Washington State
Fetal Alcohol Syndrome Diagnostic & Prevention Network
(FASDPN)

30th Annual Report

Summary of Progress from July 1,1995 through June 30, 2025

www.fasdpn.org
www.fasdwa.org

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UW FASDPN website www.fasdpn.org

WA State FASD website www.fasdwa.org

FAS DPN FAS Diagnostic & Prevention Network

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What is FASD?

Fetal alcohol syndrome (FAS) is a permanent birth defect syndrome caused by maternal consumption of alcohol during pregnancy. FAS is characterized by growth deficiency, permanent brain damage, and unique facial features. Not all children exposed to alcohol during gestation are born with FAS. Many are born with the same severity of brain damage, but do not have the facial features that permit a diagnosis of FAS. These children need the same social, educational, and healthcare services as children with FAS and far outnumber children with FAS. The full spectrum of damage caused by prenatal alcohol exposure is called Fetal Alcohol Spectrum Disorders (FASD). For every child with FAS, there are 10 with FASD.

What is the Fiscal Impact of FASD on Washington State?

- It costs WA an estimated 2 million dollars in lifetime social and health care services for every child born with FASD.
- It costs Medicaid 9 time more to cover the medical expenditures for a child with FAS than for a child without FAS.
- Preventing FASD in just one child will pay for over 5 years of the FASDPN operating costs.
- Prevention starts with diagnosis. Women at highest risk for producing children with FASD are women who have already given birth to a child with FASD. The FASDPN clinic identifies over 100 high-risk women annually through the diagnosis of their children.
- It costs Washington State 30 times more to raise a child with FASD than to prevent FASD in a child.
- Published empirical data confirms FASD prevention efforts are working in WA State and FASD diagnoses lead to effective intervention.

VII. FASD Facts

- FASD is 100% preventable. The FASDPN has empirical evidence documenting it is successfully preventing FASD in WA.
- FASD is the leading known cause of intellectual disabilities.
- An estimated 870 children are born with FASD in WA each year (1% of all births).
  An estimated 70,000 individuals with FASD of all ages currently live in WA State.
- FASD is not just a health care issue. Its primary impact is on schools, foster/ adoptive care, the justice system, and mental health services.
- Less than 10% of adults with FASD live independently or remain employed.

What is the WA FAS Diagnostic and Prevention Network (FASDPN)?

- The University of Washington FASD diagnostic clinic opened in 1993. It has been providing FASD diagnostic services for 33 years.
- The clinic expanded into the statewide WA FASDPN in 1995 through RCW 70.96A.500 and is the first program of its kind in the nation.
- The WA FASDPN has included up to 6 Satellite clinics led by the Core diagnostic/research/training site at the University of Washington. See our interactive data Tableau Dashboards
- The WA State FASDPN is recognized as a national/international model for FASD diagnosis and prevention demonstrating an invaluable partnership between academic research and public health through interagency collaboration (WA FASD Interagency Workgroup).
- Our Mission is FASD prevention through FASD screening, diagnosis, intervention, research, and training.

What does the FASDPN do for children, families, and health care professionals in WA? (2014 FASD State Recommendations)

Diagnostic Program

- The FASDPN provides 100% of the interdisciplinary FASD diagnostic evaluations in WA State. The FASDPN is currently funded to conduct 70 diagnostic evaluations annually. The demand for FASD diagnostic evaluations exceeds the State's current capacity to provide timely FASD diagnostic evaluations. The average wait time for a family seeking an evaluation is 2 to 12 months.
- The FASDPN provides accurate diagnoses and comprehensive care plans for individuals under 22 years of age with prenatal alcohol exposure. Patient satisfaction is high. 92% of families report they received help from us they could not receive elsewhere. 89% report the FASD diagnosis afforded them access to interventions that met their needs. 99% would recommend our diagnostic services to other families in similar need.
- We developed the evidence-based FASD 4-Digit Code Diagnostic System and FAS Facial Recognition Software that is used worldwide.

Training Program

- We provide FASD training to 1000s of community health care, educational, correctional, and social service students and providers statewide.

Screening Program

- We used our FAS Facial Recognition Software to screen all children entering King County Foster Care for FAS for 10 years. The prevalence of FAS in King County foster care is 10 times higher (1/100) than in the general population (1/1000). Early accurate diagnosis is confirmed to reduce secondary disabilities like school failure, job loss, and trouble with the law.

Intervention Services

- Patients/families report tremendous access to and benefit from interventions recommended by the FASDPN clinics. FASDPN published research confirmed early diagnosis and a stable, nurturing home environment led to significantly reduced brain dysfunction. The FASDPN has attracted millions of dollars in free assessment (e.g., MRIs, neuropsychological exams) and intervention services (e.g., 9-month in-home intervention) for hundreds of WA children through the FASDPN research program. Family advocacy is provided by FASD Focus NW.org .

Primary Prevention Program

- We identify women at highest risk to give birth to children damaged by prenatal alcohol, namely the birth mothers of children diagnosed with FASD at our FASDPN clinics. We provide the women with referrals to appropriate community-based programs including the Parent-Child Assistance Program to help them reduce their use of alcohol during pregnancy and practice effective family planning.
- Published evidence supports WA FASD prevention efforts are working! A significant reduction in maternal drinking during pregnancy correlated with a significant reduction in the number of children being born with FAS in WA State.

Research Program

- The FASDPN has attracted millions of research dollars to WA State to support free neuropsychological evaluations, MRIs, and 9-month, in-home intervention services for children and families impacted by FASD (Families Moving Forward).

Executive Summary

The mission of the Washington State Fetal Alcohol Syndrome Diagnostic & Prevention Network (FASDPN) since its inception in 1993 is primary and secondary prevention of fetal alcohol spectrum disorders (FASD) through screening, diagnosis, intervention, research, and training/education. Primary prevention refers to prevention of FASD births. Secondary prevention refers to prevention of secondary disabilities among individuals exposed to and damaged by prenatal alcohol exposure. The FASDPN's innovation and utility have been nationally and internationally recognized and replicated. A summary of our accomplishments to date is presented in our Legislative Fact Sheet above and detailed in full below.

Washington is one of very few states that has significantly reduced the prevalence of drinking among pregnant women through primary prevention efforts such as those conducted by the FASDPN and the WA State Parent-Child Assistance Program (P-CAP). Women in Washington State reported a significant decrease in their consumption of alcohol during pregnancy from 7.8 percent in 1993 to 3.9 percent in 1998, exceeding the Health People 2010 National Goal of 6% (Washington State DOH, May 2002). This significant decline in the prevalence of maternal drinking during pregnancy corresponded to a significant decline in the prevalence of FAS among foster children born between 1993 to 1998. These observations strongly support that FAS prevention efforts in Washington State were working (Astley, 2004). A comprehensive summary of WA State efforts to prevent FASD from 1968-2004 are posted on the WA FASD website in a document entitled FASD: WA State History.

It is paramount that WA State sustain its successful efforts to reduce the incidence of FASD. Unfortunately, the most recent CDC Pregnancy Risk Assessment Monitoring System (PRAMS) data for WA documents a small, but steady increase in maternal reporting of drinking during pregnancy, in contrast to the steady decline observed in the early 1990s (Astley Hemingway et al., 2023). Preliminary data document this increase in drinking is associated with an increase in prevalence of FAS in foster care among children born after 1998. To reverse this trend, the WA FAS Interagency Workgroup intensified its efforts on FASD identification, prevention, intervention, and policy as outlined in House Bill 2737. The WA FAS Interagency Workgroup, chaired by Susan Astley Hemingway, PhD, submitted a comprehensive report entitled "Recommendations from the WA FASD IAWG" to the State Legislature in December 2014 to describe the impact of FASD on WA State; identify evidence-based practices for early screening, diagnosis, prevention, and intervention; and recommend policy changes. In 2024 the WA State Legislature approved House Bill 1168 to once again expand diagnostic services and increase availability of intervention.

2025 marks the 33rd year of operation for the University of Washington FASDPN core clinical/research/training clinic and the 30th year of legislative support for the expansion of the UW clinic into a statewide network of FASD clinics (FASDPN). The FASDPN has achieved each of it's missions as described below We are gratified with our successes in the last three decades and are appreciative of the continued support we receive from the Washington State Legislature and Health Care Authority. This annual report summarizes our activities and progress through June 30, 2025. Essentially all tasks that were proposed to be completed by this date are completed; all work planned to be ongoing at this time is ongoing. The remainder of this report provides further detail on the background and establishment of the FASDPN and our accomplishments to date.

Full Report

I. What is Fetal Alcohol Spectrum Disorder (FASD)?

FASD is an umbrella term used to describe the spectrum of adverse outcomes that can occur in an individual whose mother drank alcohol during pregnancy. These outcomes may include physical and neuropsychological abnormalities with lifelong implications. The term FASD was not intended for use as a clinical diagnosis. Rather, the spectrum of diagnoses that fall under the umbrella of FASD include FAS, Static Encephalopathy/Alcohol-Exposed, and Neurodevelopmental Disorder/Alcohol-Exposed. FAS is a permanent birth defect syndrome characterized by growth deficiency, a unique cluster of minor facial anomalies and structural, neurological and/or functional brain abnormalities. FAS was first discovered by Christy Ulleland, MD at the University of Washington in 1972 (Ulleland et al., 1972). The term FAS was first coined in the medical literature in 1973 by University of Washington professors Kenneth Jones MD and David Smith MD (Jones & Smith, 1973). FASD is the leading known cause of intellectual disability and is 100% preventable. The incidence of FAS is estimated to be 1 to 3 per 1,000 live births in the general population, similar to the incidence of down syndrome (Abel & Sokol, 1987). The prevalence of FAS in King County foster care is 10 times greater than in the general population or approximately 1 out of every 100 children (Astley, et al., 2002). In Washington State an estimated 200 infants are born with full FAS each year. Not all infants exposed to and damaged by prenatal alcohol exposure have FAS. Many infants damaged by prenatal alcohol exposure have brain damage that can be as severe as the damage seen in infants with FAS, but do not have the physical anomalies (growth deficiency and/or facial anomalies) that permit a diagnosis of FAS. The medical, educational, and social service needs of these individuals with Static Encephalopathy/Alcohol Exposed and Neurodevelopmental Disorder/Alcohol Exposed are no different than those with FAS (Jirikowic et al, 2010). In Washington State, an estimated 870 children are born with FASD each year (1% of births) and approximately 70,000 individuals with FASD of all ages currently live in Washington State. Early diagnosis, intervention and a stable, nurturing home environment with intervention and accommodations helps reduce the prevalence of secondary disabilities such as school failure, unemployment, and trouble with the law. This was confirmed in a publication (Astley, 2010) summarizing the outcome of the first 1,400 patients diagnosed at the FASDPN clinics. Despite heavy prenatal alcohol exposure, 9.3% of patients evaluated in the clinic present with normal growth and development. The two features that significantly differentiated this small group of children from the much larger group of children that presented with significant cognitive/behavioral impairments was an early diagnosis and a stable, nurturing home environment.

II. Establishment of and Funding History for the FAS Diagnostic and Prevention Network (FASDPN)

Fetal Alcohol Spectrum Disorder (FASD) has been identified as an important health issue. The 1994 Washington State Public Health Improvement Plan identified maternal substance abuse during pregnancy and the resulting alcohol related birth defects as an important public health issue. The March of Dimes Western Washington Chapter Needs Assessment (1992) community Delphi survey found the communities' top concern was perinatal substance abuse and its resultant problems. The Washington State 1995 MCH Title X Block Grant identified substance use/abuse during pregnancy and its resultant negative outcomes as an area of focus for 1995. In 1992, Congress mandated the CDC to lead national efforts in FASD prevention. In response to the mandate, the CDC released a Request of Proposals that would fund 5 clinical research teams nationwide to empirically assess proposed methods for FASD prevention. The University of Washington was one of the five recipients of the CDC funding. The UW proposed to identify and intervene with women at highest risk for bearing

children with FAS/D by opening the first ever interdisciplinary FASD diagnostic clinic. Women at highest risk for bearing children with FAS/D are women who have already given birth to a child with FAS/D.

Back in 1992, FASD was not easily assigned to any specific medical specialty or governmental agency for overall leadership. Psychiatrists are primarily interested in problems of substance abuse, obstetricians are primarily interested in pregnancy risk reduction, pediatricians and pediatric subspecialties like genetics, dysmorphology, neurology, and developmental disabilities are primarily interested in the diagnosis and management of affected children (it is unclear who has specialty concern for affected adults). All of these groups express interest and some expertise in dealing with a portion of the FASD management problem, but no specialty is positioned to assume responsibility for the whole. Similarly, in government, the challenges faced by these affected individuals requires the involvement of schools, social service agencies, alcohol treatment agencies, the criminal justice system, vocational rehabilitation, developmental disabilities, health agencies, etc. All of these agencies have an important role to play in helping affected patients, but no single agency is in a position to organize and direct services across recognized divisional and departmental boundaries.

