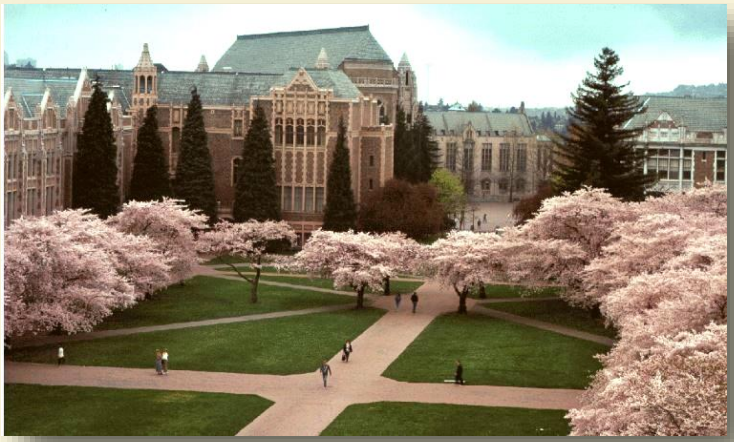
FASD
Diagnosis, Intervention & Prevention



Susan (Astley) Hemingway PhD

Professor Epidemiology/Pediatrics
Director Washington State FAS Diagnostic & Prevention Network (FASDPN)
University of Washington
Seattle WA, U.S.A
astley@uw.edu www.fasdpn.org

Learning Objectives

Participants will understand the following:

- What FASD is.
- How prevalent it is.
- What level of alcohol exposure can cause FASD.
- How to diagnose FASD and why a diagnosis is important.
- The profile of damage caused by prenatal alcohol exposure.
- What types of interventions are recommended across the lifespan.
- How diagnosis leads to prevention.
- How to obtain FASD diagnostic training.

What is the WA State FASDPN?

The FAS Diagnostic & Prevention Network is a network of FASD diagnostic clinics in WA State led by the core clinical/research/training program at the University of Washington.

Mission: Prevention of FASD through screening, diagnosis, intervention, surveillance, public health policy, training and research.

Established in 1993.

Diagnosed over 3,000 individuals with prenatal alcohol exposure.

Established the largest FASD clinical/research database used to develop the FASD diagnostic tools and establish a diagnostic evidence base.

Trained over 150 FASD diagnostic teams worldwide.

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.

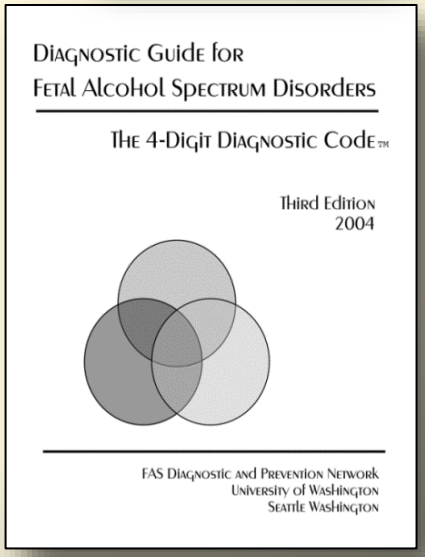
FASD diagnoses are conducted by an interdisciplinary team using the FASD 4-Digit Code

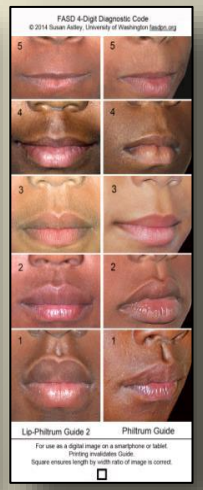
Interdisciplinary Diagnostic Team

- Pediatrician
- Psychologist
- Speech Language Pathologist
- Occupational Therapist
- Social Worker
- Family Advocate

