FETAL ALCOHOL SPECTRUM DISORDERS: RELEVANCE TO FOSTER CARE.
Understanding, Identifying, and Helping the Highest Risk Babies, Children, & Caregivers

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http://depts.washington.edu/fadu/

1-20-05
# Fetal Alcohol Spectrum Disorders: Relevance to Foster Care

<table>
<thead>
<tr>
<th>Time</th>
<th>Presenter</th>
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</thead>
<tbody>
<tr>
<td>9:30-10:30</td>
<td>Ann Streissguth</td>
</tr>
<tr>
<td>10:30-10:50</td>
<td>Nancy Whitney</td>
</tr>
<tr>
<td>10:50-11:10</td>
<td>Break</td>
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<tr>
<td>11:10-12:00</td>
<td>Therese Grant</td>
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<tr>
<td>12:00-12:30</td>
<td>Julie Gelo</td>
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<tr>
<td>12:30-1:30</td>
<td>Group Discussion</td>
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<tr>
<td>1:30</td>
<td>Adjourn</td>
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</tbody>
</table>
- IN GRATITUDE -

THIS RESEARCH FUNDED BY:

- National Institute on Alcohol & Alcoholism
- Centers for Disease Control
- Indian Health Service
- Spencer Foundation, Thrasher Foundation
- UW Alcoholism & Drug Abuse Institute
- Foundations Fund for Research in Psychiatry
- UW Medical Student Research Training Prgm
- UW Royalty Research Fund, Dana Foundation
- Center for Substance Abuse Prevention
- March of Dimes, Robert Wood Johnson
- Washington State DSHS
This Work is Done by a Team

- In Gratitude - My Colleagues:

• David Smith & Ken Jones, 1973

• Jim Hanson, John Graham, Sterling Clarren, Jon Aase
  • Paul Lemoine, Philippe Dehaene

• Donald Martin, Helen Barr, Paul Sampson, Fred Bookstein

• Joan Martin, Sharon L. Ramey, Cindy Herman, Betty Darby

• Heather C. Olson, Robin LaDue, Paul Connor, Janet Huggins

• Therese Grant, Cara Ernst, Pam Phipps

• David Haynor Christine Gleason, Raymond Sze

• Kieran O’Malley, Kay Kelly, Eric Schnapper
23,000 children (Birth to age 5) are accepted into Child Protective Services each year.

Case files are opened on nearly 5,000 with child abuse & neglect

“Therapeutic treatment available for only 250 of the 4,800 children designated to need help.

State Budget is only $7 million per year for neglected & abused infants

Approximately 1% of state funding for corrections “

Past Month Alcohol, Tobacco, and Illicit Drug Use by Age Group

% reporting

Alcohol 56.8 49 16.4
Tobacco 42.9 28.9 15.6
ANY Illicit Drug 15.9 4.2 9.7
MJ 13.6 3 4.2
Illicit other than MJ 4.6 5.9 1.7

SOURCE: Substance Abuse and Mental Health Services Administration, Summary of Findings from the 2000 National Household Survey on Drug Abuse, NHSDA Series H-13, Rockville, MD.
ETHANOL CROSSES THE PLACENTA FREELY
For Prevention and Intervention:

BOTH THE MOTHER
AND THE INFANT
ARE OUR TARGETS
Fetal Alcohol Spectrum Disorders

Fetal Alcohol Syndrome (FAS) 1973
(Face Growth Brain) Jones, Smith, Hanson, Clarren

Fetal Alcohol Effects (FAE) 1976
(Examined & exposed, some alc. effects, not FAS)

Alcohol-Related Neurodevelopmental Disorders (ARND) 1996
Institute of Medicine, 1996

Static Encephalopathy: Alcohol Exposed 1997
Sterling Clarren, Susan Astley,
UW FAS Diagnostic Clinic 206-685-9888
Central Nervous System Dysfunction
Organic Brain Damage

- Hyperactivity, attentional deficits
- Intellectual deficits, learning disorders
- Problems with memory, language & judgment
- Developmental delay, microcephaly
- Fine & gross motor problems, seizure disorder
- Mental retardation, structural brain damage