Providing diagnostic and intervention services to both mother and child through a FASD Diagnostic Clinic not only benefits the mother and child but has the potential of being a very cost-effective approach to FASD primary prevention (Astley et al., 2000a). Based on the results of the study published by Astley et al., (2000a), one out of every three patients evaluated in the FASDPN clinics is diagnosed with FAS or Static Encephalopathy/Alcohol Exposed. The birth mothers of one out of every three of these children can be directly contacted. Half of the birth mothers directly contacted will still be at risk for producing more children damaged by prenatal alcohol exposure. Thus one out of every 18 children evaluated in the FASDPN clinics has a birth mother who can be found and is at risk for giving birth to more children damaged by prenatal alcohol exposure. The cost to society to raise a child with FAS was estimated to be $1,000,000 in the 1980s (Abel and Sokol, 1987). A diagnostic evaluation for a child through a FASDPN clinic cost approximately $1,200 in 2007 (Astley et al., 2007a). Providing effective intervention to the highest risk birth mothers through the Parent-Child Assistance Program cost an estimated $3,800 per year per woman over three years in 1999 (Grant *et al*., 1999). One out of every 10 children evaluated in the FASDPN clinic is diagnosed with full FAS. If, on average, 18 children must be diagnosed to identify and intervene with one high-risk mother, the approximate cost to find and provide effective intervention services to the birth mother would be $33,000 ($21,600 to diagnose 18 children and $11,400 to provide three years of advocacy services to the mother through the P-CAP program). Thus, the cost of raising a child with FAS would be roughly 30 times the cost of preventing FAS in the child. The benefit to the mothers, their children, and society would be immeasurable.

Establishment of the FASDPN: In 1992 the University of Washington entered into a 5-year Cooperative Agreement with the CDC to conduct a FAS primary prevention study that focused on identifying and profiling the needs of women at high risk for giving birth to children with FAS. To identify the women, the CDC provided funds to establish an interdisciplinary FASD Diagnostic Clinic at the Institute on Human Development and Disability at the University of Washington (UW). This was the first ever interdisciplinary FASD diagnostic clinic in the world. The purpose of the clinic was to identify high-risk women through the diagnosis of their affected children. Although the UW clinic had the capacity to see 160 patients per year, the demand for diagnostic services far exceeded its capacity. In 1995, two additional FASD diagnostic clinics, led by the UW FASD clinic, were established in Federal Way and Everett through support from the Western Washington March of Dimes Birth Defects Foundation (Fig. 1). In 1996, the WA State Legislature through Senate Bill 5688

went one step further and expanded the single UW FASD clinic into a statewide network of six Satellite clinics led by the core clinical/research/training site at the University of Washington. In 2019, a 7th FASDPN site was established in King/Snohomish Counties: Wonderland's Hope Rising FASD diagnostic clinic.

The six Satellite FASDPN clinics were established in Spokane, Yakima, Whitman, Pierce, South King and Snohomish Counties (listed below). The University of Washington core staff provided FASD diagnostic training. A diagnostic manual "Diagnostic Guide for FAS and Related Conditions" (Astley & Clarren 1997, 1999; Astley Hemingway 2004, 2024), standardized diagnostic forms, and neuropsychological and motor-sensory assessment batteries were created to assure consistency and accuracy of diagnosis across all FASDPN sites. A comprehensive set of educational materials was also distributed. All sites were networked via interactive video teleconferencing and a centralized database was established.

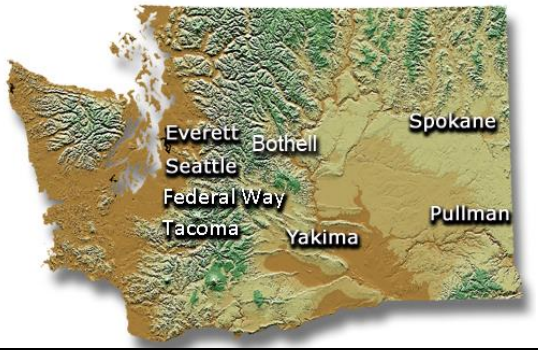


Figure 1. Locations of FASDPN clinics from 1993 to present.

A. Core FASDPN Clinical/Research/Training Site:
   1. University of Washington, Institute on Human Development and Disability, Seattle. Susan J. (Astley) Hemingway, Ph.D. Director (1993 to present).

B. Six contracted Satellite FASDPN Sites:
   1. Pierce County: Mary Bridge Children's Hospital, Tacoma (1996-1999).
   2. South King County: Federal Way Public Health Clinic, Federal Way (1995-2004).
   3. Whitman County: Wilson Psychological Services, Pullman. (1997-2007).
   4. Spokane County: Sacred Heart Hospital, Spokane. (1997-2010).
   5. Yakima County: Children's Village, Yakima. (1997-2017).
   6. Snohomish County: Providence Medical Center, Everett. (1995-2017).

C. One noncontracted Satellite FASDPN site opened in 2019.
   1.King County: Wonderland Developmental Center, Hope Rising, Bothell (2019-present).

Overall, the six contracted Satellite FASDPN sites were maintained for an impressive number of years with four of the six open for 16 to 21 years. The primary reason for closure was insufficient funds, largely resulting from the 2007-8 recession.

Funding History for the Satellite Clinics: The six Satellite FASDPN clinics were community-based and community-owned since their inception in 1996. Each Satellite clinic conducted 1 or 2 diagnoses per month. Up until 2008, the Satellite clinics never received funding support through the FASDPN-

DASA contract. The Satellite FASDPN clinics were supported through a variety of mechanisms including: in-kind service from local professionals, in-kind space from local medical/public health facilities, fee for service (billing Medicaid and/or private insurance), cost shifting (the psychologist, speech language pathologist, and occupational therapist in a clinic are often 'on loan' one day per month from the local school district); and funds from local philanthropic agencies (e.g., March of Dimes, United Way). The Satellite clinics demonstrated the cost of conducting a single diagnostic evaluation in 2008 was approximately $3,500 in Washington State. This cost included administrative costs and professional fees and was commensurate with the cost of an evaluation in a typical neurodevelopmental clinic. Only a small portion of the cost could be billed to and collected from Medicaid and/or private insurance. Securing the remaining funds continued to be the number one challenge for these regional clinics. Many states have replicated the WA State FASDPN model and have encountered similar funding challenges. Alaska established 12 FASD Diagnostic Clinics in 1998. In a report prepared by the Alaska Mental Health Trust Authority, the average cost of a FASD diagnostic evaluation in Alaska in 2001 was $4,821. Like WA, Alaska demonstrated only $1,076 (22%) could be billed to and collected from Medicaid and/or private insurance. Recognizing that Medicaid and/or insurance alone would not cover the full cost of a diagnosis, Alaska established a FASD Diagnostic Services Provider Agreement in 2005. Qualified Alaska FASD diagnostic clinics received a Provider Agreement payment of $3,000 per diagnostic evaluation to cover the costs not covered by Medicaid/insurance. The Alaska Agreement was shared with the Washington State Legislature in Jan 2008. In 2008, the WA Legislature approved $100,000 to cover the cost of 50 FASD diagnostic evaluations conducted by four FASDPN Satellite clinics (Yakima, Pullman, Spokane, and Everett). These funds helped sustain these 4 clinics for a few more years, but by 2017, all four closed due to insufficient funds. The cost of $2,000 per diagnostic evaluation is reflective of costs 15-20 years ago. The current cost of an FASD diagnostic evaluation in 2024 in WA is roughly $6,500. By 2017, most of the FASDPN Satellite clinics closed due to insufficient funds. In 2024, the Legislature approved WA Second Substitute House Bill 1168 to re-establish FASD diagnostic and intervention services statewide. Establishing FASD diagnostic clinics statewide would provide more equitable access to diagnostic services and shorten the wait time for families.

III. Interagency Collaboration and Personnel

Interagency Collaboration: From 1997 through 2014, the FASDPN met with representatives from NOFAS-WA, FASFRI, FADU, P-CAP, OSPI, MAA, CA, ITEIP, JRA, DOC, DOH, DSHS, DCFS, MCH, and IHS quarterly through the FAS Interagency Work Group (FAS IAWG) as stipulated by Senate Bill 5688. These meetings facilitated the development and implementation of all components of the FASDPN program. FASDPN staff members have also participated as speakers for the annual FASD conferences held by the FAS IAWG in 1999, 2000, 2001, 2005. Starting in 2007, the FAS IAWG merged its annual FASD conference with the ongoing Co-Occurring Disorders Conference. The FASDPN created and maintains WA State's FASD website. In 2015, the focus of the FAS IAWG was House Bill 2737. The FAS IAWG submitted a report entitled "Recommendations from the Washington State Fetal Alcohol Spectrum Disorders (FASD) Interagency Work Group" to the Governor and Legislature in December 2014. As an example of the benefits of working collaboratively with State agencies, in March 2015 DDD posted Management Bulletin D15-012 that expanded eligibility from just FAS to the full spectrum of FASD. The more rigorous, evidence-based method of diagnosis (the FASD 4-Digit Code) paved the way for this expanded DDD eligibility.

Key personnel at the University of Washington FASDPN Core site during the 2025 fiscal year are listed below. Those marked with a * have been with the FASDPN for over 20 years.

*Susan (Astley) Hemingway, Ph.D. FASDPN Director, Professor of Epidemiology/Pediatrics

*Julie Bledsoe, M.D.	Professor and Pediatrician
*Julian Davies, M.D.	Professor and Pediatrician
Julia Mattson, M.D.	Professor and Developmental Pediatrician
*Allison Brooks, Ph.D.	Psychologist
*Erin Olson, PhD.	Professor and Psychologist
*John Thorne, Ph.D, SLP	Professor and Speech/Language Pathologist
*Tracy Jirikowic, Ph.D., OTR/L	Professor and Occupational Therapist
Jennifer Nash, Ph.D. OTR/L	Occupational Therapist
Misty Pruner, Ph.D. OTR/L	Occupational Therapist
Sandra McIntire	Program Assistant
*Faye Louie, B.S.	Clinic Coordinator

IV. Mission of the FASDPN

The mission of the Washington State Fetal Alcohol Syndrome Diagnostic & Prevention Network (FASDPN) is primary and secondary prevention of fetal alcohol spectrum disorders (FASD) through screening, diagnosis, intervention, research, and training/education. The FASDPN has achieved each of these missions as outlined below.

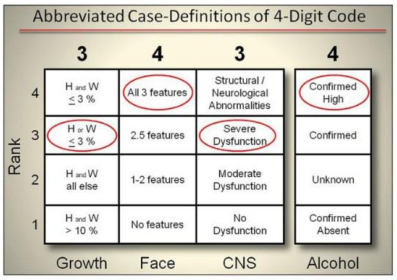
IV.A. Diagnosis

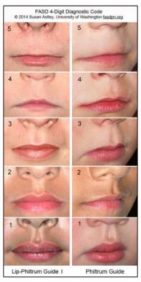
IV.A.1. FASD Diagnostic Model and Method

FASD Diagnostic Model: In 1993, the UW opened the first-ever interdisciplinary FASD diagnostic clinic sponsored by the Center for Disease Control (CDC) as a FASD primary prevention study. Data collected in the clinic was used to develop and validate the FASD 4-Digit Diagnostic Code in 1997 (Astley & Clarren, 1997, 2000). In 2024, the 4th edition of the 4-Digit Code was released (Astley Hemingway, 2024). The 4-Digit Code and interdisciplinary approach to diagnosis is used worldwide.

FASD is characterized by growth deficiency, a unique cluster of 3 minor facial anomalies and structural, neurological and/or functional abnormalities of the brain. Individuals with prenatal alcohol exposure present with a wide range of outcomes, most of which are not specific to (caused only by) prenatal alcohol exposure and often manifest differently across the lifespan. Professionals from multiple disciplines (medicine, psychology, speech-language pathology, occupational therapy) are needed to accurately assess and interpret the broad array of outcomes that define the diagnoses. The pattern and severity of outcome is dependent in part on the timing, frequency, and quantity of alcohol exposure (which is rarely known with any level of accuracy) and the fetus' genetic vulnerability to prenatal alcohol exposure (Astley et al., 2019a). The pattern and severity of outcome is also dependent on the other prenatal and postnatal risk factors that are prevalent among individuals with prenatal alcohol exposure (Astley, 2010; Astley et al., 2020). The FASDPN interdisciplinary team conducts an FASD diagnostic evaluation in one 4-hour evaluation. In preparation for the evaluation, all birth, medical, school and social service records are collected and reviewed. A summary of these records is presented to the team in the first half hour of the diagnostic evaluation. In the next 2 hours, the medical doctor conducts an interview with the caregiver(s) while the psychologist, speech-language pathologist and occupational therapist conduct standardized neuropsychological assessments on the patient. The team reconvenes for one hour and derives the FASD 4-Digit Code and composes a comprehensive intervention recommendation report. In the final half-hour of the evaluation the results are shared with the caregivers and a comprehensive medical summary report is submitted to the patient's medical records.