Observe a day in clinic on Fridays
astley@uw.edu

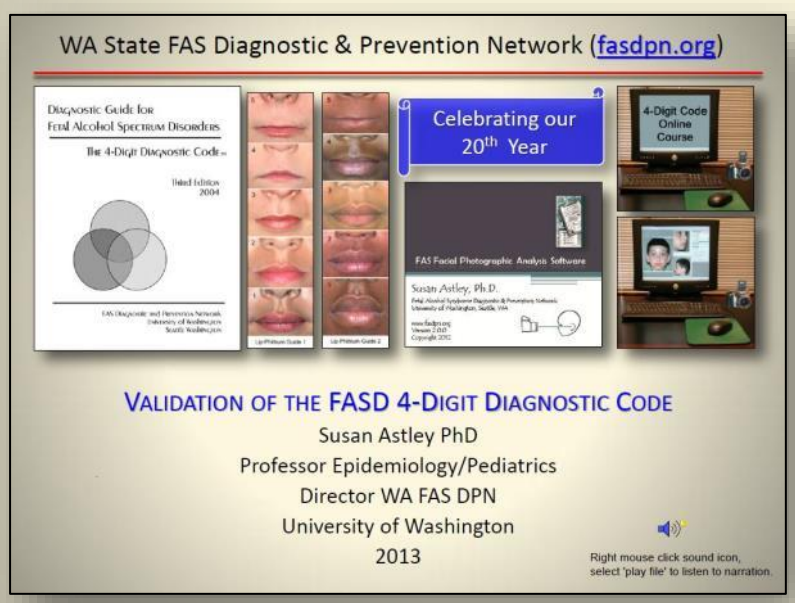
Diagnostic Tools





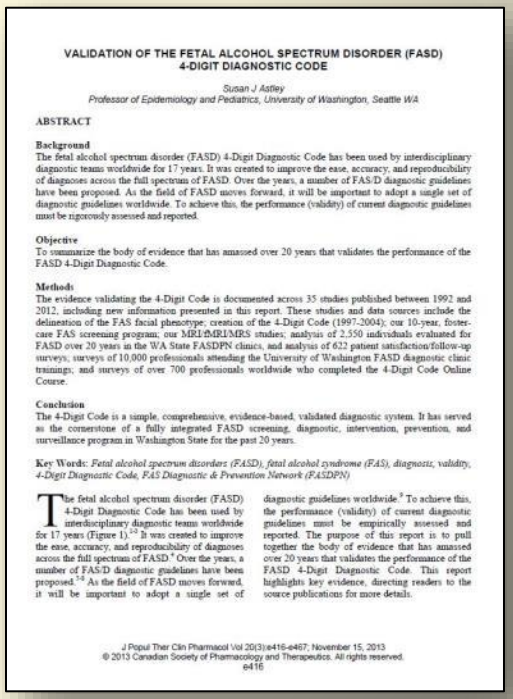
The FASD 4-Digit Code is Fully Validated

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.



Audio Narrated pdf

http://depts.washington.edu/fasdpn/pdfs/astley-validation-2013post-audio.pdf



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 FAS/D 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/fMRI/MRS 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).[1-3] It was created to improve the ease, accuracy, and reproducibility of diagnoses across the full spectrum of FASD.[4] Over the years, a number of FAS/D diagnostic guidelines have been proposed.[5,6] As the field of FASD moves forward, it will be important to adopt a single set of diagnostic guidelines worldwide.[7] 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.

Published Paper

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

FASD 4-Digit Diagnostic Code

Abbreviated Case-Definitions of 4-Digit Code

Rank	3 Growth	4 Face	3 CNS	4 Alcohol
4	H and W ≤ 3 %	All 3 features	Structural / Neurological Abnormalities	Confirmed High
3	H or W ≤ 3 %	2.5 features	Severe Dysfunction	Confirmed
2	H and W all else	1-2 features	Moderate Dysfunction	Unknown
1	H and W > 10 %	No features	No Dysfunction	Confirmed Absent

4-Digit Codes cluster into Diagnostic Categories

FAS / Alcohol Exposed

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

PFAS / Alcohol Exposed

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

4 Diagnoses under the FASD Umbrella

Diagnosis		Growth	FAS Face	CNS		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 in Washington State

Among 3,000 patients (birth –adult) with prenatal alcohol exposure evaluated at the FASDPN clinic over the past 30 years:

4 Diagnoses under the FASD Umbrella

	Diagnosis		Growth	FAS Face	CNS		Alcohol
5 %	1. FAS	Fetal Alcohol Syndrome	growth	face	severe		alc
5 %	2. PFAS	Partial FAS		face	severe		alc
25 %	3. SE/AE	Static Encephalopathy / Alc Exposed			severe		alc
45 %	4. ND/AE	Neurobehavioral Disorder / Alc Exposed				moderate	alc

Prevalence of FAS/D

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

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

Prevalence of FASD	
FASD	1/100
Autism	1 / 45

Prevalence of FAS	
FAS	1/1000
Down syndrome	1 / 1000

The Importance of Early Diagnosis and Intervention

It is important to note that the majority of children who have cognitive or other developmental challenges as the result of prenatal alcohol exposure typically do not exhibit these challenges fully until school-age. The CNS damage is present at birth, but infants/toddlers are too young to engage in assessments of executive function, memory and higher order language skills.

