disorders

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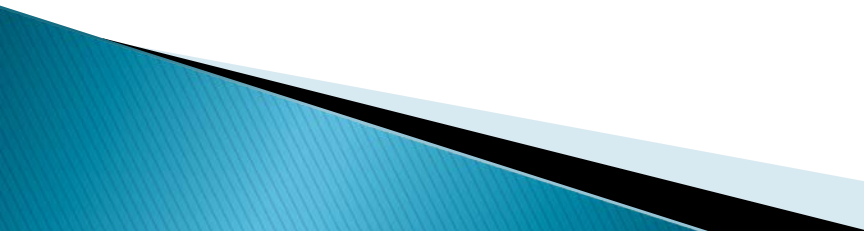
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Fetal Alcohol Spectrum Disorders (FASD)


- ▶ 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 expected in systems of care
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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 avoided or decreased
 - ▶ Diagnoses can be questioned
 - ▶ Approaches can be modified to optimize success
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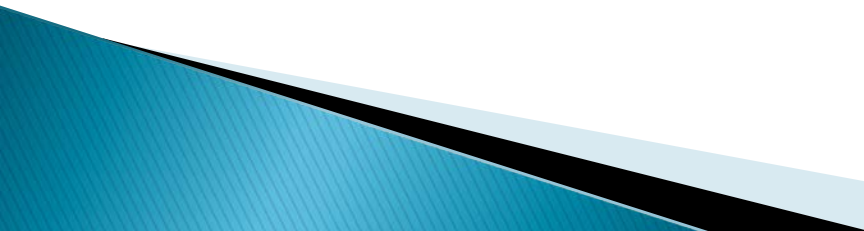
Consequences of Not Recognizing an FASD in an Individual

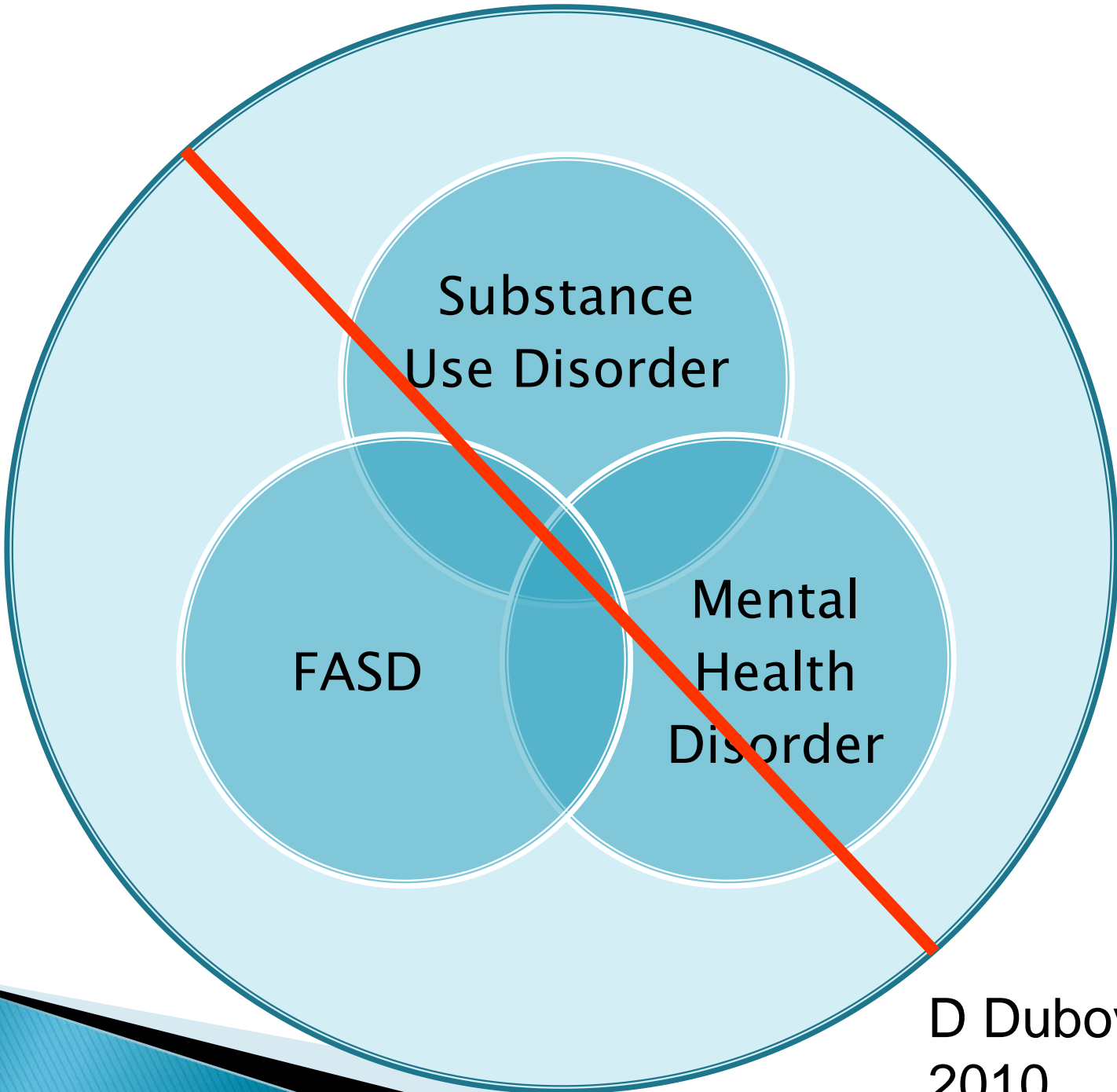
- ▶ Many moves as children
 - ▶ Repeated abuse and trauma
 - ▶ Fail with typical education, parenting, treatment, justice, vocational, and housing approaches
 - ▶ Think they are “bad” or “stupid”
 - ▶ High risk of being homeless, in jail, or dead
 - ▶ They are viewed as non-compliant and unmotivated
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Consequences of Not Recognizing an FASD in a Caregiver

