

Recommendations from the
Washington State
Fetal Alcohol Spectrum Disorders (FASD) Interagency
Work Group



December 2014

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An electronic version of this report is posted on the WA FASD-IAWG website.

<http://depts.washington.edu/fasdwa/PDFs/FASD-IAWG-Dec2014-Report.pdf>

EXECUTIVE SUMMARY

This report was written in response to a component of House Bill 2737 (introduced in January, 2014; did not pass) concerning Fetal Alcohol Syndrome (FAS) and Fetal Alcohol Spectrum Disorders (FASD). FAS is a permanent birth defect syndrome caused by maternal consumption of alcohol during pregnancy. FASD is the name for the full spectrum of damage caused by prenatal alcohol exposure. FAS and FASD are 100% preventable. The purpose of this report is to describe the problem in Washington State, identify evidence-based practices for early screening, diagnosis, prevention, and intervention, and recommend policy changes.

The report draws attention to the fact that in Washington State an estimated 870 children are born with FASD each year (1% of all births), and approximately 70,000 individuals with FASD of all ages currently live here. FASD is the leading known cause of intellectual disabilities, its primary impact is on schools, foster and adoption services, the justice system, and mental health services; fewer than 10% of adults with FASD live independently or remain employed. It costs an estimated 2 million dollars in lifetime social and health care services for every child born with FASD. Annual Medicaid costs are 9 times more annually for a child with FASD compared to a child without FASD. It costs 30 times more to raise a child with FASD than to prevent FASD in the child.

The report highlights the substantial contributions made by clinicians and researchers in Washington State to developing evidence-based practices recognized and replicated globally to address FASD. These include screening, diagnosis and surveillance contributions. The University of Washington FAS Diagnostic & Prevention Network (FASDPN) clinic introduced the interdisciplinary approach to FASD diagnosis in 1992 and developed rigorous, validated tools (the FASD 4-Digit Diagnostic Code and FAS facial recognition software) to improve diagnostic accuracy. These tools and clinical model have been adopted worldwide and serve as the cornerstone for FAS screening in Washington's foster care system. FAS screening serves the dual purpose of identifying children at risk and tracking FAS prevalence over time. FAS screening has confirmed 1 out of every 100 children in Washington's foster care system has FAS. FAS screening has also confirmed the prevalence of FAS decreased significantly in Washington State as did maternal drinking during pregnancy, documenting Washington State's FASD prevention efforts are working, It "takes a village" to prevent FASD. The University of Washington FASDPN has trained thousands of healthcare, educational, correctional, and social service providers about the integral role they play in our ongoing, statewide effort to prevent FASD. The report also describes the widely-replicated, and highly successful FASD prevention model, the Parent-Child Assistance Program (PCAP). PCAP works with women who are at highest risk for delivering children with FASD, and demonstrates consistently positive research outcomes and significant cost savings for Washington State. Evidence-informed intervention best practices are also described, based on over two decades of research conducted at the University of Washington (e.g. studies of risk and protective factors for adverse life outcomes associated with FASD; the utility of

neuropsychological assessments in helping adults with FASD; Families Moving Forward with FASD, a clinician-guided intervention model meeting the needs of families affected by FASD).

Although Washington's prevention efforts are working, the State's capacity to screen, diagnose, treat, and prevent FASD falls far below the statewide need/demand for such services (e.g., the current average wait time for a family seeking a FASD diagnostic evaluation is 9 months). The report makes the following key recommendations:

Screening and Diagnosis of FASD

- Maintain current diagnostic capacity for the core University of Washington FASDPN Clinic, and if possible increase FASD diagnostic capacity through the FASDPN Network Clinics.
- Increase capacity for neuropsychological assessment of adults on Medicaid.
- Educate clinicians statewide on the importance of screening for and documenting prenatal alcohol exposure.

Prevention of FASD

- Maintain current PCAP funding in eleven counties and if possible expand PCAP to additional counties that have high rates of prenatal substance abuse, such as Thurston.
- Increase residential and outpatient substance abuse treatment capacity for pregnant and parenting women across the state.
- Increase distribution of the WA Department of Health "Substance Abuse During Pregnancy: Guidelines for Screening and Management".

Interventions for Individuals with FASD

- Reinstate funding support for community advocacy groups like NOFAS WA.
- Increase the capacity of intervention programs like Families Moving Forward.

Policy Changes to Improve FASD Identification, Prevention, and Intervention

- Explore all available opportunities to diversify funding sources, including maximizing federal Medicaid funding in order to reduce the fiscal impact on state general funds.
- Revise Developmental Disability Administration (DDA) eligibility criteria so that applicants with FASD, not just those with FAS, can be considered for eligibility under "another neurological or other condition."

INTRODUCTION

[House Bill 2737](#) concerning Fetal Alcohol Exposure (**Appendix A**) was introduced on January 29, 2014 and was referred to Early Learning & Human Services. A public hearing in the House Committee on Early Learning & Human Services was held on February 13, 2014. This bill proposed the WA Fetal Alcohol Spectrum Disorder Interagency Work Group (FASD-IAWG) develop recommendations and provide a report by December 2014 to the appropriate committees of the legislature relating to:

- Identification of evidence-based practices for early screening and diagnosis of fetal alcohol spectrum disorders (FASD);
- Identification of evidence-based practices for prevention of FASD;
- Identification of evidence-based practices for interventions that can be used with individuals experiencing FASD; and
- Recommendations of policy changes that would improve the identification, prevention, or interventions related to FASD.

Although the bill did not pass, the FASD-IAWG made a commitment to produce the report requested in the draft legislation.

MEMBERSHIP

The Fetal Alcohol Spectrum Disorders Interagency Work Group (FASD-IAWG) was first established in 1995 through [Substitute Senate Bill 5688](#) (**Appendix B**). Senate Bill 5688 stipulated *“The department of social and health services, the department of health, the department of corrections, and the office of the superintendent of public instruction shall execute an interagency agreement to ensure the coordination of identification, prevention and intervention programs for children who have fetal alcohol exposure, and for women who are at high risk of having children with fetal alcohol exposure.”* The FASD-IAWG has been meeting biannually since 1995. Its mission and accomplishments are presented on its website fasdwa.org. The agenda for 2014 was to develop and advance recommendations concerning FASD and summarize these recommendations in a December 2014 Report for distribution to appropriate committees of the legislature.

The 2014 FASD-IAWG is co-chaired by the FASD State Coordinator from DSHS (Sarah Pine), the director of the University of Washington Fetal Alcohol Syndrome Diagnostic and Prevention Network (Susan Astley, Ph.D.), and the director of the University of Washington Fetal Alcohol and Drug Unit (Therese Grant, Ph.D.). The Work Group includes several clinicians from the University of Washington FASD Diagnostic Clinic, the director of the University of Washington FASD Legal Issues Resource Center, a FASD Educator, the Director of NOFAS WA, and a young adult with FAS. Other members include the Assistant Secretary of DSHS/BHSIA, and representatives from DOH, DOC, and OSPI. A list of the individuals who served on this Work Group can be found in **Appendix C**.

2014 MEETINGS

The Working Group conducted meetings on the following dates:

June 12, 2014; September 15, 2014; October 29, 2014; December 1, 2014

WORK GROUP MEETING RECORDS

Please note that minutes from each meeting of the Work Group are available by contacting Sarah Pine, FASD State Coordinator.

BACKGROUND

Work Group members felt it necessary to provide the following background on fetal alcohol spectrum disorders in Washington State to serve as a basis for the recommendations which follow.

What is FAS and FASD and How is it Diagnosed?

Fetal alcohol syndrome ([FAS](#)) is a permanent birth defect syndrome caused by maternal consumption of alcohol during pregnancy. FAS is characterized by growth deficiency, brain damage, and a unique cluster of facial features. Not all children exposed to and damaged by alcohol during gestation are born with FAS. Most are born with brain damage, but do not have the unique facial features of FAS. These children need the same social, educational, and healthcare services as children with FAS and far outnumber, by 10 to 1, children with FAS. The full spectrum of damage caused by prenatal alcohol exposure is called Fetal Alcohol Spectrum Disorders (FASD). There are four diagnoses under the umbrella of FASD.

