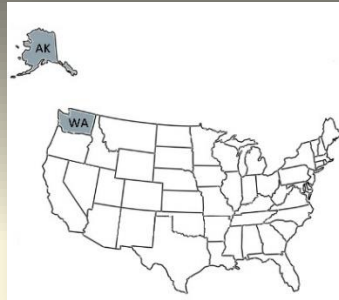


# Population-Based FASD Screening, Diagnosis, Surveillance, Intervention, Prevention and Policy Development:

## Statewide Sustainable Success Stories From Washington State & Alaska



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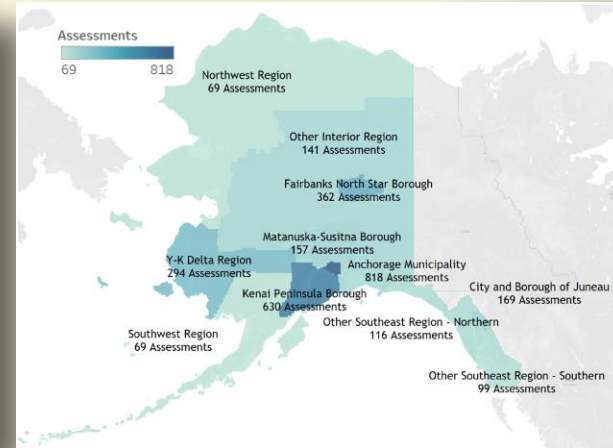
# Washington State (WA) & Alaska (AK)

