Fetal Alcohol Spectrum Disorders (FASD) Webinar

Colorado FASD Commission & Colorado Department of Education

Acknowledgements

* The Colorado Fetal Alcohol Spectrum Disorder Commission
* The Colorado Department of Education

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Together We Can

Vision

All students in Colorado will become educated and productive citizens capable of succeeding in a globally competitive workforce.

Mission

The mission of CDE is to shape, support, and safeguard a statewide education system that prepares all students for success in a globally competitive world.
Outcomes

- Participants will have a basic understanding of FASD; the etiology and its impact on neurodevelopment, social emotional aspects, and learning.
- Participants will have a set of simple and practical strategies to use with students in the classroom or school setting.

FASD - The Basics Webinar

- Section 1: Understanding Fetal Alcohol Spectrum Disorders (FASD)
- Section 2: Individuals with an FASD – Strengths & Difficulties
- Section 3: Practical Strategies
- Case Study
- Section 4: Resources & Additional Webinars

Section 1 includes:
- Fetal Alcohol Spectrum Disorders (FASD)
- Diagnostic Terminology
- Facts About FASD and Prevalence
- Economic Costs of FAS-FASD
- Facts About Alcohol Use Among Pregnant Women
- Cause of FASD
- What’s a Standard Drink?
Fetal Alcohol Spectrum Disorders (FASD)

- Umbrella term describing the range of effects that can occur in an individual whose mother drank alcohol during pregnancy.
- May include physical, mental, behavioral, and/or learning disabilities with possible lifelong implications.
- Not a formal diagnosis.

Diagnostic Terminology

Fetal Alcohol Syndrome (FAS)

- The term FAS was first used in 1973 by Dr. David Smith and Dr. Ken Lyons Jones at the University of Washington.
- While FASD describes a range of disorders, FAS is a specific birth defect caused by alcohol use while pregnant.
- FAS is a diagnosis: It is a medical diagnosis Q86.0 in the International Classification of Diseases (ICD-10).

Other Diagnostic Terminology

- Alcohol-related neurodevelopmental disorder (ARND)
- Neurobehavioral Disorder
- Partial FAS (pFAS)
- Static encephalopathy (an unchanging injury to the brain)
- Neurobehavioral Disorder Associated with Prenatal Alcohol Exposure (NDPAE)
Full-blown fetal alcohol syndrome (FAS) represents only the “tip of the iceberg” relative to all alcohol-related effects.

Facts About FASD

- FASD are the leading known cause of preventable mental retardation.¹
- FASD are more common than autism.²
- The effects of FASD last a lifetime.
- People with an FASD can grow, improve, and function well in life with proper support.
- **FASD is 100% preventable.**

Prevalence Rates

- **FAS**
  - 0.2-1.5 cases per 1,000 births
  - Translates to about 1,000 – 6,000 alcohol-affected births per year

- **FASD**
  - 9-10 cases per 1,000 births
  - Approximately 40,000 alcohol-affected births per year¹
Economic Costs of FAS

- FAS alone is estimated to cost the United States nearly $4 billion each year.
- The average lifetime cost for each child with FAS is almost $3 million.

Many Doors, No Master Key: Resources Needed for Brandon, Age 1-2 Years

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<th>Education</th>
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Many Doors, No Master Key: Resources Needed for Brandon, Elementary School Years

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Facts About FASD

- No amount of alcohol consumption during pregnancy is proven to be safe.¹
- FASD is not caused by the biological father’s alcohol use.  
  **FASD is not caused intentionally by the mother:** Many women simply may not know when they are first pregnant or may not be aware of the harm that alcohol consumption during pregnancy can cause.

Facts About Alcohol Use Among Pregnant Women

- Nearly 12 percent of pregnant women report using alcohol in the past month.
- Past-month alcohol use among pregnant women and recent mothers aged 15 to 44 did not change significantly between 2002-2003 and 2006-2007.
- Nearly 16 percent of pregnant women aged 15 to 17 used alcohol in the past month, and they consumed an average of 24 drinks in that month (i.e., they drank on an average of 6 days during the past month and had an average of about four drinks on the days that they drank).

