Center for Adoption Support & Education welcomes you to
Strengthening Your Family
an empowering and inspiring webinar series

What Prospective and Adoptive Parents Should Know About Fetal Alcohol Syndrome Disorder

featuring Barb Clark

If you experience difficulty with audio using your computer speakers, click on the tab “Communicate” at the top and then choose “Speaker/Microphone Audio Test” from the drop down menu. Test your speaker – your microphone will not work as we have muted all participants so that background noise will not be an issue. To use your telephone for audio, click on the “Event Info” tab to access the phone numbers, access code, and your attendee ID # (which is unique to you).

All participants will be muted throughout the presentation.
Understanding the FASD Diagnosis

Presented by Barb Clark, Hennepin and partial Dakota counties Family Resource Coordinator
Jockey Being Family®

Jockey Being Family generously funds our monthly Strengthening Your Family webinar series.

Who is Jockey Being Family?
Jockey International is a manufacturer, distributor and retailer of underwear and sleepwear for men, women, and children and is active in more than 120 countries. Jockey® created Jockey Being Family, a foundation that helps adoptive families remain strong and stay together-forever because Jockey believes that even one failed adoption is too many. To learn more about Jockey Being Family, please visit www.jockeybeingfamily.com

Jockey International’s C.E.O., Debra Waller, was adopted herself as an infant.

“Jockey Being Family is about bringing people together and it is exhilarating to have impacted the lives of so many families. We set out to strengthen adoptive families but we here at Jockey have also been equally touched by this program, the families, and their stories.”

-Debra S. Waller
Center for Adoption Support and Education, Inc.

a non-profit adoptive family support center, since 1998

With decades of experience, our mission is to strengthen the well-being of children and families of all adoptive experiences by providing them the adoption-centered services and resources they need, including:

• Pre- and post-adoption counseling, assessment and therapeutic services
• Individual and group therapy for kids, teens and adults
• Crisis intervention, support and assistance with school issues
• Training, education & interactive workshops – for families, educators and professionals
• Nationally recognized post-adoption models
• TAC: Training for Adoption Competency
• Our newest Game: 52 Ways to Talk about Adoption

• Award-winning print publications, articles, newsletters and online resources

For more information, visit www.adoptionsupport.org
Minnesota Organization On Fetal Alcohol Syndrome
Our **mission** is to eliminate disability caused by alcohol consumption during pregnancy and to improve the quality of life for those living with Fetal Alcohol Spectrum Disorders throughout Minnesota.

Our **vision** is a world in which women do not drink alcohol during pregnancy and people living with Fetal Alcohol Spectrum Disorders are identified, supported, and valued.
Objectives

• Describe basic brain functioning in relation to FASD brain damage
• Learn how prenatal exposure to alcohol may affect learning and behavior
• Discover interventions and strategies for success
• Learn about resources can be useful in multiple settings
What is FASD?

A group of birth defects that can result from prenatal exposure to alcohol

May include physical, mental, behavioral, and learning disabilities

Prenatal alcohol exposure affects each person differently

Brain

Permanent damage, lasts a lifetime
FASD is NOT a Diagnosis

**FAS**  
Fetal Alcohol Syndrome

**PFAS**  
Partial Fetal Alcohol Syndrome

**ARND**  
Alcohol Related Neurodevelopmental Disorder

**ARBD**  
Alcohol-Related Birth Defects

**FAE**  
Fetal Alcohol Effects (Outdated Term)

Source: Stratton et al, 1996
Facts about FASD

• For some groups, current prevalence of FAS is estimated to be 6-9 per 1,000 children.
• For some groups, current prevalence of FASD is estimated to be 24-48 per 1,000 children, or close to 4%
• 1 out of 68 children have an Autism diagnosis. Autism and FASD have many similarities.
• 4th grade is when the majority of students with FASD start to struggle more with school.
• Estimated that 70-80% of children in foster care have an FASD
• FASD occurs in all racial, ethnic and socioeconomic groups
Prevalence of Birth Defects Per 1,000 Live Births