## FASD Diagnostic Clinic Locations over the Decades

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Washington State

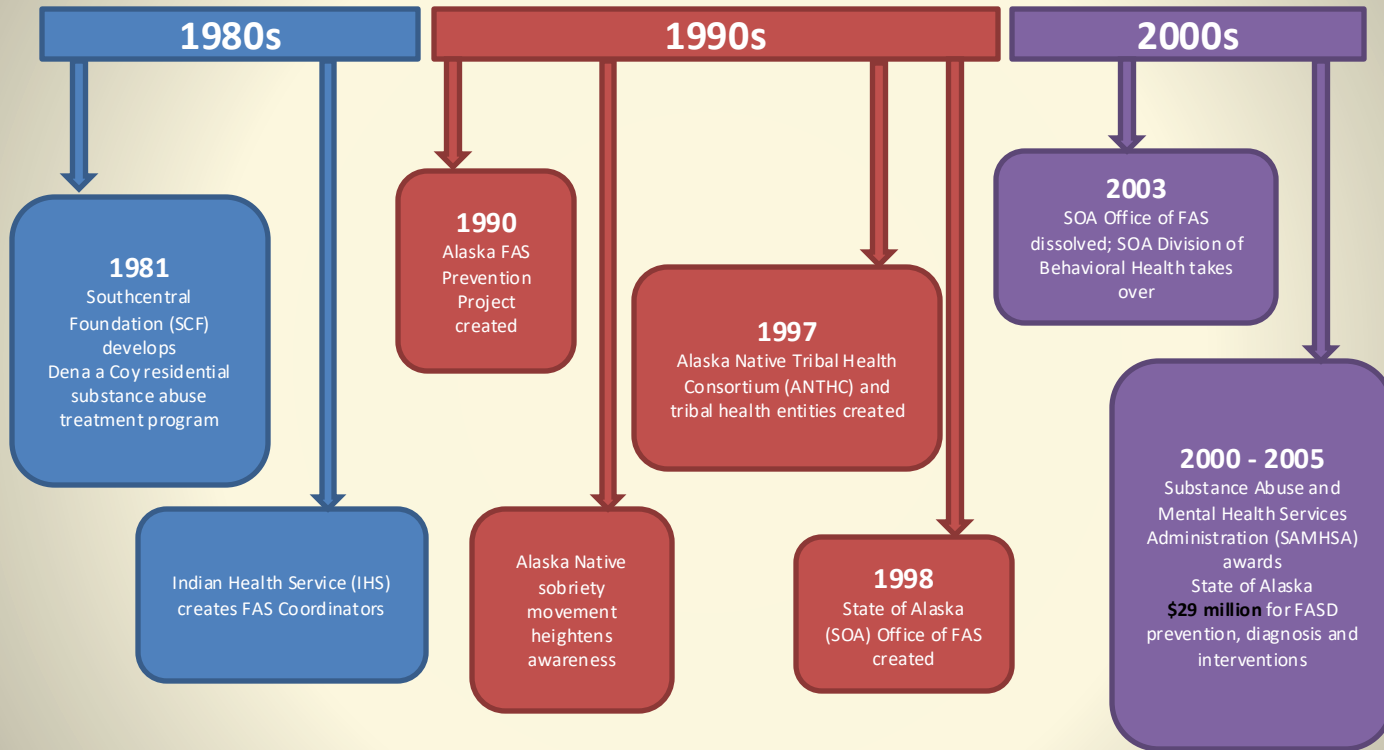


Alaska

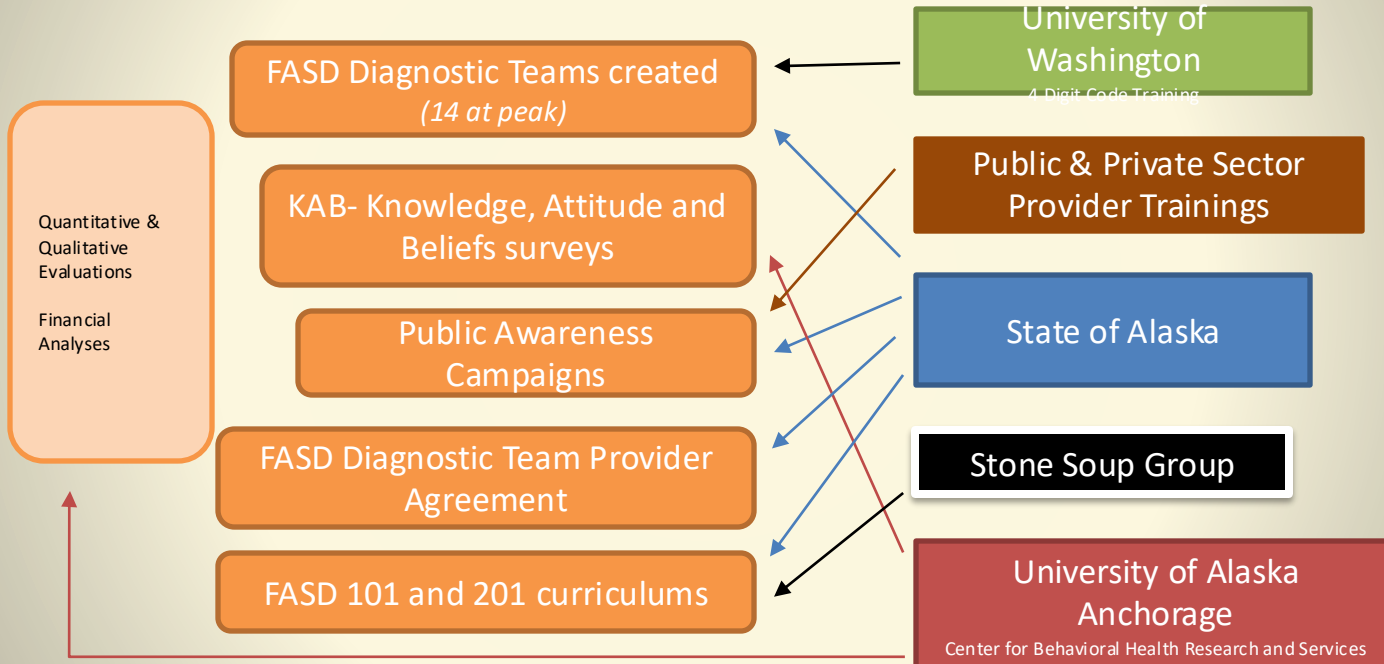
(Astley) Hemingway SJ, Baldwin M, Pierce-Bulger M. (2024)

[Washington and Alaska statewide FASD diagnostic clinical networks: Comparison of three decades of 4-Digit Code diagnostic outcomes and prenatal alcohol exposure histories.](#) *Advances in Pediatric Research* 10:072.

doi: 10.35248/2385-4529.23.10.072.



# SAMHSA Funded Projects: 2000 - 2005



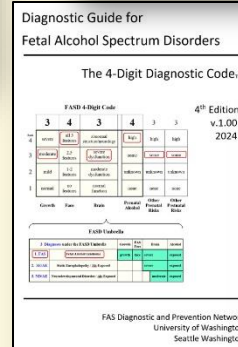
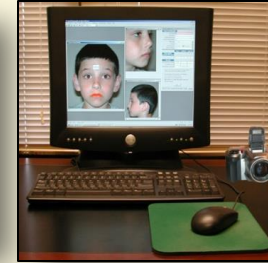
# FASD diagnostic evaluations were conducted in WA and AK by interdisciplinary teams using the FASD 4-Digit Code

## Interdisciplinary Diagnostic Team



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

## Free Diagnostic Tools

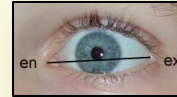


The diagnostic evaluation is conducted in one 4-hour appointment and generates a comprehensive diagnostic summary report and intervention recommendations.