Four Diagnoses under the Umbrella of FASD					
Diagnosis		Growth	FAS Face	Brain	Alcohol
1. FAS	Fetal Alcohol Syndrome	growth	face	severe	alc
2. PFAS	Partial FAS		face	severe	alc
3. SE/AE*	Static Encephalopathy / Alc Exposed			severe	alc
4. ND/AE	Neurobehavioral Disorder / Alc Exposed			moderate	alc

* Also referred to as:

- Alcohol Related Neurodevelopmental Disorder (ARND) or
- Neurodevelopmental Disorder Prenatal Alcohol Exposed (ND-PAE)

Diagnosis of FASD is conducted by an interdisciplinary team using evidence-based diagnostic guidelines. This diagnostic model was first introduced by the University of Washington in 1993 and has been adopted as best practice worldwide ^(SAMHSA, 2014). An interdisciplinary team of clinicians (medical doctor, psychologist, speech language pathologist, occupational therapist, social worker, and family advocate) is required to diagnosis FASD because the damage caused by prenatal alcohol exposure impacts all aspects of an individual’s growth and brain development. The expertise of a medical doctor is required to assess the physical and neurological components of the disorder (i.e., growth deficits, facial anomalies, seizures). The expertise of a psychologist, speech language pathologist, and occupational therapist is required to assess the brain function component of the disorder. Deficits occur across multiple domains of brain function including attention, cognition, memory, language, and motor skills. The collective expertise of this team is also required to generate an effective, comprehensive intervention plan. The WA FASDPN conducts an FASD diagnostic evaluation in one 4-hour appointment using the FASD 4-Digit Code ^(Astley, 2004). The patient receives an accurate diagnosis and comprehensive intervention plan at the end of the 4-hour appointment and receives a 12-page [comprehensive medical summary report](#) the following week.

What is the Fiscal Impact of FASD on Washington State?

- It costs an estimated [2 million dollars](#) in lifetime [social and health care services](#) for every child born with FASD (Lupton et al., 2004; Thanh & Jonsson, 2009). [870 children](#) with FASD are born each year in Washington State (SAMHSA, 2006)
- In 2005 it cost Medicaid 9 times more in annual medical expenditures to care for a child with FASD than to care for a child without FASD (\$16,782/child/year vs. \$1,859/child/year) (Amendah et al., 2011). For comparison, it cost Medicaid \$10,709/child/year to care for a child with Autism Spectrum Disorder.
- Washington State is the only place in the world that has [successfully reduced the prevalence of maternal drinking during pregnancy statewide \(14% to 4%\), and documented that reduction in drinking correlated with a significant decrease in the birth rate of FAS in high-risk foster care \(6% to 2%\)](#) (Astley, 2004). This was achieved within 5 years of opening two world-renowned, evidence-based programs supported in part through [RCW 70.96A.500](#):
 1. The Fetal Alcohol Syndrome Diagnostic & Prevention Network (FASDPN)
 2. The Parent-Child Assistance Program (PCAP).
- With the combined efforts of these programs, it [costs 30 times less](#) to prevent FASD in a child, than to raise a child with FASD (Astley et al., 2000).
- Among those born with FASD, the WA FASDPN clinics have confirmed early diagnosis and a nurturing home environment [significantly reduces disability and lifetime costs](#) (Astley, 2010).

FASD Facts

- [FAS was discovered in 1968](#) (Ulleland, 1972). Washington State is world renowned for this discovery.
- An estimated 870 children are born with FASD in Washington State each year ([1% of all births](#)).
An estimated 70,000 individuals with FASD of all ages currently live in Washington State. (SAMHSA, 2006)
- FASD is 100% preventable. Washington State has published empirical evidence confirming its FASD [prevention efforts are working](#). (Astley, 2004)
- FASD is the leading known cause of intellectual disabilities- (Stratton, 1996).
- FASD is not just a health care issue. Its primary impact is on schools, foster and adoption services, the justice system, and mental health services.
- Less than 10% of adults with FASD live independently or remain employed (Streissguth, Barr, Kogan, & Bookstein, 1996)
- An [early accurate diagnosis, intervention, and a nurturing home environment](#) are 3 factors empirically confirmed to substantially improve brain function and lifetime achievement among individuals with FASD (Astley, 2010; Streissguth, Barr, Kogan, & Bookstein, 1996)

What has Washington State Achieved to Date Regarding Evidence-Based and Best Practices for FASD Screening, Diagnosis, Prevention, Intervention, and Policy?

➤ EVIDENCE-BASED PRACTICES FOR EARLY SCREENING AND DIAGNOSIS OF FASD

1. **The Washington State FAS Diagnostic & Prevention Network (fasdpn.org)** is a network of interdisciplinary community-owned FASD diagnostic clinics led by the core clinical/research/training clinic at the University of Washington. The University of Washington clinic conducts 90% of the FASDPN diagnostic evaluations. The Network clinics conduct 10% of the FASDPN diagnostic evaluations. The FASDPN has been funded by the WA General Fund since 1995.

The FASDPN was established in 1995 through enactment of [RCW 70.96A.500 \(Fetal Alcohol Screening and Assessment Services\)](#) (**Appendix D**).

“Findings—Purpose—1995 c 54: The legislature finds that fetal alcohol exposure is among the leading known causes of mental retardation in the children of our state. The legislature further finds that individuals with undiagnosed fetal alcohol exposure suffer substantially from secondary disabilities such as child abuse and neglect, separation from families, multiple foster placements, depression, aggression, school failure, juvenile detention, and job instability. These secondary disabilities come at a high cost to the individuals, their family, and society. The legislature finds that these problems can be reduced substantially by early diagnosis and receipt of appropriate, effective intervention.”

The accomplishments of the FASDPN to date are described in full on its website (fasdpn.org) and briefly summarized below:

- A. **The FASDPN has provided 100% of the interdisciplinary FASD diagnostic and treatment evaluations in Washington State for the past 20 years.** The FASDPN was the first to introduce the highly effective and cost efficient [interdisciplinary approach to FASD diagnosis](#) ^(Clarren & Astley, 1998; Astley, 2010). It was also the first to introduce an evidence-based FASD diagnostic system (the [FASD 4-Digit Code](#) ^(Astley, 2013)). This FASD diagnostic model is now recognized as [clinical best practice](#) ^(SAMHSA, 2014) and replicated [internationally](#).



[Twenty years of FASDPN patient surveys](#) ^(Astley, 2014) document:

- 98% of families report receiving information not available to them elsewhere.
- 89% report the diagnosis afforded them access to interventions that met their needs.
- 100% report they would recommend the service to others.

In the words of one caregiver of a 10-year old child who received a FASD diagnosis ““I cannot say enough good things about your services. A proper diagnosis has resulted in: change of school placement, OT/PT services provided by the school district, a referral to mental health in hopes of finding a therapist w/background in neurodevelopmental problems and patient’s psychiatrist reducing his medications.”

B. The FASDPN provides 100% of the FAS screening and surveillance in Washington State.

Through translational research (the rapid translation of research into clinical practice) the FASDPN created an [evidence-based FAS screening tool](#) (Astley et al., 1996, 2002) by first identifying the unique facial features of FAS and then creating [FAS facial recognition software](#) to identify these facial features from a digital photograph (Astley, 2014a). This software is now used worldwide.



The FASDPN used this facial recognition software to screen all children entering the King County Foster Care Passport Program over a 10 year period for FAS. This required nothing more than a digital facial photograph and a 5 minute computerized analysis. All children who screened positive for the FAS facial features received a full FASD diagnostic evaluation. Over 95% of the screen-positives received a diagnosis of FAS. This screening led to the discovery that [one out of every 100 foster children in foster care has FAS](#) (10 times higher than in the general population) (Astley et al., 2002).

This FAS screening program also led to the discovery that the [prevalence of FAS births in Washington State decreased significantly](#) in the same years [maternal drinking during pregnancy in Washington State decreased significantly](#). (Astley, 2004)

The FASDPN currently provides FAS photo screening for Child Health & Education Tracking (CHET) and the Foster Care Assessment Program (FCAP).

C. The UW FASDPN provides FASD training to hundreds of Washington State healthcare, educational, correctional, and social service providers annually.

[Training opportunities](#) include:

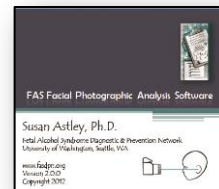
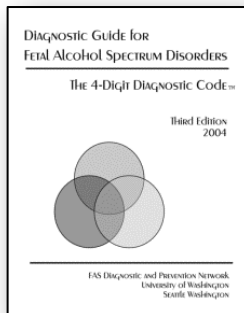
- The [1-Day Observation Training](#): Community professionals learn how to coordinate their efforts with the services of the FASDPN clinics to best serve individuals with FASD. These community professionals from healthcare, education, corrections, and social service are the professionals the FASDPN relies on to identify and refer individuals to the FASD clinics. They are also the professionals the FASDPN clinic will refer the patient back to for ongoing intervention services. By directly observing the FASDPN diagnostic team conduct two FASD diagnostic evaluations, their community role in this process

becomes crystal clear. Over 10,000 Washington State professionals have been trained to date. Training evaluations are sent monthly to the State. 100% have rated the training good to excellent.

In the words of one community professional who attended the training: *“To the inspiring FASD team members: Thank you so much for allowing me to observe your evaluations. What a treat to be able to watch in awe as each and every one of you evaluated and gained support with both child and mom with such grace and expertise. From the clinic coordinator’s initial communication, to the incredible training, the lightning fast pace at which you produce those reports, the humility in delivering the diagnostic news, etc., etc.; from one outside agency, I will be happy to refer kids here (as we have in the past) and feel honored to be able to share my first-hand experience of the process! Thanks for the opportunity.”*

- [Diagnostic Team Training](#): The UW FASDPN clinic provides diagnostic teams with instruction on how to establish an interdisciplinary FASD diagnostic clinic using the FASD 4-Digit Code. Over 150 teams have been trained worldwide including 6 in Washington State.
- [FASD 4-Digit Code Online Course](#): The UW FASDPN clinic provides accredited online instruction for how to use the FASD 4-Digit Diagnostic Code. Over 700 professionals worldwide have completed the course. On a scale of 1 to 5, with 5 being excellent, the average score for the Online Course is 4.9.

