

Making the Connection Between the Brain and Behavior as Key in Addressing Challenging Behaviors

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Objectives

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

- ▶ Identify the estimated prevalence of FASD in the overall population
- ▶ Describe brain issues that affect the behaviors of individuals with an FASD
- ▶ Discuss how viewing FASD as co-occurring with other disorders is different than the general view of addressing co-occurring disorders
- ▶ Describe a positive focused system of care
- ▶ List 4 strengths often seen in individuals 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, from mild to severe
 - They may be manifested differently
- ▶ There is no way to predict how much alcohol will cause how much damage in any individual
- ▶ FASD is a lifelong, full body disorder



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Fetal Alcohol Spectrum Disorders (FASD)

- ▶ Behavior often appears to be purposeful
- ▶ Typical approaches to “challenging” behaviors often don’t work
- ▶ Many individuals with an FASD have other difficulties
- ▶ Not all individuals prenatally exposed to alcohol have an FASD, but across the spectrum of FASD there is brain damage
- ▶ FASD does not excuse behavior, it explains behavior



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Diagnostic Terms

- ▶ Fetal Alcohol Syndrome (FAS)
- ▶ Fetal Alcohol Effects (FAE)
 - No longer used
- ▶ Partial Fetal Alcohol Syndrome (pFAS)
- ▶ Alcohol Related Neurodevelopmental Disorder (ARND)
- ▶ Alcohol Related Birth Defects (ARBD)
- ▶ Neurodevelopmental Disorder Associated with Prenatal Alcohol Exposure (NDD-PAE)



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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



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Incidence and Prevalence of FASD

- ▶ Much higher percentage in systems of care e.g.:
 - Special education
 - Mental health including domestic violence and trauma programs
 - Child welfare
 - Corrections, including drug, mental health, and family courts
 - Vocational services
 - Services for the homeless
- ▶ Majority undiagnosed



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Prevalence in Hawai'i

- ▶ Population of Hawai'i (2021): 1,442,000
 - At 5%, 72,100 people would have an FASD
- ▶ Women in Hawai'i (2020): 707,824
 - At 5%, 35,391 women would have an FASD
- ▶ Population of children birth–19 in Hawai'i (2020): 324,993
 - At 5%, there would be 16,249 children to age 19 with an FASD
- ▶ Number of births in Hawai'i (2020): 15,785
 - At 5%, 789 children would have been born with an FASD in 2020



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Alcohol Use in Hawai'i

- ▶ Prevalence of heavy drinking among adults in Hawai'i was 18.6% (NIH 2010)
- ▶ According to an American Addiction Centers study, from 2020–2021, Hawai'i increased its alcohol consumption by 23%



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Systems Impacted by FASD

- ▶ Every system of care is impacted by FASD
 - Parenting
 - Education
 - Mental health treatment
 - Substance use treatment
 - Child welfare
 - Justice – both juvenile and adult
 - Job training
 - Housing
 - Health care



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Chronological vs Functional Age

- ▶ Think about the functional age of the individual as well as the chronological age
 - The functional age is, in many ways, more important as the chronological age
 - People don't have the same functional age in every area of functioning
 - Functional age needs to be taken into account
 - Functional age does not mean that is the age you treat the person



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Chronological vs Functional Age for an 18 Year Old with an FASD

Adapted by Lakeland Centre for FASD from Streissguth and Clarren

- ▶ Expressive language..... 20 years
- ▶ Receptive language..... 8 years
- ▶ Reading ability..... 16 years
- ▶ Comprehension..... 6 years
- ▶ Money/time concepts..... 8 years
- ▶ Physical maturity..... 18 years
- ▶ Emotional maturity..... 6 years
- ▶ Social skills..... 7 years
- ▶ Daily living skills..... 11 years



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Adaptive Functioning in FASD

LaDue, Streissguth et al 1992

Vineland Adaptive Functioning Scale	Mean Chronological Age	Age Equivalent
Communication Domain (written & verbal)	17.3 years	8.1 years
Socialization Domain (interpersonal skills; ability to follow social rules)	17.3 years	6.9 years
Daily Living Domain (hygiene, household tasks, use of money & time, job skills)	17.3 years	9.2 years
Composite Score	17.3 years	8.0 years

