Screening and Intervention Strategies

Before we begin...
- Do you know where the bathrooms are?
- Please take the pre-test at top of page
- Cell phones turned off or silent

Sources
The sources for information in this training include March of Dimes, National Institute on Alcohol Abuse and Alcoholism, the FASD Center for Excellence, the National Organization on Fetal Alcohol Syndrome, and the Institute of Medicine. Most of the citations can be found on the web site of the FAS Community Resource Center at www.fascrc.com

Meet Baby Annie

Impact on the Family
- A personal perspective
- John’s story, from infancy to adulthood
- The ideal life situation shown here is not the common experience of most families.
- John has graciously given permission for these stories to be shared, in order to increase understanding about persons with fetal alcohol disorders.

Agenda
- Review FASD Basics
- Impact on Brain Function and Behavior
- Physical Symptoms
- Neurological Symptoms
- Prescreening and Screening
- Intervention Strategies for All Ages
Definitions and Diagnostic Terms

FASD = Fetal Alcohol Spectrum Disorders
FASD is an umbrella term, not a diagnosis
FASD includes the following diagnoses:
• FAS = Fetal Alcohol Syndrome
• pFAS = Partial Fetal Alcohol Syndrome
• ARND = Alcohol Related Neurodevelopmental Disorders (formerly called Fetal Alcohol Effects or FAE)

What Does FASD Look Like?
There may or may not be
• physical symptoms
• birth defects
• facial features
• developmental delays

In most cases, the child with FASD looks just like any other child.

Diagnostic Criteria for Full FAS
• Growth deficiency
• Microcephaly (small head circumference)
• Facial characteristics
• Organic brain damage
• History of prenatal exposure to alcohol

Facial Characteristics in Infancy
• Small eye openings
• Smooth philtrum
• Thin upper lip
• Less than 10% of children with FASD have distinctive FAS facial features

Most Cases of FASD are Invisible
• Only 11% of children with FAS or ARND receive a diagnosis by age 6 --1996 Streissguth
• The facial features of FAS are not always easily recognized during the early years
• Facial features of FAS result from drinking during brief period, 3rd week after conception.

FASD and Developmental Disabilities

- The causes of most cases of cognitive disabilities remain unknown
- Alcohol during pregnancy is the leading preventable cause of birth defects, cognitive disabilities, and neurobehavioral disorders
- Only 15% of people with FASD qualify for developmental disability services

Alcohol is a Teratogen

- Alcohol causes more damage to the developing baby’s brain than any other substance, including marijuana, cocaine, meth, and heroin.
  -- Institute of Medicine Report to Congress

About Birth Mothers…

- Birth mothers who drink generally do not intend to harm their babies.
- Some birth mothers quit drinking after they find out they are pregnant.
- Almost all birth mothers who continue to drink are victims of sexual and/or physical abuse.
- About half of birth mothers have undetected Fetal Alcohol disorders themselves.
  --Sterling Clarren Study

Look Who's Drinking

- Half of all women of childbearing age drink alcohol
- Half of all pregnancies are unplanned
- The rate of drinking reported by pregnant women in their first trimester is 23%.
  --SAMHSA 2008 National Survey on Drug Use and Health

How Alcohol Affects the Developing Fetus

- Tiny molecule passes through placenta
- BAC in mother = BAC in baby
- Placenta is formed and functioning about 15-18 days after conception
- Weeks 2-10, baby is vulnerable to structural damage
- Brain is vulnerable during entire pregnancy

Effects of Ethanol Exposure on the Developing Embryo

- Induces cell death
- Disrupts the proliferation and differentiation of brain cells.
- Suppresses breathing movements during time before birth.
- Interferes with function of lungs
Effects of Ethanol Exposure on the Developing Embryo

- Yields ocular and forebrain abnormalities after early exposure.
- Alters genetic expression of tissue in craniofacial areas – underdeveloped jaw, cleft in lip or palate.
- Compromises development of the midline neural tube and forebrain.

Effects of Ethanol Exposure on the Developing Embryo

- Causes alterations in GABA(A) receptor expression in the hippocampus, thus contributing to behavioral disorders.
- Increases levels of maternal cortisol (stress hormone).

Effects of Ethanol Exposure on the Developing Embryo

- Causes long-term disruption in regulation of vasopressin, a neurotransmitter associated with social behaviors and mating.
- Disrupts production of oxytocin, which is important for bonding and attachment.

