FETAL ALCOHOL SYNDROME DIAGNOSTIC & PREVENTION NETWORK

FAS DPN

Center on Human Development and Disability

University of Washington
Seattle, Washington

FAS Diagnostic & Prevention Network
FAS DPN

Overview

*T*he FAS DPN is a network of five community-based clinics in Washington State (Everett, Federal Way, Pullman, Spokane and Yakima) linked by the core clinical / research / training clinic at the Center on Human Development and Disability at the University of Washington in Seattle, Washington. The network was established in 1993 through support from the March of Dimes, Centers for Disease Control and the Chavez Memorial Fund. In 1995, further support was received from the Washington State Department of Social and Health Services through the enactment of Senate Bill 5688.

Each clinic in the Network uses the same multi-disciplinary approach to diagnosis and the same systematic method of diagnosis-the 4-Digit Diagnostic Code. Over 2,000 patients have been diagnosed to date.

The mission of the FAS DPN is primary and secondary prevention of FAS through screening, diagnosis, prevention, training and research.

The Washington State FAS DPN has expanded both nationally and internationally through the training of multidisciplinary clinical teams. Over 70 teams have been trained across the U.S. and Canada. The National FAS DPN expands by 6 to 10 new sites per year.

Major accomplishments of the FAS DPN include:

Screening/Surveillance:

- Creation of FAS Facial Photographic Analysis software.
- Ongoing population-based FAS screening/surveillance in foster care.

Diagnosis

- Creation of the 4-Digit Diagnostic Code.
- Establishment of the WA State FAS DPN multidisciplinary clinics.
- Diagnosis of over 2,000 patients.

Prevention

- Published lifetime profile of 80 birth mothers of children with FAS.
- Ongoing assessment of prevention effectiveness through population-based FAS surveillance.

Training / Education

- Weekly, 1-day, clinic-based training for community social and healthcare professionals.
- Biannual, 2-day training for interdisciplinary teams worldwide.
- Online Course: FASD 4-Digit Code.
- Distribution of training materials: Diagnostic Guide, FAS Tutor CD-ROM, Lip-Philtrum Pictorial Guide.
- FAS DPN website http://depts.washington.edu/fasdpn.

Research

- Establishment of FAS DPN Clinical Database on over 2000 patients.
- Facial photographic Image Analysis Laboratory and Photo Archive.
- CDC-sponsored intervention study 2001-2005.
- NIAA-sponsored MRI/MRS/fMRI study 2002-2005.

Screening/Surveillance

*F*etal alcohol syndrome (FAS) is a permanent birth defect caused by maternal consumption of alcohol during pregnancy. FAS is characterized by growth deficiency, central nervous system dysfunction, and a unique cluster of minor facial anomalies. FAS is the leading known cause of mental retardation in the Western World and is entirely preventable.

Primary prevention of FAS and prevention of secondary disabilities (e.g., school/job failure, depression, trouble with the law) among individuals with FAS are paramount. To both implement and measure the impact of prevention efforts, one must be able to accurately screen, diagnose and intervene with high-risk populations. Until recently, accurate screening and diagnostic tools did not exist. With the creation of the FAS Facial Photographic Screening Tool, the FAS 4- Digit Diagnostic Code and the establishment of the Washington State FAS Diagnostic and Prevention Network of clinics, FAS screening, diagnosis and prevention are now being effectively and efficiently conducted in Washington State.

Targeting FAS prevention efforts to high-risk populations is an efficient and effective use of limited resources. Children in foster care are an ideal population to target for several reasons. *First*, the risk of FAS in this population is likely to be high. *Second*, early diagnosis helps reduce the risk of secondary disabilities. *Third*, if a child's disabilities are fully known and disclosed at the time of placement, foster care systems will be able to establish more appropriate placements, foster/adoptive parents will be better prepared to meet their child's needs and the children are less likely to experience multiple failed placements. *Finally*,

the population is readily accessible and thoroughly tracked.

In 1996, the computerized FAS Facial Photographic Screening/Diagnostic Tool was developed by the FAS DPN. A Windows-based version of the software was created in 2003 for distribution to medical/research professionals. The tool measures the magnitude of expression of the three facial features of FAS (small palpebral fissures, smooth philtrum and a thin upper lip) from a digital facial photograph. The tool performed with 100% accuracy during its development and diagnostic use in over 2,000 patients seen in the FAS DPN clinics.