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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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Roles for People Living/Working with Individuals with an FASD

- ▶ Identifying a probable FASD in the individual
- ▶ Forming trusting relationships with these people with whom you are working
- ▶ Helping them understand why they've had some of the difficulties they've had and how they learn best
- ▶ Identifying and building on strengths



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Roles for People Living/Working with Individuals with an FASD

- ▶ Educating significant others about FASD
- ▶ Identifying a possible FASD in family members and significant others
 - Including children
- ▶ Educating other providers (e.g., child welfare, corrections, vocational rehabilitation, housing, education) about FASD and how to best support these individuals and their families



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Roles for People Living/Working with Individuals with an FASD

- ▶ Acting as a role model and mentor for the individual in how to respond in varying situations
- ▶ Sharing information about prevention
- ▶ Considering a diagnostic evaluation where appropriate and possible
 - Do not wait for this to intervene
- ▶ Providing warm handoffs
- ▶ Addressing issues of stigma



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The Importance of Raising Awareness of Stigma

- ▶ Stigma impacts individuals' feelings about themselves
- ▶ Stigma impacts people's feelings and beliefs about others
- ▶ Stigma causes people to make sweeping judgements of whole groups of people
- ▶ Stigma impacts individuals' decisions regarding seeking treatment
 - E.g., medical; mental health



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Groups that Experience Stigma

- ▶ Individuals with mental illness
- ▶ Individuals with intellectual disabilities
- ▶ Individuals with physical disabilities
- ▶ Individuals with FASD
- ▶ Individuals with substance use disorders
- ▶ Individuals who are, or have been, in detention or jail
- ▶ Individuals who are LGBTQ
- ▶ Individuals of differing cultures
- ▶ Individuals who look different

▶ Anyone who is different



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Societal Impacts on Stigma

- ▶ Media
 - News reports
 - TV shows
 - SNL
 - Advertisements
 - Prevention messages
 - Medical literature
- ▶ Political individuals and groups
- ▶ Religious groups



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Methods to Reduce Stigma

- ▶ Recognize that we all have a role in addressing stigma
- ▶ Be aware of your own attitudes
- ▶ Educate yourself and others
- ▶ Model appropriate language
 - Use person first language
 - Avoid grouping people
- ▶ Address misperceptions from others
- ▶ Focus on positives
- ▶ Create an inclusive environment



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Recovering Mothers Anonymous

- ▶ Meeting every Thursday at 7 PM Eastern time
- ▶ Treatment centers participate
- ▶ Developed and coordinated by Kathy Mitchell, birth parent and vice-president and spokesperson of NOFAS for years
- ▶ www.Recoveringmothers.org
- ▶ Ktmitchellconsulting@gmail.com



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Importance of Preventing FASD: Facts to Consider

- ▶ Preventable
- ▶ No known safe amount of alcohol or safe time during pregnancy
- ▶ Of all drugs of abuse, alcohol causes the most serious neurobehavioral damage
 - New research on cannabinoids and alcohol
- ▶ First weeks of fetal development are critical
- ▶ Most people don't recognize pregnancy this early in fetal development



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Importance of Preventing FASD: Facts to Consider

- ▶ Close to 50% of pregnancies are unplanned
- ▶ FASD can occur in any community
- ▶ Men have a role
 - Genetics
 - Epigenetics



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Recognition of Pregnancy

Phil May, Presentation for North Carolina Conference 2020

- ▶ Mothers who gave birth to children with:
 - FAS: 8.3 weeks
 - pFAS: 6.9 weeks
 - ARND: 8.0 weeks
 - Controls: 5.7 weeks



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Past Month Substance Use in Ages 12 and Up: 2018 Data

National Survey on Drug Use and Health (August 2019)

- ▶ Alcohol: 139.8 Million
- ▶ Tobacco: 58.8 Million
- ▶ Marijuana: 27.7 Million
- ▶ Rx Pain Reliever Misuse: 2.9 Million
- ▶ Heroin: 354,000



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Alcohol Use During the Pandemic