D. The UW FASDPN has developed the largest [FASD clinical/research database](#) and conducts translational research that has led to the development of FASD screening, surveillance, diagnostic, and intervention programs and tools used worldwide.



Publications resulting from this research are posted on fasdprn.org.

➤ **EVIDENCE-BASED PRACTICES FOR FASD PREVENTION**

1. The **Parent-Child Assistance Program (PCAP)** (<http://depts.washington.edu/pcapuw/>) has been funded through Washington State DSHS Division of Behavioral Health and Recovery (DBHR) since 1997 by a combination of Federal Medicaid and State General Funds. PCAP:
 - A. Enrolls women in Washington State who are at highest risk for delivering children with FASD: those who have an alcohol abuse problem, or who have already delivered a child with FASD.
 - B. Provides intensive case management intervention to nearly 900 women and their families in eleven Washington State counties.
 - C. Demonstrates consistently positive research outcomes and publishes findings in peer-reviewed journals (<http://depts.washington.edu/pcapuw/>).
 - D. Demonstrates significant [cost savings for Washington State](#) (Casey Family Programs & Grant, 2013).
 - E. Has been identified as an evidence-based practice by federal programs and clearinghouses, including the Association of Maternal and Child Health Programs (2012), the California Evidence-Based Clearinghouse for Child Welfare (2010,2013), and the Office of Juvenile Justice and Delinquency Prevention Model Program (2005, 2010).
 - F. Maintains quality control and project fidelity via consistent statewide training and evaluation.
 - G. Conducts research that has led to the development of [screening and treatment modifications for adults with FASD](#) that are being tested and adopted worldwide (Grant, Brown, Graham et al., 2013).
 - H. Utilizes its statewide database to examine questions relevant to state child welfare policy and practices. For example, recurrent childbearing among substance-abusing mothers is a serious concern nationwide. PCAP clinical observations indicated that mothers whose children were removed from their custody often reacted by having a “replacement” baby. PCAP examined repeat alcohol/drug-exposed births among 795 clients. Consistent with our hypothesis we found that among women whose most recently delivered child had been removed from their care, the odds of having a subsequent birth increased *nearly two-fold* and the odds of having a subsequent *exposed birth increased three-fold*. [The published paper](#) discusses child welfare policy and practice implications and offers recommendations (Grant, Graham, Ernst et al., 2014).
 - I. Utilizes its statewide database to collaborate with researchers at WSU in studying questions related to maternal substance abuse (e.g. rural/urban differences in substance abuse and mental health treatment services and outcomes; effects of contingency management on tobacco cessation recidivism).
 - J. Trains and consults on the PCAP model throughout the world. In 2009 the Government of Alberta Institute of Health Economics recommended that Canada encourage programs based on the PCAP model (Institute of Health Economics, 2009). PCAP has now been replicated at forty Canadian sites with funding from provincial governments.

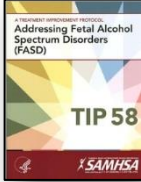
Mothers enrolled in PCAP are some of the highest risk women in Washington State, and they exemplify the intergenerational nature of familial substance abuse and dysfunction. [They were themselves the neglected and abused children in our communities just a decade or two ago](#) ^(Grant, Huggins, Graham et al., 2011). As children, over 90% had substance abusing parents, 63% were physically and/or sexually abused, 64% ran away from home, 30% had child welfare services involvement, and over half did not graduate from high school. As young mothers, they are likely to give their babies the same kind of upbringing they experienced as children unless we reach out with care, engagement, and intervention.


All PCAP clients have substance abuse disorders. Most are on Medicaid and have publicly funded core services available to them, but they do not tend to access these services or succeed on their own. For example, before enrollment in PCAP, 34% did not have a regular healthcare provider and 88% were not using a family planning method; 86% had previously been in inpatient or outpatient treatment (an average of three times); 43% were homeless or transient. The PCAP model, based on relational theory and motivational interviewing concepts, *offers outreach and engagement* to clients from trained, supervised case managers who provide support, structured goal setting, and consistent coaching ^(Grant, Ernst, & Streissguth, 1999). PCAP case managers are realistic role models who inspire hope—many are in long-term recovery and have overcome difficult life circumstances similar to those experienced by clients.


The PCAP approach makes a difference to clients:

- *“There were times when I felt like I was going to relapse and my case manager would be there for me, and she’d keep checking on me and I’d get through it. I’ve learned so much about myself and being responsible again and being a good mother. It was all what she taught me—she changed my life for me.”*
- *“She helped me establish goals; she’s helped me achieve my goals. She’s taught me responsibility, dependability. After three years of working with her, I see myself as a strong, independent woman.”*
- *“Before PCAP I never thought about goals. They showed me the right direction. They showed me that I am responsible. That no matter who I am or what I do, I am somebody. It is never too late.”*

➤ **EVIDENCE-BASED AND BEST PRACTICES FOR FASD INTERVENTION**

1. **The Substance Abuse and Mental Health Services Administration (SAMHSA)** most recent Treatment Improvement Protocol (TIP) #58 is entitled "[Addressing Fetal Alcohol Spectrum Disorders](#)" (SAMHSA, 2014). Members of the University of Washington FADU and FASDPN programs, as well as members of the IAWG were coauthors of this document. FASD programs developed in Washington State are referenced throughout the TIP. It offers best-practices guidelines based on an evidence base of scientific research findings and clinical practice theory and principles. The TIP provides: 1) appropriate counseling methods for behavioral health practitioners; 2) support for program administrators to implement recommendations; and 3) an in-depth literature review.
 

2. **NOFAS WA** (nofaswa.org). [Substitute Senate Bill 5688](#) also stipulated "*The interagency agreement shall provide a process for community advocacy groups to participate in the review and development of identification, prevention, and intervention programs administered or contracted for by the agencies executing this agreement.*" NOFAS WA is a nonprofit 501(C) (3) family advocacy program established in 2003. NOFAS WA is an alliance of families and professionals supporting individuals with FASD, the families that care for them, and the systems that serve them. It hosts programs like FASt Friends, Teen Group, Family Camp, Trainings, and Conferences to empower families to succeed. NOFAS WA is an affiliate of the National Organization of Fetal Alcohol Syndrome. NOFAS Washington State received periodic funding support from the State prior to 2008 for targeted activities like Family Camp.
 

3. **Families Moving Forward with FASD** (<http://depts.washington.edu/fmffasd/>). Intervention services guided by clinicians with expertise/experience in FASD best meet the needs of families. Evidence-based programs like the University of Washington [Families Moving Forward](#) (FMF) with FASD provide this clinician training and parent support (Bertrand, 2009).
 

4. **Families confirm access to effective intervention starts with an accurate FASD diagnosis.** [Twenty years of patient surveys](#) confirm the FASDPN's interdisciplinary approach to diagnosis using the 4-Digit Code afforded them substantial access to community-based interventions that met their needs (Astley, 2014). For a patient to derive the greatest benefit from their FASD diagnostic evaluation, they need an interdisciplinary team that can: 1) render an accurate diagnosis under the umbrella of FASD; 2) generate a comprehensive intervention plan tailored to their specific needs and circumstances; and 3) present all of this in a comprehensive medical summary report that effectively informs and educates the family and their community service providers. In one 4-hour FASD evaluation, the patient is evaluated by a pediatrician, psychologist, speech language pathologist, and occupational therapist. Patients reported this single 4-hour assessment provided them with more information and access to

services than the multitude of uncoordinated services the families reported accessing prior to coming to the FASDPN clinic.

