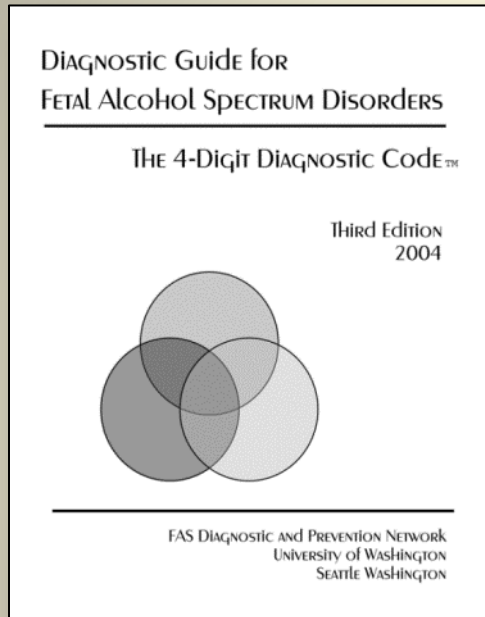


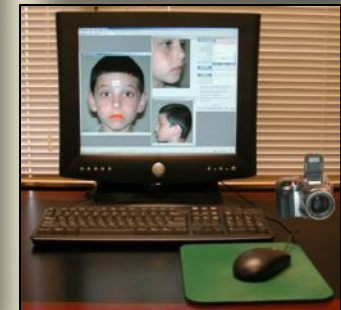
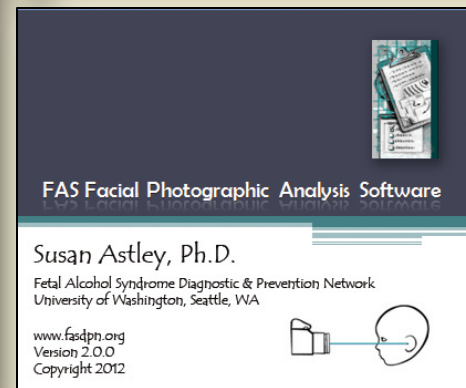
FASD Diagnosis and Intervention

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



Celebrating our
21st Year



The FASD 4-Digit Diagnostic Code

Used worldwide since 1997

What is Fetal Alcohol Syndrome (FAS)?

FAS is characterized by:

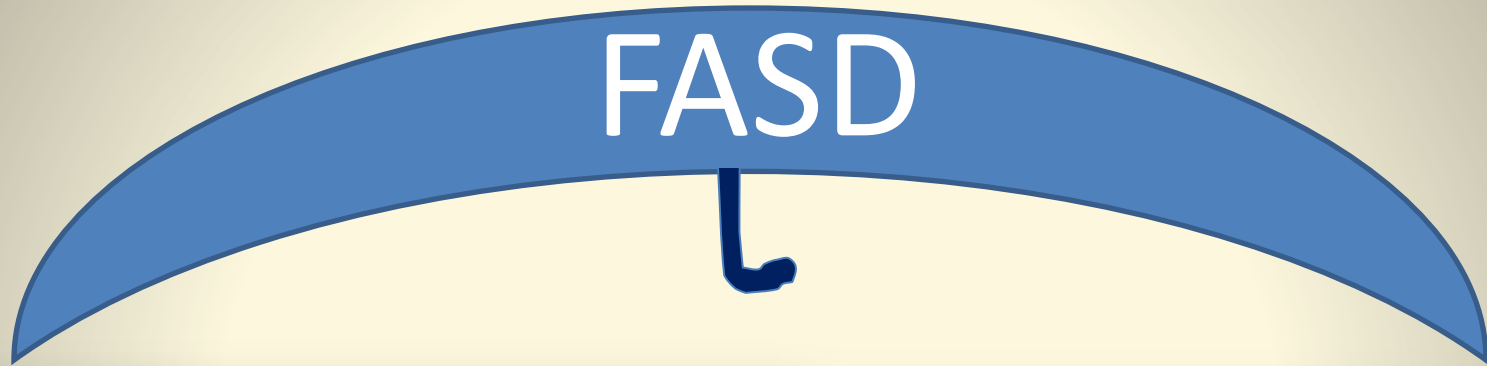
1. Growth deficiency
2. Unique facial features
3. CNS abnormalities (evidence of structural, neurological, or functional impairment)
4. Prenatal alcohol exposure

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

Leading known cause of developmental disabilities.

100% preventable.

What is Fetal Alcohol Spectrum Disorder (FASD)?



4 Diagnoses	Description
FAS	Severe brain dysfunction, facial features, growth deficiency
Partial FAS	FAS without the growth deficiency
Static Encephalopathy/Alcohol-Exposed	Severe brain dysfunction without the facial features
Neurobehavioral Disorder/Alcohol-Exposed	Moderate brain dysfunction without the facial features.

The diagnoses FAS, PFAS, SE/AE and NE/AE fall under the umbrella of FASD.