Most infants/toddlers with alcohol exposure look broadly normal on the Bayley Developmental assessment, but with closer inspection 87% had at least 1 subtest on the Bayley 1.5 SDs below the mean, qualifying them for early intervention. In WA State, alcohol exposure alone qualifies birth to three for early intervention.

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

> Our recent study (Astley, Bledsoe, Davies, 2016) confirmed the presence of one or more of the sentinel physical features (growth deficiency, FAS facial phenotype and/or microcephaly) accurately predict which alcohol-exposed infants will present with severe brain dysfunction later in childhood.

Bottomline…It is keenly important to conduct a FASD diagnostic evaluation as early as possible (birth to three) to document alcohol exposure in the medical record and begin early intervention. When the child reaches 8 years of age, have them return for re-evaluation to upgrade their FASD diagnosis if necessary. Do not wait until 8 years of age to conduct the first FASD evaluation.

There is no known safe amount or safe time to drink during pregnancy

Alcohol can cause problems for the baby throughout pregnancy, including before a woman knows she is pregnant.

It is never too late to stop or reduce alcohol use during pregnancy. Stopping alcohol use will improve the baby's health and well-being.

The higher the exposure, the greater the risk.

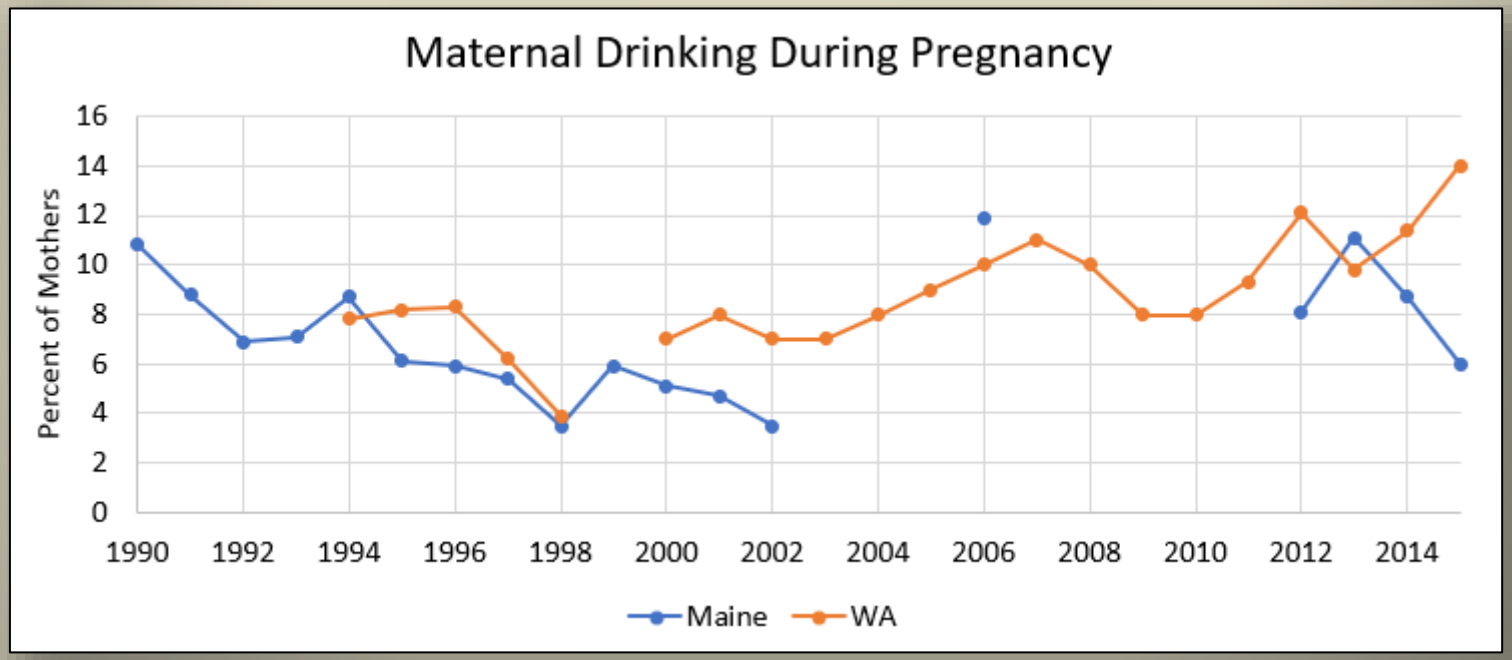
But risk is not simply based on the amount of exposure. Fetal genetics plays a role. Some fetuses are genetically more vulnerable to the adverse effects of alcohol than others.