# Introduction to the FASD 4-Digit Diagnostic Code

Abbreviated Case-Definitions of 4-Digit Code

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



**4-Digit Codes cluster into Diagnostic Categories**

**FAS / Alcohol Exposed**

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

**Static Encephalopathy / Alcohol Exposed**

3133 3233 4133 4233 3134 3234 4134  
 4234 3143 3243 4143 4243 3144 3244 etc.

3 Diagnoses under the FASD Umbrella					
	Diagnosis	Growth	FAS Face	Brain	Alcohol
1. <b>FAS</b>	<u>Fetal Alcohol Syndrome</u>	growth	face	severe	alc
2. <b>SE/AE</b>	Static Encephalopathy / Alc Exposed			severe	alc
3. <b>ND/AE</b>	Neurodevelopmental Disorder/Alc Exposed			moderate	alc

# Sharing the Diagnosis with the Family

FASD 4-Digit Code						
	4	4	3	4	3	4
Rank 4	severe	all 3 features	abnormal structure/neurology	high	high	high
Rank 3	moderate	2.5 features	severe dysfunction	some	some	some
Rank 2	mild	1-2 features	moderate dysfunction	unknown	unknown	unknown
Rank 1	normal	no features	normal function	none	none	none
	<b>Growth</b>	<b>Face</b>	<b>Brain</b>	<b>Prenatal Alcohol</b>	<b>Other Prenatal Risks</b>	<b>Other Postnatal Risks</b>

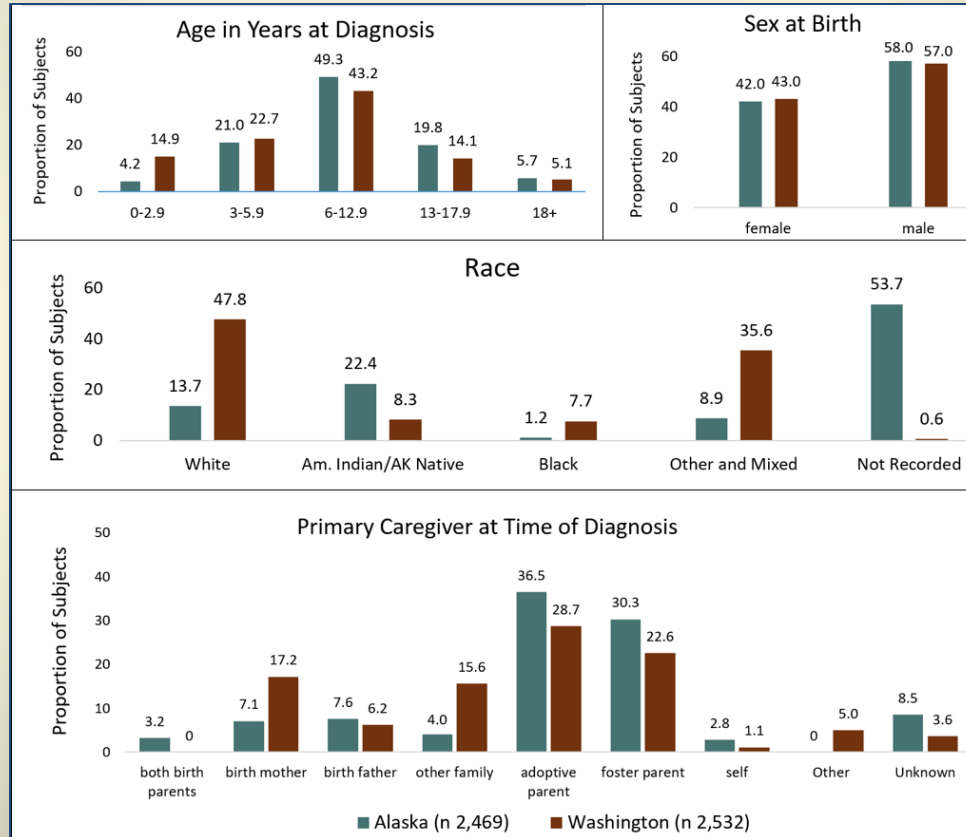
  

FASD Umbrella					
3 Diagnoses under the FASD Umbrella		Growth	FAS Face	Brain	Alcohol
1. FAS	<u>Fetal Alcohol Syndrome</u>	growth	face	severe	exposed
2. SE/AE	Static Encephalopathy / Alc-Exposed			severe	exposed
3. ND/AE	Neurodevelopmental Disorder / Alc-Exposed			moderate	exposed