- ▶ Day drinking is more popular
 - ▶ Increased social media “jokes” about drinking during the day
 - ▶ Zoom happy hours
 - ▶ 54% increase in national sales of alcohol for the week ending March 21, 2020 compared to one year earlier
 - ▶ 262% increase in online sales from 2019
- JAMA Netw Open 2020 3(9) e2022942



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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 (PCAP)—a 3-year case management model for women at highest risk



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Alcohol and Women

- ▶ All beverages with alcohol are harmful to the fetus
 - E.g., wine spritzers, beer, wine, mixed drinks
- ▶ A drink ≠ a drink ≠ 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



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Possible Protective Factors

- ▶ Good prenatal care
- ▶ Antioxidants
- ▶ Choline
- ▶ Zinc
- ▶ Iron



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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



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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
 - Are viewed as being non-compliant or uncooperative with treatment plans, child welfare instructions, or court orders
 - Have children removed from their care
 - Fail to follow through with multiple instructions
 - Have parental rights terminated



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Thinking and Behaviors of Parents with an FASD That Can Lead to Difficulties

- ▶ Viewed as being non-compliant and uncooperative with service/treatment plans
- ▶ May end up in drug court due to substance issues
- ▶ May end up in mental health court
- ▶ May end up in family court due to issues with their youth
 - Will not follow what is occurring in court
 - Will not follow through with instructions
 - May be jailed and/or have youth removed from their 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
- ▶ Abuse and trauma can be decreased or avoided
- ▶ Approaches can be modified
- ▶ Diagnoses can be questioned



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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 is extremely limited
- ▶ A screening protocol is important in identifying individuals who have a probable FASD
- ▶ A screen is not diagnostic but can indicate that a person may well have an FASD
- ▶ A positive screen has to result in modification of approaches



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Screen for Identifying Individuals with a Probable FASD

- ▶ In response to requests from substance use treatment providers, we developed the Life History Screen to identify older adolescents and adults who have a probable FASD
- ▶ There are questions in 9 categories
- ▶ The screen is to be given to everyone
- ▶ How questions are asked and explained is an essential component to training on the screen
- ▶ The comfort of the interviewer is key

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Life History Screen

- ▶ We recognized that the screen will most likely identify others with subtle cognitive impairments that impact interventions
- ▶ The screen is not meant to be a burden but rather a guide for future work
- ▶ A German study has been done to validate the LHS
 - 92.8% of all participants were correctly identified using the LHS
- ▶ A modification of the LHS has been developed for children and adolescents for Michigan DHHS

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Recognizing Those with an FASD

- ▶ Once we recognize those with an FASD, we need to implement modifications to approaches
- ▶ We need to modify the environment rather than expecting the individual to change their behavior
 - **We** need to change what **we** do and how **we** do it
 - We need to identify and build on their strengths and abilities

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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

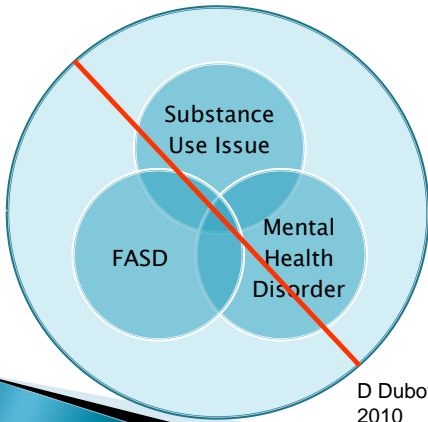
- ▶ Our values and biases may come into play
 - About behaviors
 - About drinking during pregnancy
 - Stigma gets in the way
- ▶ It may bring up issues in our own lives
- ▶ It means re-examining our practices
- ▶ It is easier to view the person as having the responsibility to change
- ▶ We think we need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

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Challenges in Recognizing FASD

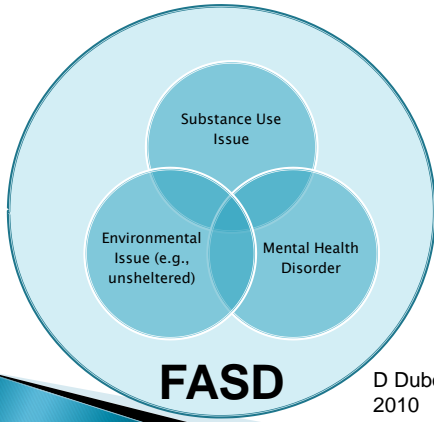
- ▶ In order to improve outcomes, the concepts of dependency and enabling as negative terms need to be re-thought
 - Taking someone to their appointment, checking on the person regularly, or filling out forms with them may be what the person needs
- ▶ Treatment of co-occurring issues must be different if a person also has an FASD