This was clearly illustrated in our twin study:

- Non-identical twins exposed to the same level of alcohol often have strikingly different outcomes. It is not uncommon for one to be born with FAS while the other is born normally developed.
- Identical twins typically have identical outcomes.

Maternal Drinking during Pregnancy

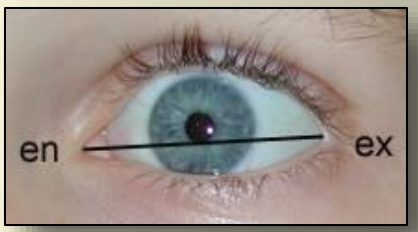
CDC PRAMS Data: Maine and WA State



https://www.maine.gov/dhhs/mecdc/public-health-systems/data-research/prams/fact-sheets-and-data.shtml

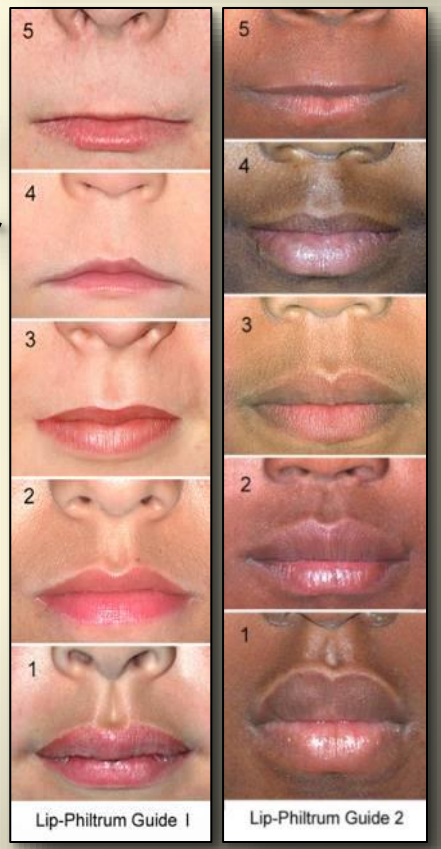
4-Digit Code FAS Face (Rank 4)

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



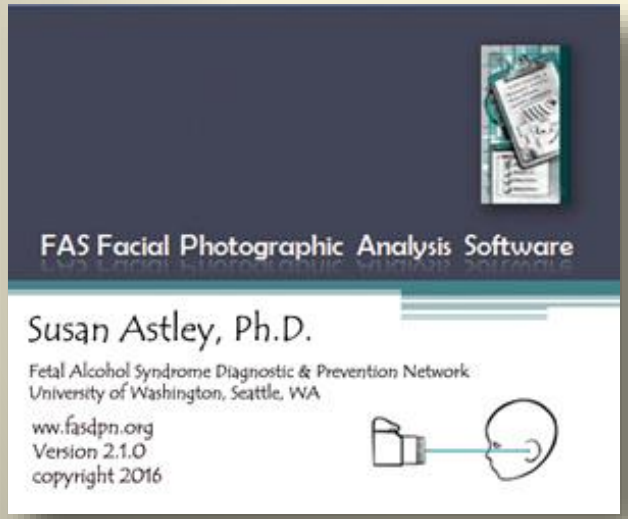
Free Digital Lip-Philtrum Guides

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



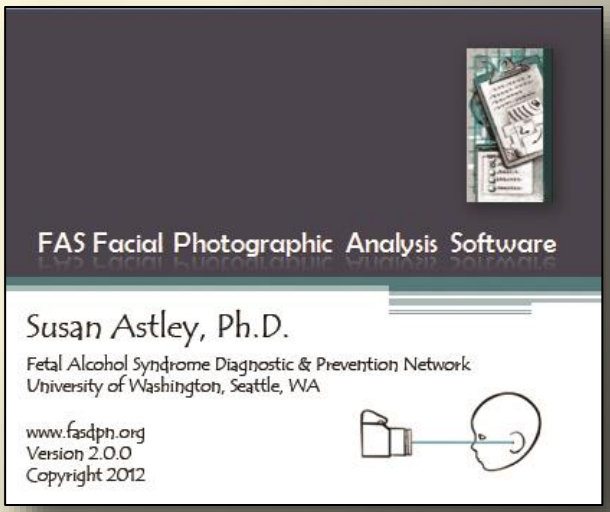
10-Year Foster Care FAS Screening using Photos

