FASD: Why Can’t We See It?

Larry Burd, PhD
Director, North Dakota Fetal Alcohol Syndrome Center
larry.burd@med.und.edu  701–777–3683
Of all the substances of abuse (including cocaine, heroin, and marijuana), alcohol produces by far the most serious neurobehavioral effects in the fetus.

<table>
<thead>
<tr>
<th>EFFECT</th>
<th>ALCOHOL</th>
<th>MARIJUANA</th>
<th>COCAINE</th>
<th>HERION</th>
<th>TOBACCO</th>
</tr>
</thead>
<tbody>
<tr>
<td>Low Birth Weight</td>
<td>✔</td>
<td>❌</td>
<td>✔</td>
<td>❌</td>
<td>❌</td>
</tr>
<tr>
<td>Impaired Growth</td>
<td>❌</td>
<td>❌</td>
<td>✔</td>
<td>❌</td>
<td>❌</td>
</tr>
<tr>
<td>Facial Malformation</td>
<td>❌</td>
<td>❌</td>
<td>❌</td>
<td>❌</td>
<td>❌</td>
</tr>
<tr>
<td>Small Head Size</td>
<td>❌</td>
<td>❌</td>
<td>❌</td>
<td>❌</td>
<td>❌</td>
</tr>
<tr>
<td>Intellectual &amp; Developmental Delays</td>
<td>❌</td>
<td>✔</td>
<td>✔</td>
<td>❌</td>
<td>❌</td>
</tr>
<tr>
<td>Hyperactivity, Inattention</td>
<td>❌</td>
<td>❌</td>
<td>✔</td>
<td>❌</td>
<td>❌</td>
</tr>
<tr>
<td>Sleeping Problems</td>
<td>❌</td>
<td>❌</td>
<td>✔</td>
<td>❌</td>
<td>❌</td>
</tr>
<tr>
<td>Poor Feeding</td>
<td>❌</td>
<td>❌</td>
<td>✔</td>
<td>❌</td>
<td>❌</td>
</tr>
<tr>
<td>Excessive Crying</td>
<td>❌</td>
<td>❌</td>
<td>✔</td>
<td>❌</td>
<td>❌</td>
</tr>
<tr>
<td>Higher Risk for Sudden Infant Death Syndrome</td>
<td>✔</td>
<td>❌</td>
<td>✔</td>
<td>❌</td>
<td>❌</td>
</tr>
<tr>
<td>Organ Damage, Birth Defects</td>
<td>❌</td>
<td>❌</td>
<td>✔</td>
<td>❌</td>
<td>❌</td>
</tr>
<tr>
<td>Respiratory Problems</td>
<td>❌</td>
<td>❌</td>
<td>✔</td>
<td>❌</td>
<td>❌</td>
</tr>
</tbody>
</table>
New Concepts on Fetal Exposure

1. Teratogenic Fraction
2. Effects: First in - to - last out
3. Cumulative Dosimetry
FASD - Familial and Generational Effects

Mortality Risk
- Maternal
- Case
- Sibling

4 fold

Stillbirth 4 fold
SIDS 10 fold
Infectious Illness 10 fold

FAS - Red
PFAS - Yellow
ARND - Green
How We Do It  

Exposure Assessment

Exposure  

When was your last drink?

Risk Stratification  

<table>
<thead>
<tr>
<th>Before</th>
<th>Pregnancy</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Pre-awareness</td>
</tr>
<tr>
<td>Unexposed</td>
<td>Exposed</td>
</tr>
</tbody>
</table>

Dosimetry  

Charting PAE During Pregnancy

On average, how many days per week did you drink during pregnancy?  _____ (a)

On an average drinking day, during pregnancy, how many drinks did you have?  _____ (b)

How many days per month did you have 4 or more drinks during pregnancy?  _____ (c)

What is the most you had to drink on any one day during pregnancy?  _____ (d)

What is a drink? Alcohol %  __________  Drink Volume _____
When Mother is missing, dead and no useful historian is available