Cause of FASD

- The sole cause of FASD is the fetus being exposed to alcohol during the pregnancy.
- Alcohol is a *teratogen*: A drug or other substance capable of interfering with the development of a fetus, causing birth defects.

“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
Cause of FASD

* All alcoholic beverages are harmful.
* Binge drinking is especially harmful.*
* While it’s true that not every woman who drinks during pregnancy will have a child with FASD, that does not mean that these disorders are rare or random.
* Any time a pregnant woman consumes alcohol, it becomes possible that her baby will have FASD.
  * Binge = 4 or more standard drinks on one occasion for women

Timeline of Fetal Development

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<th>7</th>
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<td>Teeth</td>
<td>Palate</td>
<td>Nose</td>
<td>Ears</td>
<td>Palate</td>
<td>External Genitalia</td>
<td>Missed Period Noted</td>
<td>Typical time of first prenatal visit</td>
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What’s A Standard Drink?
What’s a Standard Drink?

In recent research, frequent drinkers and the majority of women reported drinking larger-than-standard drinks:

- Daily drinkers were consuming drinks that were anywhere from three to six times the size of a standard drink.
- The majority of drinkers underestimated the number of fluid ounces they were consuming by about 30%.

Section 2 includes:

- Primary & Secondary Disabilities That Can Occur in Persons With an FASD
- Typical Strengths of Persons With an FASD
- Typical Difficulties for Persons With an FASD
- Functional Assessment & Planning
- Risks of Not Accurately Identifying and Treating an FASD
- Factors Associated With Reduced Life Complications

Primary Disabilities That Can Occur in Persons With FASD

Primary:

- Brain development and wide range of IQ
- Lower level of adaptive functioning
IQ Distributions in Primary Disabilities
Sample: FAS & FAE (Streissguth, 1996)

Unrecognized FASD
- A number of adolescents and adults have FASD, most often undiagnosed and unrecognized
- These individuals often fail in our traditional treatment programs
  - They say they know what they need to do and don’t follow through
- Caregivers with an unrecognized FASD are often labeled as non-compliant, uncooperative, uninvolved, or sabotaging
  - They don’t follow through on instructions
- There are very few services that have been developed or modified to support individuals with FASD yet they are in every system of care.

Secondary Disabilities That Can Occur in Persons With FASD
Secondary:
- Mental Health Problems 90%
- Disrupted school experience 60% (i.e. suspended, expelled, etc.)
- Trouble with the Law 60%
- Confinement 50% (incarceration/inpatient)
- Inappropriate sexual behavior 50%
- Alcohol/drug problems 30%

Streissguth, 1996
Typical Strengths of Persons With an FASD

- Friendly and cheerful
- Likable
- Desire to be liked
- Helpful
- Verbal
- Determined
- Have points of insight
- Hard working
- Not malicious
- Every day is a new day!

Risks of Not Accurately Identifying and Treating an FASD

For the individual with an FASD:
- Unemployment
- Loss of family
- Homelessness
- Jail
- Premature death
- Increased substance use
- Wrong treatment or intervention is used

Factors Associated With Reduced Life Complications

- Stable home
- Early diagnosis
- No violence against oneself
- More than 2.8 years in each living situation
- Recognized disabilities
- Diagnosis of FAS
- Good quality home from ages 8 to 12
- Basic needs met for at least 13 percent of life

Streissguth, 1996
Domain Areas – Hierarchy
Neurocognitive Development

- Attention
- Processing Speed
- Memory
- Sensory-Motor:
  - Fine Motor
  - Gross Motor

Domain Areas (cont.)

- New Learning
- Language:
  - Receptive Language
  - Expressive Language
  - Social Pragmatics
- Visual-Spatial
- Social/Emotional/Behavioral
- Executive Functioning
  - Initiation
  - Reasoning
  - Planning
  - Mental Flexibility

Attention: The ability to sustain focus on the information necessary for learning or completing tasks

- There are numerous types of attention: selective, sustained, shifting and divided attention. Being able to attend to a task, to shift from task to task and to ignore competing distractions so that one can stay focused on the original task at hand, explains why attention is a fundamental skill necessary for all levels of learning.