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 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

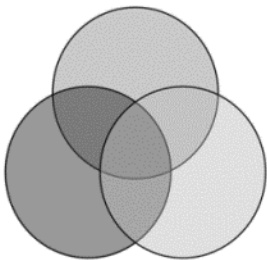
All tools available at
fasdpn.org



DIAGNOSTIC GUIDE FOR FETAL ALCOHOL SPECTRUM DISORDERS

THE 4-DIGIT DIAGNOSTIC CODE™

Third Edition
2004




FAS DIAGNOSTIC AND PREVENTION NETWORK
UNIVERSITY OF WASHINGTON
SEATTLE WASHINGTON



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Printing invalidates Guide.
Square ensures length by width ratio of image is correct.



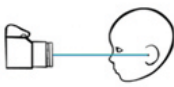
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FAS Facial Photographic Analysis Software

Susan Astley, Ph.D.
Fetal Alcohol Syndrome Diagnostic & Prevention Network
University of Washington, Seattle, WA

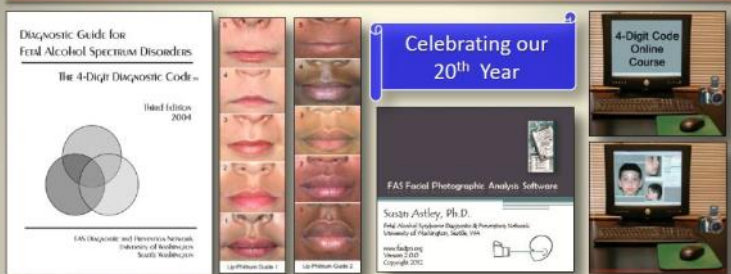
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The FASD 4-Digit Code is Fully Validated

Astley SJ. [Validation of the fetal alcohol spectrum disorder \(FASD\) 4-Digit Diagnostic Code](#). J Popul Ther Clin Pharmacol Vol 20(3):e416-467;November 15, 2013.

WA State FAS Diagnostic & Prevention Network (fasdnpn.org)



VALIDATION OF THE FASD 4-DIGIT DIAGNOSTIC CODE
Susan Astley PhD
Professor Epidemiology/Pediatrics
Director WA FAS DPN
University of Washington
2013

Right mouse click sound icon, select 'play file' to listen to narration.

Audio Narrated pdf

<http://depts.washington.edu/fasdnpn/pdfs/astley-validation-2013post-audio.pdf>

astley@uw.edu

VALIDATION OF THE FETAL ALCOHOL SPECTRUM DISORDER (FASD) 4-DIGIT DIAGNOSTIC CODE

Susan J Astley
Professor of Epidemiology and Pediatrics, University of Washington, Seattle WA

ABSTRACT

Background

The fetal alcohol spectrum disorder (FASD) 4-Digit Diagnostic Code has been used by interdisciplinary diagnostic teams worldwide for 17 years. It was created to improve the ease, accuracy, and reproducibility of diagnoses across the full spectrum of FASD. Over the years, a number of FASD diagnostic guidelines have been proposed. As the field of FASD moves forward, it will be important to adopt a single set of diagnostic guidelines worldwide. To achieve this, the performance (validity) of current diagnostic guidelines must be rigorously assessed and reported.

Objective

To summarize the body of evidence that has amassed over 20 years that validates the performance of the FASD 4-Digit Diagnostic Code.

Methods

The evidence validating the 4-Digit Code is documented across 35 studies published between 1992 and 2012, including new information presented in this report. These studies and data sources include the delineation of the FAS facial phenotype, creation of the 4-Digit Code (1997-2004); our 10-year, foster-care FAS screening program; our MRI/MRGLIMS studies; analysis of 2,550 individuals evaluated for FASD over 20 years in the WA State FASDPN clinics; and analysis of 622 patient satisfaction/follow-up surveys; surveys of 10,000 professionals attending the University of Washington FASD diagnostic clinic trainings; and surveys of over 700 professionals worldwide who completed the 4-Digit Code Online Course.

Conclusion

The 4-Digit Code is a simple, comprehensive, evidence-based, validated diagnostic system. It has served as the cornerstone of a fully integrated FASD screening, diagnostic, intervention, prevention, and surveillance program in Washington State for the past 20 years.

Key Words: Fetal alcohol spectrum disorders (FASD), fetal alcohol syndrome (FAS), diagnosis, validity, 4-Digit Diagnostic Code, FAS Diagnostic & Prevention Network (FASDPN)

The fetal alcohol spectrum disorder (FASD) 4-Digit Diagnostic Code has been used by interdisciplinary diagnostic teams worldwide for 17 years (Figure 1).¹⁻² It was created to improve the ease, accuracy, and reproducibility of diagnoses across the full spectrum of FASD.³ Over the years, a number of FASD diagnostic guidelines have been proposed.⁴⁻⁹ As the field of FASD moves forward, it will be important to adopt a single set of

diagnostic guidelines worldwide.⁸ To achieve this, the performance (validity) of current diagnostic guidelines must be empirically assessed and reported. The purpose of this report is to pull together the body of evidence that has amassed over 20 years that validates the performance of the FASD 4-Digit Diagnostic Code. This report highlights key evidence, directing readers to the source publications for more details.