FASD Diagnostic Method: The FASDPN created the FASD 4-Digit Code in 1997 to guide interdisciplinary teams in the diagnosis of the full spectrum of FASD. A pictorial representation of the FASD 4-Digit Code is presented in Fig. 2). The four digits reflect the magnitude of expression of the four key diagnostic features of FASD in the following order: (1) growth deficiency, (2) the FAS facial phenotype, (3) brain structural, neurological and functional abnormalities, and (4) prenatal alcohol exposure. The magnitude of expression of each feature is ranked independently on a 4-point Likert scale with 1 reflecting complete absence of the FAS feature and 4 reflecting a strong "classic" presence of the FAS feature. Thus, the 4-Digit Code 4444 reflects the most severe expression of FAS (significant growth deficiency, all three FAS facial features, structural/neurological evidence of brain damage, and confirmed prenatal exposure to alcohol). At the opposite end of the scale is the 4-Digit Code 1111 reflecting normal growth, none of the three FAS facial features, no evidence of brain abnormalities, and confirmed absence of prenatal alcohol exposure. Every combination of 4-Digit Code has been observed among individuals with prenatal alcohol exposure evaluated in the WA State FAS Diagnostic & Prevention Network. The 4-Digit Code is fully validated (Astley, 2013) and serves as the cornerstone of a fully integrated and highly successful screening, diagnostic, prevention and surveillance program in Washington State (Astley et al., 2002; Astley, 2004a, 2013; Hemingway (Astley) et al., 2024).





3 Diagnoses under the FASD Umbrella

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

4-Digit Codes within each FASD Diagnostic Category

Category	Diagnostic Name and Codes
A	Fetal alcohol syndrome 1333 1433 2333 2433 3333 3433 4333 4433 1334 1434 2334 2434 3334 3434 4334 4434 1343 1443 2343 2443 3343 3443 4343 4443 1344 1444 2344 2444 3344 3444 4344 4444
B	Sentinel physical finding(s) / static encephalopathy / alcohol exposed 3133 3233 4133 4233 3134 3234 4134 4234 3143 3243 4143 4243 3144 3244 4144 4244
C	Static encephalopathy / alcohol exposed 1133 1233 2133 2233 1134 1234 2134 2234 1143 1243 2143 2243 1144 1244 2144 2244
D	Sentinel physical finding(s) / neurodevelopmental disorder / alcohol exposed 1323 2323 3123 3323 4123 4323 1324 2324 3124 3324 4124 4324 1423 2423 3223 3423 4223 4423 1424 2424 3224 3424 4224 4424
E	Neurodevelopmental disorder / alcohol exposed 1123 1223 2123 2223 1124 1224 2124 2224

C

Figure 2.

FASD 4-Digit Diagnostic Code (2024).

A) Abbreviated case-definitions for the fetal alcohol spectrum disorder (FASD) 4-Digit Code (Astley Hemingway, 2024). The 4-Digit Code 3434 is one of 40 4-Digit Codes that fall under the diagnostic category FAS.

B) The Rank 4 FAS facial phenotype requires 3 features: 1) palpebral fissure lengths 2 or more standard deviations below the mean; 2) a smooth philtrum (Rank 4 or 5 on the University of Washington Lip-Philtrum Guide); and 3) a thin upper lip (Rank 4 or 5 on the University of Washington Lip-Philtrum Guide).

C) The 4-Digit Code produces three diagnostic subgroups under the umbrella of FASD: FAS (Diagnostic Category A), SE/AE (Diagnostic Categories B, C), and ND/AE (Diagnostic Categories D, E). Abbreviations: H: height percentile; W: weight percentile.

IV.A.2. FASD Diagnostic Outcomes and Patient Satisfaction

Of the 3,084 patients diagnosed in the FASDPN from 1993 through 2023, 3.3% received a diagnosis of FAS, 4.5% Patial FAS, 26.7% Static Encephalopathy/Alcohol-Exposed and 45.6% Neurodevelopmental Disorder/Alcohol-Exposed (Fig. 3A). The majority of patients were school-aged at the time of their diagnosis with 13.8% birth to 3 years of age and 5.3% 18 years and older (Fig. 3B). More detailed socio-demographics are provided in our profile of the first 1,400 patients diagnosed (Astley, 2010) and via our interactive Tableau Dashboards (e.g., Fig. 4) that are periodically updated. Seventy-eight percent of the patients seen in the FASDPN clinics were no longer in the care of their biological parents. The FASDPN provides accurate diagnoses and comprehensive care plans for individuals under 22 years of age with prenatal alcohol exposure. Ninety-four percent of families report they received medical/educational/social services in our clinics they could not find elsewhere. Ninety-nine percent would recommend the clinic to other families in similar need. Ninety-four percent of families report the intervention services we recommended met some to all their needs (Astley, 2014). A comprehensive profile of the first 1,400 patients evaluated in the WA FASDPN clinics was published in 2010 (Astley, 2010).

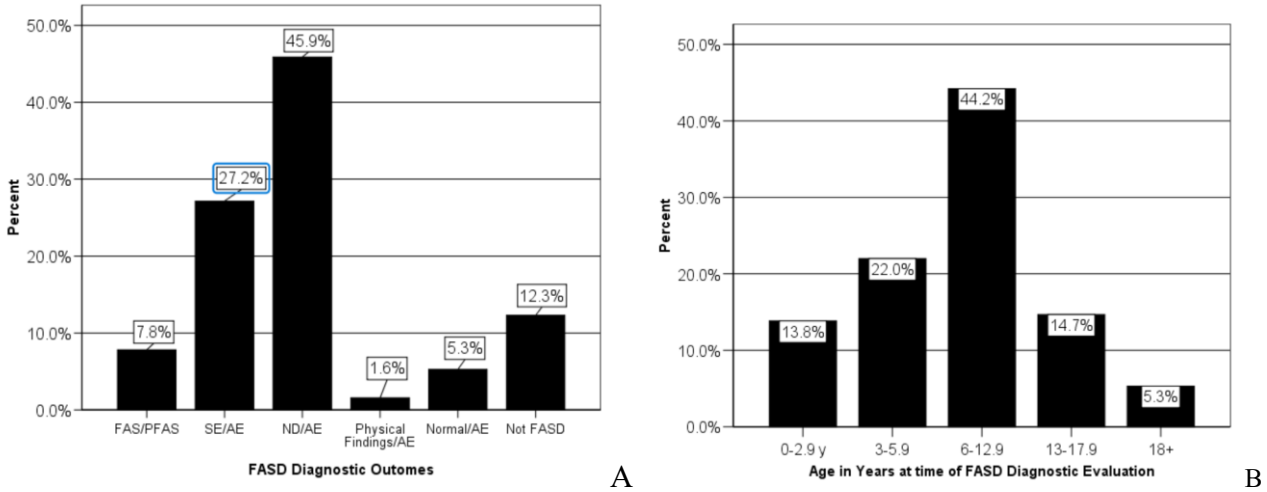


Figure 3. FASD diagnostic outcomes (A) and age distribution (B) of the 3,302 patients diagnosed at the FASDPN clinics from 1993-2024. *FAS/PFAS: fetal alcohol syndrome/partial FAS. SE/AE: static encephalopathy/alcohol exposed. ND/AE: neurodevelopmental disorder/alcohol exposed*.

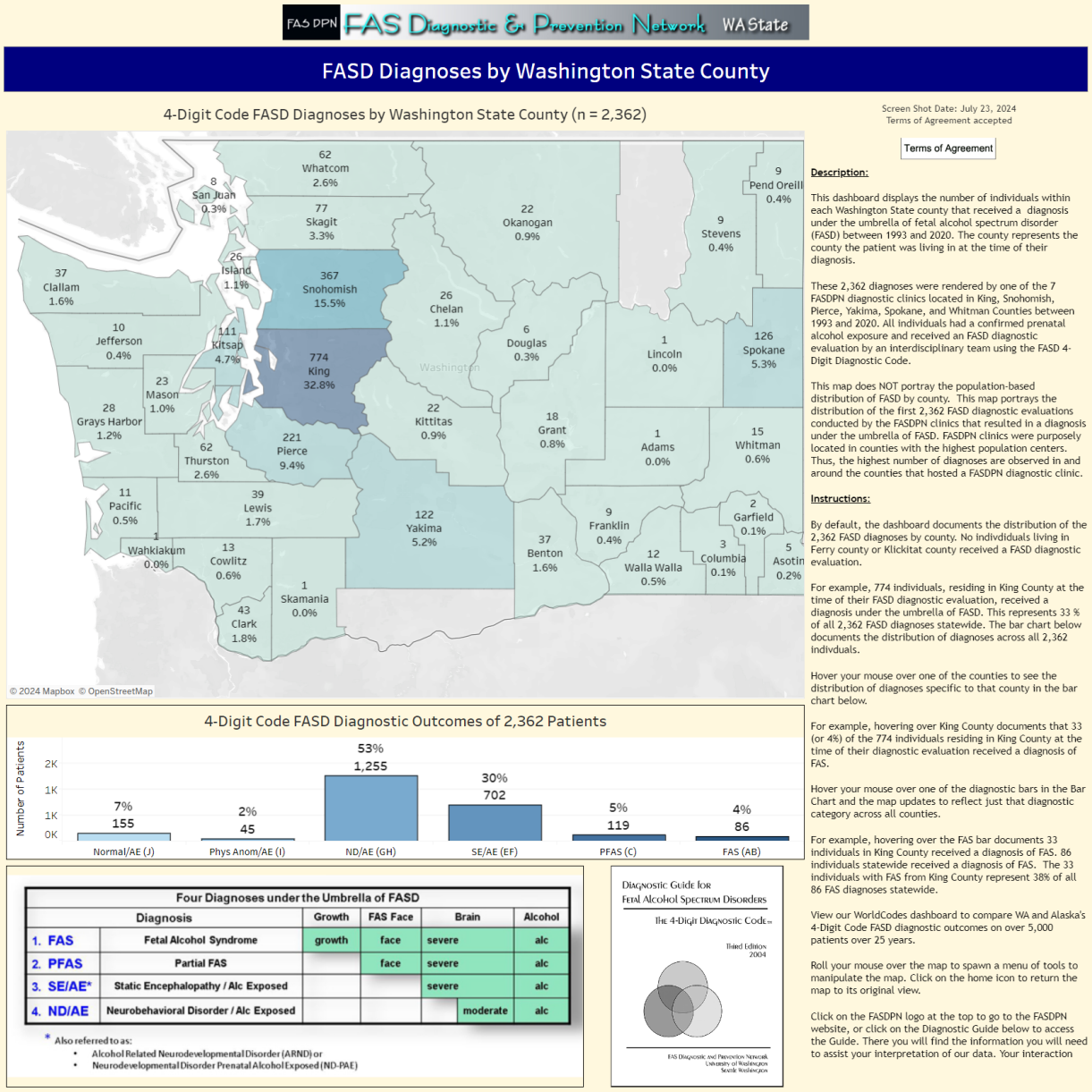


Figure 4. [FASDPN Interactive Tableau Dashboards](#). This interactive dashboard displays the number and proportion of individuals receiving a diagnosis under the umbrella of FASD based on the Washington State County they resided in at the time of their FASD diagnostic evaluation. These evaluations were conducted on 2,362 patients between 1993 and 2021. This dashboard is updated periodically

IV.A.3. FASD Diagnostic Demand and Capacity over 30 years

The original University of Washington interdisciplinary FASD Diagnostic Clinic was funded by the CDC from 1993 – 1997 as part of a national FASD prevention study. The CDC-sponsored University of Washington FASD Clinic had the capacity to conduct 160 diagnostic evaluations per year. Patients often had to travel long distances to obtain these FASD diagnostic services in Seattle. In 1995, two additional FASD diagnostic clinics, led by the UW FASD clinic, were established in Federal Way and Everett through support from the Western Washington March of Dimes Birth Defects Foundation. In 1996, one year prior to the completion of the 5-year CDC FAS Prevention Study, funds were received

from WA DSHS, through Senate Bill 5688, to continue support of the University of Washington FASD Diagnostic Clinic and expand it into the Washington State FAS Diagnostic & Prevention Network (FASDPN) through the addition of six Satellite clinics statewide.