# Sociodemographics of the AK and WA FASD Clinical Populations

Alaska ( 2,469 )

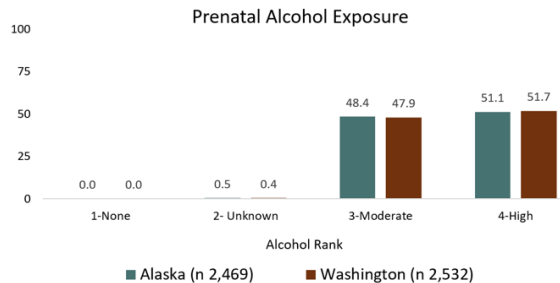
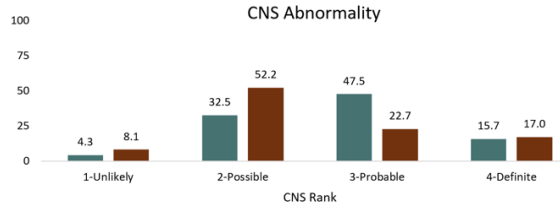
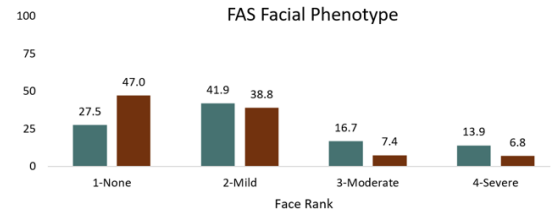
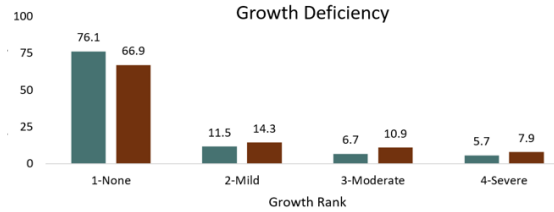
Washington (2,532 )



Alaska ( 2,469 )

Washington (2,532 )

Proportion of Subjects

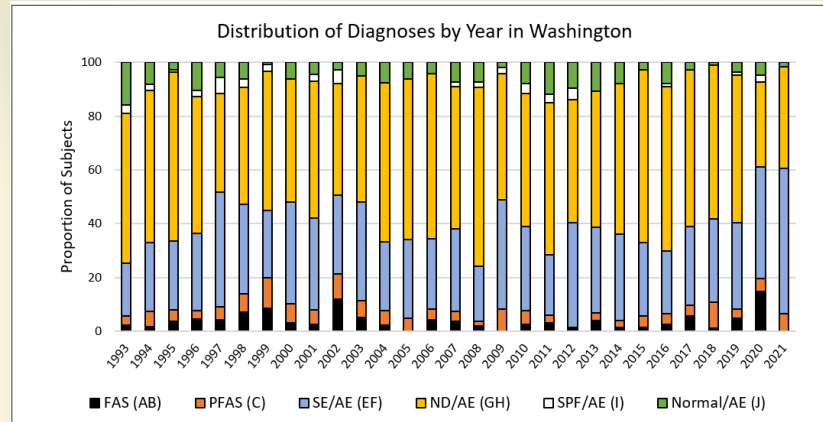


Proportion of Subjects from  
AK and WA  
with Ranks 1-4 for:

Growth deficiency,  
FAS facial features,  
CNS abnormalities and  
Prenatal alcohol exposure