J Popul Ther Clin Pharmacol Vol 20(3):e416-467; November 15, 2013
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e416

Published Paper

<http://depts.washington.edu/fasdnpn/pdfs/validation2013FAR.pdf>

Training a FASD Diagnostic Team

The University of Washington has trained over 150 interdisciplinary FASD diagnostic teams worldwide.

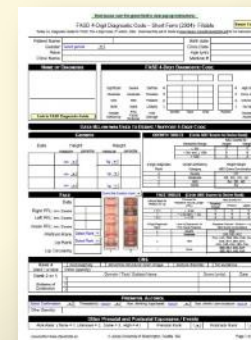
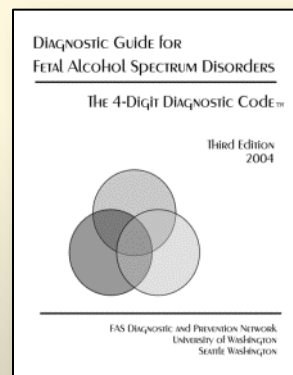
The training is described on the [FASDPN](http://fasdpn.org) website:

Step 1. All team members complete the FASD 4-Digit Code Online Course.

<http://depts.washington.edu/fasdpn/htmls/online-train.htm>

Step 2. Obtain Diagnostic tools from the FASDPN website (many are available free)

<http://depts.washington.edu/fasdpn/htmls/diagnostic-tools.htm>



The FASD 4-Digit Diagnostic Code

	3	4	3	4
Rank 4	≤ 2 %	All 3 features	Structural / Neurological Abnormalities	Confirmed High
Rank 3	3 - 5 %	2.5 features	Severe Dysfunction	Confirmed
Rank 2	6 -10 %	1-2 features	Moderate Dysfunction	Unknown
Rank 1	> 10 %tile	No features	No Dysfunction	Confirmed Absent
	Growth	Face	CNS	Alcohol

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

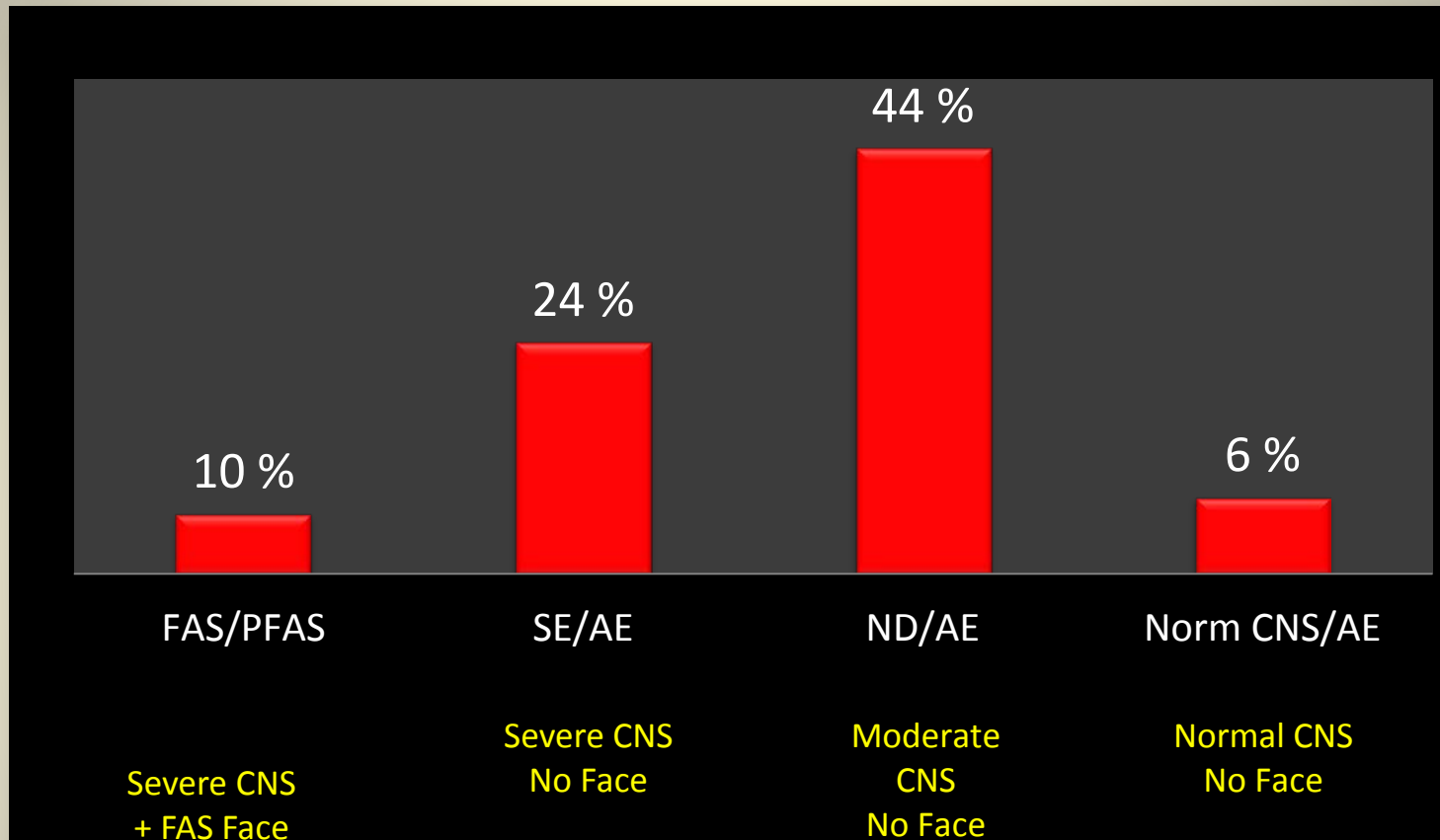
C Partial FAS (alcohol exposed)