5. UW Fetal Alcohol and Drug Unit researchers have developed practices effective with people who have FASD and published these in peer-reviewed papers:

- In 1992-1996 the Centers for Disease Control and Prevention (CDC) funded Dr. Ann Streissguth to study the occurrence and range of adverse effects of FASD across the lifespan. The study documented risk and protective factors among 451 individuals diagnosed with an FASD (age range 6 to 51 years). The Final report and the [2004 published paper](#) continue to be cited worldwide as the most definitive sources of information on this topic. (Streissguth et al., 1996, 2004)
- People with FASD are at high risk for substance abuse problems. Using the PCAP database, UW researchers conducted the [first study of substance abuse treatment participation among people with FASD](#) compared to those without FASD (Grant, Brown, Graham & Ernst, 2014). Findings: women with FASD were less likely to attend and complete inpatient and outpatient treatment; those with FASD were more likely to complete treatment within a residential versus outpatient setting. Detailed recommendations were developed for treatment accommodations to address impairments in FASD (Grant, Brown, Dubovsky, & Ries, 2013)
- UW researchers developed and tested a [27-item Life History Screen interview protocol \(LHS\)](#) to screen individuals at treatment intake for characteristics typically found in FASD in order to inform assessments and treatment planning (Grant, Brown, Graham, et al., 2013). Findings: the LHS shows promise as an efficient self-report screen for identifying possible FASD. Researchers in Canada and Germany are now conducting government-funded studies to further develop psychometric properties of the LHS.
- People with FASD have 5 times greater risk for suicide attempt than those in the general population. UW researchers described [clinical profiles of a sample of people with FASD](#), identified suicide risk and protective factors, and made recommendations for reducing suicide attempt among people with FASD (Huggins et al., 2008)
- People with FASD are at high risk for criminal justice system involvement. UW researchers have developed detailed strategies for assessing prenatal alcohol exposure in legal settings (Brown et al., accepted)
- Early intervention can reduce the likelihood that people with FASD will have adverse lifelong effects. UW researchers described how [neonatal cranial ultrasound results led to an early FAS diagnosis](#) and successful intervention in an infant whose mother was enrolled in PCAP (Grant, Bookstein, Whitney, & Streissguth, 2006)
- UW researchers described the [neuropsychological assessments administered to PCAP clients who have FASD](#), and illustrated how results have been used to help multidisciplinary teams respond effectively to affected individuals (Sparrow et al., 2013)



➤ **POLICIES THAT IMPROVED FASD IDENTIFICATION, PREVENTION, AND INTERVENTION.**

1. Washington State was the first to discover FAS in 1968. In 1973 the University of Washington introduced the term FAS into the medical literature. These actions paved the way for the following national public health policies:
 - A. In 1981, The FDA posted the first **Surgeon General’s Advisory on Alcohol and Pregnancy**: *“According to the Surgeon General, Women should not drink alcoholic beverages during pregnancy because of the risk of birth defects”*.
 - B. In 1988 the [Alcohol Beverage Labeling Act](#) was enacted. *“Government Warning: (1) According to the surgeon general, women should not drink alcoholic beverages during pregnancy because of the risk of birth defects. (2) Consumption of alcoholic beverages impairs our ability to drive a car or operate heavy machinery, and may cause health problems.”*
2. In 1992, Washington State was the first state to establish the position of **“FAS State Coordinator”**. In 2003, SAMHSA expanded this to the [National Association of FASD State Coordinators](#) (SAMHSA 2003, 2014).
3. In 1992, the University of Washington opened the [first interdisciplinary FASD diagnostic clinic](#) (Clarren & Astley, 1998). In 1997 the UW went on create the **first case-defined FASD diagnostic system** (the FASD 4-Digit Diagnostic Code) (Astley & Clarren, 1997). This interdisciplinary approach to FASD diagnosis using rigorous case-defined guidelines is now regarded as clinical best practice worldwide (SAMHSA, 2014).
4. In 1993, Washington State enacted [RCW 66.16.110 Birth Defects from Alcohol-Warning Signs](#). *The board shall cause to be posted in conspicuous places, in a number determined by the board, within each state liquor store, notices in print not less than one inch high warning persons that consumption of alcohol shortly before conception or during pregnancy may cause birth defects, including fetal alcohol syndrome and fetal alcohol effects.*
5. In 1995 Washington State was the **first to establish a statewide network of clinics** (the WA FAS Diagnostic & Prevention Network) through [Senate Bill 5688](#). This Senate Bill served as the template for legislatures [nationwide](#) to establish statewide FASD diagnostic networks.
6. **The FASD Interagency Work Group** ([fasdwa.org](#)). In 1995, the FASD-IAWG was established through [Senate Bill 5688](#) to ensure coordination of DSHS, DOH, DOC, OSPI, and UW programs for individuals impacted by FASD and women at risk of bearing children with FASD. In 2004 the IAWG composed and posted on its website a comprehensive [historical record](#) of all programs and policies related to FASD implemented in Washington State.
7. In 1998, Washington State enacted [RCW 13.34.805: Drug-Affected and Alcohol-Affected Infants – Comprehensive Plan](#). *The Department of Health and the Department of Social and*



Health Services shall develop a comprehensive plan for providing services to mother who (a) have delivered a drug or alcohol exposed or affected infant, and (b) meet the definition of at-risk eligible persons in RCW 74.09.790 and who have a child up to three years of age. The services to be provided by the plan will include those defined in RCW 74.09.790. The plan shall provide for the coordination of services through community-based programs and among: (i) The department; (ii) the departments' divisions; and (iii) other state agencies. The plan shall include recommendations to the legislature for implementing the plan and any alternative methods for addressing the needs of these mothers and their children

8. In 2004, Governor Locke proclaimed September 9th as " **FASD Awareness Day**". First recognized in 1999, International FASD Awareness Day helps raise awareness about the range of conditions that can result from alcohol use during pregnancy. September 9, 2004 was enacted as National FASD Day by the 108th congress of the U.S.

CURRENT CHALLENGES AND RECOMMENDED SOLUTIONS

Washington State is the leader in the field of FASD, being the first to discover FASD, and the first to develop evidence-based tools and programs for the screening, diagnosis, intervention, and prevention of FASD. Although Washington State's prevention efforts are working, the State's capacity to screen, diagnose, treat, and prevent FASD falls far below the statewide need/demand for such services. Our recommendations below focus primarily on increasing the capacity of our evidence-based screening, diagnosis, intervention, and prevention efforts.

A. Screening and Diagnosis of FASD

1. **Challenge:** Washington State's FASD diagnostic capacity does not meet diagnostic demand. An estimated 870 children with FASD are born each year in Washington State. At 2014 funding levels, the WA FASDPN is funded to conduct only 110 diagnostic evaluations per year. The average wait time for a family seeking a FASD diagnostic evaluation is 9 months. For children birth to three years of age, this translates into lost opportunities for early intervention.

Solution: Maintain current FASD diagnostic capacity at the core University of Washington FASDPN Clinic, and if possible increase FASD diagnostic capacity through the FASDPN Network Clinics. Doubling statewide capacity would reduce average wait time to 4.5 months.

Cost: A FASD diagnostic evaluation at the FASDPN costs \$2,900. Doubling diagnostic capacity would cost \$319,000 (110 x \$2,900).

Cost Savings: *Each \$2,900 evaluation conducted by the FASD saves \$4,900 in ineffective diagnostic evaluations. Twenty years of patient records [confirm](#) that patients with prenatal alcohol exposure seek out an FASD evaluation by any means possible (Astley, 2014).* A 4-hour interdisciplinary FASD diagnostic evaluation conducted by a pediatrician, psychologist, speech language pathologist, occupational therapist,

social worker and family advocate at the FASDPN costs \$2,900. The cost of this evaluation (4 hours with an interdisciplinary, and 3-days effort by the clinic coordinator who schedules the appointment, collects all historical records (birth, school, medical, placement) that contain vital information required to derive the FASD diagnosis, and constructs the 12-page template medical summary report) is \$2,900. A family seeking a diagnosis by scheduling four separate, uncoordinated evaluations with these same clinicians would cost over \$7,800. The former results in an accurate FASD diagnosis and effective intervention plan. The latter does not. This interdisciplinary approach of FASD diagnosis is recognized as [best practice nationwide](#) ^(SAMHSA, 2014). An early accurate FASD diagnosis reduces [the lifetime cost of an individual's FASD disability](#) by hundreds of thousands of dollars ^(Olson et al., 2007; Astley, 2010). The [benefit](#) ^(HeraldNet, 12/24/14) to the individual and their family is immeasurable.

- 2. Challenge:** A comprehensive neuropsychological assessment is an important component of a FASD diagnostic evaluation and is essential to informing effective treatment and service delivery. Children and adolescents referred to the FASD diagnostic clinics often have these assessments conducted by the schools and shared with the clinics. The FASD clinics collect these existing records to reduce the time and cost of the FASD evaluation. Adults referred to the clinics rarely have this data in their records. Most adults seeking an FASD diagnostic evaluation are on Medicaid and most neuropsychologists do not accept Medicaid payment. Therefore most adults seeking an FASD diagnostic evaluation do not have affordable access to adult neuropsychological evaluation services. This can prevent them from receiving a FASD diagnostic evaluation.

Solution: Increase capacity for neuropsychological assessment of adults on Medicaid.

Cost of Medicaid reimbursement: approximately \$720 per neuropsychological assessment. Actual cost per assessment: approximately \$1,700 to \$2,500, often not fully covered by insurance.

- 3. Challenge:** Programs working with at-risk children are not screening effectively for prenatal alcohol exposure. Clinicians are more likely to screen for illicit drug use during pregnancy than alcohol use, even though alcohol is more harmful to the developing fetus.

Solution: Educate clinicians statewide on the importance of screening for and documenting prenatal alcohol exposure. Documentation of prenatal alcohol exposure serves to identify at-risk children that require close developmental monitoring. The [1-Day Training](#) at the UW FASDPN clinic provides this training.