- In addition, the inability to inhibit an impulse is a problem with attention and is often the underlying issue with Attention Deficit Hyperactivity Disorder ("hyperactivity" is often more about the inability to stop acting upon every impulse that comes to mind).
Memory: The mental ability to store and retrieve words, facts, procedures, skills, concepts and experiences.

- The general memory process is complex and entails memory creation, storage of information and retrieval. Additionally, there are several types of memory. For example, some primary types of memory are short-term, working, visual, auditory, procedural and declarative memory.
- Damage to any brain area that assists in the formation, storage or retrieval of information can degrade overall memory performance.

Processing Speed: How quickly information is received, processed, and/or outputted.

- A common consequence of a brain injury is the slowing of information processing. Slowed information processing impacts a person's ability to think efficiently and may hinder the effectiveness of other abilities such as memory. Although there are different reasons for slowed processing after an injury, one major reason is that the "wires" of the brain (neurons) can no longer communicate with each other efficiently.
- Another reason for slowed processing speed is that the brain might have to re-route signals around the damaged area (which takes longer).

Sensory Motor: Perceiving and responding to what is seen, heard, smelled, tasted, felt and touched.

- Generally speaking, the parietal lobe of the brain (top brain area) processes most sensory information and integrates it to construct a picture of one's environment. Damage to the parietal lobe may interfere with body awareness, cause attention problems, and degrade the accurate processing of auditory, olfactory, taste, tactile, and visual information.
- Fine Motor: Involves the use of small muscles of the hands to make smooth, coordinated or fine motions.
- Gross Motor: Involves the coordinated use of the large muscles of the body.
New Learning: The ability to learn new concepts and information.

- Receiving and processing new information to create learning is a remarkably complex neurological phenomenon. A novel academic task requires several brain areas working in concert to produce understanding. Once new information is processed, the new information is sent to other areas of the brain so the information can be comprehended on a deeper level.

Visual-Spatial: The ability to generate, retain, retrieve and transform well-structured visual images.

- Visual-spatial processes are largely associated with the occipital lobe of the brain, which is located at the back of the brain. When visual information is processed in the occipital lobe, it divides the information and sends it to the lower left part of the brain (temporal lobe) or to an upper part of the brain called the parietal lobe. Damage to the back and left side of the brain can degrade a person’s ability to process images of known objects. Injury to the back to upper regions of the brain may cause problems with spatial and location tasks.

Language-Receptive: The ability to understand language.

- Understanding spoken language is typically associated with the left hemisphere of the brain. Young children typically understand what is told to them (receptive language) before they can express themselves, but damage to the left side of the brain hinders their ability to understand language.

Language-Expressive: The ability to express one’s thoughts and feelings into words and sentences.

- The ability to speak logically and express oneself using language involves the left hemisphere of the brain.

Social Pragmatics: Pragmatics are the verbal and nonverbal rules of social language and interactions.
Social and Emotional: The awareness of social issues and one's emotional status. Behavioral self-regulation, control and self-monitoring are also part of this domain.

- The ability to interact successfully with other people and control one's emotions involves a higher order cognitive skill set. There are two primary areas associated with behavioral and emotional regulation. 1) The frontal cortex, implicated in pro-social behaviors. Specifically, the front part of the brain, near the eyes, assists with impulse control. 2) The limbic system. The limbic system is made of several smaller parts that are associated with creating all emotions. When these deep brain structures are damaged, it is common that the person develops severe emotional difficulties.

Executive Functions: Reasoning

Reasoning: The use of deliberate and controlled mental operations to solve novel and on the spot problems

- Many aspects of reasoning are similar to the process of new learning. Reasoning is the foundation for problem solving and ultimately overall intelligence. Higher order reasoning involves the effective integration and processes of the entire cerebral (brain) structure. Since the frontal cortex is considered the “manager” of the brain, this region is typically needed in reasoning as it orchestrates how information is processed. However, many areas of the brain are needed for deep thinking.

Executive Functions: Mental Flexibility

Mental Flexibility: The ability to easily shift from one idea, train of thought, activity or way of looking at things.