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

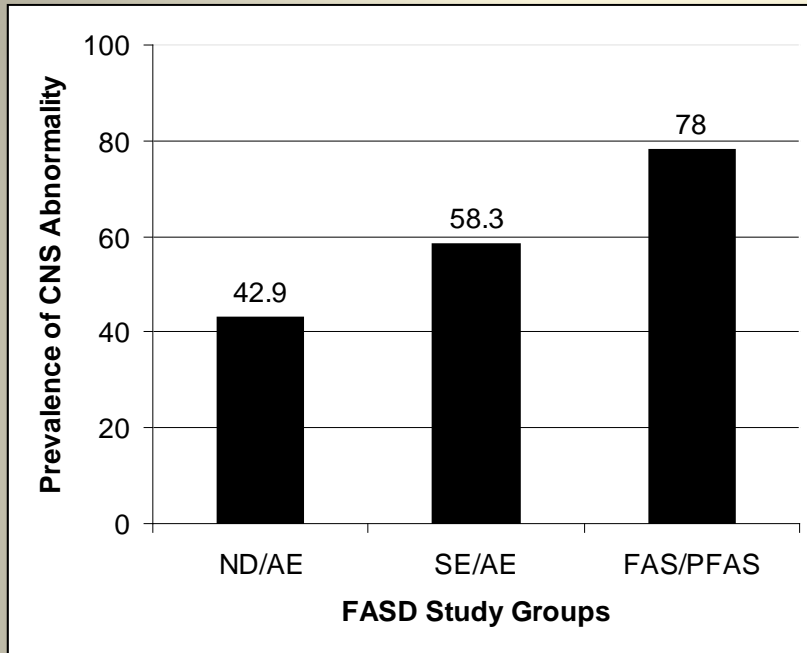
Diagnosis		Growth	FAS Face	Brain		Alcohol
1. FAS	Fetal Alcohol Syndrome	growth	face	severe		alc
2. PFAS	Partial FAS		face	severe		alc
3. SE/AE	Static Encephalopathy / Alc Exposed			severe		alc
4. ND/AE	Neurobehavioral Disorder / Alc Exposed				moderate	alc

Diagnostic Outcomes of 2,600 Patients

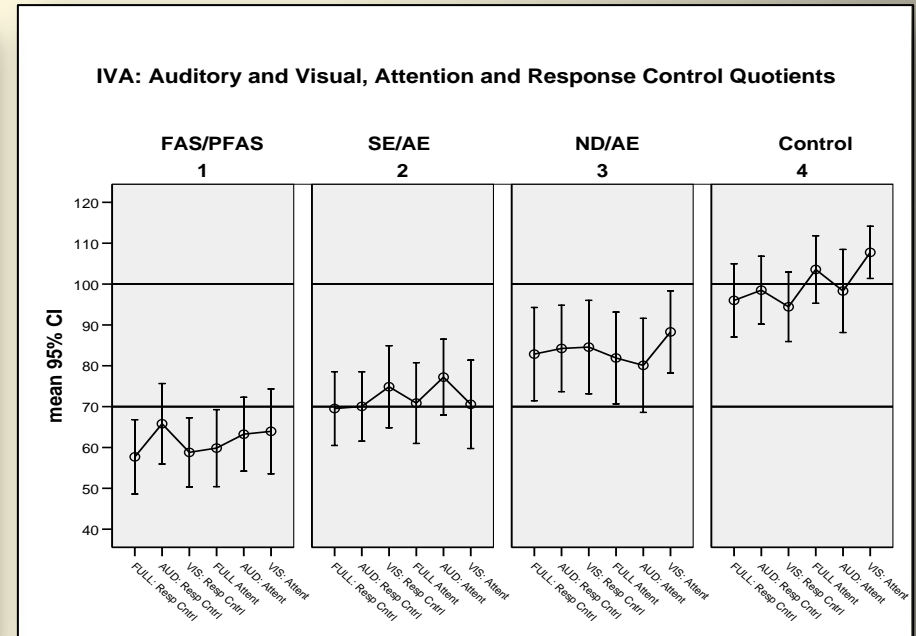


Prevalence of FAS	
General population	1 / 1,000
Foster Care	1 / 100
FASD Clinic	1 / 10