- Maternal Risk Score
# Estimating Exposure Risk

## Maternal Risk Score

- Age over 25 years
- Unmarried, divorced, widow, living with partner
- On TANF, WIC, Social Security or income < $16,000 per year
- Did not graduate from high school
- Poor diet
- Smokes more than 1/2 pack per day
- Drinks, but less than 2 days/week & less than 2 drinks/drinking day
- Age first drunk less than 15 years
- In treatment over three times
- In treatment in last 12 months
- Previous child died
- Previous child with FASD, or developmental disability
- Children out of home (foster care or adopted)
- Heavy drinker (drinks 3 or more drinks/day for 3 or more days per week, or more than 5 drinks/day on 6 or more occasions)
- Uses inhalants, sniffs or illegal drugs

<table>
<thead>
<tr>
<th>Score</th>
<th>Risk Category</th>
<th>Recommendations</th>
</tr>
</thead>
<tbody>
<tr>
<td>0</td>
<td>None</td>
<td>Standard prenatal care</td>
</tr>
<tr>
<td>5</td>
<td>Low</td>
<td>Standard prenatal care</td>
</tr>
<tr>
<td>20-40</td>
<td>Moderate</td>
<td>Standard prenatal care and FASD education</td>
</tr>
<tr>
<td>45-50</td>
<td>High</td>
<td>High risk pregnancy, alcohol-drug abuse treatment</td>
</tr>
<tr>
<td>55-105</td>
<td>Very High</td>
<td>High risk pregnancy, alcohol-drug abuse treatment</td>
</tr>
</tbody>
</table>
## Diagnostic Criteria for FASD

<table>
<thead>
<tr>
<th></th>
<th>CNS</th>
<th>FACE</th>
<th>GROWTH</th>
<th>HISTORY</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>FAS</strong></td>
<td>YES (3+ Domain</td>
<td>YES (3 of 3)</td>
<td>YES (≤ 10%)</td>
<td>N/A</td>
</tr>
<tr>
<td></td>
<td>Deficits)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>PFAS</strong></td>
<td>YES (3+ Domains</td>
<td>YES (2 of 3)</td>
<td>N/A</td>
<td>YES</td>
</tr>
<tr>
<td></td>
<td>Deficits)</td>
<td></td>
<td></td>
<td>(Confirmed)</td>
</tr>
<tr>
<td><strong>ARND</strong></td>
<td>YES (2+ Domain</td>
<td>N/A</td>
<td>N/A</td>
<td>YES</td>
</tr>
<tr>
<td></td>
<td>Deficits)</td>
<td></td>
<td></td>
<td>(Confirmed)</td>
</tr>
</tbody>
</table>
Criteria are Age Dependent
FASD Prevalence

- 1% of live births
- 20% recurrence risk
- More severe in younger sibs
- 5% ever diagnosed
- Increasing rates of neuropsychiatric disorders
Neurobehavioral Expression of FASD

“No, I won’t.”

“Let’s wait; I want to talk this over...”

“OK!”
Fetal Alcohol Spectrum Disorders (FASD)

See PAE, Think Impairment

ARND: Risk Factors Ahead
- Exit 1: Abuse/Neglect
- Exit 2: Mental Disorders
- Exit 3: School Problems
- Exit 4: Legal Problems
- Exit 5: Substance Abuse
- Exit 6: Dependent Living
Green Light problems in the last year

“No, I won’t.”

“Let’s wait; I want to talk this over...”

“OK!”

My plan:

1)
2)
3)
Typical FASD: Look for Impairment
Behind the Face of FASD: We See

- ADHD
- Depression
- Cognitive Impairment
- Intellectual Disability
- Learning Disabilities
- Substance Abuse
- Judgment Deficits
FASD and Comorbid Mental Disorders

- ADD/ADHD
- ID/MR
- Learning Disability
- Oppositional Defiant Disorder
- Depression
- Psychotic Disorder
- Bi-polar Manic Depressive Disorder
- Anxiety Disorder
- PTSD
- Reactive Attachment Disorder
- Obsessive Compulsive Disorder
FASD Forecast

The Future of FASD: Increasing Severity of Neurobehavioral Impairments
In Canada youth 12–18 years of age with FASD have a 19 fold increase risk of incarceration.