- ▶ Labeled as neglectful, uncaring, or sabotaging
 - ▶ Removal of their children from their care
 - Frequently occurs with women in treatment
 - ▶ Fail to follow through with multiple instructions
 - ▶ Parental rights are terminated
 - ▶ Women may have another alcohol exposed pregnancy
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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
 - ▶ Treatment of co-occurring issues must be different if a person also has an FASD
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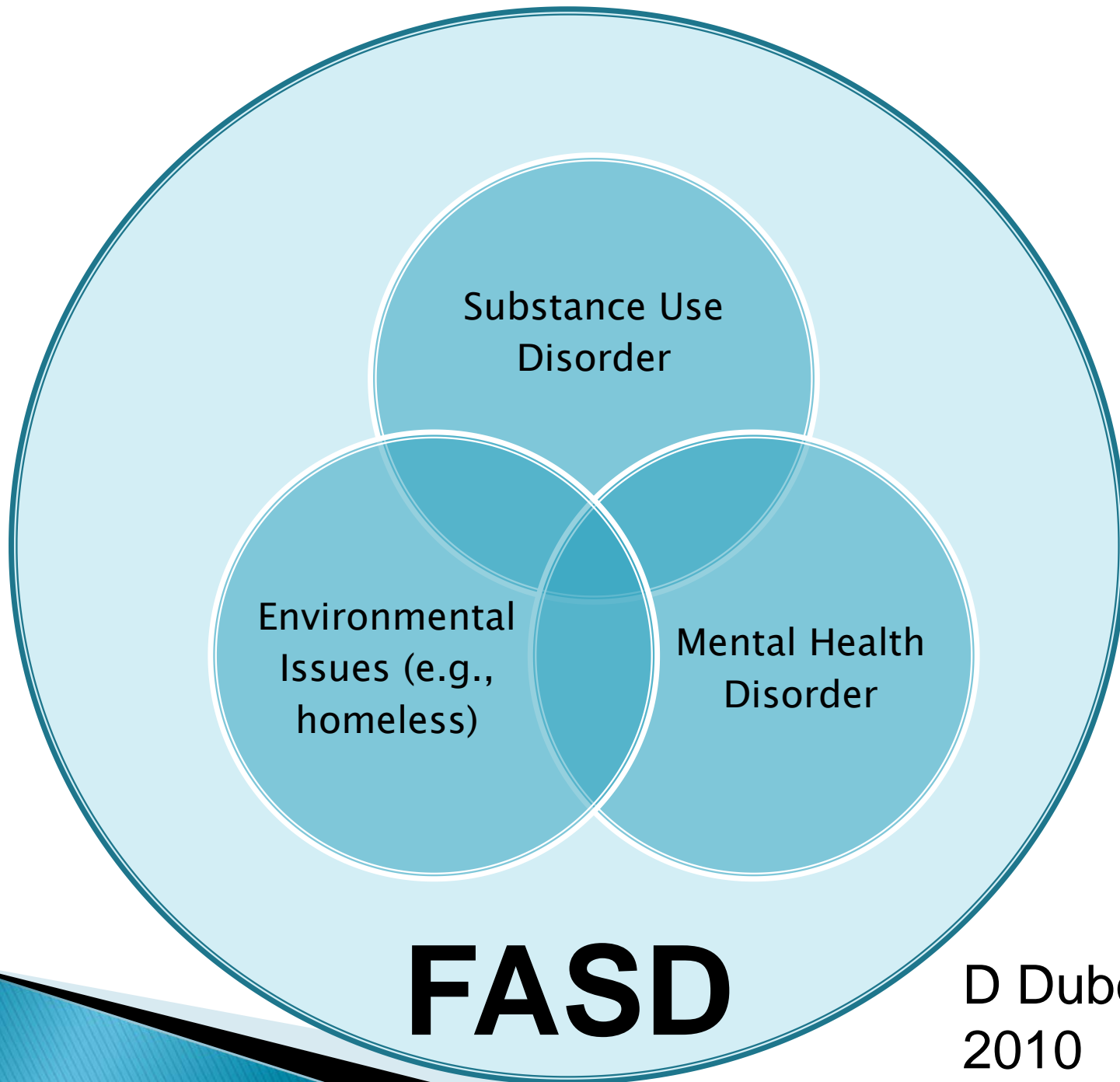