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D Dubovsky 2010

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D Dubovsky 2010

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Common Misdiagnoses for Individuals with an FASD

- ▶ ADHD
- ▶ Oppositional Defiant Disorder
- ▶ Conduct 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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Common Misdiagnoses for Individuals with an FASD

- ▶ Adolescent depression
- ▶ Bipolar disorder
- ▶ Intermittent Explosive Disorder
- ▶ Autism/High Functioning Autism
- ▶ Reactive Attachment Disorder
- ▶ Traumatic Brain Injury
- ▶ Antisocial Personality Disorder
- ▶ Borderline Personality Disorder

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Similarities Between FASD and Autism

- ▶ Both are developmental disabilities
- ▶ Both affect normal brain function, development, and social interaction
- ▶ In both, the individual often has difficulty developing peer relationships
- ▶ In both, there is often difficulty with the give and take of social interactions
- ▶ In both, there are impairments in the use and understanding of body language to regulate social interaction

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Similarities Between FASD and Autism

- ▶ In both, there is difficulty expressing needs and wants, verbally and/or non-verbally
- ▶ A short attention span is often seen in individuals with Autism and an FASD
- ▶ In both, we may see an abnormal sensitivity to sensory stimuli, including an over- or under-sensitivity to pain



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Differences Between FASD and Autism

FASD	Autism
Difficulties begin at birth	Difficulties may begin after a period of normal growth
Able to relate to others	Difficult or impossible to relate to others in a meaningful way
Stereotyped movements not typically seen	Stereotyped movements e.g., hand flapping; toe walking
Spoken language, although at times slow to develop, is typical	Difficulty in both verbal and non-verbal communication



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Differences Between FASD and Autism

FASD	Autism
Spontaneously talkative	Robotic, formal speech and echolalia
Social and outgoing	Often aloof, preferring to be alone
Expresses a range of emotions	Restricted in emotional expression
Funny; good sense of humor	Difficulty expressing humor
Microcephaly more common	Macrocephaly more common



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Importance of Understanding Normal Child and Adolescent Development

- ▶ If a person has behavioral issues, we often do not stop to consider whether some of the person's behaviors might be "normal" for a certain developmental stage, regardless of the person's chronological age
- ▶ Recognizing this we can begin to separate out "normal" behaviors and not respond to them as "the beginning of the end"
- ▶ We can help the person work through some developmental issues from earlier in their life



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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 Damage in FASD That Impacts Behavior

- ▶ Damage to working memory
 - Inability to follow multiple directions
 - Seen as oppositional rather than that they don't remember what they need to do
- ▶ Damage to the ability to recognize danger and fear and know what to do
 - Repeatedly put themselves in dangerous situations with dangerous people



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Brain Damage in FASD That Impacts Behavior

- ▶ Damage to abstract thinking
 - Difficulty with a sense of time
 - E.g., keep changing their story as to when and where something happened resulting being seen as lying
 - Dismissed as a victim or witness; not believed when accused of being a perpetrator
 - Difficulty with a sense of space
 - May stand much too close to others, being seen as challenging them



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Brain Damage in FASD That Impacts Behavior

- ▶ Damage to abstract thinking
 - Take words and expressions very literally
 - Cannot predict the consequences of their actions
 - Are surprised when they are in trouble even if they have gotten into trouble for the same thing before
 - May not recognize what can get them in trouble with the law
 - E.g., sending nude self photos; viewing and sharing porn; driving a getaway car; doing what a friend asks



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Brain Damage in FASD That Impacts Behavior

- ▶ Damage to the ability to apply what is learned in one situation to another
 - If they are told not to associate with a specific person, they might associate with a similar person
 - Cannot take what a judge says and apply it later
 - Ordering parents to parenting classes isn't effective



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Brain Damage in FASD That Impacts Behavior