Cost: Doubling diagnostic capacity doubles the number of 1-Day Training sessions available at no additional cost. The training sessions at the UW FASDPN take place

during each FASD diagnostic evaluation and are conducted by the team already assembled to conduct the diagnostic evaluation.

B. Prevention of FASD

1. **Challenge:** The State First Steps Database (2010) identified at least 2,606 alcohol and drug-abusing pregnant or postpartum women (PPW) with Medicaid births. PCAP has the capacity to serve approximately 900 (35%) of these women. Approximately 1,700 women who are eligible for PCAP are not being served. Most PCAP sites have waiting lists.

Solution: Maintain current PCAP funding in eleven counties and if possible expand PCAP to additional counties that have high rates of prenatal substance abuse, such as Thurston.

PCAP Cost: Approximately \$5200 per client per year including direct services to families, and training and evaluation by the University of Washington. The cost of a full site serving approximately 100 women (e.g. in Thurston County) is \$520,000 per year. It is not reasonable or cost effective to operate PCAP in remote counties where need is low, but statewide cost to serve even half of the eligible women not being served (approximately 850) is \$4.42 million per year.

Cost Savings (Casey Family Programs & Grant, 2013).

- *Fewer substance exposed births.* At exit from PCAP, 79% of moms are no longer at risk for delivering another alcohol/drug affected infant because they are in successful recovery or are using family planning on a regular basis. The estimated total lifetime cost for every infant born with Fetal Alcohol Syndrome (FAS) is \$2 million. [PCAP data show over \\$20 million in lifetime cost savings](#) because of effective intervention among the PCAP mothers who were former binge drinkers.
 - *Reduced dependence on child welfare.* Children of mothers in PCAP who were in out-of-home care and reunified at PCAP exit had a shorter length-of-stay (3.8 months), on average, than Washington's statewide average (20.4 months). For each successful reunification, [savings of over \\$21,000 per child can be realized](#).
 - *Reduced dependence on public assistance.* From 2007 to 2012, Temporary Assistance for Needy Families (TANF) was the main source of income for 61% of women entering PCAP compared to only 31% at exit.
 - *Increased employment.* From 2007 to 2012, employment was the main source of income for 3% percent of women entering PCAP, compared to 27% at exit, resulting in greater tax revenue from increased earnings.
2. **Challenge:** Women with alcohol abuse disorders need high-quality treatment, and those with more severe substance abuse or cognitive problems need residential treatment. In Washington State there are only 156 state-funded PPW residential treatment beds, with only 130 slots for childcare.

Solution: Increase PPW residential and outpatient substance abuse treatment capacity across the state.

Cost: In 2013 the average cost was \$7,545 per client for residential treatment services and \$1,274 per client for outpatient treatment.

Cost Savings Increasingly strong evidence finds that [treatment pays for itself](#) ^(Center for Substance Abuse Treatment, 2002). Every \$1 invested yields a return of between \$4 and \$7 in reduced drug-related crime, criminal justice costs, and theft. Savings can exceed costs by 12 to 1 when health care savings are included. Among pregnant women who are treated, newborns weigh more, have greater gestational age, are less likely to require care in the neonatal intensive care unit (NICU), and have shorter NICU stays if admitted. Residential and combined residential-outpatient treatment appear to be the most cost effective treatment modalities

3. **Challenge:** FASDs are preventable, and health care providers are in an ideal position to screen women for alcohol use and risk for becoming pregnant. Most health care providers do not discuss FASD prevention with women.

Solution: The Washington State Department of Health has developed comprehensive recommendations and guidelines, entitled "[Substance Abuse During Pregnancy: Guidelines for Screening and Management](#)" ^(WA DOH, 2013). These guidelines need to be more widely distributed to healthcare providers throughout the state via no-cost websites and list serves.

Cost: The Guidelines can be promoted and distributed throughout the state at little cost via current health care and substance abuse websites and list serves.

Interventions for Individuals with FASD

1. **Challenge:** Families are the primary support structure for children and adults in Washington State living with FASD. Family advocacy is vital for supporting these families. NOFAS WA hosts programs like FASt Friends, Teen Group, Family Camp, Trainings, and Conferences to empower families to succeed. NOFAS WA is a nonprofit that struggles to keep its programs open.

Solution: Reinstate funding support for community advocacy groups like NOFAS WA.

In 1995, [Senate Bill 5688](#) stipulated the participation of community advocacy groups. DSHS provided \$100,000/year support for community advocacy programs between 1995 and 2008. Families would benefit greatly if this support was reinstated.

2. **Challenge:** Intervention services guided by clinicians with expertise/experience in FASD best meet the needs of families. Evidence-based programs like [Families Moving Forward \(FMF\)](#) with FASD provide this clinician training and parent support. The current capacity of programs like FMF is too low to meet statewide demand.

Solution: Increase the capacity of programs like FMF.

D. Policy Changes to Improve FASD Identification, Prevention, and Intervention

1. **Challenge:** FASD diagnostic and prevention efforts in Washington State are limited by their heavy reliance on State General Funds. More specifically:

- A. FASD diagnostic capacity through the FASDPN clinics is limited in Washington State because over [70%](#) of patients seeking a diagnostic evaluation are on Medicaid ^(Astley, 2010) and Medicaid and/or private insurance alone covers less than one third of the cost of a diagnosis. This is not unique to Washington State. In a formal [study](#) conducted by the University of Alaska Anchorage in 2004 ^(BHRS, 2004), the average cost of conducting a FASD diagnosis in the State of Alaska using the University of Washington interdisciplinary model was \$4,821. Only \$1,076 could be billed to and collected from Medicaid and/or private insurance. Recognizing that Medicaid and/or insurance alone did not cover the full cost of a diagnosis, Alaska established a [Provider Agreement](#) payment of \$3,000 per FASD diagnosis to assist interdisciplinary teams in recovering the cost of a diagnosis in their community ^(State of Alaska, 2012). Washington State established a similar provider agreement in 2007. The cost of a FASD evaluation in Washington State is approximately \$2,900. The WA FASDPN clinics receive \$2,000 per evaluation from State General Funds to offset what cannot be reimbursed through Medicaid and/or private insurance.

- B. FASD prevention efforts through PCAP have been funded through WA DSHS Division of Behavioral Health and Recovery (DBHR) since 1997 by a combination of Federal Medicaid and State General Funds.

Solution: Explore all available opportunities to diversify funding sources, including maximizing federal Medicaid funding in order to reduce the fiscal impact on state general funds. **Update:** Discussions are currently underway with members of IAWG and key State Agency personnel to address this issue.

2. **Challenge:** Many patients with FASD are unable to access existing effective interventions recommended by the FASDPN clinics. These interventions include services for cognitive, behavioral, language, and motor sensory impairments. Qualifying for services through the [DDA](#) (Developmental Disability Administration) can be an important first step in obtaining [services and supports](#).

Solution: Revise [DDA eligibility criteria](#) so that applicants with FASD, not just those with FAS, can be considered for eligibility under “*another neurological or other condition*.” **Update:** Members of the IAWG have been working effectually for the past six months to formulate these revisions. We are pleased to report the revisions are near completion with a projected implementation date of early 2015, pending approval.

References

- Amendah D, Grosse S, Bertrand J. Medical expenditures of children in the United States with fetal alcohol syndrome. *Neurotoxicology and Teratology* 33 (2011) 322–324.
- Association of Maternal & Child Health Programs. The Parent-Child Assistance Program. Innovation Station, 2012. Available at:
<http://www.amchp.org/programsandtopics/BestPractices/InnovationStation/ISDocs/PCAP.pdf#search=PCAP>
- Astley SJ. Palpebral fissure length measurement: accuracy of the FAS facial photographic analysis software and inaccuracy of the ruler. *J Popul Ther Clin Pharm* Vol 21(3):e520-e537; Dec 1, 2014a.
- Astley SJ. [Twenty years of patient surveys confirm a FASD 4-Digit-Code interdisciplinary diagnosis afforded substantial access to interventions that met patients' needs](#). *J Popul Ther Clin Pharmacol* Vol 21 (1):e81-e105; March 6, 2014.
- Astley SJ. [Validation of the fetal alcohol spectrum disorder \(FASD\) 4-Digit Diagnostic Code](#). *J Popul Ther Clin Pharmacol* Vol 20(3):e416-467; November 15, 2013.
- Astley SJ. [Diagnosing Fetal Alcohol Spectrum Disorders \(FASD\)](#). In: Aduato SA and Cohen DE (eds.) *Prenatal Alcohol Use and Fetal Alcohol Spectrum Disorders: Diagnosis, Assessment and New Directions in Research and Multimodal Treatment*, Bentham Science Publishers Ltd. [Bentham eBooks](#), pp 3-29, 2011.
- Astley SJ. [Profile of the first 1,400 patients receiving diagnostic evaluations for fetal alcohol spectrum disorder at the Washington State Fetal Alcohol Syndrome Diagnostic & Prevention Network](#). *Canadian Journal of Clinical Pharmacology*, Vol 17 (1) Winter 2010:e132-e164:March 26, 2010.
- Astley SJ. [Diagnostic Guide for Fetal Alcohol Spectrum Disorders: The 4-Digit Diagnostic Code](#), 3rd edition. 2004 University of Washington Publication Services, Seattle WA.
- Astley SJ. [Fetal alcohol syndrome prevention in Washington State: Evidence of success](#). *Paediatric and Perinatal Epidemiology*, 2004;18:344-351.