<table>
<thead>
<tr>
<th>Birth Defect</th>
<th>Rate of Occurrence</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cerebral Palsy[1]</td>
<td>2 in 1,000</td>
</tr>
<tr>
<td>Spina Bifida[2]</td>
<td>0.7 in 1,000</td>
</tr>
<tr>
<td>Down Syndrome[3]</td>
<td>1.4 in 1,000</td>
</tr>
<tr>
<td>Fetal Alcohol Syndrome (FAS)[4]</td>
<td>9 in 1,000</td>
</tr>
<tr>
<td>Autism[5]</td>
<td>14 in 1,000</td>
</tr>
<tr>
<td>Fetal Alcohol Spectrum Disorders (FASD)[4]</td>
<td>24-48 in 1,000</td>
</tr>
</tbody>
</table>

Alcohol is a teratogen—a substance that the fetus is exposed to that impedes growth and disrupts normal development.
Factors that affect each pregnancy

Risks with Known Prenatal Alcohol Exposure:

- Not always going to result in an FASD
- Manifestations are unique in each individual

Factors that affect each pregnancy:

- Blood alcohol concentration of the mother
  - Binge drinking is especially harmful
- Timing of the exposure
- Resiliency of the fetus
- Metabolism and diet of the mother

Source: Davies & Bledsoe, 2005
• Only 10% of children with an FASD present facial features
• Facial features most prominent between ages of 2-10
• Most serious characteristics of FASD = invisible symptoms due to brain damage
FAS Facial Features

CDC 2004
Might also have: Low set ears, flat mid-face, up-turned nose, small chin, and epicanthal folds.

FAS Facial Characteristics – Image courtesy of FASTAR.
Behavior and Learning Symptoms

- Poor impulse control
- Lack of control over emotions
- Difficulty learning from consequences
- Hyperactivity/Impulsiveness - ADHD common
- Inappropriately friendly to strangers
- Poor judgment and decision making
- Difficulty with abstract concepts
- Inability to manage money
- Sleep difficulties
Behavior and Learning Symptoms

- Stubbornness/Perseveration
- Difficulty with the passage of time
- Passivity
- Fearlessness – high-risk behaviors
- Poor self-image
- Depression
- Irritability
- Attention deficits
- Memory deficits
- Sensory processing issues
- Immature social behavior
FASD Indicators

• In foster care or raised in adoptive home
• History of chemical dependency/child protection
• Immature & poor social behavior
• Adaptive behaviors lower than IQ indicates
• Easily distracted, hyperactive, inattentive, impulsive
FASD Indicators

• Involvement with justice system
• May give inconsistent answers to questions
• Unable to connect actions with consequences
• Does not seem affected by past punishments
• Truancy and school difficulties
## Developmental Skills Timeline

With most kids with an FASD, we should cut their age in half, and that is often the age they are functioning at in most areas. Imagine sending a 9 year old into the real world with little to no support...

<table>
<thead>
<tr>
<th>SKILL</th>
<th>DEVELOPMENTAL AGE EQUIVALENT</th>
</tr>
</thead>
<tbody>
<tr>
<td>Actual age</td>
<td>18 yrs.</td>
</tr>
<tr>
<td>Expressive language</td>
<td>20 yrs.</td>
</tr>
<tr>
<td>Comprehension</td>
<td>6 yrs.</td>
</tr>
<tr>
<td>Money and time concepts</td>
<td>8 yrs.</td>
</tr>
<tr>
<td>Emotional maturity</td>
<td>6 yrs.</td>
</tr>
<tr>
<td>Physical maturity</td>
<td>18 yrs.</td>
</tr>
<tr>
<td>Reading ability</td>
<td>16 yrs.</td>
</tr>
<tr>
<td>Social Skills</td>
<td>7 yrs.</td>
</tr>
<tr>
<td>Living skills</td>
<td>11 yrs.</td>
</tr>
</tbody>
</table>

Common Misdiagnoses or Co-occurring diagnoses of FASD

- Attention Deficit/Hyperactivity Disorder (ADHD)
- Bipolar Disorder
- Major Depressive Disorder
- Posttraumatic Stress Disorder
- Obsessive-Compulsive Disorder
- Generalized Anxiety Disorder
- Reactive Attachment Disorder (RAD)
- Autism
- Oppositional Defiant Disorder
- Conduct Disorder
- Mild, Moderate, or Severe Mental Retardation
- Antisocial Personality Disorder
- Borderline Personality Disorder
Interventions and Strategies
There is no cookbook approach