Popova L., Am J Epidemiol, 2012
THE ARND BEHAVIORAL CHECKLIST

NAME/ID: ______________________ DOB: __/__/____ AGE: _______ SEX (circle one): F M
RACE (circle one): Caucasian Native American African American Other DATE OF EXAM: __/__/____

In order to complete this checklist:
1) Behaviors must be impaired for the age of the person being assessed.
2) Interviewee needs to have known the person being assessed for at least one month.

CHECK ALL THAT APPLY FOR THE APPROPRIATE AGE RANGE:

<table>
<thead>
<tr>
<th>BEHAVIOR</th>
<th>3-6 yrs.</th>
<th>7 yrs. +</th>
</tr>
</thead>
<tbody>
<tr>
<td>Hyperactive</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Poor attention</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Impulsive</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Disorganized</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Seems unaware of consequences of actions</td>
<td></td>
<td></td>
</tr>
<tr>
<td>No fear</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Would leave with a stranger</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Poor social skills</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Few friends</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Will talk or interact with anyone</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Easily manipulated and set up by others</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Socially inept (inappropriate speech or touching)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Difficultly staying on topic during conversation</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Always talking</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Cocktail speech - little content</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Too loud</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Can’t remember from one day to the next</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Below average IQ (&lt; 85)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Poor school performance</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Suspended or expelled from school</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Poor sleeper</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Can’t follow routine - needs reminders to get dressed, brush teeth, etc.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Temper tantrums</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Extreme mood swings</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Requires constant supervision</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Been in trouble with the law</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Inpatient treatment for mental health or substance abuse, or in jail for a crime</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Inappropriate sexual behavior</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Poor motor skills</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Has or needs glasses</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Had foster care or was adopted</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Medication for behavior - ever</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mother used alcohol during any pregnancy (OPTIONAL)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mother used alcohol in last five months of this pregnancy (OPTIONAL)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mother has been in treatment for alcohol use (OPTIONAL)</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

For additional forms or information on ARND, contact:
Larry Burd, Ph.D.
301 N. Columbia Road, Suite 9037
Grand Forks, ND 58202-9037
701-777-3583
www.online-clinic.com

TOTAL CHECKED: [16] [20]
(Continue assessment if score is greater than or equal to above)
Management of FASD?
Think ARND (90 – 95%)

Not FAS (<5%) – diagnosis very complex

Almost everyone is undiagnosed
Risk Factors Ahead

Exit 1  Abuse/Neglect
Exit 2  Foster Care
Exit 3  Impairments
Exit 4  Legal Problems
Exit 5  Substance Abuse
Exit 6  Dependent Living
3) FASD: What we First See

Behavior + Impairment

A Better View

Behavior + Impairment

Inconsistent Performance

Typical Day
### Behavior often persists over the lifespan

#### Same Behavior Different Age

<table>
<thead>
<tr>
<th>Age</th>
<th>Behavior</th>
</tr>
</thead>
<tbody>
<tr>
<td>2</td>
<td>Irritable, impulsive, difficult, requires lots of attention</td>
</tr>
<tr>
<td>4</td>
<td>Poorly organized, can’t finish, easily distracted, forgets</td>
</tr>
<tr>
<td>6</td>
<td>Loses and forgets, comprehension deficits, social deficits</td>
</tr>
<tr>
<td>8</td>
<td>Can’t finish, loses stuff, needs help every day, avoidant/aggressive</td>
</tr>
<tr>
<td>12</td>
<td>School problems, doesn’t get stuff home or back to school, social deficits, extra help-helps</td>
</tr>
<tr>
<td>14</td>
<td>Late, social deficits, school problems, cognitive delays, behavior problems, does best at home, school problems often severe</td>
</tr>
<tr>
<td>20</td>
<td>Can’t get things finished, avoidant, anxious, easily overwhelmed, memory is poor, why doesn’t he/she change, poor choices</td>
</tr>
<tr>
<td>24</td>
<td>Late or missing meetings, easily overwhelmed, avoidant, social choices are poor, nods in agreement but doesn’t understand, can’t finish (treatment, parenting classes after 20+ years who/what needs to change?</td>
</tr>
</tbody>
</table>
FASD Management