- Astley SJ, Bailey D, Talbot T, Clarren SK. [Fetal alcohol syndrome \(FAS\) primary prevention through FAS diagnosis: I. Identification of high-risk birth mothers through the diagnosis of their children](#). Alcohol & Alcoholism, 2000;35 (5):499-508.
- Astley SJ, Bailey D, Talbot T, Clarren SK. [Fetal alcohol syndrome \(FAS\) primary prevention through FAS diagnosis: II. A comprehensive profile of 80 birth mothers of children with FAS](#). Alcohol & Alcoholism, 2000;35 (5):509-519.
- Astley SJ, Clarren SK. [A case definition and photographic screening tool for the facial phenotype of fetal alcohol syndrome](#). Journal of Pediatrics, 1996;129:33-41.
- Astley SJ, Clarren SK. [Diagnosing the full spectrum of fetal alcohol exposed individuals: Introducing the 4-Digit Diagnostic Code](#). Alcohol and Alcoholism, 2000;35 (4): 400-410.
- Astley SJ, Stachowiak J, Clarren SK, Clausen C. [Application of the fetal alcohol syndrome facial photographic screening tool in a foster care population](#). Journal of Pediatrics, 2002;141(5):712-7.
- Behavioral Health Research and Services (BHRS), State of Alaska, Technical Report #28. . [Cost of the FASD Diagnostic Process in Alaska](#). 2004. <http://www.uaa.alaska.edu/cbhrs/completedprojects/upload/cost-report.pdf>
- Bertrand J. (Research Consortium Authors include: Heather Olson and Susan Astley). [Interventions for children with fetal alcohol spectrum disorders \(FASDs\): Overview of findings for five innovative research projects](#). Research in Developmental Disabilities 2009, doi:10.1016/j.ridd.2009.02.003.
- Brown, N. N., Burd, L., Grant, T. Edwards, W. Adler, R., Streissguth, A. Prenatal Alcohol Exposure: An Assessment Strategy for the Legal Context. International Journal of Psychiatry and Law (accepted).
- Casey Family Programs & Grant, T. (2013). Parent-Child Assistance Program Outcomes Suggest Sources of Cost Savings for Washington State. Available at: http://depts.washington.edu/pcapuw/inhouse/PCAP_Cost_Savings_Brief_Feb_2013.pdf
- Center for Substance Abuse Treatment (2002). Cost effectiveness and cost benefit analysis of substance abuse treatment: A literature review. Available at: http://www.lewin.com/~media/lewin/site_sections/publications/2485.pdf
- Clarren SK and Astley SJ. [Identification of Children with Fetal Alcohol Syndrome and Opportunity for Referral of their Mothers for Primary Prevention - Washington, 1993-1997](#). Morbidity and Mortality Weekly Report, 1998;47(40):860-864.
- Clarren SK, Carmichael Olson H, Clarren SGB, Astley SJ. [A Child with Fetal Alcohol Syndrome](#). In Guralnick MJ (ed.), Interdisciplinary Clinical Assessment of Young Children with Developmental Disabilities. Baltimore, Maryland: Paul H. Brookes Publishing Co., 307-326. Baltimore, Maryland: Paul H. Brookes Publishing Co., 307-326.

- Ernst, C.C., Grant, T.M., Streissguth, A.P., & Sampson, P.D. (1999). Intervention with high-risk alcohol and drug-abusing mothers: II. 3-year findings from the Seattle model of paraprofessional advocacy. *Journal of Community Psychology*, 27(1): 19-38.
- Grant, T.M., Bookstein, F.L., Whitney, N.L., & Streissguth, A. (2006). Neonatal cranial ultrasound leads to early diagnosis and intervention in baby of alcohol-abusing mother. *Mental Health Aspects of Developmental Disabilities*, 9(4):125-127.
- Grant, T.M., Brown, N.N., Graham, J.C., & Ernst, C.C. (2014). Substance abuse treatment outcomes in women with fetal alcohol spectrum disorders. *The International Journal of Alcohol and Drug Research*, 3(1), 43-49.
- Grant, T.M., Brown, N.N., Graham, J.C., Whitney, N., Dubovsky, D., & Nelson, L. (2013). Screening in treatment programs for fetal alcohol spectrum disorders that could affect therapeutic progress. *The International Journal of Alcohol and Drug Research*, 2(3), 37-49. DOI:10.7895/ijadr.v2i3.116.
- Grant, T.M., Brown, N. N., Dubovsky, D., Sparrow, J., & Ries, R. (2013). The impact of prenatal alcohol exposure on addiction treatment. *Journal of Addiction Medicine*, 7(2):87-95. DOI: 10.1097/ADM.0b013e31828b47a8.
- Grant, T.M., Ernst, C.C., & Streissguth, A.P. (1996). An intervention with high risk mothers who abuse alcohol and drugs: The Seattle advocacy model. *American Journal of Public Health*, 86(12): 1816-1817.
- Grant, T.M., Ernst, C.C., & Streissguth, A.P. (1999). Intervention with high-risk alcohol and drug-abusing mothers: I. Administrative strategies of the Seattle model of paraprofessional advocacy. *Journal of Community Psychology*, 27(1): 1-18.
- Grant, T., Ernst, C., Streissguth, A., & Stark, K. (2005). Preventing alcohol and drug exposed births in Washington State: Intervention findings from three Parent-Child Assistance Program sites. *American Journal of Drug and Alcohol Abuse*, 31(3): 471-490.
- Grant, T.M., Graham, J.C., Ernst, C.C., Peavy, K.M., & Brown, N.N. (2014). Improving pregnancy outcomes among high-risk mothers who abuse alcohol and drugs: Factors associated with subsequent exposed births. *Children and Youth Services Review*, 46: 11-18. DOI: 10.1016/j.childyouth.2014.07.014
- Grant, T., Huggins, J., Connor, P., Pedersen, J., Whitney, N., & Streissguth, A. (2004). A pilot community intervention for young women with fetal alcohol spectrum disorders. *Community Mental Health Journal*, 40(6): 499-511.
- Grant, T., Huggins, J., Connor, P., & Streissguth, A. (2005). Quality of life and psychosocial profile among young women with fetal alcohol spectrum disorders. *Mental Health Aspects of Developmental Disabilities*, 8(2): 33-39.

- Grant, T., Huggins, J., Graham, C., Ernst, C., Whitney, N., & Wilson, D. (2011). Maternal substance abuse and disrupted parenting: Distinguishing mothers who keep their children from those who do not. *Children and Youth Services Review*, 33(11):2176-2185.
- HeraldNet. Jackson High's Brandan Gelo is growing through love of music. By Amy Nile, Herald Writer. December 24, 2014 <http://m.heraldnet.com/heraldnet/db/285569/content/RykITdIN> (Brandan Gelo is a member of the WA FASD-IAWG).
- Huggins, J.E., Grant, T., O'Malley, K., & Streissguth, A.P. (2008). Suicide attempts among adults with fetal alcohol spectrum disorders: Clinical considerations. *Mental Health Aspects of Developmental Disabilities*, 11(2):33-41.
- Institute of Health Economics, Alberta, Canada. Consensus Statement on Fetal Alcohol Spectrum Disorder (FASD) – Across the Lifespan. Volume 4. October 7 - 9, 2009. http://www.ihe.ca/documents/FinalWeb_FASDStatement.pdf.
- Jirikowic T, Gelo J, Astley S [Children and youth with fetal alcohol spectrum disorders: Summary of intervention recommendations after clinical diagnosis](#). *Intellectual and Developmental Disabilities* 2010;48(5):330-344.
- Jones K, Smith D. Recognition of the fetal alcohol syndrome in early infancy. *Lancet*. 1973; 2:999-1001.
- Lupton C, Burd L, Harwood R. [Cost of fetal alcohol spectrum disorders](#). *Am J MedGenet C Semin Med Genet*. 2004 May 15;127C(1):42-50.
- Olson HC, Jirikowic T, Kartin D, Astley SJ. [Responding to the challenge of early intervention for fetal alcohol spectrum disorders](#). *Infants & Young Children*, 2007;20(2);172-189.
- Olson HC, Oti R, Gelo J, Beck S. [Family matters. Fetal alcohol spectrum disorders and the family](#). *Developmental Disabilities Research Reviews* 2009;15:235-249.
- Rasmussen, C., Kully-Martens, K., Denys, K., Badry, D., Henneveld, D., Wyper, K., & Grant, T. (2012). The effectiveness of a community-based intervention program for women at risk for giving birth to a child with Fetal Alcohol Spectrum Disorder (FASD). *Community Mental Health Journal*, 48(1): 12-21. DOI: 10.1007/s10597-010-9342-0. Epub 2010 Aug 8.
- Sparrow, J., Grant, T.M., Connor, P., & Whitney, N. (2013). The value of the neuropsychological assessment for adults with fetal alcohol spectrum disorders: A case study. *The International Journal of Alcohol and Drug Research*, 2(3), 79-86. DOI:10.7895/ijadr.v2i3.107.
- State of Alaska, Dept Health & Social Services, Div Behavioral Health. FASD Diagnostic Services Provider Agreement. FASD Diagnostic PA (Rev 2/12). <http://aws.state.ak.us/OnlinePublicNotices/Notices/View.aspx?id=156388>
- Stratton K, Howe C, Battaglia F. Fetal Alcohol Syndrome: Diagnosis Epidemiology Prevention and Treatment. Institute of Medicine. Washington D C National Academy Press; 1996.