Effects of Ethanol Exposure on the Developing Embryo

- Impacts the limbic system and reduces capacity to adapt to stress.
- Moderate exposure (2 drinks/day) alters dopamine levels that affect behavior and disrupt the reward cycle in the brain.
- Alters serotonin neurotransmission in discrete brain regions permanently.
- Slows the migration and reduces the development of serotonin neurons by 20%-30%.
The corpus callosum is sometimes smaller than normal. But most persons with FASD will have an MRI that appears to be normal. --2003 Ed Riley.

Why is FASD Different?
- Often unrecognized or misdiagnosed
- Symptoms are invisible
- Wide array of developmental levels
- Normal appearance and intelligence
- Birth mothers are blamed and judged
- Lack of support from family/community
- Overshadowed by neglect/abuse
- Discomfort with “fetal” issues
- Denial about alcohol as a drug

“Executive Functions” of the prefrontal cortex
- Inhibitions
- Planning
- Time perceptions
- Internal ordering
- Working memory
- Self monitoring
- Verbal self-regulation
- Motor control
- Regulation of emotions
- Motivation

Neurological signs in early years
- Poor habituation
- Irritability – intense response to stress
- Longer time to recover from stress
- Sensitivity to external stimuli
- Feeding problems
- Disrupted sleep cycles
- Developmental delays

These symptoms may or may not be present.
Neurological signs during childhood

• Difficulties with bonding and attachment
• Inappropriately affectionate to strangers
• Inability to form healthy relationships
• Memory deficits (forget the rules)
• Poorly formed conscience (lying/stealing)
• Stubborn, compulsive, perseverate, tantrums
• Arrested social development (“Think Young”)
• Poor judgment, lack of impulse control

Sensory Issues

The most troublesome symptoms are perceived as behavior problems:

• Willful misconduct
• Manipulation
• Trying to get attention
• Lazy
  “It’s not that they won’t, they can’t.”
  -Diane Malbin www.fascets.org

John at School

Misinterpretation of sexual behaviors

FASD and Social Development

Research on comparison of social abilities among:

• Children with FAS
• Children with same IQ (no FAS)
• Control group (normal children)

Researchers: Ed Riley and associates

Social Abilities Assessment

• Vineland Adaptive Behavior Scales
• Parent Version
• “VABS-II”
• Administered by school psychologist

Comparison of social abilities of children with fetal alcohol syndrome to those of children with similar IQ scores and normal controls

**Vineland Scores**

- **Social skills**
  - Researchers: Ed Riley, Sarah Mattson

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**Why We Need the Vineland**

- If we only look at IQ scores and academic achievement, we will miss the measurements that mean the most, that show impairment in their ability to function in life.

  \[\text{Bledsoe 2010, APA online training}\]

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**Arrested Social Development**

- Social developmental age is reflected in emotional regulation and conscience development.
- With FAS, social development is arrested rather than delayed (Riley et all 1998).
- **Behavioral profile of children with FAS does not change when they become adults** (Steinhausen et all 1993).
- The 18-21 year old with FAS may be functioning intellectually at the level of a 12-16 year old but socially-emotionally at the level of a 4-6 year old.

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**Most Common Symptoms Across the Spectrum**

Most children with FASD have
- Memory deficits
- Lack of impulse control
- Poor judgment
- Emotional dysmaturity

"Think Young"
Secondary Disabilities
94% - Mental health issues (depression)
80% - Trouble with independent living
80% - Trouble with employment
70% - Trouble in school
60% - Trouble with the law
60% - Confinement in prison or institution
45% - Legal problems with sexual behaviors
50% - 70% Adults abuse alcohol/drugs

Protective Factors
• Early diagnosis
• Eligibility for services
• Appropriate intervention services
• Stable home environment
• No domestic violence

Factors that Affect Behavior
• Dehydration
• Medication
• Diet
• Fatigue
• Sensory overload
• Emotional stress
• Neurotransmitter imbalance

Services For Children With FASD
• Only 15% of children with Fetal Alcohol disorders qualify for disability services.
• Between 75%-80% of children with FAS are in foster/adoptive care, where the prevalence of FAS is 10 times higher

Adjust Your Expectations
"The greatest obstacle that individuals with FAS disorders must overcome is the chronic frustration of not being able to live up to the unrealistic expectations of others."
-- Dr. Calvin Sumner, FAS/ADHD expert

Co-occurring Disorders
• Attention Deficit Hyperactive Disorder (with or without hyperactivity)
• Bi-Polar Disorder
• Oppositional Defiant Disorder
• Conduct Disorder
• Reactive Attachment Disorder
• Autism or Asperger’s
• Schizophrenia
• Anxiety Disorder
Greatest Challenges for Teens

- Behavior problems become more pronounced
- Physical symptoms are less apparent
- More than half of adults with FASD have clinical depression.
- 43% have threatened or contemplated suicide.
- 23% have attempted suicide. --Streissguth 1996

In John’s Words…

www.YouTube.com/TriLevelMan

“I have the amazing ability to function at three different levels at the same time!”