# Prevalence of FASD Diagnoses by Year of Diagnosis (1993-2021) in WA and AK FASD Clinics

Washington



Normal/AE



SPF/AE



ND/AE



SE/AE



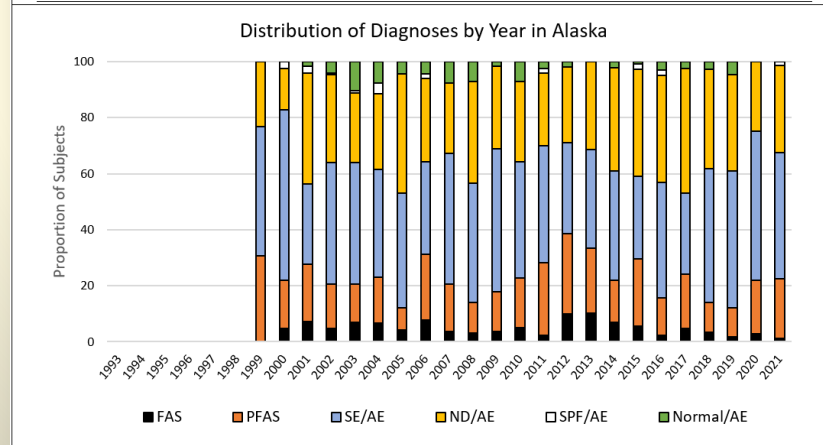
PFAS



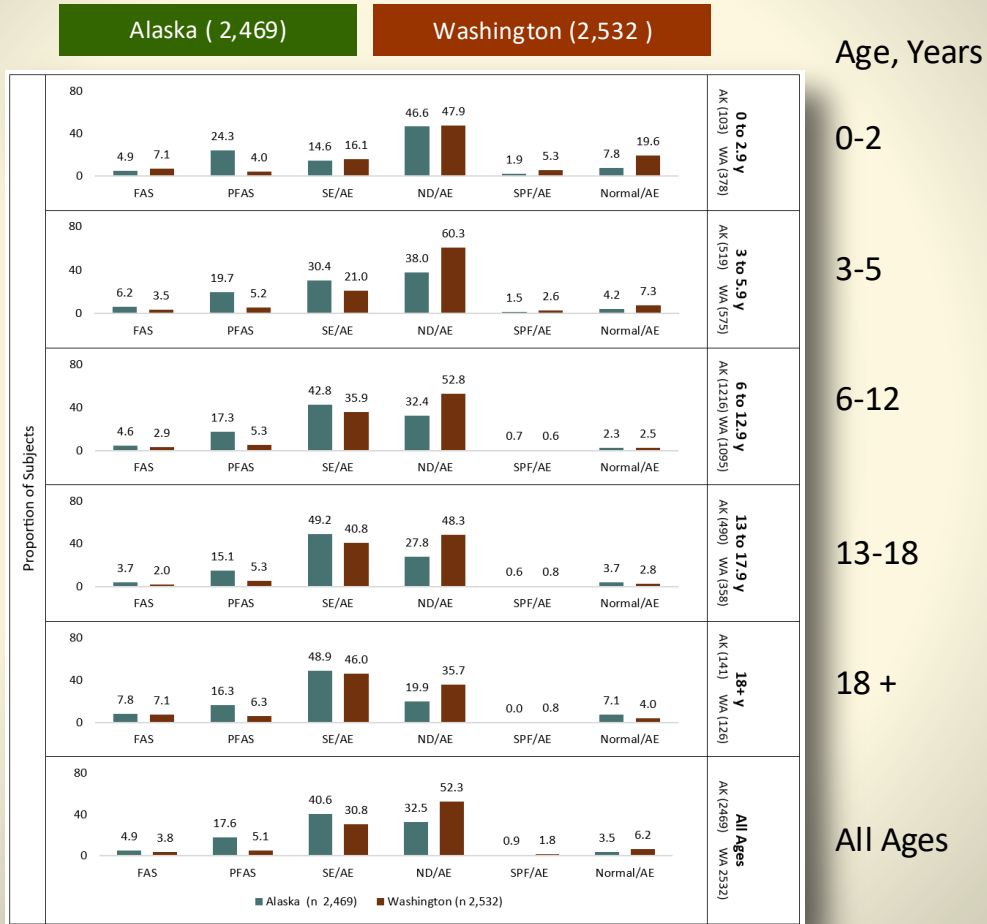
FAS




Alaska

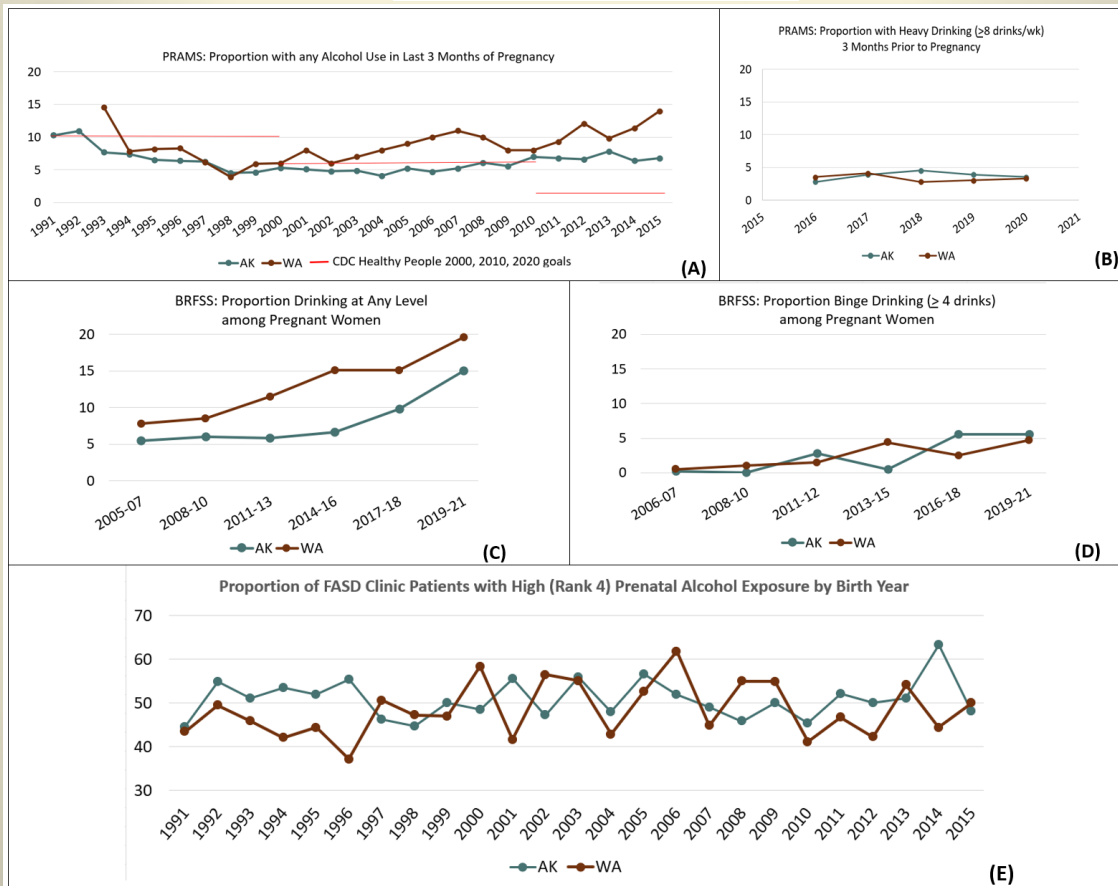


# Prevalence of FASD Diagnoses by Age in the AK and WA FASD Clinical Populations



# Proportion of Women Consuming Alcohol during Pregnancy by Year (1991 – 2021)

AK  WA 