10-Year Photo screening confirmed the Rank 4 FAS face is HIGHLY specific to PAE.

- > 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.



Does Intervention Work?

YES !

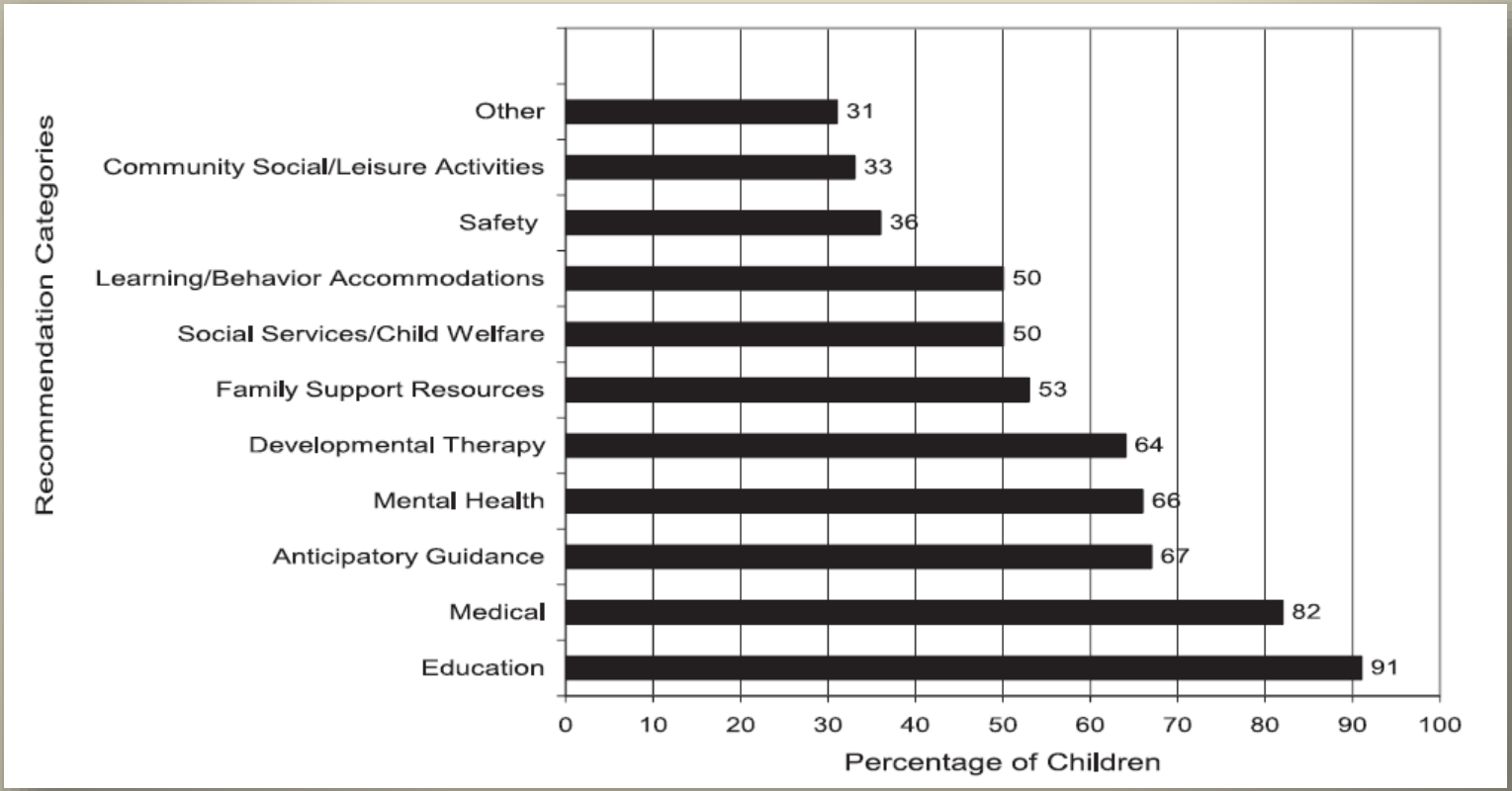
The two factors that predicted the best outcomes in children with prenatal alcohol exposure are:

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 patents' 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.