- Streissguth, A. P., Barr, H. M., Kogan, J., & Bookstein, F. L., (1996). Understanding the Occurrence of Secondary Disabilities in Clients with Fetal Alcohol Syndrome (FAS) and Fetal Alcohol Effects (FAE). Final Report to the Centers for Disease Control and Prevention (CDC), August, 1996. Seattle, University of Washington, Fetal Alcohol & Drug Unit, Tech. Rep. No. 96-06.
- Streissguth, A.P., Bookstein, F.L., Barr, H.M., Sampson, P.D., O'Malley, K., Kogan Young, J. (2004). Risk factors for adverse life outcomes in fetal alcohol syndrome and fetal alcohol effects. Journal of Developmental and Behavioral Pediatrics, 25(4), 228-238. Available at:
http://journals.lww.com/jrnldb/Abstract/2004/08000/Risk_Factors_for_Adverse_Life_Outcomes_in_Fetal.2.aspx
- Substance Abuse and Mental Health Services Administration (SAMHSA) (2003). National Association of FASD State Coordinators (updated in 2014). Available at:
<http://fasdcenter.samhsa.gov/statesystemsofcare/nafsc.aspx>
- Substance Abuse and Mental Health Services Administration. Addressing Fetal Alcohol Spectrum Disorders (FASD). Treatment Improvement Protocol (TIP) Series 58. HHS Publication No. (SMA) 13-4803. Rockville, MD: Substance Abuse and Mental Health Services Administration, 2014.
- Substance Abuse and Mental Health Services Administration. FASD by the Numbers, Jan 2006.
- Thanh NX, Johsson E. Costs of fetal alcohol spectrum disorders in Alberta, Canada. Can J Clin Pharmacol Vol 16(1) Winter 2009:e80-e90; Jan 16, 2009.
- Ulleland CN. The Offspring of Alcoholic Mothers. Annals NY Academy of Sciences, 1972;197:167-169.
- WA DOH. Substance Abuse During Pregnancy: Guidelines for Screening. Revised Edition 2013.

Appendices

- A. [House Bill 2737 \(2014\)](#)
- B. [Substitute Senate Bill 5688 \(1995\)](#)
- C. FASD Interagency Work Group Members (2014)
- D. [RCW 70.96A.500](#) Fetal Alcohol Screening and Assessment Services (1995)

APPENDIX A

H-3637.2

HOUSE BILL 2737

State of Washington

63rd Legislature

2014 Regular Session

By Representatives Kagi, Sawyer, Smith, Ryu, Gregerson, Goodman, and Freeman

Read first time 01/29/14. Referred to Committee on Early Learning & Human Services.

1 AN ACT Relating to fetal alcohol exposure; amending RCW 70.96A.510;
2 adding new sections to chapter 66.28 RCW; and creating a new section.

3 BE IT ENACTED BY THE LEGISLATURE OF THE STATE OF WASHINGTON:

4 NEW SECTION. **Sec. 1.** (1) The legislature finds that fetal alcohol
5 exposure can cause serious mental and physical disorders and
6 disabilities in children. These disorders are preventable if a mother
7 does not drink during pregnancy. With the advent of private alcohol
8 retailers, there is now increased access to alcohol. The legislature
9 intends to require signage warning women about the dangers of fetal
10 alcohol exposure in all stores selling alcohol.

11 (2) The legislature further finds that by collecting evidence-based
12 practices around the identification, prevention, and interventions for
13 fetal alcohol spectrum disorders, the number of affected individuals
14 can decrease and those who are affected can improve their lives.
15 Finally, by convening a work group of stakeholders, the legislature can
16 become better informed about steps that can be taken to appropriately
17 address fetal alcohol exposure.

1 NEW SECTION. **Sec. 2.** A new section is added to chapter 66.28 RCW
2 to read as follows:

3 (1) At a minimum, premises that serve alcohol for on-premises
4 consumption, grocery store licensees, beer and wine specialty shop
5 licensees, breweries, wineries, and taverns shall post in a conspicuous
6 place easily seen by patrons a printed sign at least eighteen inches by
7 twenty-four inches in size, with letters at least two inches high,
8 warning that consumption of alcohol during pregnancy can cause birth
9 defects.

10 (2) This section does not apply to self-service minibars in hotel
11 guest rooms.

12 NEW SECTION. **Sec. 3.** A new section is added to chapter 66.28 RCW
13 to read as follows:

14 The board shall have the authority to adopt rules to carry out
15 section 2 of this act in a manner that will increase the visibility of
16 signage. The contents of section 2 of this act provide the minimum
17 requirements regarding warning that consumption of alcohol during
18 pregnancy can cause birth defects, but the board may adopt additional
19 rules beyond those minimum requirements to ensure that customers
20 observe these warnings.

21 **Sec. 4.** RCW 70.96A.510 and 1995 c 54 s 3 are each amended to read
22 as follows:

23 (1) The department of social and health services, the department
24 of health, the department of corrections, and the office of the
25 superintendent of public instruction shall execute an interagency
26 agreement to ensure the coordination of identification, prevention, and
27 intervention programs for ~~((children))~~ individuals who have fetal
28 alcohol exposure, and for women who are at high risk of having children
29 with fetal alcohol exposure.

30 The interagency agreement shall provide a process for community
31 advocacy groups to participate in the review and development of
32 identification, prevention, and intervention programs administered or
33 contracted for by the agencies executing this agreement.

34 (2) The interagency agreement shall provide for a work group
35 cochaired by the department of social and health services, the
36 University of Washington fetal alcohol syndrome diagnostic and

1 prevention network, and the University of Washington fetal alcohol and
2 drug unit to address fetal alcohol exposure issues related to
3 identification, prevention, and intervention. This work group shall
4 include the department of health, the department of corrections, the
5 office of the superintendent of public instruction, and other
6 interested organizations identified by the department of social and
7 health services, the University of Washington fetal alcohol syndrome
8 diagnostic and prevention network, and the University of Washington
9 fetal alcohol and drug unit.

10 (3) By December 1, 2014, the work group shall develop
11 recommendations and provide a report to the appropriate committees of
12 the legislature relating to:

13 (a) Identification of evidence-based practices for early screening
14 and diagnosis of fetal alcohol spectrum disorders;

15 (b) Identification of evidence-based practices for prevention of
16 fetal alcohol spectrum disorders;

17 (c) Identification of evidence-based practices for interventions
18 that can be used with individuals experiencing fetal alcohol spectrum
19 disorders; and

20 (d) Recommendations of policy changes that would improve the
21 identification, prevention, or interventions related to fetal alcohol
22 spectrum disorders.

--- END ---

APPENDIX B

CERTIFICATION OF ENROLLMENT

SUBSTITUTE SENATE BILL 5688

Chapter 54, Laws of 1995

54th Legislature
1995 Regular Session

Fetal alcohol exposure prevention

EFFECTIVE DATE: 7/23/95

Passed by the Senate March 13, 1995
YEAS 48 NAYS 0

JOEL PRITCHARD

President of the Senate

Passed by the House April 5, 1995
YEAS 95 NAYS 0

CLYDE BALLARD

**Speaker of the
House of Representatives**

Approved April 17, 1995

MIKE LOWRY

Governor of the State of Washington

CERTIFICATE

I, Marty Brown, Secretary of the Senate of the State of Washington, do hereby certify that the attached is **SUBSTITUTE SENATE BILL 5688** as passed by the Senate and the House of Representative on the dates hereon set forth.

MARTY BROWN

Secretary

FILED

April 17, 1995 – 3:45 p.m.

**Secretary of State
State of Washington**

SUBSTITUTE SENATE BILL 5688

Passed Legislature - 1995 Regular Session

State of Washington

54th Legislature

1995 Regular Session

By Senate Committee on Human Services and Corrections (originally sponsored by Senators Hargrove, Long, Franklin, Rasmussen, C. Anderson, Kohl, Prentice, McAuliffe, Fairley, Drew, Smith, Heavey, Sheldon, Wojahn, Bauer and Winsley)

Read first time 03/01/95.