## Can FASD be Prevented?

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# YES !


In **Washington State** from 1993-1998:


The prevalence of drinking (PRAMS) in the last 3 trimesters dropped from 15%  4%

The prevalence of FAS births among foster children dropped from 7%  2%

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

In **Alaska** from 1996 - 2002:

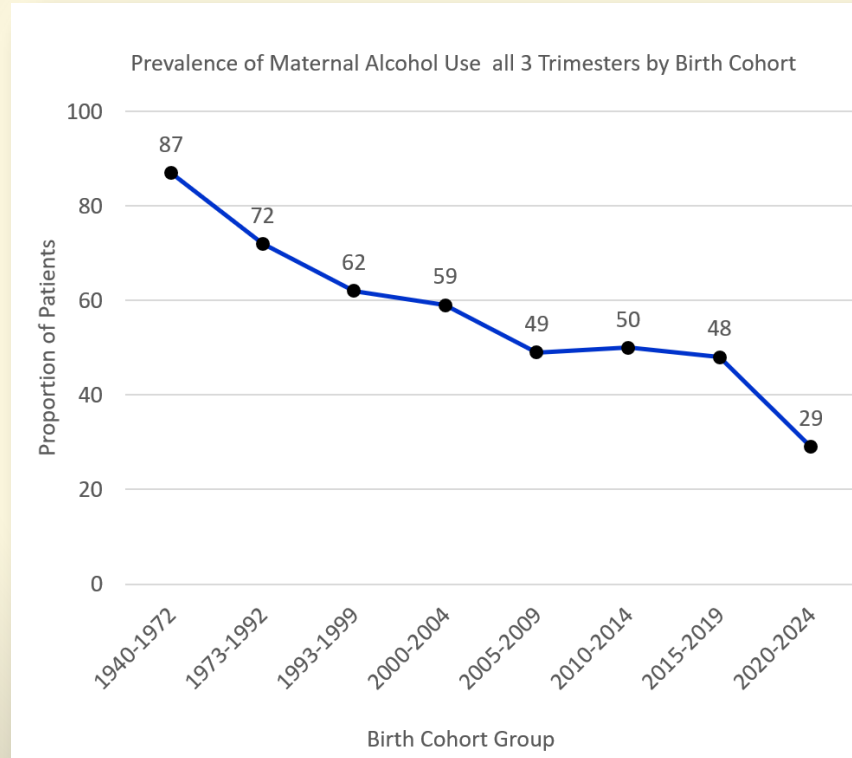
The prevalence of drinking in the last 3 trimesters dropped from 12%  5%