- ▶ Damage to the parts of the brain responsible for the expression of emotion
 - Appear to be disinterested in court
 - May laugh when they hurt someone
 - May laugh when someone is talking to them about the seriousness of their actions
 - This is seen as a lack of conscience and remorse
 - May walk around with an angry expression when not angry



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Brain Damage in FASD That Impacts Behavior

- ▶ Damage to the systems that control stress and anxiety
 - Results in over-reacting to minor stressful situations due to an over-release of a hormone
 - E.g, someone bumps into him or her and they punch, kick, or stab the person; there's a change in their schedule or those around them and they melt down; someone touches their things and they attack
 - This is seen as purposeful behavior rather than the physiological body response that it is



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Brain Damage in FASD That Impacts Behavior

- ▶ Damage to the ability for messages to correctly get transmitted in the brain
 - Results in slow reaction time which is often perceived as willful refusal
 - E.g., police officer tells the person to move and they don't move immediately; they are told what to do and don't respond immediately
- ▶ Damage to the ability to process humor
 - They will laugh along with a person joking with them but perceive that the person hates them or is out to get them



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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
- ▶ 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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Sayings That May Be Misinterpreted

- ▶ Clean your room
- ▶ Take a shower
- ▶ Go take a hike
- ▶ Go to your room and think about what you did wrong
- ▶ Behave yourself
- ▶ Come over anytime
- ▶ Don't drink and drive
- ▶ Follow the rules
- ▶ Do what I told you to do



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Prevalence of FASD in Substance Use Treatment

- ▶ Estimates of those with FASD who have substance use issues are 35%
- ▶ For those in substance use treatment who do not do well with typical treatment modalities, it could be that 50% or more may have an FASD
 - Especially those who are in treatment for the third or more time
- ▶ The majority of individuals with an FASD are not diagnosed



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Importance of Addressing FASD in Substance Use Treatment

- ▶ Individuals with an FASD are at high risk of substance use disorders
 - They experience most of the vulnerabilities
- ▶ Typical treatment modalities such as cognitive behavioral therapy, group therapy, motivational interviewing and reward and consequence are not effective due to brain functioning in FASD
- ▶ Family members may have an unrecognized FASD



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Factors that Contribute to Vulnerability to Substance Use

Brenda Knight and Dan Dubovsky

- ▶ Genetics
- ▶ Mental health
- ▶ Physical health
- ▶ Exposure to social, emotional, physical and/or sexual trauma
- ▶ Attachment issues
- ▶ Brain function



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Factors that Contribute to Vulnerability to Substance Use

Brenda Knight and Dan Dubovsky

- ▶ Effects of living with chronic pain, sleep problems and fatigue
- ▶ Difficulties with emotional regulation
- ▶ Perseveration in behavior
- ▶ Poor nutrition
- ▶ Living with a hidden disability
- ▶ Feeling overwhelmed with daily issues
- ▶ Feeling hopeless



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Factors that Contribute to Vulnerability to Substance Use

Brenda Knight and Dan Dubovsky

- ▶ Family patterns of alcohol or other substance use
- ▶ Social and/or spiritual isolation
- ▶ The COVID pandemic
- ▶ Exposure to destructive role models
- ▶ Peer pressure
- ▶ Financial instability
- ▶ Lack of access to appropriate supportive housing in safe neighborhoods



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Difficulties in Treatment for Individuals with an FASD

Dubovsky (2000)

- ▶ Sporadic in keeping appointments
- ▶ Uneven follow-through with treatment plans
- ▶ Difficulty with multiple tasks
- ▶ Say they understand and know what they need to do when they don't
- ▶ Misinterpret others' words, actions or body language



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Difficulties in Treatment for Individuals with an FASD

Dubovsky (2000)

- ▶ Consistently get into difficulty with others
- ▶ Do not succeed in reward and consequence systems
 - Most of our programs utilize some type of reward and consequence system
- ▶ Have difficulty changing behavior in different situations



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Difficulties in Treatment for Individuals with an FASD

Dubovsky (2000)

- ▶ Viewed as manipulative, unmotivated and non-compliant
- ▶ Difficulty doing things on their own
- ▶ Cannot take what they hear in group and think about what that has to do with them
- ▶ Very literal in their thinking
 - We often use abstract concepts