- Controlling the thoughts and actions of the brain falls under the function of the frontal lobe. Although there are different brain areas that also help with initiation, organization, planning and flexibility, these four “executive functions” are primarily regulated by the upper brain areas located behind the forehead. People with damage to the frontal lobe may become more rigid in their thinking and less adaptable to change.
Planning: The ability to set a goal, identify a sequence of actions to reach the goal and carry out that sequence of steps.

Planning is a future oriented process requiring forethought, estimation and problem solving. Similar to the same neurological structures involved with regulation, organization, and problem solving, the upper frontal lobe is intimately tied to planning.

Organization: The ability to create and maintain orderliness in thoughts, activities, materials and the physical environment.

The upper frontal region of the brain, behind the forehead, controls planning and organization of thoughts and activities. The ability to sequence thoughts in a logical fashion and translate those thoughts into action to organize a person’s environment involves communication between the frontal cortex and left hemisphere of the brain. Damage to the front and/or the left hemisphere of the brain may cause disorganized thinking and ordering of materials.

Initiation: The ability to independently start an action or activity.

Since the frontal regions of the brain are largely responsible for action and movement, it is not surprising these same areas are responsible for initiation. It is also not surprising that emotions help start actions, so the deeper emotional centers of the brain are implicated in initiation. A child’s inability to get tasks completed may be related to problems with initiation within the brain.
The child exhibits delays in adaptive living skills, including but not limited to with Activities of Daily Living (ADL).

Some Examples:
- Personal hygiene and grooming
- Housework
- Managing money
- Use of telephone or other form of communication
- Community mobility
- Care of pets
- Meal preparation and cleanup
- Safety procedures and emergency responses

The child exhibits delays in academic skills, including but not limited to reading, writing, and math delays that cannot be explained by any other disability. They may also demonstrate an extremely uneven pattern in cognitive and achievement testing, work production and academic growth.

- Can’t entertain themselves
- Go off with strangers
- Followers
- Don’t maintain good hygiene
- Have difficulty with multiple directions, multiple tasks, changing tasks, and multiple plans
- Do not complete tasks/chores
- Appear to be oppositional
- Repeatedly break the rules (due to lack of understanding and generalization)
Typical Difficulties for Individuals with FASD

- Don’t learn from their mistakes
  - Don’t benefit from natural consequences
- Frequently do not respond to point or level systems
  - Difficulty with cause and effect
    - Can’t anticipate consequences of actions
  - Literal thinking
    - Lack of abstract thinking
    - Historical and future time is an abstract concept
- Difficulty with time
- Problems managing money

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Typical Difficulties for Individuals with FASD

- Have difficulty determining what to do in a given situation
- Come across as more intact than they actually are
  - Do not ask questions
  - Desire to fit in
  - Say they understand and know what they need to do when they really don’t
    - Attempt to feel more in control
    - Attempt to be like everyone else
- Verbal expressive language is often much better than verbal receptive language

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Typical Difficulties for Individuals with FASD

- Uneven in school, work, and development
  - Sometimes they “get it” and sometimes they don’t
  - They may know something one day but not the next
- Experience multiple losses
- Seen as lazy, uncooperative and unmotivated
- Don’t accurately pick up social cues
- No filtering of what they are thinking
  - Whatever they are thinking is said
  - No recognition of possible consequences
- Misinterpret others’ words, actions or body movements
**FAS TIMELINE**

*Actual age of individual: 14*

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<th>Skill</th>
<th>Developmental age equivalent</th>
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<tr>
<td>Emotional maturity</td>
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<td>Physical maturity</td>
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<tr>
<td>Reading ability</td>
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<tr>
<td>Social skills</td>
<td>7</td>
</tr>
<tr>
<td>Living skills</td>
<td>6</td>
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*Chronological age*  

0 5 10 15 20

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**Functional Assessment & Planning**

- It is important to conduct a functional assessment as part of the evaluation process. Students may score within normal limits on formal assessments but have difficulty applying their knowledge.
- Planning – “A team approach will help classroom teachers meet the complex needs of students with an FASD. Successful collaboration involves teachers, parents, students and administrators as well as community service providers”

Center for Disabilities, Sanford School of Medicine of the University of S. Dakota, 2009

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**Section 3 includes:**
- Practical Strategies
- Case Study
1. **Concrete** - Students with FAS do well when parents and educators talk in concrete terms, don’t use words with double meanings, idioms, etc. Their social-emotional understanding is far below their chronological age, it helps to “think younger” when providing assistance, giving instructions, etc.