The prevalence of FAS births within the general population dropped from 20  14  
per 10,000

Schoellhorn, J. **Decline in the birth prevalence of fetal alcohol syndrome in Alaska.** State of Alaska Epidemiology Bulletin No 3, Feb. 17, 2010 [cited 2023 Dec 1].

## Prevention: Further Evidence of Success in WA State

The prevalence of maternal drinking all 3 trimesters decreased significantly across the birth cohorts of 2,083 FASDPN patients.



Data generated by FASD diagnostic clinics are instrumental in guiding public health policies to better meet the needs of individual with FASD and their caregivers.

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In Washington:

1997: WA Senate Bill 5688 expanded the single clinic to a statewide network of clinics.

1997: WA State supported Parent-Child Assistance Program.

2001: WA State law requiring warning signs at all points of purchase for alcohol.

2015: Acceptance of FASD as a qualifying condition for DDA.

2022: WA House Bill 2008 eliminates the use of IQ as a qualifying condition for DDA.

2023: WA House Bill 1168 expanding FASD diagnosis, intervention.

In Alaska:

1999: Senator Stevens obtains \$29 million for AK to fund the creation of FASD diagnostic clinics statewide.

2001: AK statute requires warning signs at all points of purchase for alcohol.

2012: AK legislature recognizes September 9<sup>th</sup> as FASD Awareness day in AK.

2012: AK Senate Bill 151 establishes FASD as a mitigating factor for felony criminal offenses.

2018: AK FASD Strategic Plan, Governor's Council on Disabilities and Special Education.

2020: AK FASD Diagnostic Team Data Analysis, Policy & Recommendations. AK Mental Health Trust Authority.

# Comparing FASD team systems

## Washington

- University-based model
- Service delivery, teaching, research & prevention mission
- FASD evaluation records embedded in University Hospital system
- Ongoing funding from state legislature
- FASDPN teams maintained long term & have more uniformity of practice than AK teams

## Alaska

- Community-based model
- Diagnosis & referrals for care primary focus; some provider/community education as team desires
- Records of evaluations kept by agency (or not)
- State ongoing funding via Provider Agreement team reimbursement model (\$3K/diagnosis- now \$4K)
  - 2 long term survivors in DD agencies
  - Newest 'survivor' in pediatric specialty practice

# Results & Conclusions

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## **Results:**

FASD diagnostic outcomes were similar across 2,532 Washington and 2,469 Alaskan patients with PAE. PAE in each State followed similar annual trajectories from 1991-2021. Both States documented significant decreases in FAS and PAE in the 1990s. Clinic data helped guide public health policies.

## **Conclusions:**

Both States demonstrated the feasibility and value of establishing statewide interdisciplinary FASD diagnostic clinical networks using the FASD 4-Digit-Code. Legislative support, centralized data collection, and use of a single, evidence-based FASD diagnostic system have been key to the long-term, ongoing success of these two diagnostic networks.

## All FASD 4-Digit Code diagnostic tools, forms and trainings are FREE

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**Training opportunities** are posted here: <https://depts.washington.edu/fasdpn/htmls/training.htm>

- 1-Day Observation of FASDPN clinic (in person or remote).
- 2-Day FASD diagnostic Team Training (in person or remote)
- 4-Digit Code Online Course

**Diagnostic Tools and Forms** are posted here: <https://depts.washington.edu/fasdpn/htmls/diagnostic-tools.htm>

- 4-Digit Code Diagnostic Guide (2024).
- Lip-Philtrum Guides
- FAS Facial Photographic Analysis Software (2026)
- 4-Digit Code Diagnostic Forms

Submit our order form to obtain the free Lip-Philtrum Guides, Facial Software and 4-Digit Code Online Course.