Substance
Use Disorder

FASD

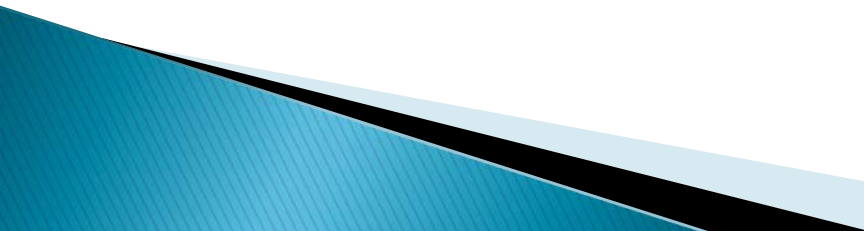
Mental
Health
Disorder

D Dubovsky
2010

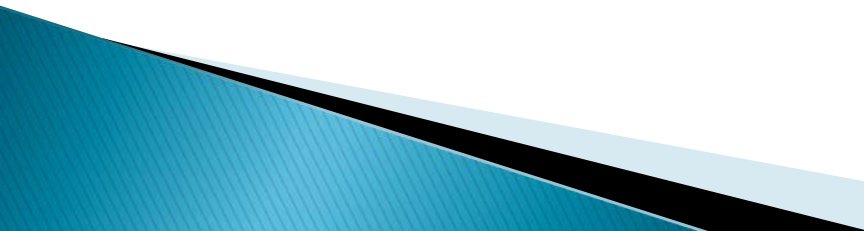


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So How Do We Recognize Individuals Who May Have an FASD?

- ▶ 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 we suspect an FASD
 - ▶ If prenatal alcohol exposure is known, it is very important to document it
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Screen for Identifying Individuals with a Possible FASD

- ▶ Called the Life History Screen (LHS)
 - ▶ Published in the International Journal of Alcohol and Drug Research
 - ▶ Aside from demographics, there are 30 questions in the current version of the screen, broken down into 9 categories
 - ▶ 11 of the questions are asked in the ASI
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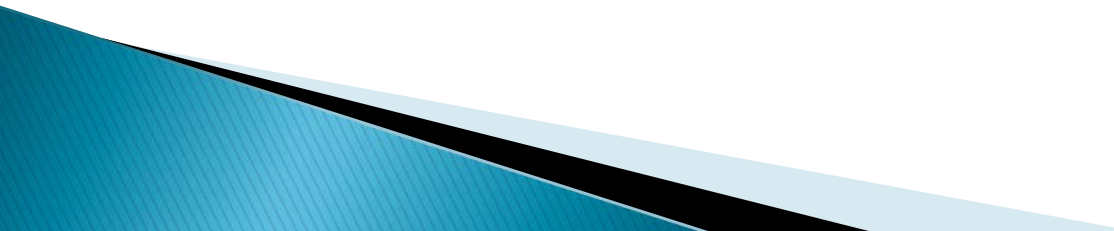
Life History Screen (LHS)

