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
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.
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 psychologist
• 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


Published Paper
http://depts.washington.edu/fasdpn/pdfs/valid2013FAR.pdf

Audio Narrated pdf

astley@uw.edu
### The FASD 4-Digit Diagnostic Code

<table>
<thead>
<tr>
<th>Rank</th>
</tr>
</thead>
<tbody>
<tr>
<td>4</td>
</tr>
<tr>
<td>3</td>
</tr>
<tr>
<td>2</td>
</tr>
<tr>
<td>1</td>
</tr>
</tbody>
</table>

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

3434 is one of twelve 4-Digit Codes for FAS

astley@uw.edu
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>FAS 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>face</td>
<td>severe</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></td>
<td>alc</td>
</tr>
<tr>
<td>4. ND/AE</td>
<td>Neurobehavioral Disorder / Alc Exposed</td>
<td>moderate</td>
<td></td>
<td>alc</td>
</tr>
</tbody>
</table>
### Gender, Racial and Age Profile of 2,600 Patients

#### Male

<table>
<thead>
<tr>
<th>Age Group</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<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 + years</td>
<td>10 %</td>
</tr>
</tbody>
</table>

#### Race

<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>

astley@uw.edu
Prevalence of FAS/D

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

### Prevalence of FAS

<p>| | |</p>
<table>
<thead>
<tr>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>General population</td>
<td>1/1,000</td>
</tr>
<tr>
<td>Foster Care</td>
<td>1/100</td>
</tr>
<tr>
<td>FASD Clinic</td>
<td>1/10</td>
</tr>
</tbody>
</table>

### Prevalence of FASD

<p>| | |</p>
<table>
<thead>
<tr>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>FASD</td>
<td>1/100</td>
</tr>
<tr>
<td>Autism</td>
<td>1/68</td>
</tr>
</tbody>
</table>

### Prevalence of FAS

<p>| | |</p>
<table>
<thead>
<tr>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>FAS</td>
<td>1/1000</td>
</tr>
<tr>
<td>Down syndrome</td>
<td>1/1000</td>
</tr>
</tbody>
</table>
If a child does not present with the FAS facial phenotype, they are not at risk for FASD.

This statement is:

• Correct
• Incorrect
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).

Astley
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 will not be evident until their adolescent years.”

Over half of the children with full FAS seen in the FASDPN Clinic had Bayley developmental outcomes within the normal range.
There is no known safe amount of alcohol during pregnancy

- The higher the consumption, the higher the risk of FASDs.
- All types of alcohol can adversely affect the fetus, including beer, wine, malt, and hard liquor.
- 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 drinking. It is never too late to stop.
- Some fetuses are more vulnerable to the effects of alcohol than others. Genetics plays a role. Non-identical twins exposed to the same level of alcohol often have different outcomes. It is common for one to be born with FAS while the other is born normally developed. Identical twins have identical outcomes.
If a 5 year old child with prenatal alcohol exposure presents with normal development, the child is not at risk for FASD.

This statement is:

• Correct
• Incorrect
4-Digit Code FAS Face (Rank 4)

1) Short PFL \( \leq -2 \text{ SD} \)
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

Contact astley@uw.edu
FAS Facial Analysis Software

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

astley@uw.edu
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.)

Only those with the Rank 4 FAS Face have Disproportionately Smaller Frontal Lobe Volumes

This is particularly compelling since the morphogenesis of the middle and upper face is heavily influenced by signals emanating from the forebrain to the frontonasal prominence.

The more severe the 4-Digit Code FAS face, the more severe the abnormalities in brain structure, function, even development.

The more severe the FAS face....

The higher the score, the more severe the neurological impairment.

The lower the IQ, the smaller the OFC, the greater the impairment in visual motor integration.

The greater the prevalence of developmental delay under age 3.

The more domains of significant dysfunction.

astley@uw.edu
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


astley@uw.edu
Types of Intervention Recommendations

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


astley@uw.edu
## Patient Satisfaction (2,600 patients)

<table>
<thead>
<tr>
<th>Service Description</th>
<th>Satisfaction Rate</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>

Astley SJ. Twenty years of patient surveys confirm a FASD 4-Digit-Code interdisciplinary diagnosis afforded substantial access to interventions that met patients' needs. J Popul Ther Clin Pharmacol Vol 21 (1):e81-e105; March 6, 2014.
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%

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

8. Astley et al., MRI outcomes from a comprehensive magnetic resonance study of children with FASD, ACER 2009;33(10).

All literature referenced in this presentation is available at: www.fasdpn.org/htmls/literature.htm
University of Washington FAS DPN Website

fasdpn.org