But they look so “normal”… How can we tell?

Pre-Screening for Possible FASD

- Has the child been in the care of someone other than birth mother for 30 days or longer?
- Is there a record of any other siblings who have a disorder associated with prenatal exposure to alcohol?
- One or more of the following symptoms:

Red Flag Symptoms

- Lack of eye contact during infancy
- Did not like to be cuddled as a baby
- Ever suspended from school or kicked out of a program due to behavior issues
- Accepted behavior management techniques just not very effective
- Makes the same mistakes over and over, in spite of the consequences

Red Flags - Adults

- History of alcohol abuse in birth family?
- Multiple home placements?
- Special ed classes in school?
- Suspended or dropped out from school?
- History of depression? ADHD? abuse? neglect?
- More than 1 jobs in past 2 years?
- Trouble managing money?
- Are friends older or younger?

--Robin LaDue 2000, Streissguth 1996
How to Approach the Family

• “Your child seems to have symptoms of a neurodevelopmental disorder associated with frontal lobe dysfunction, which can lead to behavior problems that are not easy to cope with. This can be a result of traumatic brain injury or prenatal exposure to lead, mercury, or alcohol.”

How to Approach the Family

• “The most common cause of preventable neurobehavioral disorders is prenatal exposure to alcohol. We know that about 25% of women drink during pregnancy, often before they know they are pregnant. The Division is conducting a survey to determine how many individuals might have undetected Fetal Alcohol Disorders. Would you like to have your child screened for Alcohol Related Neurodevelopmental Disorder?”

Effective Intervention

There is no single program or plan that works for all persons with FASD
Each plan needs to be individualized according to the person’s needs

Clear understanding, realistic expectations, and creative problem solving will bring about solutions that work.

Assessment Tools

• Bayley Scales (infants, toddlers)
• IQ test (WISC, WAIS, or Woodcock Johnson)
• Bender test (visual motor activities)
• Functional Behavior Assessment
• Social Problem Solving Inventory (judgment)

Intervention Guidelines: SCREAMS Model

• Structure: routine, easy steps, ABC Rules
• Cues: for meds, appointments, manners
• Role models: TV, movies, friends, family
• Environment: avoid chaos, stimulation
• Attitude: understand FASD neurology (who?)
• Meds and diet: restore balance and control
• Supervision: many need 24/7

Intervention for Infants

• Swaddling
• Soft clothing
• Facing away during bottle feeding
• Frequent feedings
• Frequent naps
• Avoid chaos and over-stimulation
• White noise or gentle music
• Sensory integration therapy
Astrocytes and Neurotransmitters

What do these pictures tell us?

Neurotransmitters
Keep us Happy

- Dopamine (excited happy) “Yeay!!!”
- Serotonin (calm happy) “Mmmmm.”
- Oxytocin (trust and love) “Awwww.”
- Beta-Endorphin (opiate “high”) “Ahhhh.”
- Testosterone (sex drive) “Yahoo!!!”
- Cortisol (stress) “Ayyyyyeeeee!!!”

Neurotransmitters
Out of Balance

- Low Dopamine … depression, cutting
- Low Serotonin … depression, impulsive
- Low Oxytocin … distant, mistrustful
- Low Beta-Endorphin … cravings
- High Testosterone … libido, aggression
- High Cortisol … overstressed: fight or flight reflex = run, fight, shut down

Maximize Brain Function

Eliminate Additives
- No food coloring (especially Red 40)
- No preservatives (MSG)
- No nutrisweet (aspartame)

Add Vitamins:
- Daily vitamin (color free)
- Omega E (fish oil, flaxseed)
- Lecithin (Choline)
- Chocolate, turkey, potatoes, bananas

Neurotransmitters
Back in Balance

- Increase Dopamine
- Increase Serotonin
- Increase Oxytocin
- Increase Beta Endorphin
- Decrease Testosterone
- Decrease Cortisol

Pain vs. Pleasure

The Dopamine Effect
“It’s all in your head.”