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Difficulties in Treatment for Individuals with an FASD

Dubovsky (2000)

- ▶ Problems in 12 step programs
 - 90 meetings in 90 days
 - Take the initiative to attend and find a sponsor
 - Relies on inner reflection and individual processing of information
 - Need to be independent and self-motivated to succeed



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Difficulties in Treatment for Individuals with an FASD

Dubovsky (2000)

- ▶ Wander away, “fade out,” “space out,” and/or talk inappropriately in group situations
- ▶ Need a tremendous amount of one-to-one support
- ▶ Seem to have the same issues from week to week
- ▶ They “just don’t get it”



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Difficulties in Job Situations for Individuals with an FASD

Dubovsky (2000)

- ▶ Misinterpret others’ words, actions or body language



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Misinterpreting Others' Words or Actions

Dubovsky (2003)

- ▶ Someone stares at them and they think they are angry at them
- ▶ The boss yells and they take it personally
- ▶ A customer is having a bad day and they think it has to do with them
- ▶ A customer complains and s/he thinks the person is mad at her/him and yells at the customer



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Difficulties in Job Situations for Individuals with an FASD

Dubovsky (2000)

- ▶ Difficulty with multiple directions
 - Especially when verbal
- ▶ Do not ask for help when needed
 - They don't want anyone to know there is anything different about them
 - Better to be seen as "bad" than "stupid" in their words
- ▶ Seen as lazy, uncooperative and unmotivated
- ▶ They "just don't get it"



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Difficulties Managing Money for Individuals with an FASD

Dubovsky (2000)

- ▶ Spend all their money in the first week or so of the month
- ▶ Repeatedly ask for help with money for food or housing
- ▶ Whatever is in their pockets is spent
- ▶ An ATM card entitles one to take money out of the bank (even if they don't have the money in the bank)
- ▶ They "just don't get it"



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Reasons for Increased Interactions With the Justice System

Adapted by D Dubovsky From Conry Et Al (1997)

- ▶ Poor judgment
- ▶ Impulsiveness
- ▶ Desire to be liked
- ▶ Problems with social cues
- ▶ No filtering mechanism between what they think and what they say
- ▶ Inability to recall proper actions when needed
- ▶ Better to be seen as “bad” rather than “stupid”
 - Don’t want anyone to know they don’t understand



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Reasons for Increased Interactions With the Justice System

Adapted by D Dubovsky From Conry Et Al (1997)

- ▶ Inability to anticipate the consequences of their actions
 - Get arrested multiple times for similar crimes
- ▶ Little concept of the effect of their behaviors or actions on others
- ▶ Their verbal expressive language is much better than their receptive language
 - They come across as more intact than they are
 - They cover up for lack of understanding
- ▶ Physical response due to history of abuse



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Reasons for Increased Interactions With the Justice System

- ▶ Don’t understand Miranda rights read to them
- ▶ Will agree to what happened even if they didn’t do it
 - Will say what they think the person wants to hear
- ▶ Not believed as they keep changing their story
- ▶ Dress inappropriately for court
- ▶ Appear to be disinterested in court
 - Have difficulty following verbal discussions



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What to Expect from a Person with an FASD

- ▶ Risk of issues around sexuality
- ▶ Issues with social media
- ▶ Suicide risk
- ▶ Sleep disturbances



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Issues in Sexuality for Those with an FASD

- ▶ Risk for HIV and sexually transmitted infections
 - Difficulty avoiding dangerous situations
 - Difficulty negotiating safe sex
 - Difficulty remembering to use safe sex techniques
- ▶ Risk of involvement in sex trafficking
- ▶ Risk of unwanted pregnancy



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Social Media Risks for Those with an FASD

- ▶ Naïvete and gullibility lead to believing anything someone writes
- ▶ Belief that information is not available for more than a brief moment on sites such as snapchat
- ▶ Poor judgement in information to share or not share
- ▶ Difficulty recognizing dangerous people or situations



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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



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Sleep

- ▶ Sleep is a universal process across species
- ▶ It is regulated by a circadian clock
- ▶ The regulator of this is in the hypothalamus
- ▶ Prenatal alcohol exposure can damage the part of the hypothalamus that regulates the circadian clock thereby disrupting sleep
- ▶ Disruption in the circadian system can have a negative impact on neuropsychological and social functioning, mood regulation, and affect