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

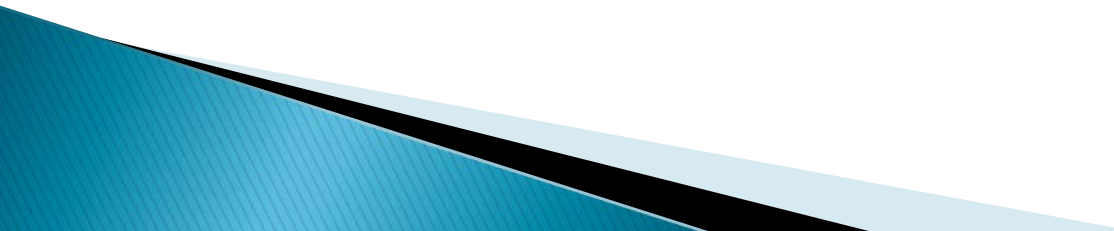
Life History Screen

- ▶ 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
 - ▶ These answers should be transferred to this form
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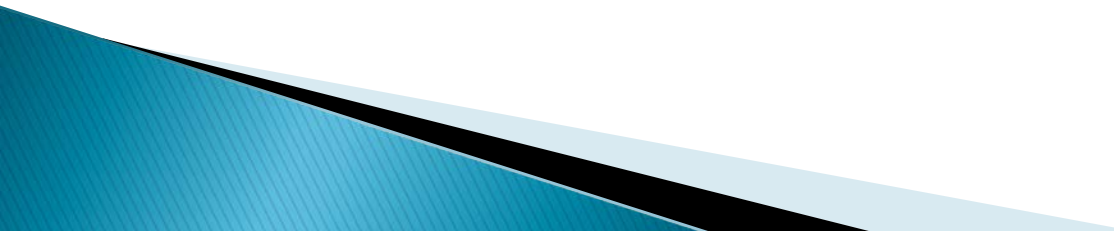
Life History Screen

- ▶ 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 meant to be a burden but rather a guide for future work
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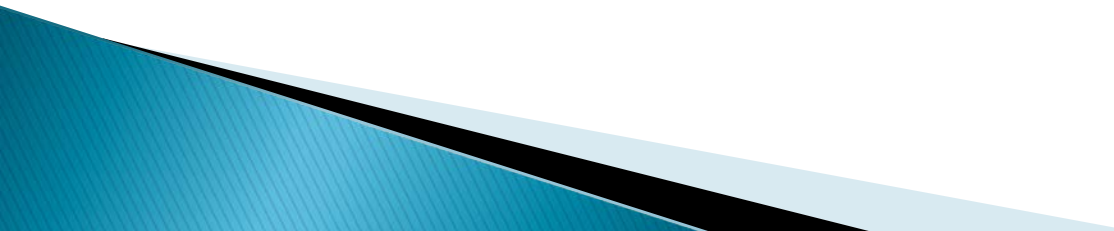
Life History Screen

- ▶ There are three key life history domains that have been identified through feedback from 22 residential substance abuse treatment centers
 - Childhood history
 - Maternal alcohol use
 - Day-to-day behaviors
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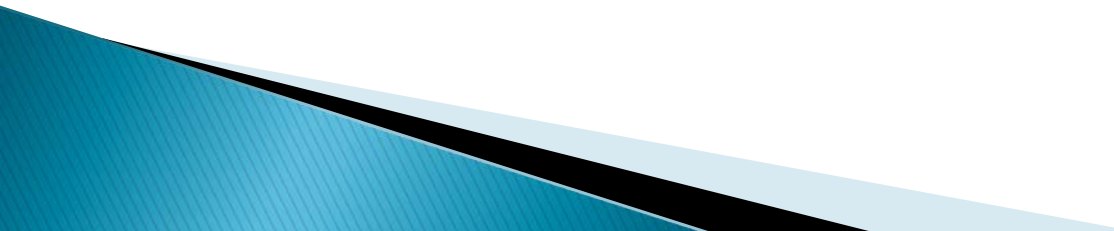
Life History Screen

- ▶ **Childhood history**
 - ▶ a. Were you raised by someone other than your biologic/birth parents?
 - ▶ b. How many living situations did you have while you were growing up (up to the age of 18)?
- 