Since the opening of the first FASD Diagnostic Clinic at the University of Washington in 1993, the Washington State FASDPN has received 5,574 requests for diagnoses and diagnosed a total of 3,302 patients through 2024, (2,448 (74%) by the University of Washington Clinic and 808 (26%) by the six Satellite Clinics). On average, over the past three decades (1993-2023), the demand for FASD diagnostic evaluations in WA has been roughly twice the diagnostic capacity of the FASDPN clinics. Requests for evaluations are made by submitting a New Patient Information Form (NPIF) (white bars in Figs 4 and 5). An individual is eligible for a FASD diagnostic evaluation if they have a reported prenatal alcohol exposure at any level. Fig. 4 documents the number of NPIFs submitted and FASD diagnoses completed by the patients' county of residence from 1993-2024. The greatest number of requests were received from the largest population centers in WA and correlated with the location of FASDPN clinics over time (e.g., Seattle, Federal Way, Tacoma, Evertt, Pullman, Spokane and Yakima). Fig. 5 documents the number of NPIFs submitted and diagnoses completed annually from 1993-2024. The pattern of requests and diagnoses annually reflects a number of factors that varied across the decades. One important factor was how many clinics were open each year and where they were located. This is portrayed in Fig. 6. In 1993 and 1994, the Seattle clinic at the University of Washington was the first and only FASD diagnostic clinic open in the U.S. (black bars in Fig. 6). Understandably, there was a large backlog of individuals seeking diagnostic evaluations. From 1995 to 2017 additional FASDPN Satellite clinics were opened (depicted by colored bars in Fig. 6), resulting in increased diagnostic demand, capacity and geographic access. The Satellite clinics were community owned and operated and did not receive funding support from the State from 1996 to 2013. The dip in diagnostic activity that occurred in 2008-2009 was due to the national recession that closed the UW FASDPN clinic for 3 months in 2009 and forced the closure of most of the Satellite clinics. It was not until 2013 that the State Legislature allocated funds to help support the Satellite clinics. These funds allowed the Yakima and Evertt clinics to reopen until 2017. By 2018, the UW Core clinic was the only clinic open. The dip in diagnostic demand and capacity in 2019-2022 reflected the impact covid had on the population seeking diagnoses and the UW's ability to safely conduct diagnoses. The UW clinic was closed from March through June of 2020 due to the covid pandemic and reopened in April 2020 using a hybrid zoom/in-person model following covid safety protocols. By 2021 the UW FASDPN clinic was back up to full capacity (70 diagnoses per year). The black bars in Fig. 6 reflect the number of diagnostic evaluations conducted annually by the UW FASDPN core clinic. The number of diagnostic evaluations conducted by the UW FASDPN clinic has varied from 50-160 per year based on funding availability. In 2019, the Hope Rising Clinic in Bothell opened. They provide diagnostic evaluations and intervention for patients with prenatal substance exposure including prenatal alcohol exposure. They were trained to use the FASD 4-Digit Code but have never had a formal contract with HCA or the UW FASDPN, thus have not been in a position to share data with the FASDPN core clinic at the University of Washington.

In fiscal year 2024, the only FASDPN clinic open in WA State was at the University of Washington in Seattle. The UW FASDPN clinic was funded to conduct 70 diagnostic evaluations per year. With over 100 patients requesting evaluations, the wait time for some patients was over 9 months. With the closure of the FASDPN satellite clinics in Spokane, Yakima and Pullman by 2017, the number of requests for evaluations from families living in eastern WA decreased considerably, not because the need decreased, but because geographic access to diagnoses decreased. Families impacted by FASD would be better served if FASD diagnostic services were more geographically dispersed and wait times were reduced.

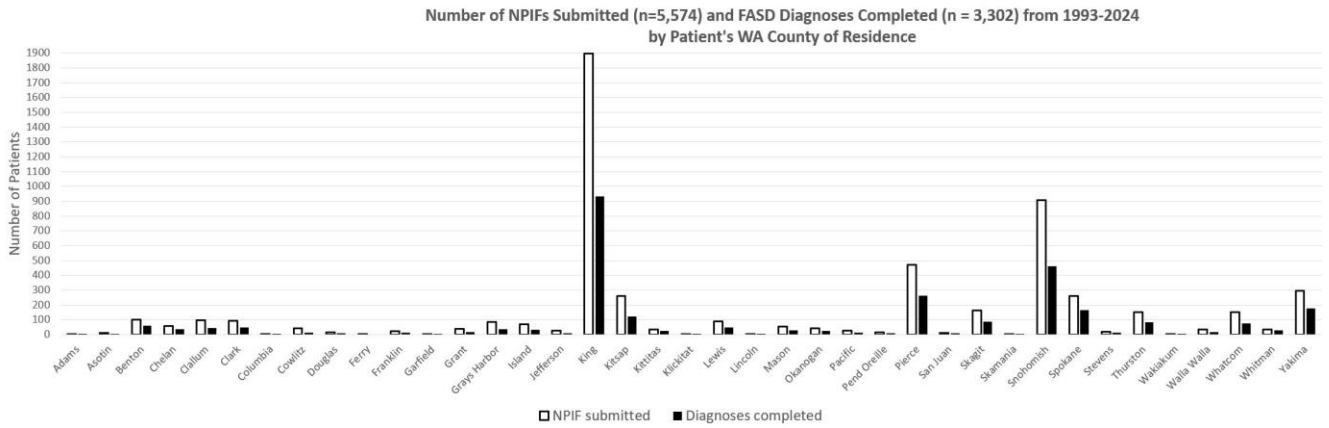


Figure 4. See interpretation of this figure in the text of Section IV.A.3 above.

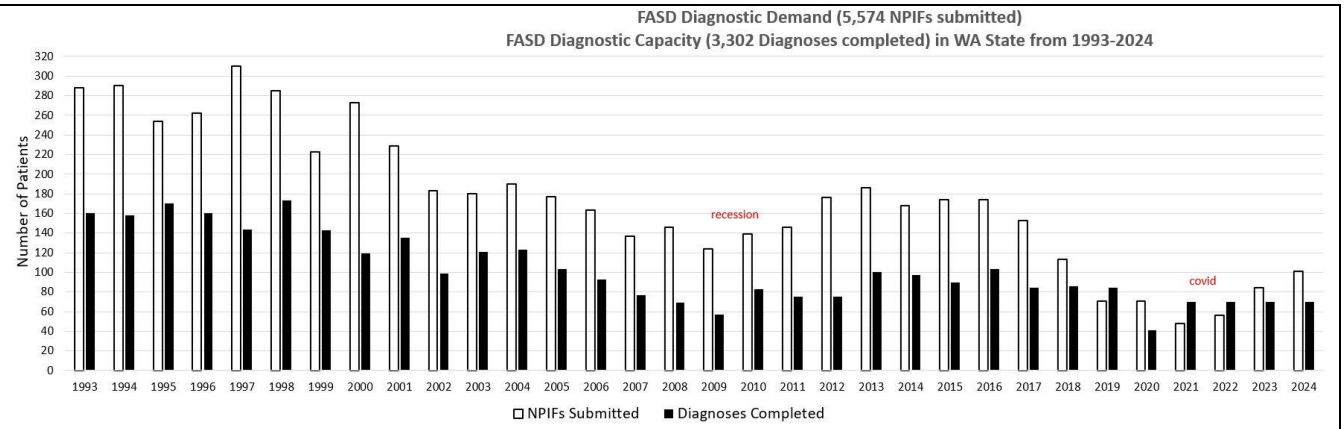


Figure 5. See interpretation of this figure in the text of Section IV.A.3 above.

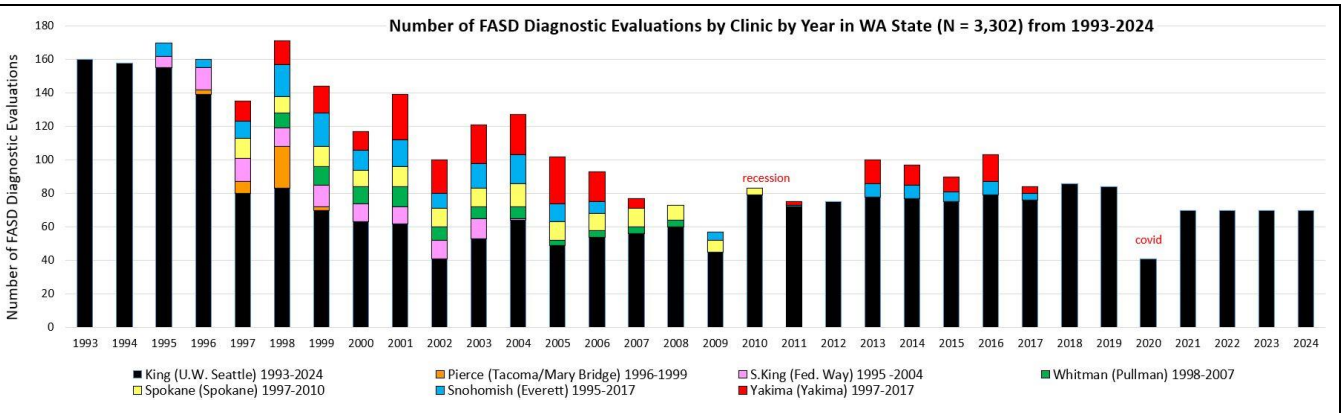


Figure 6. See interpretation of this figure in the text of Section IV.A.3 above.

IV.A.4. Creation and Distribution of FASD Diagnostic Tools and Training Materials

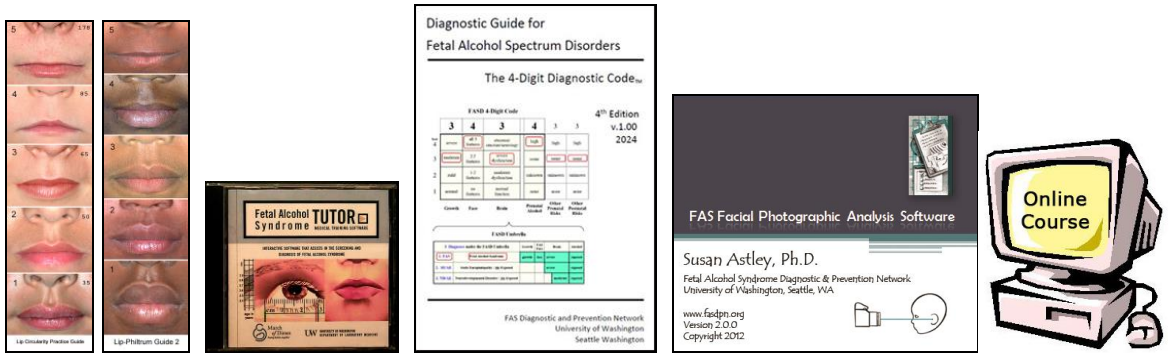


Figure 7. FASD 4-Digit Code diagnostic tools and online training course developed by the FASDPN.

The FASDPN has created and distributes FASD screening, diagnostic and prevention tools and training to a broad array of professionals worldwide (see Fig. 7 and list below). The development of these tools and training materials were supported in part by DSHS and outside contracts. These tools and training materials were developed to assure consistency and accuracy of diagnosis across all FASDPN sites. All are distributed worldwide free of charge.

1. FAS Facial Photographic Analysis Software, 1996, 2003, 2012, 2016.
2. Diagnostic Guide for FASD: The 4-Digit Diagnostic Code, 1st ed. 1997, 2nd ed. 1999, 3rd ed. 2004; 4th edition 2024.
3. FASDPN Clinical Manual, 1997, 1999, 2004
4. Community Development of a FASDPN, 1997, 1999, 2004.
5. FASDPN website (www.fasdpn.org), 1997, updated monthly.
6. Patient/Family Resource Materials and Network Clinical Staff Resource Materials, 1997
7. FASDPN Data Collection and Consent Form Instruction Guide, November 1997.
8. FASDPN Interdisciplinary Clinical Team Training Manual, 1997, 2004.
9. Communicative Behavior Assessment Guide, 1st edition, January 1998.
10. Psychological Assessment and Treatment Planning Manual, 1999.
11. FAS-Tutor™ (an instructional CD-ROM for screening and diagnosing FAS) 1999.
12. Journey through the Healing Circle, 1999.
13. A Child with FAS, In: Handbook of Clinical Assessment for Young Children with Developmental Disabilities, 2000.
14. Intervention Ideas Guide, 2000.
15. Teaching Students with FASD, 2004.
16. FASD 4-Digit Diagnostic Code Online Course, University of Washington, 2005, 2024.
17. Families Moving Forward FASD Intervention Program founded/direct by Heather Carmichael Olson PhD, 2005 to present.
18. Free digital FASD Lip-Philtrum Guides for use on smartphones, 2014.
19. Webinar: Prevention of FASD, 2014, presented by Susan Astley Hemingway, sponsored by Association of Reproductive Health Professionals.
20. Web-based "Talking with Patients about Alcohol Use During Pregnancy Clinical Minutes" 2016 sponsored by Association of Reproductive Health Professionals. Content contributed by Susan Astley Hemingway.
21. FASD: From Discovery to Prevention in WA State 2004 (video presentation) Susan Astley Hemingway PhD.
22. Tableau FASDPN interactive data dashboards.