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Sleep

- ▶ There are three stages of sleep:
 - Rapid Eye Movement (REM) sleep or active sleep
 - Non-REM (NREM) or quiet sleep
 - Transitional sleep: transitions between wake and sleep
 - The typical sleep cycle is 90 minutes



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Sleep and FASD

- ▶ Current estimates are that 51%–85% of individuals with an FASD have sleep disturbances
- ▶ These are often not recognized, especially in young children
- ▶ Sleep health is sorely neglected
- ▶ Individuals often assume that sleep disturbances are just part of life and don't mention them to providers
- ▶ Providers often don't understand sleep issues



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Types of Sleep Disturbance Reported in FASD

- ▶ Difficulty falling asleep
- ▶ Fragmented sleep
 - Shortened sleep duration
 - Night wakings
- ▶ Sleep anxiety
- ▶ Parasomnias
 - E.g., bedwetting, talking in sleep, night terrors
- ▶ Increased levels of arousal from sleep
- ▶ Sleep disordered breathing
- ▶ Melatonin secretion abnormalities

Goril et al (2016), Kheirandish et al (2006), and Wengel et al (2011)

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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
- ▶ We use what the person likes to do and does well as the motivating factor
- ▶ If he or she does not respond, we say that we haven't found the right motivating factor



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Issues in Addressing Behaviors

- ▶ Although this approach may work for some people, it is not effective with many with an FASD and many others
- ▶ If someone has difficulty in abstract thinking, they often do not know why they do not get the rewards
- ▶ There are really only two explanations if one does not get cause and effect
 - People are mean for no reason
 - They are “bad”



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Issues in Addressing Behaviors

- ▶ With repeated similar experiences, thinking they are “bad” may become their self image
- ▶ People work hard at doing things to support their self image
- ▶ Much of this is not conscious



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Issues in Addressing Behaviors

- ▶ We are a problem based society
- ▶ Professionals get paid for dealing with problems
- ▶ Meetings focus on problems
- ▶ Policies, procedures, and handbooks for many treatment programs focus on negative approaches
 - Consequences for certain behaviors
 - Many rules and what happens when they are broken



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Issues in Addressing Behaviors

- ▶ Many individuals with an 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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Issues in Addressing Behaviors

- ▶ We need to change 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
 - This is an ongoing process
- ▶ Point out small accomplishments
- ▶ This does not mean ignoring challenging behaviors



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A Positive Focused System

- ▶ Revise policies and procedures to be more positively focused
- ▶ Revise client handbooks to utilize more positive language and convey the concept that those in the program have strengths and abilities that the program will focus on supporting and growing



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Strengths

- The first step in helping someone to succeed is to identify strengths and abilities
- Everyone has strengths
- Sometimes, they get the person into difficulty
- There are times when the individual and those around cannot identify any strengths
- Our systems do not encourage the identification of strengths



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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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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



D. Dubovsky, Drexel University College of Medicine (1999)

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Strategies for Individuals with an FASD

- Reduce stimuli in the environment
 - Their room
 - Classrooms
 - Treatment settings
- Use softer lighting, colors, and sounds
 - Avoid fluorescent lights
- Be consistent in mealtimes, bedtimes, and other routines
- Any time you need to tell someone “you can’t” you must also tell them “but you can”



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Strategies for Individuals with an FASD

- Avoid using a reward and consequence system
 - Beginning sentences with “if” or “when”
- If consequences need to be used, they should be immediate, related to what occurred, and brief
- **Do not** ignore negative attempts for attention



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Addressing Sleep Disturbances

- ▶ Identify issues regarding sleep
 - Getting to sleep; staying asleep; early wakening
 - Respiratory issues during sleep
- ▶ Evaluate environmental issues that impact sleep
- ▶ Implement sleep hygiene based on the individual
- ▶ Medication may be useful depending on the sleep issues
 - E.g., melatonin may be useful for getting to sleep but not for staying asleep
 - If Restless Leg Syndrome is an issue, iron deficiency may be an issue

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Sleep Hygiene

- ▶ Establish a consistent bedtime routine
- ▶ Avoid big meals close to bedtime
- ▶ Avoid caffeine
- ▶ Comfortably cool bedroom
- ▶ Dark bedroom
- ▶ Quiet bedroom
- ▶ No TV/media in bedroom

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Sleep Hygiene

- ▶ Exercise in morning or late afternoon
- ▶ Ensure adequate exposure to natural light
- ▶ Maintain emotionally stable and positive tone
- ▶ Associate bed and bedroom with sleep
 - Don't use bedroom for punishment or play
- ▶ Use of a transitional object
- ▶ Review medications with physician as needed.