Life History Screen

- ▶ **Maternal alcohol use**
 - ▶ a. To your knowledge, did your mother ever drink alcohol that caused problems for her or others around her?
 - ▶ b. Did she drink alcohol when you were young?
 - ▶ c. Did your mother drink alcohol while she was pregnant with you?
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Screen for Identifying Individuals with a Possible FASD

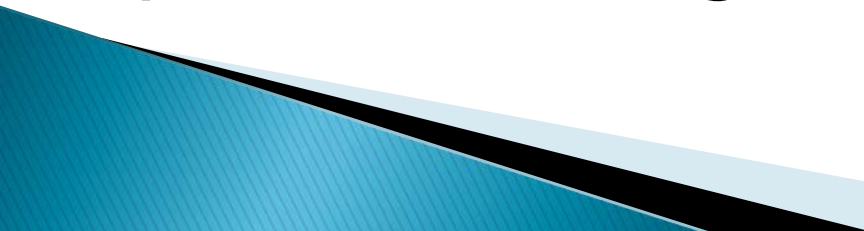
- ▶ **Day-to-day behaviors**
 - ▶ When you were a child in grade school, did you often have difficulties with any of the following?
 - Concentrating and paying attention?
 - Understanding what adults were telling you?
 - Remembering things?
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Life History Screen

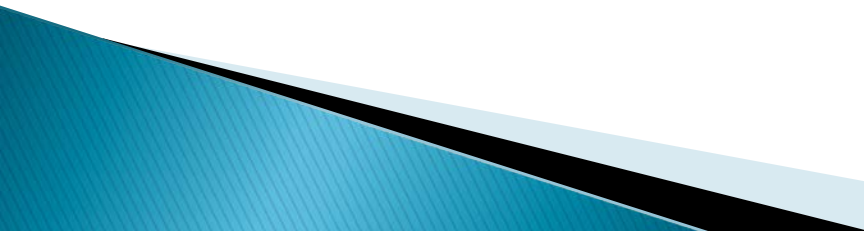
▶ Day-to-day behaviors

- ▶ As a child or as an adult have you often have difficulties with any of the following?
 - following rules and instructions
 - getting along with others without arguing or fighting
 - being on time
 - keeping enough money to last you throughout the month
 - doing things that later you wish you hadn't done
 - 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


Life History Screen

- ▶ 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
 - ▶ Validation of the screen and cut off points is being developed
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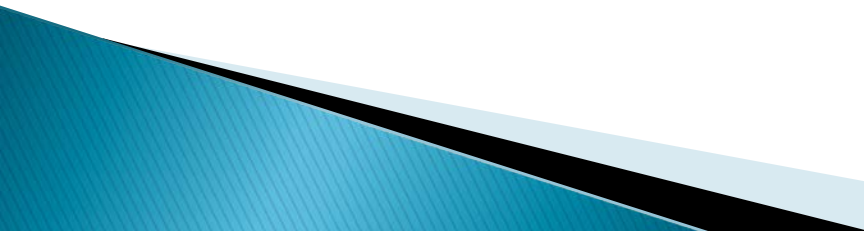
A Strengths Based Approach to Improving Outcomes

- ▶ 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
- 


Modifications to Approaches for Individuals with an FASD

- ▶ Modifications are based on scientific knowledge of brain damage in FASD
 - Anecdotal information reports the usefulness of these modifications
 - Proposals are being developed to do more testing of them
 - ▶ All modifications do not need to be used with every person
 - ▶ The team should identify the modifications to be implemented for a particular individual and family
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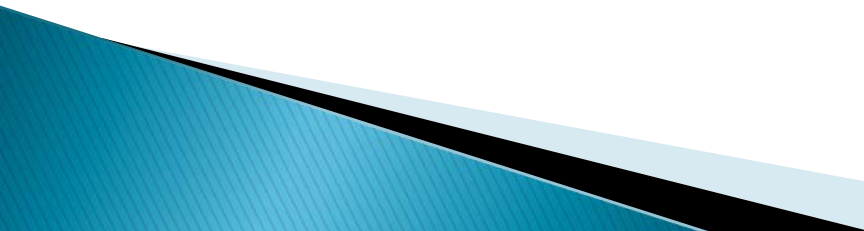
Modifications to Approaches for Individuals with an FASD