What’s your favorite D-booster?
Balancing the Neurotransmitters

• Increase Dopamine
  – Lots of personal attention
  – Vigorous exercise (track, basketball, swimming)
  – Rewards, awards
  – Excitement
  – Humor, silliness
  – Games, contests, prizes
  – Music, dance
  – Medications (Stimulants: Ritalin, Adderall)

• Increase Serotonin
  – Attention
  – Affection
  – Praise
  – Active Listening
  – Mild exercise (walking, swinging)
  – Chocolate (short term effects)
  – Medications (SSRIs = antidepressants like Paxil, Celexa, Prozac, Zoloft)

• Increase Oxytocin
  – Cuddling
  – Massage
  – Thumb sucking, blankies
  – Trust-based relationships
  – Generosity and gift giving
  – Pleasant sensory experiences
  – Pets that like to be cuddled

• Increase Beta Endorphin
  – Exercise, daily: swim, walk, run, basketball, track
  – Vitamin, daily (especially B12, C)
  – Foods high in certain vitamins and nutrients
    • Chocolate
    • Bananas
    • Strawberries
    • Grapes
    • Oranges
    • Nuts
    • Ice cream
    • Pasta

• Decrease Testosterone
  – SSRIs (Paxil, Celexa, Prozac Zoloft)

• Decrease Cortisol
  – Stress management skills
  – Recognize and treat PTSD
  – Meditation
  – Neurobiofeedback
  – Cognitive Behavior Therapy
Positive Reinforcement

- Reinforcements
  - Token rewards, consequences not as effective as we would like
  - Rewards: concrete and immediate
- Do NOT ignore unwanted behaviors
  - Collect data
    - Day by day
    - Morning, afternoon, evening
    - Hour by hour

Daily Behavior Chart

<table>
<thead>
<tr>
<th>Time</th>
<th>Respect</th>
<th>Rules</th>
<th>Self care</th>
</tr>
</thead>
<tbody>
<tr>
<td>8-9</td>
<td>♥</td>
<td>☺</td>
<td>no shower</td>
</tr>
<tr>
<td>9-10</td>
<td>X-swear</td>
<td>X-yell</td>
<td>NC – no</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>chores w cue</td>
</tr>
<tr>
<td>10-11</td>
<td>♥</td>
<td>☺</td>
<td>⭐️</td>
</tr>
<tr>
<td>11-12</td>
<td>♥</td>
<td>☺</td>
<td>⭐️</td>
</tr>
</tbody>
</table>

Memory Enhancement

- Instructions: simple, concrete steps
- Show the child how
- Visual cues: symbols, signs, charts
- Teach one skill at a time
- Hands on activities, sensory, tactile
- Role play
- One-on-one read along stories
- Learning should be a fun experience
- Music and rhymes
- Minimize food additives

Positive Approach

- Offer cheerful encouragement
- Allow for “off” days
- One-on-one with eye contact
- Gentle pressure on shoulders
- Use appropriate humor, silliness
- Repeat, repeat, repeat
- Practice, practice, practice
- Adjust your expectations

Classroom Success

- Explain FASD to all students
- Enlist affected child in peer education
- Enlist affected child to help when able
- Establish reasonable goals
- Close monitoring at all times (1:1)
- Placement of desk close to teacher
- Minimize copying from blackboard
- Modify or minimize homework
- Watch out for “peers” – bad influence
- Minimize stress

For the IEP…

- Training on FASD for all staff (webinar)
- Close Monitoring
  - Playground time
  - Cafeteria, locker rooms, gymnasium
  - Before/after school time, between classes
  - School bus (bus aide, sit in front)
- Safe Haven = mentor, helper, aide
- Communication log, organizer
Behavioral Challenges

Internalizing behaviors:
- Anxiety
- Depression
- Withdrawalshutdown

Externalizing behaviors:
- Hyperactivity
- Delinquency (non-violent criminal behaviors: theft, lying, vandalism)
- Inappropriate sexual behaviors
- Aggression: Verbal, Physical, Threats
- Oppositional defiant disorder
- Conduct disorder ...... antisocial

Aggression in Children with FASD

Internal: Brain affected by many factors
- Nutrition (MSG, artificial colors, aspartame)
- Hydration
- Neurotransmitters and hormones
- Structural and functional brain abnormalities

External: They learn by imitating the behavior of others:
- Family violence, abuse, neglect
- School and neighborhood
- TV, movies, electronic games

What do the studies show?
- Delinquent/criminal behaviors are mostly linked to biological parents
- Aggression is more often linked to learned behavior
- Childhood aggression is an early predictor of adult crime and violence.