1 AN ACT Relating to fetal alcohol exposure; adding new sections to
2 chapter 70.96A RCW; and crating new sections.

3 BE IT ENACTED BY THE LEGISLATURE OF THE STATE OF WASHINGTON:

4 NEW SECTION. **Sec. 1.** The legislature finds that fetal alcohol
5 exposure is among the leading known causes of mental retardation in the
6 children of our state. The legislature further finds that individuals
7 with undiagnosed fetal alcohol exposure suffer substantially from
8 secondary disabilities such as child abuse and neglect, separation from
9 families, multiple foster placements, depression, aggression, school
10 failure, juvenile detention, and job instability. These secondary
11 disabilities come at a high cost to the individuals, their family, and
12 society. The legislature finds that these problems can be reduced
13 substantially by early diagnosis and receipt of appropriate, effective
14 intervention.

15 The purpose of this act is to support current public and private
16 efforts directed at the early identification of and intervention into
17 the problems associated with fetal alcohol exposure through the
18 creation of a fetal alcohol exposure clinical network.

1 NEW SECTION. **Sec. 2.** A new section is added to chapter 70.96A RCW
2 to read as follows:

3 (1) The department shall contract with the University of Washington
4 fetal alcohol syndrome clinic to provide fetal alcohol exposure
5 screening and assessment services. The University indirect charges
6 shall not exceed ten percent of the total contract amount. The
7 contract shall require the University of Washington fetal alcohol
8 syndrome clinic to provide the following services:

9 (a) Training for health care staff in community-based fetal alcohol
10 exposure clinics to ensure the accurate diagnosis of individuals with
11 fetal alcohol exposure and the development and implementation of
12 appropriate service referral plans;

13 (b) Development of written or visual educational materials for the
14 individuals diagnosed with fetal alcohol exposure and their families or
15 caregivers;

16 (c) Systematic information retrieval from each community clinic to
17 (i) maintain diagnostic accuracy and reliability across all community
18 clinics, (ii) facilitate the development of effective and efficient
19 screening tools for population-based identification of individuals with
20 fetal alcohol exposure, (iii) facilitate identification of the most
21 clinically efficacious and cost-effective educational, social,
22 vocational, and health service interventions for individuals with fetal
23 alcohol exposure;

24 (d) Based on available funds, establishment of a network of
25 community-based fetal alcohol exposure clinics across the state to meet
26 the demand for fetal alcohol exposure diagnostic and referral services;
27 and

28 (e) Preparation of an annual report for submission to the
29 department of health, the department of social and health services, the
30 department of corrections, and the office of the superintendent of
31 public instruction which includes the information retrieved under
32 subsection (1) (c) of this section.

33 (2) The department shall submit to the legislature, by January 1,
34 1996, a copy of the governor's fetal alcohol syndrome advisory board
35 report.

36 NEW SECTION. **Sec. 3.** A new section is added to chapter 70.96A RCW
37 to read as follows:

1 The department of social and health services, the department of
2 health, the department of corrections, and the office of the
3 superintendent of public instruction shall execute an interagency
4 agreement to ensure the coordination of identification, prevention and
5 intervention programs for children who have fetal alcohol exposure, and
6 for women who are at high risk of having children with fetal alcohol
7 exposure.

8 The interagency agreement shall provide a process for community
9 advocacy groups to participate in the review and development of
10 identification, prevention, and intervention programs administered or
11 contracted for by the agencies executing this agreement.

12 NEW SECTION. Sec. 4. If specific funding for the purposes of this
13 act referencing this act by bill number is not provided by June 30,
14 1995, in the omnibus appropriations act, this act is null and void.

Passed the Senate March 13, 1995.

Passed the House April 5, 1995.

Approved by the Governor April 17, 1995.

Filed in Office of Secretary of State April 17, 1995

--- End ---

APPENDIX C

Fetal Alcohol Spectrum Disorder Interagency Work Group (FASD-IAWG)

Members-2014

Name (Alphabetical Order)	Title/Admin
Susan Astley, Ph.D.	Professor of Epidemiology/Pediatrics, University of Washington, Director, WA FAS Diagnostic & Prevention Network (FASDPN) astley@uw.edu
Deanna Bedell, MSW, ACSW	Intake and Substance Abuse Program Manager, DSHS/CA
Jane Beyer	Asst. Sec., DSHS/BHSIA/ADSA
Michelle Bogart	Health Program Manager, CA
Allison Brooks, Ph.D.	Licensed Psychologist, Fetal Alcohol Syndrome Diagnostic and Prevention Network, University of Washington
Heather Carmichael Olson, Ph.D.	Clinical Professor of Psychiatry and Behavioral Sciences, University of Washington, FASDPN, Seattle Children's Hospital Child Psychiatry Outpatient Clinic
Greg Endler	Children's Mental Health Program Administrator, DSHS/BHSIA/MH
Julie Gelo & son Brandan Gelo	Director WA NOFAS, Family Advocate University of Washington FASDPN, WA Alliance for Child Welfare Excellence.
Linda Gil	Program Manager, DDD/DDA
Therese Grant, Ph.D.	Associate Professor of Psychiatry and Behavioral Sciences, University of Washington, Director, Fetal Alcohol and Drug Unit, Associate Director Alcohol & Drug Abuse Institute
Dixie Grunenfelder	Prevention Intervention, Healthy Youth Survey, OSPI
Sherry Guzman	Tulalip Tribes
Carolyn Hartness	Fetal Alcohol Spectrum Disorders Educator/Consultant
Teri Herold-Prayer	Research Manager, DOC
Tracy Jirikowic, Ph.D., OTR/L	Associate Professor of Rehabilitation Medicine, FASDPN, University of Washington
Kay Kelly	Project Director, FASD Legal Issues Resource Center, University of Washington Fetal Alcohol and Drug Unit,
Beth Krehbiel	DDA Intake and Eligibility Program Manager, DSHS-DDA
Jodi Kunkel, BSN, RN	Clinical Nurse Advisor, ADSA/HCS/SUA/Foster Well-Being
Michael Langer	Office Chief – Office of Behavioral Health and Prevention, ADSA/DBHR
Linda Lunsford	Program Manager, DDD/DDA
Chris Osborne	Supervisor, Intake & Eligibility/ Birth-3 Case Manager DSHS-Developmental Disabilities Administration Region 2- Everett/Seattle

Sarah Pine	Behavioral Health Program Manager, FASD Programs and Special Projects, DBHR. Sarah.pine@dshs.wa.gov (360) 725-3807
Sharon Reddick	Quality and Care Management Program Manager, DHS/QCM/HCA
Monica Reeves	Mental Health and Crisis Services Program Manager, DSHS/DDA
Mary Segawa	Alcohol Awareness Program Manager, Director's Office, LCB
Lauri Turkovsky, Ed.D.	Behavioral Health Program Manager, DBHR
Dawn Williams	Program Administrator – Substance Abuse Recovery Unit, DOC
Joan Zerzan, MS RD	Nutrition Consultant, Children with Special Health Care Needs Program, Access, Systems and Coordination Section, Office of Healthy Communities, Division of Prevention and Community Health, DOH

APPENDIX D

RCW 70.96A.500

Fetal alcohol screening and assessment services.

The department shall contract with the University of Washington fetal alcohol syndrome clinic to provide fetal alcohol exposure screening and assessment services. The University indirect charges shall not exceed ten percent of the total contract amount. The contract shall require the University of Washington fetal alcohol syndrome clinic to provide the following services:

- (1) Training for health care staff in community-based fetal alcohol exposure clinics to ensure the accurate diagnosis of individuals with fetal alcohol exposure and the development and implementation of appropriate service referral plans;
- (2) Development of written or visual educational materials for the individuals diagnosed with fetal alcohol exposure and their families or caregivers;
- (3) Systematic information retrieval from each community clinic to (a) maintain diagnostic accuracy and reliability across all community clinics, (b) facilitate the development of effective and efficient screening tools for population-based identification of individuals with fetal alcohol exposure, (c) facilitate identification of the most clinically efficacious and cost-effective educational, social, vocational, and health service interventions for individuals with fetal alcohol exposure;
- (4) Based on available funds, establishment of a network of community-based fetal alcohol exposure clinics across the state to meet the demand for fetal alcohol exposure diagnostic and referral services; and
- (5) Preparation of an annual report for submission to the department of health, the department of social and health services, the department of corrections, and the office of the superintendent of public instruction which includes the information retrieved under subsection (3) of this section.

[1998 c 245 § 136; 1995 c 54 § 2.]

Notes:

Findings – Purpose – 1995 c 54: “The legislature finds that fetal alcohol exposure is among the leading known causes of mental retardation in the children of our state. The legislature further finds that individuals with undiagnosed fetal alcohol exposure suffer substantially from secondary disabilities such as child abuse and neglect, separation from families, multiple foster placements, depression, aggression, school failure, juvenile detention, and job instability. These secondary disabilities come at a high cost to the individuals, their family, and society. The legislature finds that these problems can be reduced substantially by early diagnosis and receipt of appropriate, effective intervention.

The purpose of this act is to support current public and private efforts directed at the early identification of and intervention into the problems associated with fetal alcohol exposure through the creation of a fetal alcohol exposure clinical network.” [1995 c 54 § 1.]