- ▶ Reduce stimuli in their environment
 - Their room
 - Treatment settings
 - Visuals
 - Sounds
 - ▶ Use softer lighting and colors
 - Avoid fluorescent lights
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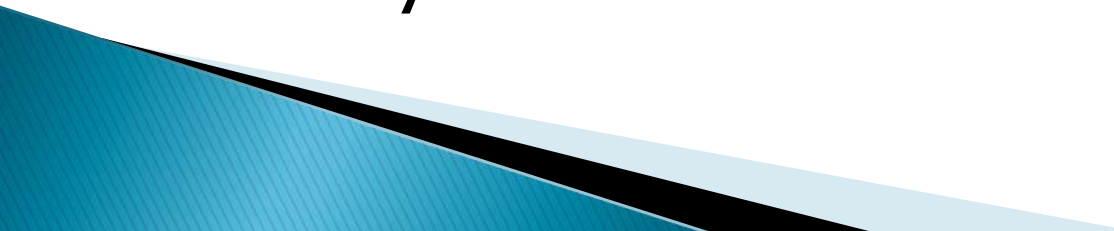
Modifications to Approaches for Individuals with an FASD

- ▶ 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
 - Work with the person to set reminders of when they have to leave for their appointments on their cell phone or other device
- 


Modifications to Approaches for Individuals with an FASD

- ▶ 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 or personnel repeatedly
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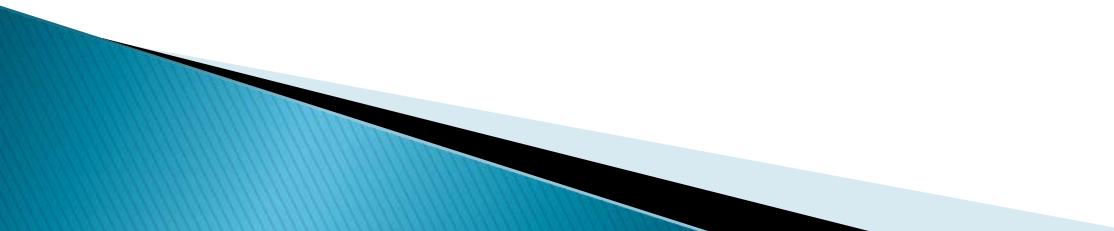
Modifications to Approaches for Individuals with an FASD

- ▶ 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 treatment buddy
 - ▶ 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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Modifications to Approaches for Individuals with an FASD

- ▶ Utilize a positive reinforcement system rather than a reward and consequence system
 - Do not use what the person likes as a reward for positive behavior and remove it for negative behavior
 - Find something the person likes to do and does well (that is safe and legal) and arrange to have the person do that regardless of behavior
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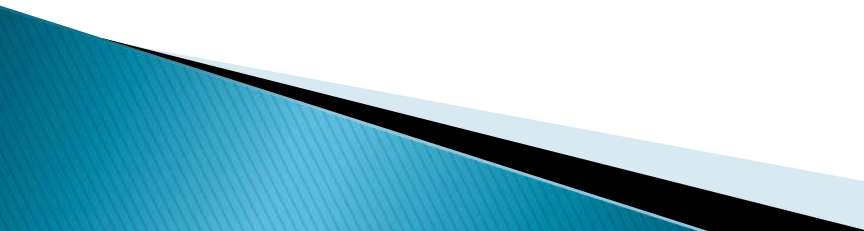
Modifications to Approaches for Individuals with an FASD

- ▶ If consequences need to be used, they should be immediate, related to what occurred, and completed preferably within the same day
 - ▶ Any time you need to tell someone “you can’t” you must also say “but you can”
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Modifications to Approaches for Individuals with an FASD

- ▶ Limit the number of plans and goals the person has
 - One overall integrated treatment plan is best
 - Provide a few steps at a time
- ▶ Plan carefully for groups
 - Shorter groups may be more useful
 - It may be helpful to have the person sit next to the facilitator in group
 - Use senses other than verbal
 - Allow them to take a break in the middle of group if necessary

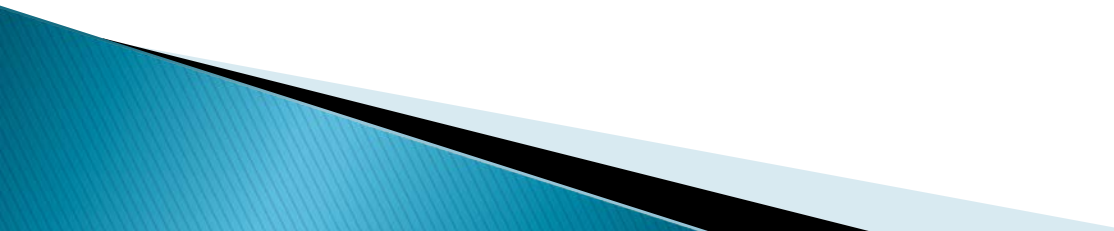
Modifications to Approaches for Individuals with an FASD