Growth Deficiency
Specific Pattern of Facial Anomalies
Central Nervous System Dysfunction
Organic Brain Damage

• Hyperactivity, attentional deficits
• Intellectual deficits, learning disorders
• Problems with memory, language & judgment
• Developmental delay, microcephaly
• Fine & gross motor problems, seizure disorder
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Central Nervous System Dysfunction
Organic Brain Damage

- Hyperactivity, attentional deficits
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- Problems with memory, language & judgment
- Developmental delay, microcephaly
- Fine & gross motor problems, seizure disorder
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### Behavioral Effects Following Prenatal Alcohol Exposure

<table>
<thead>
<tr>
<th>Humans</th>
<th>Animals</th>
</tr>
</thead>
<tbody>
<tr>
<td>Hyperactivity, reactivity</td>
<td>Activity exploration, reactivity</td>
</tr>
<tr>
<td>Attn. deficits, distractibility</td>
<td>Decreased attention</td>
</tr>
<tr>
<td>Lack of inhibition</td>
<td>Inhibition deficits</td>
</tr>
<tr>
<td>Mental retard, learning diff.</td>
<td>Impaired associative learning</td>
</tr>
<tr>
<td>Reduced habituation</td>
<td>Impaired habituation</td>
</tr>
<tr>
<td>Perservation</td>
<td>Perservation</td>
</tr>
<tr>
<td>Feeding difficulties</td>
<td>Feeding difficulties</td>
</tr>
<tr>
<td>Gait abnormalities</td>
<td>Altered gait</td>
</tr>
<tr>
<td>Poor fine/gross motor skills</td>
<td>Poor coordination</td>
</tr>
<tr>
<td>Dev. delay (motor, soc., lang.)</td>
<td>Developmental delay</td>
</tr>
<tr>
<td>Hearing abnormalities</td>
<td>Altered audi. evoked potentials</td>
</tr>
<tr>
<td>Poor state regulation</td>
<td>Poor state regulation</td>
</tr>
</tbody>
</table>

Driscoll, Streissguth, Riley 1990
Alcohol Chicks Fail Detour Learning Test

- Food
- Light
- Control chick
- Alcohol chick
Prenatal Alcohol Can Alter Pup Retrieval in FAE Mother Rats

Latency in minutes

- Controls
- Ethanol exposed

Retrieval of first pup
Retrieval of whole litter
Day 1 or 2
Brazelton Exam, Reflexes, Pressure Transducer

Outcomes most salient for prenatal alcohol

- Sucking Pressure … Poorer
- Latency to Suck …….. Poorer
- State Lability ……….. Poorer
- Habituation: Light* .. Poorer
- Reflexes …………….. Poorer

* Outcome most salient for prenatal alcohol across first 7 years of life.

Summary: Birth cohort study

**Prenatal alcohol effects are:**

- Significant across life: Birth to 21 years
- Generally dose-dependant without clear thresholds
- Resistant to covariate adjustment
- Binge pattern particularly harmful

**Neurobehavorial effects are:**

- Stronger than physical
- Not mediated by birth weight
HOW DOES ALCOHOL CAUSE BRAIN DAMAGE?

ALCOHOL CAUSES:

• Excessive cell death
• Reduced cell proliferation
• Migrational errors in brain development
• Inhibition of nerve growth factor
• Disruption of neurotransmitters
SECONDARY DISABILITIES IN Fetal Alcohol Spectrum Disorders
RISK FACTORS

For Secondary Disabilities in FASD

• Not raised in a stable, nurturant home*
• Not diagnosed at an early age*
• 72% experienced sexual or physical abuse
• Changing households every two to three years
• Not receiving Developmental Disabilities Services
  (All were born to mothers who abused alcohol)
PROTECTIVE FACTORS

MULTIVARIATE ANALYSSES SHOWED TWO STRONG
PROTECTIVE FACTORS

• Living in a stable & nurturant home
• Receiving an early diagnosis
PREVALENCE OF SECONDARY DISABILITIES Across the Life Span

Ages 6-51 (n=408-415)

Ages 21-51 (n=89-90)

- Mental Health Problems
- Trouble With the Law
- Inappropriate Sexual Behavior
- Alcohol & Drug Problems
- Problems with Employment