- Yearly follow-up
- Few live independently
- Remember the Familial and Generational Effects of FASD
- Services MATTER
### 2) Basic Cognitive Skills in Adolescents and Adults with FASD

<table>
<thead>
<tr>
<th>Characteristics</th>
<th>Grade Level</th>
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<tbody>
<tr>
<td>Reading</td>
<td>5.0</td>
</tr>
<tr>
<td>Reading comprehension</td>
<td>4.5</td>
</tr>
<tr>
<td>Oral Comprehension</td>
<td>5.0</td>
</tr>
<tr>
<td>Percent Affected</td>
<td></td>
</tr>
<tr>
<td>Memory</td>
<td>80%</td>
</tr>
<tr>
<td>Attention (ADHD)</td>
<td>75%</td>
</tr>
<tr>
<td>Executive Function Impairments</td>
<td>80%</td>
</tr>
</tbody>
</table>
Children With FASD Can Be Different to Parent

- High rates of
  - Sleep disorders
  - Eating problems
  - Toilet training difficulties
  - Temper Tantrums
  - Developmental disorders—needing therapy
  - School problems
  - Homework problems
  - Increasing severity of phenotype
Interventions

- Understand FASD
- Slow pace
- Picture schedules
- Decrease memory burden
- Manage anxiety
- Positive behavior management – less escalation
- Understand effects of comorbidity
- Comorbidity and future risk reduction
- Respite care for caretakers
General Strategies

- Plan long-term
- Teach the child/parent to ask for help
- Focus on strengths
- Use praise constantly
- Identify someone (or a team) to serve as the “external brain”
We Should Not Increase Severity

- Level Systems
- Positive Reward Deficits
- Complex Requirements
- If you ever do it = You can always do it.
- Lack of Support and Advocacy
BEDTIME SCHEDULE

PAJAMAS

BRUSH TEETH

GO POTTY

STORY TIME

LIGHTS OUT
GETTING UP

- Get up
- Go potty
- Get dressed
- Breakfast
- Get ready for school
TAKING YOUR MEDICINE

AM

RED
BLUE

PM

RED
BLUE
GREEN
Calm Down Book
For

Say:

“I want to leave!”

Do Not Talk!

Go to your spot.
Adolescents

- Think:
  - Impairment
  - Substance Abuse
    - Monitor for this
    - Track Peers
    - Treat First Time and Every Time – It’s a grave threat
    - Modify Treatment
  - Where will they live and work
  - Environment is key
  - Do Not Lose Hope
What Behavior to Start With

- Frequent
- Easy to Identify and Count
- Has a Negative and Positive Consequence
- Try to avoid infrequent behaviors to start with
Behavior Management

POSITIVE BEHAVIORS
1. Increasing specific behaviors
2. Pick behavior which competes with negative behaviors

- Schedule rewards at first.
- Then go to random chances.
- Big problems require potent rewards.

NEGATIVE BEHAVIORS
Frequent verbal behaviors - tear off one for each target behavior

- When Nathaniel has this card, he can earn rewards.
- Remove card for low level of inappropriate behavior
- 3 minutes only
- NO Card. NO reward. Offer frequent rewards.
- This is a signal that behavior is not appropriate. Can be done many times per day.

Calm Down Book
For

Have a plan.
- Practice
- Limit talking
- Reward all steps
YOU don’t have to get better to do better!

Accommodations