- ▶ Evaluate the person's ability to manage money
 - Natural consequences often set the person up to be homeless
 - Consider a representative payee if necessary
 - ▶ Complete forms and applications with the person
 - Sit in on appointments with the person when needed
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Modifications to Approaches for Individuals with an FASD

- ▶ Be careful about using 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 it

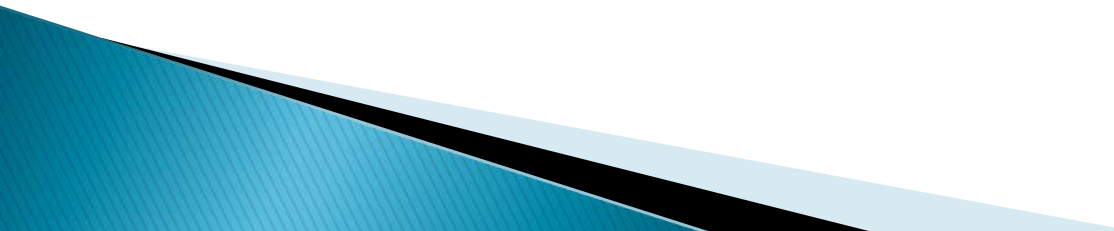
Situations That Rely on Verbal Receptive Language Processing

- ▶ 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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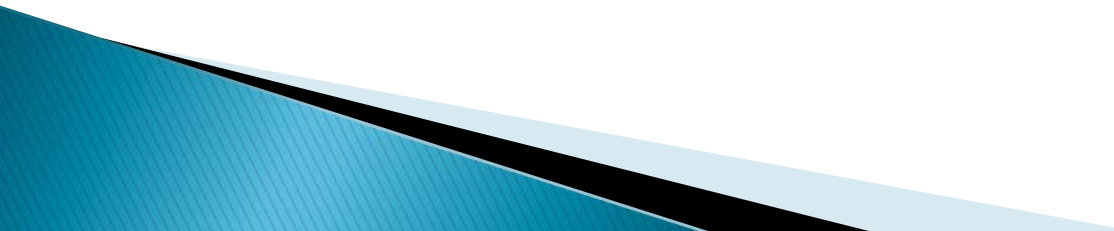
Strategies to Avoid for a Person with an FASD

- ▶ Don't just read a list of rules and regulations, hand the person a copy, and ask if they understand or have any questions
 - ▶ Don't give the person multiple directions or instructions
 - ▶ Don't assume that something learned in one situation will be able to be used in another
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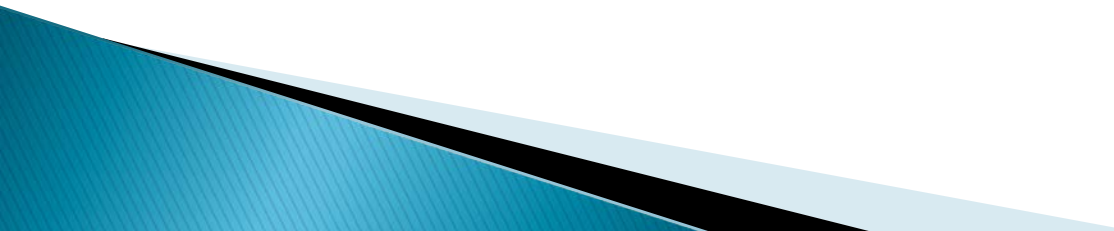
Strategies to Avoid for a Person with an FASD

- ▶ Don't set up a situation where the person is expected to think about things on their own and made decisions regarding their behavior and their life
 - ▶ Don't use what the person likes to do as a reward for good behavior and remove it for negative behavior
- 

Strategies to Avoid for a Person with an FASD

- ▶ Don't use long-term consequences or have a time gap between an action and the consequence
 - ▶ Don't use approaches that rely on verbal communication
 - ▶ Don't assume that not following through is a sign of a lack of motivation
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Strategies to Avoid for a Person with an FASD

