**FASD Diagnosis, Intervention, & Prevention**

Susan Astley PhD  
Professor Epidemiology/Pediatrics  
Director Washington State FAS Diagnostic & Prevention Network  
University of Washington  
Seattle WA, U.S.A  
astley@uw.edu  
fasdpn.org  
2017

---

**WA State FAS Diagnostic & Prevention Network (fasdpn.org)**

The FASD 4-Digit Diagnostic Code  
Used worldwide since 1997

---

**What is Fetal Alcohol Syndrome (FAS)?**

FAS is characterized by:

1. Growth deficiency
2. Unique facial features
3. CNS abnormalities (evidence of structural, neurological, or functional impairment)
4. Prenatal alcohol exposure

Prevalence: 1 to 3 per 1,000 live births (equivalent to down syndrome).

Leading known cause of developmental disabilities.

100% preventable.
Interdisciplinary FASD Diagnostic Clinic

An FASD diagnosis is conducted:
• by an interdisciplinary team
• using rigorous diagnostic guidelines.

Interdisciplinary clinical team includes:
• Pediatrician
• Psychologist
• Speech Language Pathologist
• Occupational Therapist
• Social Worker
• Family Advocate

The University of Washington FASD diagnostic evaluation is conducted in one 4-hour appointment using the FASD 4-Digit Code:
• Caregiver(s) is interviewed by pediatrician and social worker
• Child is assessed by the SLP, OT, and psychologist
• Diagnosis and Intervention Plan are shared with caregivers
• Comprehensive medical report mailed to family.

FASD 4-Digit Code Tools

All tools available at fasdpn.org

The FASD 4-Digit Code is Fully Validated

The FASD 4-Digit Diagnostic Code

<table>
<thead>
<tr>
<th>Rank</th>
<th>Growth</th>
<th>Face</th>
<th>CNS</th>
<th>Alcohol</th>
</tr>
</thead>
<tbody>
<tr>
<td>&gt; 10%tile</td>
<td>No features</td>
<td>No Dysfunction</td>
<td>Confirmed Absent</td>
<td>1</td>
</tr>
<tr>
<td>6-10%tile</td>
<td>1-2 features</td>
<td>Moderate Dysfunction</td>
<td>Confirmed Unknown</td>
<td>2</td>
</tr>
<tr>
<td>3-5%tile</td>
<td>2.5 features</td>
<td>Severe Dysfunction</td>
<td>Confirmed</td>
<td>3</td>
</tr>
<tr>
<td>≤ 2%tile</td>
<td>All 3 features</td>
<td>Structural / Neurological Abnormalities</td>
<td>Confirmed High</td>
<td>4</td>
</tr>
</tbody>
</table>

3434 is one of twelve 4-Digit Codes for FAS

Example of 4-Digit Codes for FAS and PFAS

A FAS (alcohol exposed)

2433   3433   4433
2434   3434   4434
2443   3443   4443
2444   3444   4444

B FAS (alcohol exposure unknown)

2432   3432   4432
2442   3442   4442

C Partial FAS (alcohol exposed)

1333   1433   2333   3333   4333
1334   1434   2334   3334   4334
1343   1443   2343   3343   4343
1344   1444   2344   3344   4344

4-Digit Code produces FOUR Diagnostic Subgroups under the umbrella of FASD

<table>
<thead>
<tr>
<th>Diagnosis</th>
<th>Growth</th>
<th>Face</th>
<th>Brain</th>
<th>Alcohol</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. FAS</td>
<td>Fetal Alcohol Syndrome</td>
<td>growth</td>
<td>severe</td>
<td>alc.</td>
</tr>
<tr>
<td>2. PFAS</td>
<td>Partial FAS</td>
<td>face</td>
<td>severe</td>
<td>alc.</td>
</tr>
<tr>
<td>3. SE/AE</td>
<td>Static Encephalopathy/Alc Exposed</td>
<td>severe</td>
<td>alc.</td>
<td></td>
</tr>
<tr>
<td>4. ND/AE</td>
<td>Neurobehavioral Disorder/Alc Exposed</td>
<td>moderate</td>
<td>alc.</td>
<td></td>
</tr>
</tbody>
</table>
Diagnostic Outcomes of 3,000 Patients

<table>
<thead>
<tr>
<th>FAS/PFAS</th>
<th>10%</th>
</tr>
</thead>
<tbody>
<tr>
<td>SE/AE</td>
<td>24%</td>
</tr>
<tr>
<td>NO/AE</td>
<td>44%</td>
</tr>
<tr>
<td>Norm CNS/No Face</td>
<td>6%</td>
</tr>
</tbody>
</table>

Gender, Racial and Age Profile of 3,000 Patients

<table>
<thead>
<tr>
<th>Gender, Age</th>
<th>Clinic</th>
</tr>
</thead>
<tbody>
<tr>
<td>Male</td>
<td>58%</td>
</tr>
<tr>
<td>0-3 yrs</td>
<td>18%</td>
</tr>
<tr>
<td>4-6 yrs</td>
<td>17%</td>
</tr>
<tr>
<td>6-15 yrs</td>
<td>55%</td>
</tr>
<tr>
<td>16+ yrs</td>
<td>10%</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Race</th>
<th>Clinic</th>
<th>WA State</th>
</tr>
</thead>
<tbody>
<tr>
<td>White</td>
<td>49%</td>
<td>82%</td>
</tr>
<tr>
<td>Black</td>
<td>7%</td>
<td>3%</td>
</tr>
<tr>
<td>Native American/Alaskan</td>
<td>8%</td>
<td>2%</td>
</tr>
<tr>
<td>Asian</td>
<td>&lt; 1%</td>
<td>6%</td>
</tr>
</tbody>
</table>