Dr. Astley Hemingway created the FASD 4-Digit Diagnostic Code for use by interdisciplinary teams back in 1997. It has been updated in 1999, 2004 and 2024. It is a fully validated diagnostic system that is now used worldwide. Thousands of copies of the Guide have been distributed worldwide. Requests have been made to translate the Guide into Russian, German, French, Polish, and Spanish. In 2003, the *FAS Facial Photographic Analysis Software* was created by Dr. Astley Hemingway through funding support from the Washington Research Foundation and as of June, 2024, 3,858 copies of this software have been distributed worldwide. The software is used to screen and diagnose the facial features of FAS. The software was updated in 2012 and 2016 to incorporate new palpebral fissure length normal growth charts. A CD-ROM was developed in 1999 to accompany the FASD Diagnostic Guide. The CD-ROM trained medical professionals to screen and diagnose FASD. The National March of Dimes funded the development of the CD-ROM and has distributed over 3,000 copies nationwide. The National FASD Center for Excellence (2002) described the FASDPN method of diagnosis as a clearly advanced, highly developed approach to diagnosis and screening. Our interdisciplinary approach to diagnosis is regarded as Best Practice worldwide by SAMHSA (2014). In 2015, the American Academy of Pediatrics recognized the WA FASDPN as a national/international leader in FASD. As of February 2024, all diagnostic tools (4-Digit Code Diagnostic Guide (2024), FAS Facial Software (2016), Lip Philtrum Guides (2014) and the 4-Digit Code Online Course (2024) are distributed electronically, worldwide, free of charge.

Dr. Astley Hemingway developed a comprehensive manual entitled "*Diagnostic Guide for FAS and Related Conditions. The 4-Digit Code*" to ensure diagnostic accuracy and precision across all FASDPN clinics. This guide was written in response to the documented lack of accuracy and precision of FAS diagnosis nationwide (Cordero et. al., 1994, Stratton et. al., 1995). The Guide was printed by the University of Washington Publication Services in May 1997. It was distributed by the U.W. FASDPN Core site to all FASDPN personnel free of charge and was sold nationally and internationally at cost. A second edition of the Guide was printed in May 1999 to coincide with the release of the FAS-Tutor CD-ROM. This 2nd edition provides further instruction and clarity on the use of the 4-Digit Diagnostic Code for FAS. A comprehensive summary of the 2nd edition was published in the peer-reviewed medical journal *Alcohol & Alcoholism* in July 2000. A 3rd edition was released in 2004 by Dr. Astley: *Diagnostic Guide for Fetal Alcohol Spectrum Disorders: The 4-Digit Diagnostic Code*. A 4th edition was released in 2024 by Dr. (Astley) Hemingway. The latest edition is distributed worldwide, free of charge.

FASDPN clinical team members Heather Carmichael Olson, Ph.D., Sandra Clarren, Ph.D., Sharon Beck, M.Ed. and Tracy Jirikowic, M.O.T. finalized the '*Psychological Assessment and Treatment Planning Manual'* based on information gained from conducting comprehensive psychometric evaluations at the UW FASDPN Core site in 1998. This final edition was distributed to each of the FASDPN network sites during the FASDPN "Assessing Brain Dysfunction" training in May 1999.

Robin LaDue and Carolyn Hartness authored "Journey Through the Healing Circle", a series of CDs and illustrated workbooks narrated by Native American storyteller Loyd Red Crow Westerman, who uses animal stories to talk about children with FAS and the problems families face with these effects. Funded by the WA DSHS. The series showcases the UW FASDPN clinic and interdisciplinary approach to FASD diagnosis.

Funds were received from the National March of Dimes Birth Defects Foundation to create a compact disk to instruct physicians on how to screen and diagnose FAS using the tools and manuals developed by the FASDPN. This CD entitled *FAS-Tutor™* was created through a collaborative effort between Dr. Astley Hemingway at the U.W. FASDPN and Dr. Astion in the Department of Laboratory Medicine at the University of Washington. This CD was distributed nationwide by the National March of Dimes.

FASDPN clinical team members Sandra Clarren, Ph.D. (psychologist) and Tracy Jirikowic, Ph.D. (occupational therapist) created the "*Intervention Ideas Guide, 2000*" based on information gained from conducting comprehensive psychometric evaluations at the U.W. FASDPN Core site and the collective experiences of parents and professionals who have worked with or raised children with prenatal alcohol exposure. This reference guide was distributed to each of the FASDPN network sites during the FASDPN "Organic Brain Dysfunction and Prenatal Alcohol Exposure" Training, October 2000.

Susan Astley Hemingway Ph.D. worked with a software programmer to design and develop the *FAS Facial Photographic Analysis Software* that allows clinicians and researchers to accurately and efficiently measure the magnitude of expression of the FAS facial phenotype from 2D photographs for diagnosis and screening. This software was originally developed in 1996 with funding support from the Washington Research Foundation. In 2002 funds were received to develop a Windows-based, user-friendly version that is available for distribution to medical professionals. The software was updated in 2012 and 2016. This software was used to screen all children entering long term foster care in the King County Foster Care Passport Program. The results of this screening were published in the J. Pediatrics (Astley et. al., 2002). This software is distributed free of charge and used worldwide to screen and diagnose the facial features of FAS (Fig. 7).

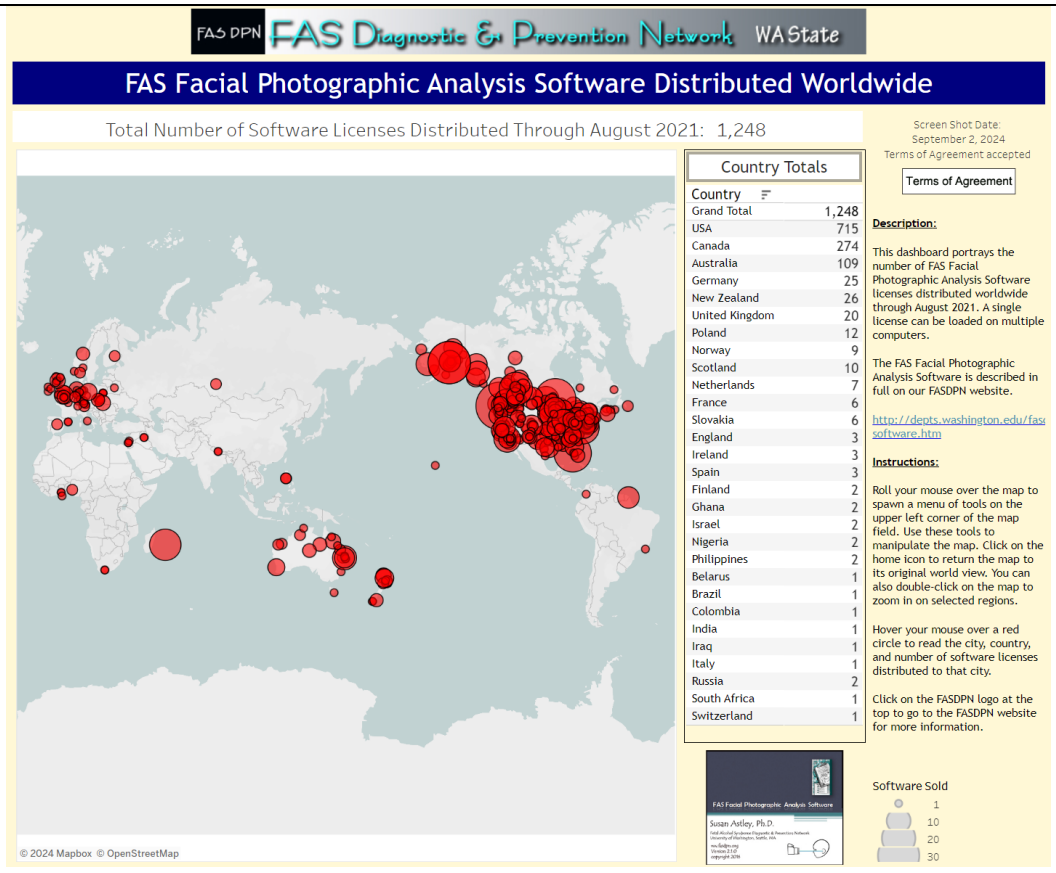


Figure 7. The FAS Facial Photographic Analysis Software has been distributed to thousands of clinicians and researchers in over 62 countries.

IV.B. FASDPN Training Programs

The U.W. FASDPN core site provides eight different FASD training programs targeted to families and professionals from WA State and around the world. Each is described below. Those marked by an asterisk are funded by this HCA contract.

1. **Training FASDPN Network Clinic Sites in Washington State***
   Over the years, there have been six FASDPN Satellite clinics in Snohomish, Pierce, South King, Yakima, Spokane and Whitman counties. In 2018, a 7th Network clinic "Hope Rising" (located in Bothell, King/Snohomish Counties) commenced training and opened in May 2019. Each Satellite clinic was locally owned and operated. Each received continuing education to stay abreast of the latest developments in diagnosis and prevention and to ensure diagnostic consistency across all sites. The continuing education is provided in two forms: 1) onsite consult on the diagnosis of patients evaluated at the Satellite clinics and 2) periodic one-day training sessions on key topics such as diagnosing organic brain damage. Each clinic sent the University of Washington the diagnostic files on all patients diagnosed. These files are reviewed for diagnostic accuracy. Feedback was provided to each clinic periodically throughout each year. A brief summary of selected one-day trainings is presented below.

   1998 FASDPN Clinic Coordinator Conference
   Six clinic coordinators attended a one-day training session. Topics included how to screen patient requests for clinic appointments, how to complete the FAS Diagnostic Evaluation Form, how to take properly aligned clinic photos, how to compose response letters to caregivers requesting appointments and how to bill for services.

   1999 Assessment of Brain Function
   The first annual one-day training session for Satellite clinics was held in Seattle. Sixteen professionals from the FASDPN Satellite clinics including psychologists, occupational therapists, speech language pathologists, and physicians attended. This session provided additional training on how to assess brain function in the FASDPN clinics. The 1999 edition of the FASDPN Psychometric Training Guide was distributed.

   2000 Organic Brain Dysfunction and Prenatal Alcohol Exposure
   The second annual one-day training session for Satellite clinics was held in Yakima, WA. Forty-six professionals from the FASDPN Satellite clinics including psychologists, occupational therapists, speech language pathologists and physicians attended. This session provided additional training on how to assess minimal brain dysfunction in the FASDPN clinics. he 2000 edition of the *Intervention Ideas Guide* was distributed.

   2002 Assessment of Brain Function
   The third annual one-day training session for Satellite clinics was held in Yakima WA in May, 2002. Fifty-two clinical team members from the FASDPN Satellite clinics attended. The FAS Facial Photographic Analysis Software was distributed to each clinic site.

   2004 Assessment of Brain Function
   The fourth annual one-day training session for Satellite clinics was held in Yakima WA in May 2004. Twenty-nine clinical team members from the FASDPN Satellite clinics attended. The primary focus was review of the upcoming CDC FAS Diagnostic Guidelines and the 3rd edition of the Diagnostic Guide for FASD.

   2006 FASD Diagnosis and Intervention
   The fifth annual one-day training session for Satellite clinics was held in Yakima WA in May 2006. Fifty-seven clinical team members from the FASDPN Satellitel clinics attended. Preliminary outcomes of the following FASDPN research projects were presented:

MRI/MRS/fMRI study, Family Intervention study, Sensory Processing study, and the Social Communication Intervention Study.

2018 Diagnostic Team Training of the Wonderland Hope Rising FASDPN Network Clinic. The Wonderland Developmental Center commenced training to become a FASDPN Network Clinic. Hope Rising opened their clinic in May, 2019.

2025 Clinical and judicial members of five WA tribes have requested FASD diagnostic training to establish several tribal FASD diagnostic teams.

2. **Training WA State Professionals at the U.W. FASDPN Clinic***

The University of Washington FASDPN core staff provides FASD training to community professionals throughout WA State. A total of 6,180 professionals have been trained to date (Table 1). Trainees learn what FASD is and how it is diagnosed; who benefits from a FASD diagnostic evaluation; what services the FASDPN clinics provide and how to utilize them; and what their role is in the referral, diagnostic, and service provision process. These trainees have included the state social workers receiving professional development training through the UW Alliance for Child Welfare Excellence. The UW FASDPN clinic is open each week to visiting professionals who want to gain an understanding of our unique, comprehensive evaluative model. Trainees attend a 30-minute introductory lecture from Dr. Hemingway and observe the clinical team conduct FASD diagnostic evaluations on two patients. The clinic staff members are available throughout the day to guide the trainees and answer their questions. Included in our list of visitors was Washington State's First Lady Mrs. Mary Lowry, Ohio State's First Lady Mrs. Hope Taft, Dr. Faye Calhoun from the National Institute of Alcohol Abuse and Alcoholism, Dr. Sami Noursi, Director National FAS Center for Excellence and Jose Cordero, M.D., Director, CDC. The clinic can host up to 350 professionals annually. The community professionals have expressed very high satisfaction with the training. Over 90% gave the training the highest possible score of 'excellent'.

In 2020 and 2021, trainings (and diagnostic evaluations) at the University of Washington clinic were interrupted by the COVID pandemic. The COVID pandemic closed the UW clinic from March through June 2020. The clinic re-opened July 2020. COVID safety policies at the UW Medical Center limited the number of trainees we were permitted to host in person in clinic. In addition, HIPAA policies prevented us from hosting trainees via Zoom. By July 2021 the UW Medical Center permitted trainees to attend both in person and via Zoom. In fiscal year July 2024-June 2025, the UW FASDPN held 35 clinics (2 patients per clinic) and trained 387 community professionals (in person and via Zoom). COVID safety policies continued to be followed.

Table 1. Total number of professionals trained by the University of Washington FASDPN Clinic.