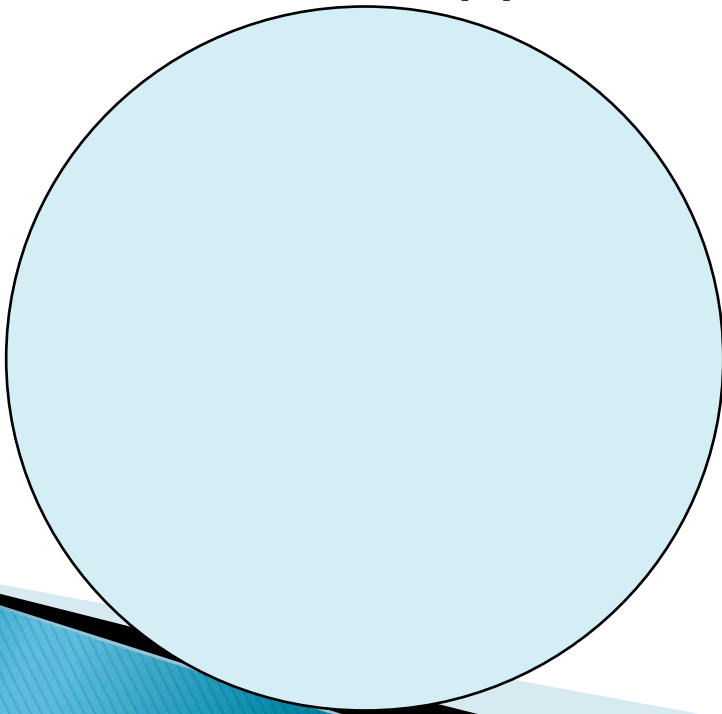
- ▶ Don't have a lot of stimuli
 - ▶ Don't change schedules for appointment days and times or activities
 - ▶ Don't have multiple plans with many goals
 - ▶ Don't use zero tolerance policies
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Circle and Fence

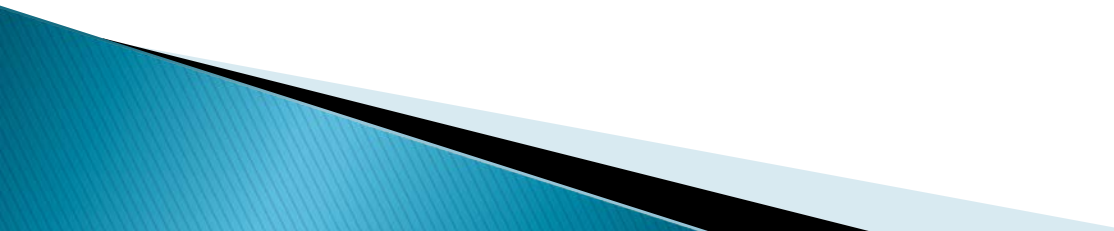
N Whitney 2010

- ▶ 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)


Circle of Support



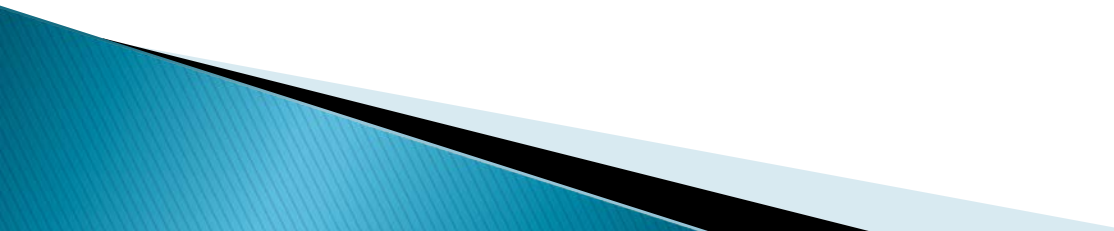
Additional Interventions to Consider

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


Final Thoughts to Keep in Mind

- ▶ Creativity is essential in the identification of services needed for the person with an FASD and her/his 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
 - E.g., the substance abuse and mental health treatment, child welfare, vocational, education, and justice systems
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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
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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 her/his best) and how do we help her/him achieve that
 - ▶ We need to foster **interdependence**
 - ▶ FASD is a human issue
 - It’s essential to really care
 - Recognizing and responding to FASD is a matter of life or death
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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: fasdcenter.samhsa.gov
 - ▶ 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
 - ▶ These sites link to many other Web sites
- 