Disrupted School Experience
Confinement
Dependent Living
PREVALENCE OF SECONDARY DISABILITIES by 3 Age Groups

Mental Health Problems
- Ages 6-11 (n=162)
- Ages 12-20 (n=163)
- Ages 21-51 (n=90)

Disrupted School Experience

Trouble With the Law

Confinement

Inappropriate Sexual Behavior

Alcohol & Drug Problems

Ages 6-11 (n=162)  Ages 12-20 (n=163)  Ages 21-51 (n=90)
IQ distributions in the Primary Disabilities Sample: FAS and FAE

- **FAS** (n = 178):
  - Mean IQ: 79

- **FAE** (n = 295):
  - Mean IQ: 90

N = 473: test ages 3-51 yrs

IQ ≤ 70: 27% (FAS), 9% (FAE)

**IQ Scores Distribution**

<table>
<thead>
<tr>
<th>IQ Range</th>
<th>Within FAS</th>
<th>Within FAE</th>
</tr>
</thead>
<tbody>
<tr>
<td>20-30</td>
<td>1/0</td>
<td>0/0</td>
</tr>
<tr>
<td>40-50</td>
<td>3/7</td>
<td>1/2</td>
</tr>
<tr>
<td>60-70</td>
<td>14/24</td>
<td>4/16</td>
</tr>
<tr>
<td>80-90</td>
<td>29/12</td>
<td>25/8</td>
</tr>
<tr>
<td>100-110</td>
<td>6/4</td>
<td>26/15</td>
</tr>
<tr>
<td>120-130</td>
<td>1/1</td>
<td>2/2</td>
</tr>
<tr>
<td>140-150</td>
<td>0/0</td>
<td>0/0</td>
</tr>
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</table>

percent

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**Legend**

- Black: FAS
- Gray: FAE
<table>
<thead>
<tr>
<th>Clinical Implications</th>
</tr>
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<tbody>
<tr>
<td>Poor judgment…………...</td>
</tr>
<tr>
<td>Attention deficits.........</td>
</tr>
<tr>
<td>Arithmetic disability……...</td>
</tr>
<tr>
<td>Memory problems.........</td>
</tr>
<tr>
<td>Difficulty abstracting….</td>
</tr>
<tr>
<td>Disoriented in…………...</td>
</tr>
<tr>
<td>time and space</td>
</tr>
<tr>
<td>Poor frustration ............</td>
</tr>
<tr>
<td>tolerance</td>
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</table>
IF YOU HAVE A CLIENT LIKE THIS:

1. Ask if their mother had an alcohol problem?
2. Ask if they sometimes do the same dumb things over and over?
3. Ask if they have trouble managing money?
4. Give an informant the FABS
5. Help them get help.
Prenatal Alcohol

Primary Disability

Brain Damage

Dysfunctional Behaviors

Secondary Disabilities

Trouble with the Law, School Disruption, Etc.
DETECTION
Incidence of FAS:
≈ 3 per 1000 births

Prevalence of ARND:
> 6 per 1000 births

Prevalence of ARND + FAS:
≈ 1 per 100 births

Seattle Longitudinal Prospective Study: Sampson, Streissguth, et al. Teratology, 1997
Patients with FAS / FAE who became Parents
Reasons for failure to care for children

<table>
<thead>
<tr>
<th>Reason for Failure</th>
<th>Females</th>
<th>Males</th>
</tr>
</thead>
<tbody>
<tr>
<td>Children Removed</td>
<td>36</td>
<td>08</td>
</tr>
<tr>
<td>Children Abandoned</td>
<td>31</td>
<td>46</td>
</tr>
</tbody>
</table>

Females: n = 30
Males: n = 14
PREVALENCE OF SECONDARY DISABILITIES: Parents vs. Non-Parents