Profession	N
Medical	1,656
Professional student	*1,292
Psychologist, therapist, counselor, social worker	1,400
Administrator, coordinator, director	501
Educator, teacher	452
Alcohol treatment or chemical dependency counselor	152
Legal system	291
Other or not specified	436
TOTAL	6,180

3. **Off-site Training of Community-based Clinics or Institutions in WA State***
One-day didactic lectures on referral, diagnosis, and treatment planning of individuals with prenatal alcohol exposure are provided upon request to groups within WA State that provide services to high-risk populations and have requested training/diagnostic services in their community. The number of trainings conducted to date are too numerous to list. Selected trainings are listed below. Webcasts of selected presentations are posted on the FASDPN website to increase access to training.

- Trained 30 JRA staff at Echo Glenn to address identification of and intervention with juveniles affected by prenatal alcohol exposure (1998).
- Provided diagnostic and primary prevention training and conducted special on-site diagnostic clinics for three WA State Native American tribes. (1997-1998).
- Trained JRA staff at Maple Lane School and DCFS foster care staff in King County on how to screen for FAS using facial photographs. (1998-ongoing).
- Conducted two lectures to DCFS, FCPP and DASA staff regarding outcomes of the FAS Screening in King County Foster Care (2002).
- Trained 200 members of the Skagit County FASD Juvenile Court Initiative including probation officers from the Skagit County Juvenile Court, officers from the courts of four tribal nations, staff from Youth and Family Services, ARIS and CHET (2005-06).
- FASDPN clinical members conduct 20-30 lectures annually to groups statewide requesting training/education on all aspects of FASD (family advocacy, adoption support, education, diagnosis, intervention, and prevention).
- The FASDPN clinical staff provided a half-day training of over 50 birth to three providers from the Experimental Education Unit at the University of Washington. Birth to three teachers from the Seattle Public Schools also attended. (2008).
- FASD: Focus on Executive Functioning Deficits. Hosted by NOFAS Washington State featuring speakers from the FASDPN. Aug 2010, Everett WA Target audience, families and professionals caring for individuals with FASD.
- FASD: From Discovery to Prevention in WA State. University of Washington Board of Regents. November 2011, Seattle WA.
- FASD: Focus on Intervention. Hosted by NOFAS Washington State featuring speakers from the FASDPN. March 2011, Everett WA Target audience, families and professionals caring for individuals with FASD.
- Institute on Human Development and Disability Core Seminar. FASD. Annually since October 2011, University of Washington. Target Audience: LEND Trainees, Birth to Three Trainees.
- Co-Occurring Disorders Conference. FASD: From Discovery to Prevention in WA State. Hosted by DSHS, DBHR, October 2011, Yakima, WA.
- FASD: Focus on Intervention. Hosted by NOFAS Washington State featuring speakers from the FASDPN, November 11, 2012, Everett WA. Target audience, families and professionals caring for individuals with FASD.
- FASD: Focus on Intervention. Hosted by NOFAS Washington State featuring speakers from the FASDPN, 2013, Everett WA. Target audience, families and professionals caring for individuals with FASD.
- Screening and referral of children with FASD. CHET Conference, April 2013, Seattle WA.
- Screening and referral of children with FASD. FCAP Conference, Sept 2013, Children's Home Society, Seattle WA.

- Developmental Medicine Teaching Rounds; FASD update presented by Dr. Astley Hemingway. October 2013, Seattle Children's Hospital.
- Advanced Practice in Primary Acute Care. FASD diagnosis, intervention and prevention. October 2013, Seattle WA.
- Astley Hemingway testimony on House Bill 2737 concerning fetal alcohol exposure. Invitation by Rep. Ruth Kagi, Chair Early Learning & Human Services Committee, Feb. 13, 2015. Olympia WA
- Webinar: Prevention of FASD, 2014, presented by Susan Astley Hemingway, sponsored by Association of Reproductive Health Professionals.
- Web-based "Talking with Patients about Alcohol Use During Pregnancy Clinical Minutes" 2016 sponsored by Association of Reproductive Health Professionals. Content contributed by Susan Astley Hemingway.
- Autism Clinic Rounds: FASD update presented by Dr. Astley Hemingway, October 2016, Seattle Children's Hospital.
- Demonstration of the FAS Facial Photographic Analysis Software developed by Dr. Astley Hemingway. 2016
- Developmental Medicine Teaching Rounds; FASD update presented by Dr. Astley Hemingway. March 2017, Seattle Children's Hospital.
- FASD from Discovery to Prevention; presented by Dr. Astley Hemingway to the Polish Institute of FASD. 2020
- Tacoma School psychologists: FASD training conducted by FASDPN psychologist Erin Olson PhD March 2022.
- WA-AK Neuropsychological Society: FASD training of 55 licensed psychologists in WA and AK by Dr. Astley Hemingway and Dr. Allison Brooks, April 2022.
- WA CHET: FASD training of 72 CHET personnel statewide by Dr. Hemingway, February 2023.
- Comparison of four international FASD diagnostic guidelines presented by Dr. Hemingway (keynote speaker) at the EUFASD international conference in September, 2024.
- Comparison of FASD diagnostic outcomes and PRAMS/BRFSS prenatal alcohol exposure histories over 20 and 30 years in AK and WA presented by Dr. Hemingway in February 2023 to the University of Alaska Anchorage CHD Project ECHO series (n = 55).
- Comparison of four international FASD diagnostic guidelines presented by Dr. Hemingway on April 13, 2024 at the International FASD conference held in Seattle WA (n = 98).
- Advancing justice for individuals with FASD across judicial systems by Dr. Julian Davies MD on April 11, 2024 at the International FASD conference held in Seattle WA (n = 250).
- WWAMI 3rd Year Psychiatry fellows in all five states attended a FASD training by Professor Erin Olson, PhD, FASDPN psychologist October 24, 2024.
- WA Alliance CaRES program FASD training in spring 2025 by Professor Erin Olson, PhD, FASDPN psychologist.

4. **Training of Washington State Students***

University students from across WA State in medicine, nursing, speech and language, occupational therapy, education, dentistry and social work regularly attend clinic to observe how the interdisciplinary clinic manages this special population. A total of 1,292 students have attended clinic to date. Residents, fellows and interns from Pediatrics, Rehabilitation Medicine, and Psychology also rotate through the U.W. FASDPN clinic. The FASDPN has hosted practicum opportunities for Epidemiology students in the Maternal Child Health program. Several students from Psychology, Epidemiology, Speech and Hearing Sciences, Orthodontics, Occupational Therapy and social work have earned their Master's and Doctorate degrees using the FASDPN

database and patient population. One student won the nation's top student award for student research.

5. **Training for FAS Facial Screening and Diagnosis***
The FASDPN provides training to medical and research personnel around in WA and around the world on how to analyze facial photographs for screening and diagnosing the facial features of FAS. The FASDPN has worked with several hundred professionals to assess several thousand photographs. These professionals include staff from WA State Foster Care Passport Program, JRA, and the Skagit Juvenile Justice FASD Initiative. The FASDPN was contracted to provide FASD screening training for a multistate FAS Screening Program sponsored by SAMHSA from 2009-2012. In November 2011, the FASDPN participated in the NIH/CDC national meeting to formulate the American Academy of Pediatrics endorsement of ARND. This work led to the inclusion of Neurodevelopmental Disorder-Prenatal Alcohol Exposed (ND-PAE) in the DSM-V in 2013.

6. **Training FASDPN Sites Outside Washington State**
The FASDPN conducts two-day training sessions on FAS screening, diagnosis, and prevention for clinical teams worldwide that would like to establish a FASDPN program in their community. These training sessions are held throughout the year. To date, over 276 teams worldwide have been trained. Our most intensive efforts in 2017-present focused on training (enrollment in the FASD 4-Digit Code Online Course) for 50 clinicians in Slovakia and 47 clinicians in Poland. Trainees complete the FASD 4-Digit Code Online Course prior to their 2-day training in Seattle. In 2019, we trained a team from Poland and Dr. Astley Hemingway provided a keynote talk on International FASD Day (September 10, 2019) in Poland. The team in Poland established the Polish Institute of FASD in June 2020 and will serve as a center of excellence for FASD diagnosis using the FASD 4-Digit Diagnostic Code. Trainees in 2024 included clinicians from Israel, New Zealand, Mexico, the Czech Republic and the Netherlands. Over 1,630 professionals from 59 countries have completed the FASD 4-Digit Code Online Course as displayed in the FASDPN Tableau Dashboard. The trainees spend the first day attending didactic lectures and receiving hands-on instruction in the specific screening and diagnostic techniques used by the FASDPN. The trainees spend the second day observing two interdisciplinary FASD diagnostic evaluations using the 4-Digit Code.

7. **Training via Video-teleconference, webinars and conferences**
The FASDPN provides FASD training to large, geographically dispersed audiences via video-teleconference, upon request. To date eight conferences/webinars have been held in 1999, 2000, 2004, 2009, 2010, 2011, 2012, 2013, 2014, 2017, 2018, 2022, and 2024 (Continuing Education for WA State nurses hosted by Children's Hospital and Regional Medical Center, FASD training via Alaska's ECHO program, training of medical and social service providers in Alberta and Ontario Canada, training FAS screeners nationwide hosted by SAMHSA, training of FASD interventionists nationwide hosted by the CDC, prevention webinar for healthcare professionals nationwide hosted by the Association of Reproductive Health Professionals). In 2017, three members of the FASDPN diagnostic team gave 5 FASD presentations at the 7th International Conference on "FASD Research: Results and Relevance; Integrating Research, Policy and Promising Practice Around the World" held in Vancouver BC. Hundreds of WA State professionals attended this conference. Three team members presented at the 2018 Adults with FASD International Conference in Vancouver BC and 7 team members presented at the 8th International Conference on FASD in Vancouver BC in 2019. Dr. Hemingway served as the keynote speaker at the 6th European Conference on FASD held in Norway in September 2022. Drs. Hemingway, Davies, Jirikowic, Pruner, Olson and Thorne served as speakers at the International Research Conferences on FASD in April 2024 and 2025 in Seattle WA. All serve on the Conference Planning Committee.

8. **Answering Questions from Families***
   The FASDPN staff answer several thousand questions annually from families and their care providers who call, send letters or leave questions on the FASDPN website (www.fasdpn.org).

IV.C. Screening and Surveillance

- A highly sensitive and specific, computerized FAS facial photographic screening/diagnostic tool was developed by the FASDPN in 1996 (Astley & Clarren, 1996). It was used to screen and diagnose several thousand individuals. In 2003/2016, this photographic tool was upgraded to the FAS Facial Photographic Analysis Software by Dr. Astley Hemingway. Thousands of copies of the software have been distributed worldwide to date.

- A centralized, computer photographic analysis laboratory at the University of Washington FASDPN was established in 1998 and provides analysis of facial photographic data sets worldwide. Several thousand photographs have been analyzed to date. This service is supported on a self-sustaining revenue budget at the University of Washington.

- The FASDPN implemented computerized FAS photographic screening in two high-risk populations (foster care and juvenile justice) in 1999 in Washington State using the FAS Facial Photographic Analysis software developed by Dr. Astley Hemingway. All children/adolescents who screened positive (had the facial features of FAS) received a FAS diagnostic evaluation at a FASDPN Clinic. All children entering long term foster care in the King County Foster Care Passport Program were screened for FAS for 10 years with 98% participation. The prevalence of FAS in this foster care population was one out of every 100 children, or 10 to 15 times greater than the prevalence of FAS in the general population (1/1,000). The results of this screening were published in the Journal of Pediatrics (Astley, et al., 2002). Eight hundred and fifty adolescents in JRA were screened between 1999 and 2001. Several screened positive for FAS.

- The Washington State Birth Defects Surveillance System was an active surveillance system from 1986 to 1991. Since then, the system has been passive, relying on hospitals to report cases of children with birth defects. Back in the 1990s an enhancement project was in progress to develop a web-based, electronic reporting system to reduce the reporting burden to hospitals.

- The FASDPN participated in the Skagit County FASD Juvenile Justice Initiative to establish methods to screen, diagnose, and intervene with youth entering the juvenile justice system. The project was one of five funded nationally by the SAMHSA FASD Center of Excellence. This national effort by SAMHSA to screen, diagnose, and prevent FASD was extended to 2012. SAMHSA utilized the screening and diagnostic tools and models established by the WA State FASDPN.

- The FASDPN participated in the National Children's Study to estimate the prevalence of FAS nationwide and in WA State. The photographic methodology established by the FASDPN to screen FAS in the King County Foster Care Passport Program was used.

- The FASDPN participated in the WA State Department of Corrections Adaptive Supports Program, Screening Offenders for Intellectual Disabilities, and Traumatic Brain Injury study. The

FASDPN used the FAS Facial Photographic Analysis Software to screen facial photographs of study subjects for FAS (2013-2015).