Weblinks

Aims to reduce PAE and improve outcomes in children with FASD
SAFEST Choice Learning Collaborative

Works to increase awareness of FASD in Maine
fasdmaine.org

Alcohol use of childbearing age women by State: CDC BRFSS data
weblink

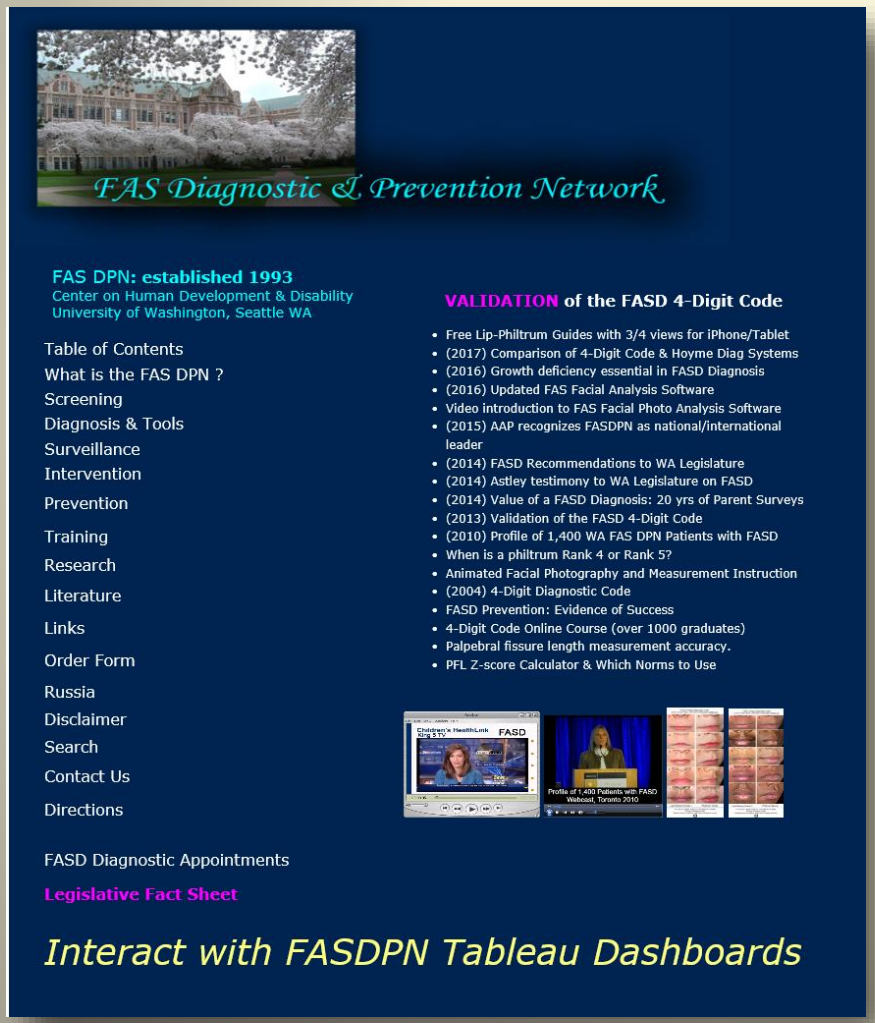
Number of children in Maine in foster care by county and year
Annie E. Casey KIDS Count website

Babies born exposed/affected to substances in Maine
weblink

PRAMS Pregnancy Risk Assessment Monitoring System CDC for Maine
weblink

CDC FASD website
weblink

University of Washington FASDPN Website fasdpn.org



FASD diagnostic training (online and in person) is available for individuals and teams. Join our clinic virtually to observe an interdisciplinary diagnostic evaluation.

https://depts.washington.edu/fasdpn/htmls/training.htm

Interact with our FASDPN Tableau Dashboards

Explore how outcomes vary by exposure, age, race, sex.

http://depts.washington.edu/fasdpn/htmls/Tableau-FASDPN.htm