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Sleep Hygiene

- ▶ Use earplugs or a white noise machine to block out sounds from the environment
- ▶ Use a soft night light if there is fear of the dark
- ▶ Broad spectrum light therapy
- ▶ Be aware of sensory issues
 - No bright colors or patterns on walls, linens
 - Same soothing color on walls and linens
 - Remove tags and wrinkles
 - Be aware of issues relating to smells such as perfumes, soaps, laundry detergent, foods
 - Few toys in the room

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The Lay of the Land Health Survey Take Aways

Himmelreich, Lutke, and Hargrove (2020)

- ▶ Individuals with an FASD have significantly higher prevalence of many health issues than the general population
- ▶ Many individuals with an FASD experience significant health issues
- ▶ FASD is a “whole body disorder”
- ▶ Individuals with an FASD may not recognize their health issues

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The Lay of the Land Health Survey Take Aways

Himmelreich, Lutke, and Hargrove (2020)

- ▶ They may have difficulty conveying their physical feelings or experiences to health care providers
- ▶ They may not be taken seriously by health care providers
- ▶ They may not feel comfortable being examined and touched by someone they do not know, e.g., a health care provider
- ▶ Their health issues may be seen as behavior issues

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Safe vs Unsafe

- ▶ It's important to be able to identify who is a safe person for you
 - Who can you trust
 - Who can you hang out with
 - Who can you go to when you have a problem
- ▶ It's also important to be able to identify who is not a safe person
- ▶ Who gets you into trouble
- ▶ Who do you get into trouble with
- ▶ Who "eggs you on" to do the wrong thing



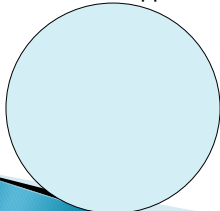
109

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



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Concepts to Keep in Mind

- Behavior due to the prenatal alcohol exposure is caused by the damage to the brain
- **All** interventions for a person with an FASD need to be modified taking into account the damage to the brain and the way the person's brain processes information
- We need to modify the person's environment to help them reach their full potential
- We need to use a strengths approach to address behavioral issues



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Concepts to Keep in Mind

- ▶ Support families in supporting individuals with an FASD
- ▶ Provide respite with people who understand FASD
- ▶ Increase social supports for the family
 - Especially for those with a lot of acting out behaviors in the community
- ▶ Help the family advocate for appropriate services throughout the lifespan
- ▶ If a family member has an FASD, the approach to them has to be modified

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Concepts to Keep in Mind

- ▶ Positive interventions require people who are:
 - Patient
 - Encouraging
 - Hopeful
 - Supportive
 - Committed to developing relationships
 - Non-judgmental
 - Not punitive
 - Creative and flexible
 - Able to use humor appropriately
 - Able to identify strengths

Alaska FASD 201 Curriculum

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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 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
- ▶ Acknowledge the positives of FASD
- ▶ We need reminders of what has been accomplished
 - Especially when things are not going well



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FASD Is a Human Issue

- ▶ Always remember that recognizing and correctly addressing FASD and other neurocognitive impairments can be a matter of life or death
 - What you do concerning this issue 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/
- ▶ FASD United (formerly National Organization on Fetal Alcohol Syndrome (NOFAS): www.fasdunited.org
- ▶ Proof Alliance: www.proofalliance.org
- ▶ Vermont Alcohol & Drug Information Clearinghouse (Recovering Hope): <https://vadic.org/publications/recovering-hope-mothers-speak-out-about-fetal-alcohol-spectrum-disorders/>.
- ▶ These sites link to many other Web sites