Structural and Functional Brain Abnormalities



Brain Structure

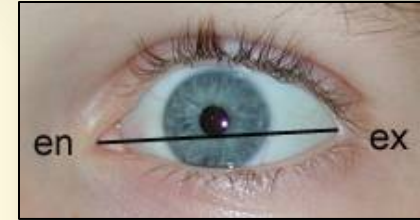


Brain Function

The structural and functional abnormalities of the brain become more severe as you advance from ND/AE to SE/AE to FAS/PFAS.

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



FAS



Free Digital Lip-Philtrum Guides

For use on your smartphone
or computer tablet




Contact astley@uw.edu

FAS Facial Analysis Software

Available from:

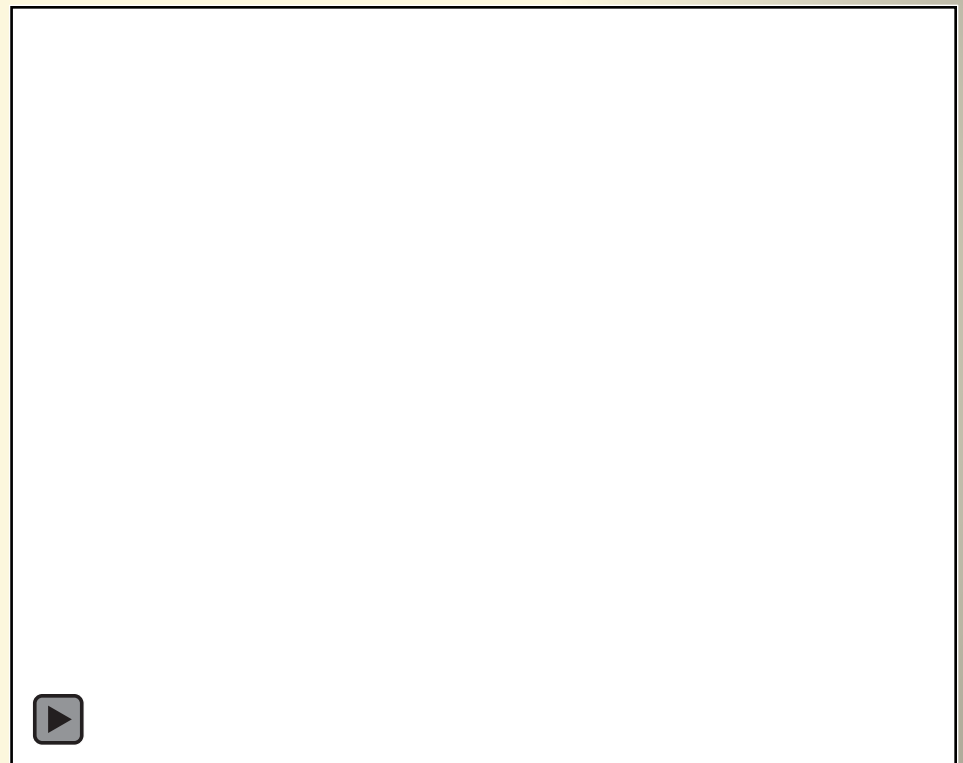
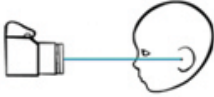
<http://depts.washington.edu/fasdpn/htmls/face-software.htm>



FAS Facial Photographic Analysis Software

Susan Astley, Ph.D.
Fetal Alcohol Syndrome Diagnostic & Prevention Network
University of Washington, Seattle, WA

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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.)



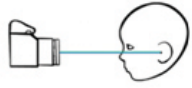
Astley SJ et al Application of the fetal alcohol syndrome facial photographic screening tool in a foster care population. *Journal of Pediatrics*, 2002;141(5):712-7.