2. **Consistency** - Because of the difficulty students with FAS experience trying to generalize learning from one situation to another, they do best in an environment with few changes. (i.e. language - teachers and parents can coordinate with each other to use the same words for key phases and oral directions).

3. **Repetition** - Students with FAS have chronic short-term memory problems; they forget things they want to remember as well as information that has been learned and retained for a period of time. In order for something to make it to long-term memory, it may simply need to be re-taught and re-taught.
4. Routine - Stable routines that don’t change from day to day will make it easier for students with FAS to know what to expect next and decrease their anxiety, enabling them to learn.

5. Simplicity - Remember to Keep it Short and Sweet (KISS method). Students with FAS are easily overstimulated, leading to "shutdown" at which point no more information can be assimilated. Therefore, a simple environment is the foundation for an effective school program.

6. Specific - Say exactly what you mean. Remember that students with FAS have difficulty with abstractions, generalization, and not being able to "fill in the blanks" when given a direction. Tell them step by step what to do, developing appropriate habit patterns.
7. **Structure** - Structure is the "glue" that makes the world make sense for a student with FAS. If this glue is taken away, the walls fall down! A student with FAS achieves and is successful because their world provides the appropriate structure as a permanent foundation.

8. **Supervision** - Because of their cognitive challenges, students with FAS bring a naiveté to daily life situations. They need constant supervision, as with much younger children, to develop habit patterns of appropriate behavior.

When a situation with a student with FAS is confusing and the intervention is not working, then:

- **Stop Action!**
- **Observe.**
- **Listen carefully to find out where he/she is stuck.**
- **Ask: What is hard? What would help?**
- **If NOTHING ELSE, remove the word “don’t”**
Case Study - Bryan

- Seven year old-first grader
- Often in trouble – stealing, pinching, getting out of seat
- Classroom management system – never earned a reward
- Removal = returns to same behavior
- Academically behind in reading and writing
- Parents are frustrated with the behavior
- Considering retention
- What types of interventions would you recommend?

Case Study – Bryan

- Academic:
  - Assessment of current academic skill set (consider the Hierarchy of Neurocognitive Development)
  - Can’t vs. Won’t
- Behavior:
  - Functional Behavioral Assessment
  - Create immediate and tangible rewards
  - Environmental considerations

Section 4: Resources

- Colorado Fetal Alcohol and Other Prenatal Substance Prevention Outreach Project (COFAS), University of Colorado Anschutz Medical Center: http://www.ucdenver.edu/life/services/AMEC/ProgramAreas/cofas/Pages/FetalAlcoholSpectrumDisorder.aspx
Section 4: 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
- National Clearinghouse for Alcohol and Drug Information (NCADI): ncadi.samhsa.gov

Additional FASD Webinars

Topics:
- Classroom Strategies for Elementary
- Classroom Strategies for Secondary
  (each of the webinars will be recorded and available on the CDE Website: www.cde.state.co.us/cdesped/FASD.asp)

When:
- 2013-14 School Year

Questions:
- For more information: contact Debora Toliver toliver_d@cde.state.co.us

Video Clips:
- Making Friends (Sheldon)- http://www.youtube.com/watch?v=k0xjUHeEG3U&sns=em
- Invisible disability (is viewed as higher functioning) - http://www.youtube.com/watch?v=K0VRFkOxAFg&feature=player_detailpage
Evaluation and Contact Hours

- Please complete the evaluation upon completion of the webinar at https://www.surveymonkey.com/s/FASD_Webinar_eval

- Upon completion of the evaluation, a certificate of attendance will be emailed to the email address you provided at the time of registration (please allow up to 2 weeks)

- For more information or questions: please contact Deb Toliver at toliver_d@cde.state.co.us