Prevalence of FAS/D

<table>
<thead>
<tr>
<th>Prevalence of FAS</th>
</tr>
</thead>
<tbody>
<tr>
<td>General population</td>
</tr>
<tr>
<td>Foster Care</td>
</tr>
<tr>
<td>FASD Clinic</td>
</tr>
</tbody>
</table>

For every child with FAS, there are 10 times more with FASD

<table>
<thead>
<tr>
<th>Prevalence of FAS</th>
<th>Prevalence of FAS</th>
</tr>
</thead>
<tbody>
<tr>
<td>FAS</td>
<td>1/100</td>
</tr>
<tr>
<td>Autism</td>
<td>1 / 45</td>
</tr>
<tr>
<td>FASD</td>
<td>1/100</td>
</tr>
<tr>
<td>Down syndrome</td>
<td>1 / 1000</td>
</tr>
</tbody>
</table>
The structural and functional abnormalities of the brain become more severe as you advance from ND/AE to SE/AE to FAS/PFAS.

---

Proportion of subjects with FSIQ < 70 increases with increasing severity of 4-Digit Code FASD diagnosis.

FAS/PFAS and SE/AE must meet the same diagnostic threshold for severe dysfunction. That said …
Those who meet that threshold and have the FAS Face (FAS/PFAS) have more severe dysfunction than those who meet that threshold and do not have the FAS face (SE/AE).

---

Delayed Effects of FASD

"...children exposed to and damaged by prenatal alcohol exposure do deceptively well in their preschool years. The full impact of their alcohol exposure on brain function will not be evident until later in childhood."

Over half of the children with full FAS seen in the FASDPN Clinic had Bayley developmental outcomes within the normal range, only to present with severe brain dysfunction later in childhood.

How do you know which infants with prenatal alcohol exposure and normal early development will present with severe brain dysfunction later in childhood?

Our recent study (Astley, Bledsoe, Davies, 2016) confirmed the presence of sentinel physical features (growth deficiency, FAS facial features and/or microcephaly) accurately predict which alcohol-exposed infants will present with severe brain dysfunction later in childhood.
The only safe amount of alcohol for ALL fetuses is none at all.

- The higher the consumption, the higher the risk of FASD.
- Because the fetal brain continues to develop throughout pregnancy, there is no safe time for a woman to drink while pregnant. However, if a woman drinks during pregnancy, the risk can be reduced if the woman stops or reduces her drinking. It is never too late to stop.
- Some fetuses are more vulnerable to the adverse effects of alcohol than others. Genetics plays a role. Fraternal twins often have different outcomes despite identical exposures. It is not uncommon for one to be born with FAS while the other presents with normal development. Identical twins are typically identically impacted.

### 4-Digit Code FAS Face (Rank 4)

1. Short PFL ≤ -2 SD
2. Smooth Philtrum Rank 4 or 5
3. Thin Upper Lip Rank 4 or 5

Palpebral fissure length (PFL) = endocanthion to exocanthion

### Free Digital Lip-Philtrum Guides

For use on your smartphone or computer tablet
FAS Facial Analysis Software

Available from:
http://depts.washington.edu/fasdpn/htmls/face-software.htm

Seattle 10-Year Foster Care
FAS Photo Screening

FAS Facial Photographic Analysis Software
Version 2.0 (2012)

10-Year Foster Care FAS Screening using 2D Photos

10-Year Photo screening confirmed the Rank 4 FAS face is HIGHLY specific.
- > 95% of children with Rank 4 FAS face had FAS.
- 1 out of every 100 children in foster care had FAS.
(2,500 foster children screened over 10 years with 98% participation rate.)
Does Intervention Work?

YES!

The two factors that predicted the best outcomes in children with prenatal alcohol exposure are:

1. Early diagnosis and intervention
2. A stable, nurturing home environment
Types of Intervention Recommendations

120 children with FASD (0-16 years of age)

Patient Satisfaction (2,600 patients)

<table>
<thead>
<tr>
<th>Service Provided</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Would recommend clinic to other families</td>
<td>100 %</td>
</tr>
<tr>
<td>Received information they were unable to obtain elsewhere</td>
<td>92 %</td>
</tr>
<tr>
<td>Found explanation of 4-Digit Code easy to understand</td>
<td>86 %</td>
</tr>
<tr>
<td>Were somewhat to very successful in finding recommended interventions</td>
<td>90 %</td>
</tr>
<tr>
<td>Reported these services met some to all of their needs</td>
<td>96 %</td>
</tr>
</tbody>
</table>

Can FASD be Prevented?

YES!

In Washington State from 1993-1998:

The prevalence of drinking during pregnancy dropped from **15%** to **4%**

The prevalence of FAS births dropped from **7%** to **2%**

AAP Recognizes FASDPN

A new report from the American Academy of Pediatrics (AAP) said no amount of alcohol is safe for pregnant women to consume during any trimester.

“Washington State continues to be a national and international leader in FASD diagnostic, prevention, and intervention practices through a longstanding coordinated effort of diverse programs focused on their collective FASD-associated needs and building a strong FASD research and evidence basis.”

Selected References


All literature referenced in this presentation is available at: www.fasdpn.org/htmls/literature.htm

University of Washington FASDPN Website

fasdpn.org

Interact with our new FASDPN Tableau Dashboards

http://depts.washington.edu/fasdpn/html/TableauFASDPN.htm