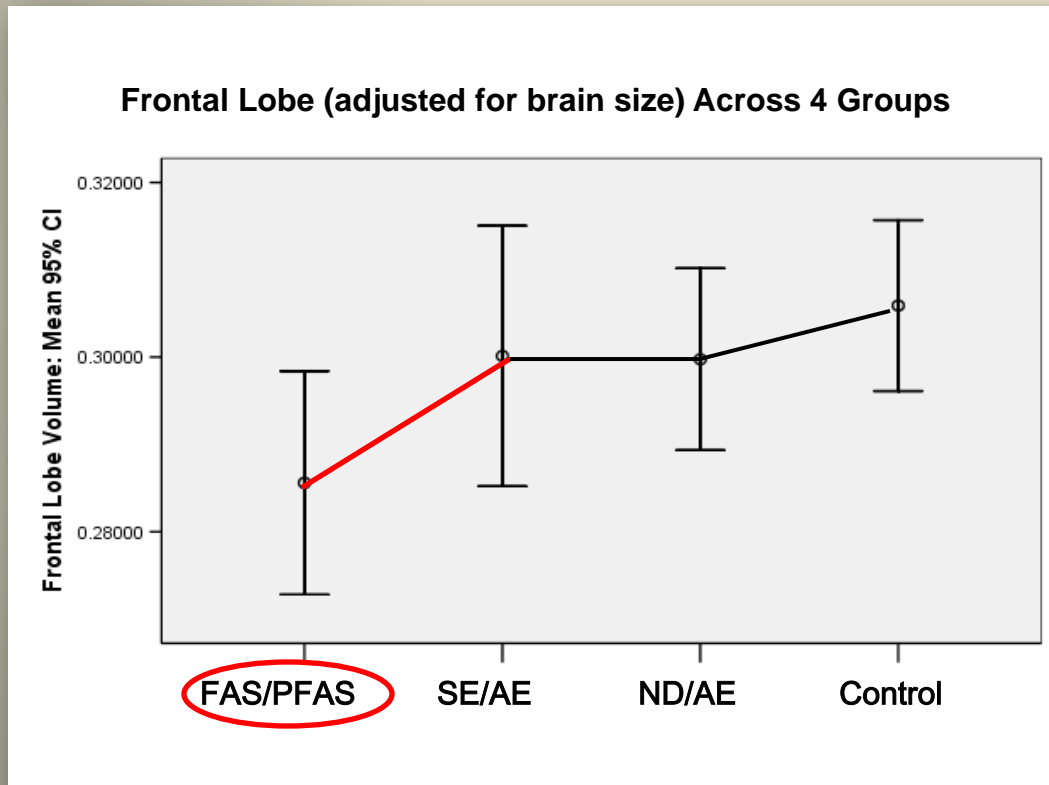
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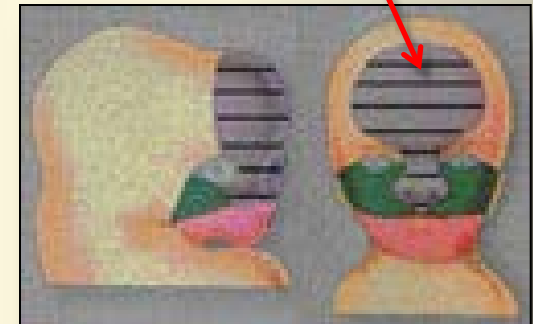
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Only those with the Rank 4 FAS Face have Disproportionately Smaller Frontal Lobe Volumes



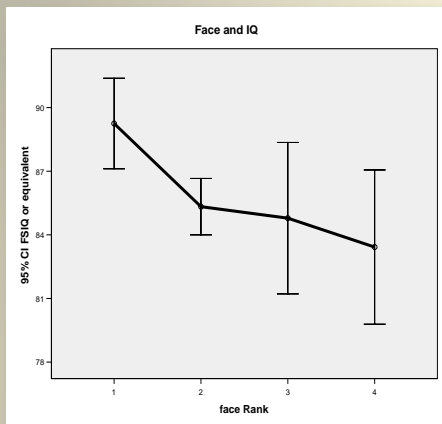
This is particularly compelling since the morphogenesis of the middle and upper face is heavily influenced by signals emanating from the forebrain to the frontonasal prominence



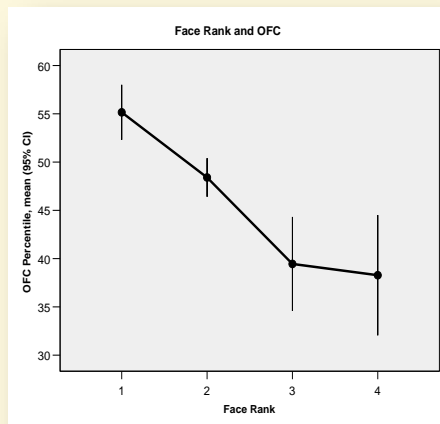
Astley SJ, et al. Magnetic resonance imaging outcomes from a comprehensive magnetic resonance study of children with fetal alcohol spectrum disorders. *Alcoholism: Clin Exp Res.* 2009;33(10):1-19.