- The FASDPN participated in the CDC-sponsored Danish Lifestyle During Pregnancy Study (2013-2019). The FASDPN analyzed 1,700 facial photographs for FAS using the FAS Facial Photographic Analysis Software. The study was published in 2019 (Kesmodel, Astley Hemingway et. al, 2019). The study documented low to moderate average alcohol consumption and isolated episodes of binge drinking in early pregnancy were associated with facial features related to FAS in five-year-old children". The FASDPN hosted this Danish team to visit the UW FASDPN in May 2022.

IV.D. Prevention: Evidence of Success in WA State

Although FAS is entirely preventable, the factors associated with maternal alcohol use during pregnancy are complex and resistant to change. Maximizing primary prevention efforts will require targeting limited prevention resources to women at highest risk for producing children damaged by prenatal alcohol exposure. One of the highest-risk, identifiable populations are women who have already given birth to a child with FAS or given birth to a child with prenatal alcohol exposure and CNS dysfunction. A five-year Cooperative Agreement between the University of Washington and the CDC (Astley & Clarren, Co-Principal Investigators) demonstrated that these women can be identified and located through the diagnosis of their children in the Washington State FASDPN. Eighty mothers who currently live in Washington State and have given birth to a child with FAS were identified and extensively interviewed by members of the U.W. FAS Clinic team. The purpose of the interview was to generate a comprehensive profile of these women and identify factors that enhanced and hindered their ability to achieve sobriety or practice effective family planning. This baseline data was collected to develop an effective primary prevention program within the FASDPN. The results of this study were summarized in a 300-page final report to the CDC entitled "*Primary Prevention of Fetal Alcohol Syndrome: Targeting Women at High Risk through the FAS Diagnostic and Prevention Network 1992-97*". This report was submitted to DASA in 1998 and is posted on the FASDPN website. The results of this study were published in the peer-reviewed medical journal *Alcohol & Alcoholism* in 2000 (Astley et al., 2000a, 2000b). One of the key findings in this study was that after the diagnosis of the 80 children with FAS, 35 of their mothers gave birth to an additional 62 children, 75% of which were prenatally exposed to alcohol and 80% of which were born without the use of contraception. Although these 62 children were not formally followed to assess their cognitive/behavioral outcomes, it is known that a minimum of six have FAS. The goal of the FASDPN Primary Prevention Program will be to measurably reduce the risk of exposure and brain damage in these children.

Two programs to date have demonstrated that reduction in risk can be achieved. The Parent-Child Assistance Program (P-CAP), directed by UW Professor Therese Grant Ph.D., has demonstrated that a measurable reduction in risk factors leading to alcohol use and poor family planning (Grant et. al., 1996) can be achieved among pregnant women abusing drugs and alcohol. A key motivating force in P-CAP is the bond between the mother and her newborn. The women who will be targeted in the FASDPN program will not be pregnant for it will be paramount to target them before they conceive. This will present a unique challenge. The ongoing work by Dee Robertson, M.D. in Portland Oregon, however, provides compelling evidence that the risk of FAS can be reduced in women who are not currently pregnant (Interagency, 1997). Dr. Roberts has demonstrated that family planning and advocacy intervention targeted to high-risk Native American women reduced the incidence of FAS in their tribes to zero over a two-year period. The FASDPN worked collaboratively with P-CAP and

solicited consultation from Dee Robertson, M.D. in Oregon during the design and implementation of the FASDPN Primary Prevention Program. The estimated cost to society to raise a single child with FAS from birth to 18 years of age is one million dollars (Abel & Sokol, 1987). Prevention of just a single FAS birth can pay for up to ten years of the primary prevention program proposed below. This program has the potential for preventing many FAS births per year in Washington State.

One of the primary goals of the FASDPN is to identify the birth mothers of children diagnosed with prenatal alcohol exposure and cognitive/behavioral dysfunction and to link these high-risk women to community-based primary prevention services such as P-CAP to reduce their risk of bearing additional children exposed to prenatal alcohol. The FASDPN identified 80 birth mothers of children diagnosed with FAS in WA State in 1992-97 and has the potential of identifying an additional 70 birth mothers annually; birth mothers of children diagnosed with FASD through the FASDPN. During the 1998-99 fiscal year, the FASDPN maternal advocate (Diane Bailey, MSN) provided comprehensive advocacy services to three of these high-risk women, enrolled two additional women in P-CAP, and provided referral and support services to ten birth mothers who attended their child's diagnostic evaluation at the U.W. FASDPN clinic. Ms Bailey also provided in-service training on motivational interviewing and birth control to P-CAP advocates and participated in case conferencing, two to three times a month, at the Seattle and Tacoma P-CAP offices. In 1999, Ms Gendler, M.S.W. joined the FASDPN as the maternal advocate, replacing Ms Bailey who went on to work for the WA State Department of Health. A grant to establish and assess the FASDPN Primary Prevention Bridges Program was submitted to NIAAA in March 1999 in response to their FAS Primary Prevention request-for-proposals. This grant was submitted by Dr. Carmichael Olson (FASDPN clinical psychologist) and represents a collaborative effort between the FASDPN, P-CAP and the FAS Interagency Work Group. The grant proposed to establish and assess a primary prevention program (the First Bridges Program) that links high-risk women identified by the FASDPN to appropriate community-based primary prevention services. The proposal received a favorable review, but the reviewers requested pilot data be collected prior to re-submission. In response, the FASDPN piloted the "FASDPN First Bridges Program." This is an approach to primary prevention that is a natural extension of the existing FASDPN clinical services and uses empirically supported brief intervention techniques.

The FASDPN First Bridges Program established a clinically feasible protocol for identifying, locating, and providing FAS prevention services to eligible high-risk women who have given birth to an alcohol-exposed child with confirmed evidence of CNS dysfunction. These women were still fertile and either actively drinking or at high risk for relapse. Aims of the prevention services were to: (1) Enhance the woman's "readiness to change" her alcohol and/or contraceptive use; and (2) Reduce self-reported "need for help" via brief intervention and linkage with community services. The results of this study were published in Alcoholism: Clinical and Experimental Research, 2002 (Carmichael et al., 2002).

In the course of providing services to the pilot group of birth mothers, FASDPN staff received training on the issues and concerns of women giving birth to children with alcohol-related disabilities. A social work internship training program was initiated, with the first student completing a nine-month practicum focused on the First Bridges Program. Data on the needs and issues of birth mothers, and methods of FAS prevention, were part of the quarterly FASDPN trainings.

WA State is Successfully Preventing FAS: The prevalence of FAS is estimated to be 1 to 3 per 1,000 live births and is the leading known cause of intellectual disabilities in the Western World. To prevent FAS, maternal alcohol consumption during pregnancy must be reduced. To assess the effectiveness of

FAS prevention efforts, one must be able to accurately estimate the prevalence of FAS over time in population-based samples. Accurate estimates of prevalence, in turn, require accurate diagnostic methods. With the establishment of the Washington State FAS Diagnostic and Prevention Network (FASDPN) of clinics, the development of the FAS Facial Photographic Screening/Diagnostic Tool, the creation of the FAS 4-Digit Diagnostic Code, the establishment of the Foster Care FAS Screening Program, and the collection of Pregnancy Risk Assessment Management System (PRAMS) data on maternal use of alcohol during pregnancy, the tools, methods and infrastructure for assessing the effectiveness of FAS primary prevention efforts in Washington State are in place. An overview of the history of FASD from discovery to prevention in WA State is presented in a webcast by Susan Astley Hemingway PhD (Seattle Children's Grand Rounds August 2012). A cross-sectional study was conducted to determine if the prevalence of FAS among children in a foster care population, born between 1993 and 1998, decreased with the documented decrease in prevalence of maternal use of alcohol during pregnancy from 1993 and 1998 in Washington State. The prevalence of maternal drinking during pregnancy in Washington State declined significantly ($p < 0.001$) from 1993 to 1998 as did the prevalence of FAS among foster children born from 1993 to 1998 ($p < 0.03$). These observations strongly support that FAS prevention efforts in Washington State are working (Astley, 2004). The results of this study were published and showcased on King5 News in Seattle as an important public health message.

A comprehensive summary of WA State efforts to prevent FASD from 1968-2004 is posted on the WA FASD website in a document entitled FASD: WA State History. It is paramount that WA State sustains its successful efforts to reduce FASD. Unfortunately, the most recent PRAMS data documents a steady increase in maternal reporting of drinking during pregnancy, in contrast to the steady decline observed in the 1990s. Preliminary data document this increase in drinking is associated with an increase in prevalence of FAS in foster care among children born after 1998. Most recently, data from the FASDPN confirms that the incidence of FAS is dropping significantly in WA across birth cohorts spanning 1940 through 2009 (see Tableau Dashboard).

IV.E. Intervention

The FASDPN has engaged in all levels of FASD intervention from guiding public health policy to conducting randomized control trials to establish an evidence base for intervention efforts. These efforts to date are summarized below.

- Diagnosis leads to successful interventions. Twenty years of patient surveys confirm FASD diagnostic evaluations conducted by the WA FASDPN afforded patients substantial access to interventions that met their needs (Astley, 2014).
- NOFAS WA (now FASD Focus NW). Directed by Julie Gelo, B.A., FASD parent advocate. Established in 2006, the mission of FASD focus NW is to educate, advocate and support individuals with FASD and their families. They envision building bridges that connect and unify professionals, individuals with FASDs, families, and community members.
- Family Intervention: Families Moving Forward" (FMF) is a CDC-sponsored, intervention research project, conducted through the FASDPN, exploring evidence-based services for children with fetal alcohol spectrum disorders (FASDs), their families, and the professionals who care for them. The program was established by a Professor of Psychology from the FASDPN, Dr. Heather Carmichael Olson PhD. At its heart, the FMF intervention model is aimed at: 1) providing ongoing support to parents and helping them better understand their challenging children 2) helping parents hone skills they already have, while adding specialized parenting techniques to their care-giving

repertoire, 3) adding value to community resources and providers that families find helpful, 4) helping families boost their progress in a positive direction, giving them reason to be more optimistic about the future, and helping reduce the chance their children will have secondary disabilities later in life. This project completed it's tenth year of funding in 2010. Sixty WA State families raising children with FASD received 9 months of in-home intervention services for free. FMF is now a program available to WA families. In 2017, Dr. Jirikowic, the OT on the FASDPN diagnostic team submitted a grant to expand the FMF program to focus on infants, birth to three.

- SNACS Clinic: The SNACS Clinic model (developed through the FMF program) is a short-term assessment and consultation service (3 to 5 sessions) using materials from the FMF Program. The research and clinical team is led by Dr. Heather Carmichael Olson and Dr. Michelle Kuhn. SNACS services are carried out by providers with advanced degrees in clinical or school psychology. This "Specialized Neurodevelopmental Assessment and Consultation Service" (SNACS) offers: (1) mental health diagnosis of conditions on the fetal alcohol spectrum (and co-occurring mental health issues); (2) customized referrals and ideas for linkages to community resources; and (3) tailored short-term consultation on issues important to individual children and families.
- Brooks Powers Group Assessment Team: Established by a psychologist serving in the FASDPN (Allison Brooks PhD), provides a range of assessments at the request of caregivers and schools. Their evaluations are intended to provide information about a child's profile of strengths in addition to identifying potential diagnoses and areas in need of intervention and support. Their providers have experience and training in FASD and understanding how information obtained from a clinical evaluation is used in an educational setting. They aim to provide information that can be useful in the process of developing educational plans, counseling and therapy interventions, parenting supports, and helping care providers coordinate services.
- Sound Families Pediatric Therapy: Established in 2024 by an occupational therapist from the FASDPN (Jennifer Nash PhD, OTR/L, IMH-E). With expertise in FASD, Dr. Nash provides OT services via telehealth for families of children 0-9 years old. Dr. Nash has been serving families in the Puget Sound community and beyond for more than twenty years as a pediatric occupational therapist and infant mental health specialist with multiple areas of focus including early intervention, trauma-informed care, child development, challenging behaviors, and sensory processing.
- DDA Eligibility Criteria: In 2015, the FASDPN worked effectively with the WA Developmental Disabilities Administration (DDA) leading to the acceptance of FASD for determination of eligibility for DDA (DDA Management Bulletin D15-012, March 13, 2015). "Diagnoses of a condition that is similar to Intellectual Disability and attributable to prenatal maternal consumption of alcohol may be accepted as an "another neurological or other condition similar to Intellectual Disability" under 388-823-0600. The diagnosis must be supported by evidence confirming prenatal alcohol exposure. This evidence may be found in medical records or other documentation."
- Early Support for Infants and Toddlers (ESIT) qualifying diagnoses: In 2020, the FASDPN worked effectively with ESIT leading to the acceptance of prenatal alcohol exposure as a qualifying condition for ESIT.
- Families Moving Forward Bridges program: NIH supported study to assess the efficacy of FASD-informed early intervention designed to meet the specific needs of young children (birth to three years) affected by prenatal alcohol exposure. Principal Investigator is Professor Tracy Jirikowic, Occupational Therapist at the FASDPN.