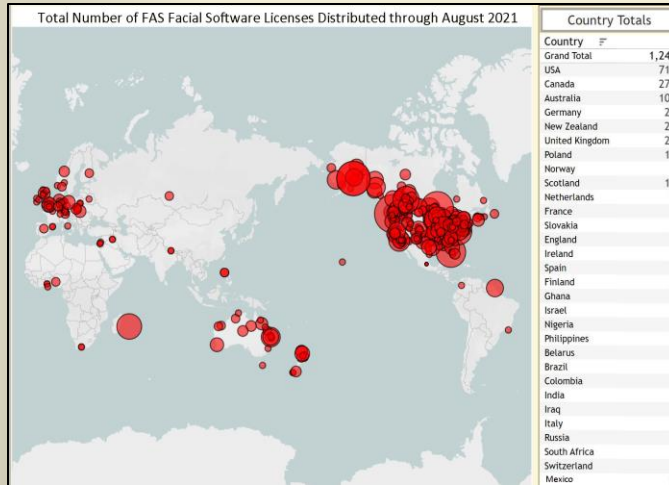
<https://depts.washington.edu/fasdpn/pdfs/guideorder.pdf>

Contact Susan (Astley) Hemingway PhD for more details [astley@uw.edu](mailto:astley@uw.edu)

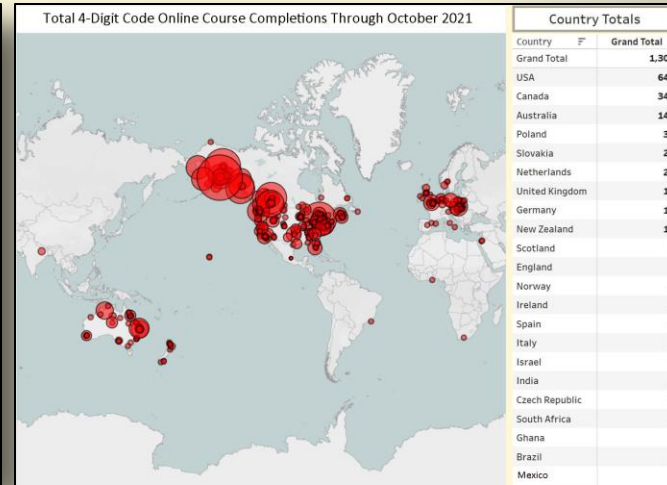
The FASDPN has trained over 150 diagnostic teams and thousands of clinicians in 62 countries.

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### FAS Facial Photographic Analysis Software



### 4-Digit Code Online Course



<https://depts.washington.edu/fasdpn/htmls/Tableau-FASDPN.htm>

[Sharing outcomes worldwide.](#)

# University of Washington FASDPN Website

[www.fasdpn.org](http://www.fasdpn.org)



## FAS Diagnostic & Prevention Network

**FAS DPN: established 1993**  
Center on Human Development & Disability  
University of Washington, Seattle WA

Table of Contents  
What is the FAS DPN ?  
Screening  
Diagnosis & Tools  
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Intervention  
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Training  
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Contact Us  
Directions

FASD Diagnostic Appointments

[Legislative Fact Sheet](#)

### VALIDATION of the FASD 4-Digit Code

- Free Lip-Philtrum Guides with 3/4 views for iPhone/Tablet
- (2017) Comparison of 4-Digit Code & Hoyme Diag Systems
- (2016) Growth deficiency essential in FASD Diagnosis
- (2016) Updated FAS Facial Analysis Software
- Video introduction to FAS Facial Photo Analysis Software
- (2015) AAP recognizes FASDPN as national/international leader
- (2014) FASD Recommendations to WA Legislature
- (2014) Astley testimony to WA Legislature on FASD
- (2014) Value of a FASD Diagnosis: 20 yrs of Parent Surveys
- (2013) Validation of the FASD 4-Digit Code
- (2010) Profile of 1,400 WA FAS DPN Patients with FASD
- When is a philtrum Rank 4 or Rank 5?
- Animated Facial Photography and Measurement Instruction
- (2004) 4-Digit Diagnostic code
- FASD Prevention: Evidence of Success
- 4-Digit Code Online Course (over 1000 graduates)
- Palpebral fissure length measurement accuracy.
- PFL Z-score Calculator & Which Norms to Use



*Interact with FASDPN Tableau Dashboards*

Interact with our FASDPN  
Tableau Dashboards

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

# Selected References: All available open access on our website

[www.fasdpn.org/htmls/literature.htm](http://www.fasdpn.org/htmls/literature.htm)

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