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

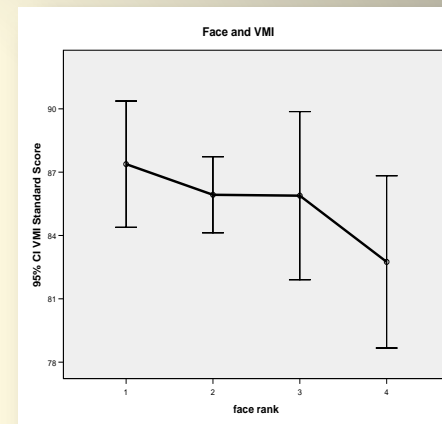
The more severe the FAS face....



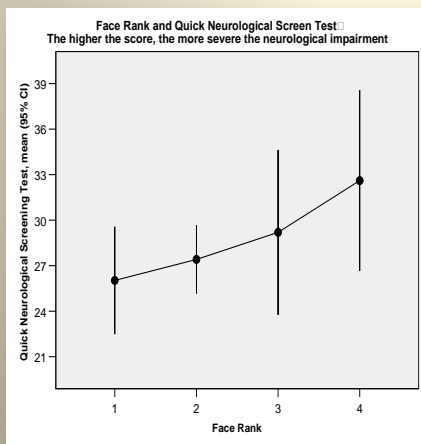
the lower the IQ



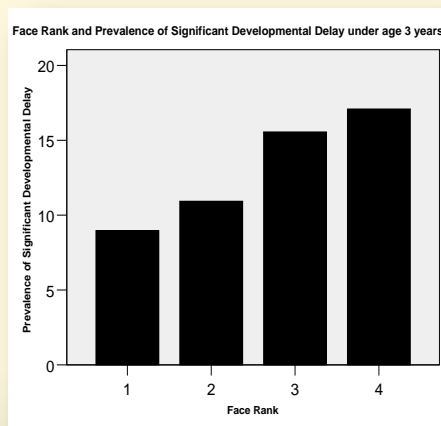
the smaller the OFC



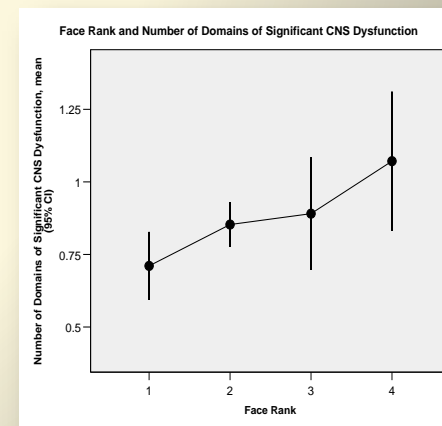
the greater the impairment in visual motor integration



the greater the neurological impairment



the higher the prevalence of developmental delay under age 3



the more domains of significant dysfunction

Does Intervention Work?

YES !

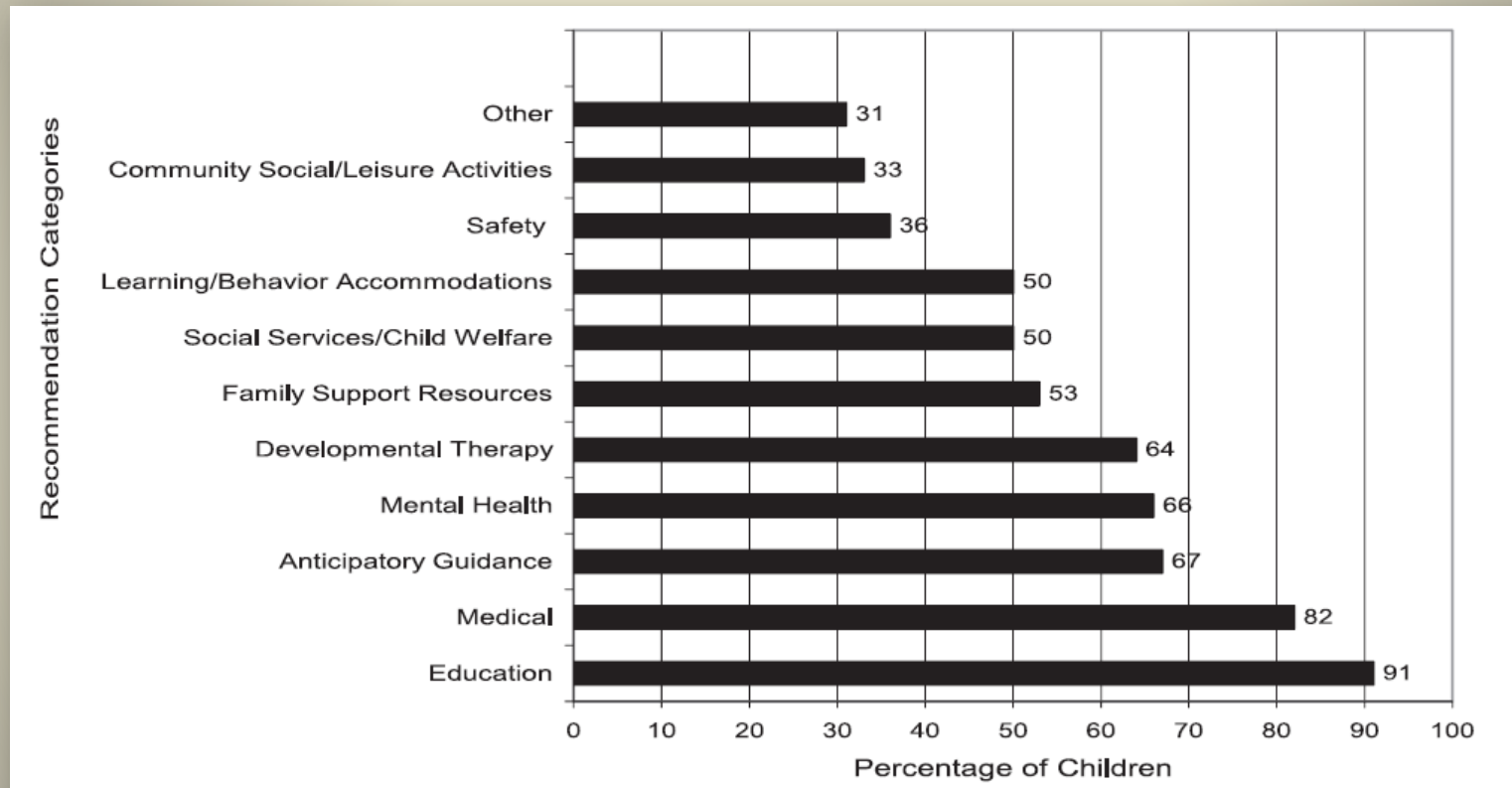
The two factors that predicted the best outcomes in children with prenatal alcohol exposure are:

1. Early diagnosis and intervention
2. A stable, nurturing home environment

Astley SJ. Profile of the first 1,400 patients receiving diagnostic evaluations for fetal alcohol spectrum disorder at the Washington State Fetal Alcohol Syndrome Diagnostic & Prevention Network. *Canadian Journal of Clinical Pharmacology*, Vol 17 (1) Winter 2010:e132-e164:March 26, 2010.

Types of Intervention Recommendations

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



Jirikowic T, Gelo J, Astley S. Children and youth with fetal alcohol spectrum disorders: Summary of intervention recommendations after clinical diagnosis. *Intellectual and Developmental Disabilities* 2010;48(5):330-344.

Patient Satisfaction (2,600 patients)

Would recommend clinic to other families	100 %
Received information they were unable to obtain elsewhere	92 %
Found explanation of 4-Digit Code easy to understand.	86 %
Were somewhat to very successful in finding recommended interventions	90 %
Reported these services met some to all of their needs.	96 %


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%  4%

The prevalence of FAS births dropped from 7%  2%

Astley SJ. Fetal alcohol syndrome prevention in Washington State: Evidence of success. Paediatric and Perinatal Epidemiology, 2004;18:344-351.

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2. 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.
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16. Astley SJ, Stachowiak J, Clarren SK, Clausen C. Application of the fetal alcohol syndrome facial photographic screening tool in a foster care population. *Journal of Pediatrics*, 2002;141(5):712-7.
17. Astley SJ. Fetal alcohol syndrome prevention in Washington State: Evidence of success. *Paediatric and Perinatal Epidemiology*, 2004;18:344-351.
18. Jirikowic T, Gelo J, Astley S Children and youth with fetal alcohol spectrum disorders: Summary of intervention recommendations after clinical diagnosis. *Intellectual and Developmental Disabilities* 2010;48(5):330-344.

University of Washington FAS DPN Website

fasdpn.org

http://depts.washington.edu/fasdpn/

Page Safety Tools

FAS DPN

Center on Human Development & Disability
University of Washington, Seattle WA

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FASD Diagnostic Appointments

[Legislative Fact Sheet](#)

Celebrating our 21st Year of FASD Clinic

VALIDATION of the FASD 4-Digit Code

- Free Lip-Philtrum Guides with 3/4 views for iPhone/Tablet
- (2014) Value of a FASD Diagnosis: 20 yrs of Parent Surveys
- (2013) Validation of the FASD 4-Digit Code
- (2011) Comparison of FASD Diagnostic Systems
- NEW FAS Facial Analysis Software (2012)
- When is a philtrum Rank 4 or Rank 5?
- (2004) 4-Digit Diagnostic Code
- FASD Prevention: Evidence of Success
- 4-Digit Code Online Course (over 800 graduates)
- Palpebral fissure length measurement accuracy.
- Animated Facial Photography and Measurement Instruction
- Response to Emily Oster (2013)
- (2005) Invalid Cartoon Knockoff of Lip-Philtrum Guide
- (2010) Profile of 1,400 WA FAS DPN Patients with FASD
- PFL Z-score Calculator
- Video introduction to FAS Facial Photo Analysis Software