<table>
<thead>
<tr>
<th>Condition</th>
<th>Parents (n=44)</th>
<th>Non-Parents (n=112)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Disrupted School Experience</td>
<td>84%</td>
<td>59%</td>
</tr>
<tr>
<td>Trouble With the Law</td>
<td>71%</td>
<td>62%</td>
</tr>
<tr>
<td>Alcohol / Drug Abuse</td>
<td>36%</td>
<td>36%</td>
</tr>
<tr>
<td>Ever Homeless</td>
<td>68%</td>
<td>36%</td>
</tr>
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DETECTION
Both landmarks and callosal outlines show hypervariability of exposed compared to normals.
Midline Corpus Callosum a Neuroanatomic Focus of Fetal Alcohol Damage *

100/117 (exposed detected) = 85% sensitivity
49/60 (unexposed not detected) = 82% specificity

FAS vs. FAE = indistinguishable
The finding is for HYPERVARIABILITY of SHAPE,
Not for mean size or volumes

* Bookstein, Sampson, Connor, Streissguth, 2002 New Anatomist;
Bookstein et al, 2001 Teratology
Corpus Callosum Shape and Neuropsychological Deficits *

90 adult males: 30 FAS, 30 FAE, 30 unexposed

12 min MRI, 5 hr. test battery

Excess shape variation in exposed patients relates to:

Two different profiles of behavior

- Thinner CC with deficits in motor function
- Thicker CC with deficits in executive function

Bookstein, Streissguth, Sampson, Connor, Barr. 2002 Neurolmage
BEHAVIORAL PHENOTYPE: FASD

Poor EXECUTIVE FUNCTION*

1. Difficulty organizing stored information to plan future activities
2. Difficulty regulating and sequencing behavior
3. Difficulty inhibiting responses
4. Lack of cognitive flexibility

(Wisconsin Card Sort, Stroop, Trails, Ruff’s Figural Fluency, Consonant Trigrams)

*Connor, Sampson, Bookstein, Barr & Streissguth 2000 Developmental Neuropsychology
More Executive Function Problems Than Expected for IQ Level in FAS/FAE
BEHAVIORAL PHENOTYPE: FASD

Poor Habituation: *
Difficulty Modulating Incoming Stimuli

1. Gets overstimulated in social situation (as in a crowded room, or among strangers)
2. Overreacts to situations with surprisingly strong emotional reactions
3. Displays rapid mood swings set off by seemingly small events
4. Has poor attention spans
5. Has trouble completing tasks

*Fetal Alcohol Behavioral Scale (FABS), parent report, Streissguth Book 1997
KEEP IN MIND:

Fetal Alcohol Spectrum Disorders are Birth Defects caused by prenatal alcohol,

and

Compounded postnatally by the consequences of a mother who abuses alcohol.
How can we detect and help families at risk in our own communities?
In Our Communities We Must:

- Screen & detect high risk mothers, at pregnancy and delivery
- Be especially alert to mothers and babies with FASD
- Get both mothers and babies into early interventions
- Keep data on what happens
Best predictor of poor child & adult outcomes

BARC *

Calculated from self-reported frequency of 4 - 5 or more drinks per drinking occasion

*Binge Alcohol Rating Criteria
Fetal Alcohol Spectrum Disorders ARE NOT HOPELESS

- An early Diagnosis
- Stable, Nurturant, Good Quality Home
- Freedom from Personal Violence
- Appropriate Institutional Supports

Can prevent secondary disabilities and enhance adult employment and independence
Recommendations for Institutional Detection of Patients with FAS/FAE

AT INTAKE

1. ASK about maternal alcohol abuse
2. LOOK at the patient
3. LEARN about the patient's past history
DID YOUR MOTHER USED TO HAVE A DRINKING PROBLEM?
FAS / FAE

Only 7 of 90 adults able to live independently and without major employment problems
WELLNESS FOR MOTHER/CHILD

1. Get an early diagnosis for babies
2. Get help for alcohol-abusing moms
3. Get babies into early intervention
4. Enlist family/peer support
WELLNESS FOR CAREGIVERS

1. Get a diagnosis if FASD suspected
2. Join an FASD support group
3. Get baby into early interventions
4. Get trainings from foster-care program
5. Help child be the best they can be
6. Watch child for developmental cues
7. Provide learning opportunities but avoid over-stimulating child with FASD
“IT IS IN THE SHELTER OF EACH OTHER THAT THE PEOPLE LIVE”

--IRISH PROVERB--