IV.F. Systematic Information Retrieval and Tableau Dashboards

In 1995, Dr. Astley Hemingway began the development of one of the world's largest, most comprehensive clinical databases on FASD with patient consent and University of Washington Human Subjects approval. The data allows the FASDPN to track regional FASD diagnostic demand, diagnostic capacity and diagnostic outcomes over time. It also allows the FASDPN to develop state-of-the-art screening and diagnostic tools and support intervention research that directly benefits WA children and their families living with FASD. The database contains information on over 5,000 families requesting diagnostic evaluations and over 3,000 patients who have received diagnostic evaluations. There are over 3,000 fields of information on each patient. A seminal report profiling the first 1,400 patients evaluated at the WA FASDPN was published in 2010 (Astley, 2010). Over 100 peer-reviewed publications have been published in the medical literature by FASDPN clinical team members using the data from the FASDPN database. The database has also supported a multitude of Master's Theses and Doctoral Dissertations by graduate students in public health, psychology, medicine, nursing, dental, social work, speech-language and occupational therapy. The database also serves as a patient registry allowing patients to enroll in FASD research studies that often provide direct benefits to participants (e.g., free neuropsychological and medical assessments, free intervention services, etc.). This patient registry paved the way for the development of the evidence-based Families Moving Forward FASD intervention program established and directed by Heather Carmicheal Olson.

An Institutional Review Board application was submitted to the University of Washington Human Subjects Division on September 5, 1995 for approval to collect, store and summarize data collected in by the UW FASD clinic. The application was approved on September 28 1995 and now has ongoing approval. All procedures are HIPAA compliant. All staff received HIPAA and IRB training. A copy of the initial approved application was submitted in Appendix H of the Year 01, Quarter 01 Report in 1995. As per IRB policy, all research studies proposing to enroll study subjects from the FASDPN are required to submit separate IRB applications. In May 2000, the UW FASDPN clinic database received University of Washington IRB approval to serve as a FAS Research Registry. This UW IRB zipline application has been renewed as an ongoing study with no end date. This facilitates the invitation and voluntary enrollment of patients with prenatal alcohol exposure into clinical research studies designed to identify effective interventions and diagnostic tools. Several million dollars in funding was received in 2001-2010 from the CDC and NIAAA to conduct these clinical research studies, providing several hundred WA State families and children with free medical care and intervention services.

With the advent of "Interactive Data Platforms", Dr. Astley Hemingway has constructed and launched an endless array of Tableau dashboards that allow people worldwide free, interactive access to the entire FASDPN database (in aggregate format without identifiers). Included are dashboards entitled FASD Diagnoses by WA State County; 4-Digit Code FASD Diagnoses Worldwide; FASD WA State FASD Diagnostic Outcomes by Patient's Birth Cohort, etc.).

In 2024, Dr. Astley Hemingway along with colleagues in Alaska published a seminal paper entitled "*WA and AK Statewide FASD Diagnostic Clinical Networks: Comparison of Three Decades of 4-Digit Code Diagnostic Outcomes and Prenatal Alcohol Exposure Histories*". FASD screening, diagnosis, intervention, research and prevention hinges on establishment of interdisciplinary FASD diagnostic clinics using an evidence-based method of diagnosis. In 1993, Washington State opened the first interdisciplinary FASD diagnostic clinic sponsored by the CDC as a FASD primary prevention study. Clinic data was used to develop the evidence-based FASD 4-Digit Diagnostic Code, paving the way for the clinic's expansion into a Statewide network of FASD diagnostic clinics (Washington Fetal Alcohol Syndrome Diagnostic & Prevention Network), now in its 31st year. Alaska adopted this

Washington model in 1999. Both States have also participated in the CDC Pregnancy Risk Assessment Monitoring System and Behavioral Risk Factor Surveillance System since the 1990s. Study objectives were to describe the two Statewide FASD diagnostic networks; graphically compare the 4-Digit-Code FASD diagnoses and Prenatal Alcohol Exposure (PAE) over 2-3 decades and illustrate how network data helped guide FASD public health policies and track successful prevention efforts. 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. Dr. Hemingway presented this work at the 2024 and 2025 International Research Conferences on FASD held in Seattle every April.

V. Funds Attracted to WA State (over 15 million dollars for WA children and families)

The University of Washington Core FASDPN clinic has successfully helped obtain over **15 million dollars** in additional funding to support FASD screening, diagnosis, and intervention for families in Washington State. Hundreds of WA State families and children have received free medical care and intervention services through these public health/research activities. Washington State's support of the FASDPN was instrumental in our being able to attract these funds and service opportunities to our State. The Washington State FASDPN continues to work directly with the CDC, NIH, FASD United and SAMSHA in a national effort to diagnose and prevent FASD.

1. *Centers for Disease Control*. FAS Prevention through development of first FASD interdisciplinary diagnostic clinic at the University of Washington This funding established the Core WA FASDPN clinic. (1992-1997).

2. Funding Source: *Washington Research Foundation* Title: Development of the FAS Facial Photographic Screening/Diagnostic Software. The FASDPN developed software to allow medical professionals to analyze facial photographs for the presence of FAS facial features. This software was used to screen all children entering the King County Foster Care Passport Program for FAS from 1999 to 2009. This software is also used in all FASDPN diagnostic clinics. Funding period: 8/1/02 through 2/28/03. Total Costs: $ 10,000.

3. Funding source: *Centers for Disease Control.* Title: Intervening with children with FASD. This study provided 60 WA State families raising children with FASD free in-home intervention for 9 months. Study period: 9/30/01 through 9/29/10. Total Costs: $2,396,497.

4. Funding Source: *National Institutes of Alcohol Abuse and Alcoholism*. Title: MRI/S in children/adolescents with FASD. This project used (magnetic resonance spectroscopy (MRS), magnetic resonance imaging (MRI), and functional MRI (fMRI)) to determine if prenatally alcohol-exposed children, with and without FAS, who present along the full continuum of mild to severe cognitive/behavioral dysfunction, have irrefutable evidence of organic brain damage in the form of chemical, structural and/or functional alterations of the brain. Sixty WA State children with FASD received free neuropsychological assessments and MRI scans. Study period: 03/01/02 through 02/28/06. Total Costs: $ 996,694.

5. Funding Source: *National FAS Center of Excellence.* Title: FAS Summer Conference. The objective of the summer camp conference was to bring together families raising children with FASD for the purpose of having fun and networking with other families and community professionals. Funding Period: August 28-31, 2003. Total Costs: $35,000.

6. Funding Source: *University of Washington Educational Outreach and Technology Transfer*. This project supported the development of the FASD 4-Digit Diagnostic Code online course targeted to medical/social service providers. Over 600 professionals have completed the course to date. Funding Period: 2003. Total Costs: $56,000.

7. Funding Source: *SAMSHA FASD Center of Excellence*. FASD Screening, Diagnosis and Intervention in Juvenile Justice. 8/2004 through 7/2007. Subcontract to FASDPN. Total Costs: Over $200,000. FASD Screening, Diagnosis and Intervention in High-Risk Populations. 6/2008 through 5/20012. Subcontract to FASDPN. Total Costs: $50,000.

8. Funding Source: *SAMSHA FASD Center of Excellence*. Provide consultation on national FASD screening, diagnosis and intervention in high-risk populations. 6/2008 through 5/20012. Subcontract to FASDPN. Total Costs: $12,000.

9. Funding Source: *National Institutes of Alcohol Abuse and Alcoholism*. Title: Sensorimotor Intervention to Affect Balance, Engagement, and Learning for Children with FASD. This study is providing WA State children with FASD free sensorimotor interventions. Funding period: 2009-2015. Total Costs: $1,000,000.

10. *Centers for Disease Control:* Arctic FASD Regional Training Center. The FASDPN team is serving as consultants for Alaska's creation of a CDC-sponsored FASD Regional Training Center. (2009-2017).

11. *National Institutes of Health:* National Child Study. The FASDPN took the lead in establishing the methodology for assessing facial anomalies from photographs for 100,000+ children who will be enrolled from birth to 21 years of age in the country's largest ever longitudinal study of child development. This study will allow the FASDPN to estimate the prevalence of FAS in the U.S. general population as well as the WA State population. (2010-2012).

12. *FASD United Policy & Training Center* https://nofaspolicycenter.org/.

13. UW ADAI; Title: Language Learning in Children with Neurodevelopmental Disorders. Kover PI. This study enrolled 50 patients from the FASDPN clinic. The children were provided free language assessments. (2016-18): Total Costs: $29,900.

14. UW ADAI; Title: Characterizing Auditory Processing in Individuals with FASD. McLaughlin PI. This study enrolled 15 children from the FASDPN clinic. These children received free language and auditory processing assessments (2016-18) Total Costs $29,586.

15. "Virtual Fetal Alcohol Spectrum Disorder Facial Photo Analysis: Validating and Optimizing the Process" Study to assess the utility of the FAS Facial Software in a telemedicine setting. Funded by Saskatchewan Health Authority. Susan Petryk PI. Susan Hemingway Co Investigator. 2040-45.
16. UW Rehabilitation Medicine; PhD Dissertation (2024) Title: Toward earlier identification and strength-based intervention for infants and toddlers with prenatal alcohol exposure: Evidence from the Washington State Fetal Alcohol Syndrome Diagnostic & Prevention Network Clinical Database. Key finding: The majority of infants/toddlers presented with clinically significant delays in development, sensory processing and/or behavioral functioning. Adverse

developmental outcomes were significantly correlated with PAE and/or postnatal risk factors. Early diagnosis led to early intervention.

17. "Advancing FASD Research, Prevention and Services Act" FASD Respect Act authorizes $50 million for FASD prevention efforts, screening and identification and FASD-informed services by federal, state, local, tribal and private stakeholders. The FASDPN team in conjunction with FASD United advocated for this congressional act in February 2021 in conference calls with Senator Patty Murray's office. This Act continues to receive endorsements from senators nationwide as of June 2025.

18. "Values and Priorities for Communication: Perspective of Adults with FASD and their Families" The purpose of the study is to understand the values and experiences of individuals with FASD and their families, with a focus on a critical time period in life – the transition from schooling to adult services. (2025-26) Total costs: $30,000.

19. "Families Moving Forward Bridges" study to examine the feasibility of implementing the early intervention in a community-based birth to 3 setting. NIH funded. 2025-27. PI: Jirikowic. Co-Investigators: Davies, Olson, Hemingway, Pruner.

VI. References and Key FASDPN Research Publications:

FASD Research: The UW FASD diagnostic clinic started in 1993 as a CDC-sponsored FASD prevention research study (Astley, et al., 2000a, b). Over the next 3 decades, the core FASDPN clinic at the University of Washington has engaged in a multitude of research studies resulting in over 100 peer-reviewed publications. The FASDPN completed an NIAAA-sponsored research study assessing the diagnostic value of magnetic resonance imaging (MRI), magnetic resonance spectroscopy (MRS) and functional MRI (fMRI) in 2009. These non-invasive tools allow medical professionals to assess the impact alcohol had on an individual's brain structure, brain chemistry, and brain function. This research would not have been possible without the FASDPN and its large clinical/research patient population. The results confirm the validity of these diagnostic tools and confirm that children along the full spectrum of FASD (not just the subset with full FAS) present with clear evidence of brain damage. The results are published in the peer-reviewed medical literature (Astley et al., 2009a, 2009b, 2009c, 2009d). A comprehensive report documenting the validation of the FASD 4-Digit Diagnostic Code was published by Astley in 2014. In 2016, the FASDPN clinical team published a seminal paper documenting the essential role of growth deficiency in the diagnosis of FASD (Astley et al., 2016). Growth deficiency is a powerful predictor of which infants with prenatal alcohol exposure will present with severe brain dysfunction later in childhood. In 2019 the FASDPN clinical team published the world's largest twin study in FASD confirming that fetal genetics contributes to fetal vulnerability to prenatal alcohol exposure (Astley, et al., 2019). The FASDPN also published a comprehensive assessment of 4 FASD diagnostic systems worldwide documenting the superior performance of the FASD 4-Digit Code. (Astley et al., 2019) Dr. Hemingway was invited to present this study to the European Union FASD meeting held in Norway in 2022 and the International FASD Conference in 2024 held in Seattle. As of 2024, the annual International FASD Conference that has been held in Vancouver BC for over 15 years will now be hosted in Seattle. In 2020, the FASDPN published seminal studies documenting the high specificity of the 4-Digit Code FASD facial phenotype (Astley et al., 2020a) and confirming prenatal alcohol exposure as the dominant risk factor among children presenting with neurobehavioral impairments (Astley et al, 2020b).

All publications written by members of the FASDPN are posted on the FASDPN literature website as free, downloadable pdf files. Below are selected publications sorted alphabetically by first author.

Abel EL, Sokol RJ. Incidence of fetal alcohol syndrome and economic impact of FAS-related anomalies. Drug Alcohol Depend 1987;19(1):51-70.

Alaska Mental Health Authority.Alaska FASD Diagnostic Team Data Analysis, Policy & Prevention Recommendations. July 2020 (2,933 diagnoses statewide from 1999-2020 by 12 interdisciplinary FASD diagnostic teams using the FASD 4-Digit Code).

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