All Youth with an FASD are Individuals
The External Brain

"Our children living with an FASD need an external brain. Someone in their life who can help them in the areas they struggle with"
The most important strategy you will learn today is...
To be patient and understanding
The 2nd most important strategy you will learn today is...
Don’t Ask Why
Fair vs. Equal

Equality is not always Justice

This is EQUALITY

This is JUSTICE
Tips for Home

• Supervision is KEY!!!!
• Get safes with keypads instead of keys
  – Lock up valuables, matches, etc.
• Alarm system
• Ask for modification or elimination of homework
• Expect inconsistency, celebrate when you are wrong!
• De-clutter as much as possible
• Try to resolve sleep issues
• Do not overschedule- simplify and build in structure in daily routine
Strategies for Transition

- Timers
- Picture schedules
- Establish routines
- Youth with transition difficulty becomes the helper
- May need to avoid waiting in lines
- Prepare students in advance for changes (i.e. substitute teachers)
Strategies for Transition

www.timetimer.com
Strategies for Success

• Adapt environment to minimize frustration
• Teach self awareness & advocacy
• Be Proactive, not reactive
• Expect inconsistency, celebrate when you are wrong!
Sensory Strategies

• Build in sensory time
• High/low impact exercise
• Yoga
• Fidgets
• Water/snacks available every 2 hours
• Nutrition
• Breathing Ball
Rage Behavior/Tantrums

Many individuals with an FASD diagnosis are ½ their chronological age.

• Remove other children if possible or remove the child from the area. Ensure safety.

• Stay calm, and try to talk as little as possible.

• Avoid using the child’s name.
Addressing Lying

• Lying needs to be understood within the context of the neurological impairment.

• The youth may have language difficulties, memory deficits, immature social skills and anxiety that underlie the fabrications. Often they are trying to “fill in the holes” from their memory issues.

• Saying the first thing that comes to mind is an impulsive response related to how youth process information and plan verbal responses.
Addressing Lying

• Do not address the lying at the wrong time (ie; if they are escalating or upset)

• Directly teach concepts of true and false

• Teach youth what “pretending” involves

• Discuss what is unreal, fictional or fantasy on television or videos

• Avoid asking rhetorical questions

• Help to distinguish the difference of lying from storytelling- Ask “Truth or story?”
Eight essentials for success

Concrete
Supervision
Consistency
Structure
Repetition
Specific
Routine
Simplicity

From 8 Magic Keys – developed by Deb Evensen and Jan Lutke 1997
“We must move from viewing the individual as failing if he or she does not do well in a program as not providing what the individual needs in order to succeed”

Dan Dubovsky, FASD Center for Excellence
Recognize strengths

• Highly verbal
• Artistic, musical
• Athletic
• Long term visual memory
• Willing
• Helpful
• Loyal
• Curious

• Generous
• Energetic and hard working
• Want to succeed
• Forgiving
• Spontaneous
• Good with young kids
• Friendly and outgoing
Don’t try harder…try differently

If you’ve told a child a thousand times and he still does not understand, then it is not the child who is the slow learner.

- Walter Barbee
Resources
Resources

Books

- Damaged Angels, Bonnie Buxton
- Try Differently Rather Than Harder, Diane Malbin
- The Best I Can Be, Liz Kulp
- When Rain Hurts, Mary Evelyn Greene
- Fetal Alcohol Syndrome, Ann Streissguth
Additional online resources

General Information on FASD & community resources

– MOFAS Resource Directory
  • [http://www.mofas.org](http://www.mofas.org)

– Center for Disease Control and Prevention, FAS site
  • [http://www.cdc.gov/ncbddd/fas](http://www.cdc.gov/ncbddd/fas)

– SAMHSA FASD Center for Excellence
  • [www.fasdcenter.samhsa.gov](http://www.fasdcenter.samhsa.gov)

– FASD Unit @ the Univ of Washington School of Medicine
Questions?

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Certificates of Attendance

Email your request to arroyo@adoptionsupport.org
For information on our monthly “Strengthening Your Family” webinar series, please visit

adoptionsupport.org/strengtheningyourfamily

Registration is FREE for first 300 registrants thanks to a generous grant from Jockey Being Family! The codes will be available on the last Tuesday of each month.

For a schedule of our pre-recorded webinars on our most requested topics, please visit

adoptionsupport.org/indemand