The Nature of Aggression
- Nature of aggression = multidimensional
- Different stimuli combine with different types of physiological and mental processes to create distinct forms of aggression.
- Predatory aggression requires self-control, lack of emotion, no empathy, used to dominate and control others.
- Intermittent explosive disorder = short period where the child loses control.
What is causing the aggression?
• Self-defensive instinct? (appropriate)
• Impulsive response to conflict, threats or aggression by others?
• What’s happening in the child’s environment? Sensory overload, peer pressure.
• What’s happening in the child’s body? Health status, emotions, thoughts.

The Easy Answer
Stable family with healthy role models who can provide close supervision

Strategies for Aggressive Behaviors in Children with FASD
• What is our primary goal?
  • Success?
  • Happiness
  • Independence and self-sufficiency?
  • Prevent secondary disabilities?
  • Safe, healthy, loved?

SCREAMS Strategies for Aggressive Behaviors
• Structure
  – Basic, simple rules
  – ABC Rules
    • Ask for help
    • Be respectful
    • Communicate your needs
  – Most important rule?
  – Everyone follows the rules

SCREAMS Strategies for Aggressive Behaviors
• Cues
  – Remind about the ABC Rules
    • Ask for help
    • Be respectful
    • Communicate your needs
  – Remember rewards and consequences
  – Remind them to make the best choice

SCREAMS Strategies for Aggressive Behaviors
• Role models
  – They learn by imitating others
  – Can we change our behaviors?
  – How can we change the behaviors of others?
  – How do we control what they see out there in the world?
SCREAMS Strategies for Aggressive Behaviors

• Environment
  – How can we prevent sensory overload?
  – Minimize stress in the classroom
  – Reduce noise and chaos at home
  – How do we affect changes in environments we don’t control?

• Attitude
  – Have realistic expectations
  – Try not to blame it all on poor parenting
  – Understand the nature of FASD
  – Brain damage + genetics + environment
  – Accept the reality of the “Invisible Gap”
  – Help the child use “Self Talk”

• Meds and Diet
  – Help the child’s brain function better
  – Find a doctor willing to learn about FASD
  – Try different meds, combo, doses
  – Nutrition – no Red40, MSG, or Nutrisweet
  – Vitamin, Omega 3, Lecithin
  – Chocolate every day
  – Hydration (weight lbs / 2 = ounces per day)

• Supervision
  – Immaturity + impulsivity + vulnerability + poor judgment = serious trouble
  – They can remember the rules and consequences, but they cannot always apply that information
  – They may be able to control impulses sometimes, but not all the time
  – What has happened in the past?
  – What are the risks if it happens again?
  – Enlist reliable, knowledgeable “external brain”

Find Their Gifts and Talents Nurture Success

• Music
• Art
• Poetry
• Dance
• Drama
• Pets and animals
• Working with hands
Self-Determination

- For many, Self-Determination becomes Self-Termination
- The smarter they are, the greater the desire to be normal, the more resistance to being controlled, the higher the expectations, the higher the risk for failure
- Independence for many will lead them to homelessness, hospitalization, institutionalization, prison, or the morgue
Setting Priorities

• Helping them to survive (literally)
• Providing a safe environment in which to realize potential and find success
• Giving them choices in how they want to live their life
• Giving them the guidance they need to make healthy choices, minimize risk

Happy, Healthy, Safe

We can work together to help families with FASD find success.

The End

Which children will survive?

• The children with FASD who achieve success as adults are the ones whose parents are
  – Stable in their own relationships
  – Have processed their own past grief
  – Talk to their children about their disability
  – Active in parent support group

Resources

• FAS Community Resource Center
  – Support groups (Phoenix, Tucson, Parker, Sierra Vista, Flagstaff)
  – Lending library (Tucson)
  – Trainers (through The Arc)
• FAS Arizona www.fasarizona.com
  Photos, personal stories, articles, online book store, reproducible documents, mail lists, referrals

www.fasstar.com

• Start at Fasstar Enterprises
• www.fasstar.com
• Click on the link for the FAS Community Resource Center
• Just google “FASD Articles”

Thank You!

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