The tool is now being used to screen all children entering out of home care in the King County Washington Foster Care Passport Program. All children who screen positive receive a full diagnostic evaluation in the University of Washington FAS DPN Clinic.

Results to Date
- The prevalence of FAS in foster care is confirmed to be 10-15 times greater than in the general population.

- The Screening Tool performs with 100% sensitivity, 99.8% specificity, 83% predictive value positive and 100 % predictive value negative.

This photographic screening tool is now being used to track the change in prevalence of FAS in foster care over time and accurately measure the effectiveness of community FAS primary prevention efforts.

Diagnosis

*T*he definition of the FAS has changed little since the 1970's when the condition was first described. For the trained clinician there is little difficulty in making the diagnosis of FAS when the typical anomalies in growth, face, and brain are all extreme and the alcohol exposure is substantial. But the physical, cognitive and behavioral features are not dichotomous, that is either normal or clearly abnormal. Rather, the features, and indeed the history of alcohol exposure, all range along separate continua from normal to clearly abnormal and distinctive.

In the absence of accurate, reproducible and unbiased methods for measuring and recording the severity of exposure and outcome in individual patients, diagnoses continue to vary widely from clinic to clinic. From a clinical perspective, diagnostic misclassification leads to inappropriate patient care, increased risk for secondary disabilities and missed opportunities for prevention. From a public health perspective, diagnostic misclassification leads to inaccurate estimates of prevalence. Inaccurate estimates thwart efforts to allocate sufficient social and health care services to this high-risk population and preclude accurate assessment of primary prevention intervention efforts. From a clinical research perspective, diagnostic misclassification reduces the power to identify important contrasts between FAS and control study groups. Non-standardized diagnostic methods limit the ability to compare outcomes between studies.

In 1997 the FASD 4-Digit Diagnostic Code was developed. The four digits of the diagnostic code reflect the magnitude of expression of four key diagnostic features of FAS in the following order: (1) growth deficiency, (2) the FAS facial phenotype, (3) brain dysfunction, and (4) gestational alcohol exposure. The magnitude of expression of each feature is ranked independently on a 4-point scale with 1 reflecting complete absence of the FAS feature and 4 reflecting a strong "classic" presence of the FAS feature. Each rank is specifically case-defined.
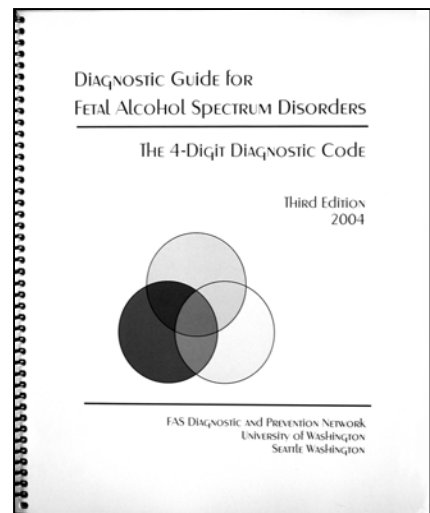
4-Digit Diagnostic Code Grid				
	3	4	4	4
Severe 4		X	X	X
Moderate 3	X			
Mild 2				
Normal 1				
	Growth	Face	CNS	Alcohol

The FASD 4-Digit Diagnostic Code:

1. Greatly increases diagnostic precision and accuracy through the use of objective, quantitative measurement scales and specific case definitions.

2. Better characterizes the full spectrum of disabilities of alcohol-exposed individuals who do and do not have FAS.

Lip-Philtrum Guide 1

Diagnostic Guide for Fetal Alcohol Spectrum Disorders

The 4-Digit Diagnostic Code

Third Edition 2004

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Prevention

*A*lthough 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. Primary prevention refers to preventing the birth of children damaged by prenatal alcohol exposure. One such population is women who have already given birth to a child with FAS.

A 5-year, FAS primary prevention study was conducted in Washington State from 1992 through 1997 to: 1) assess the feasibility of using a FAS Diagnostic and Prevention Clinic as a center for identifying and targeting primary prevention intervention to high-risk women, 2) generate a comprehensive, lifetime profile of these women and 3) identify factors that enhanced and/or hindered their ability to achieve abstinence or effective family planning.

Comprehensive interviews were conducted with 80 women who had given birth to a child with FAS to document their sociodemographics, reproductive and family planning history, social and health care utilization patterns, adverse social experiences, social support network, alcohol use and treatment history, psychosocial profile and intelligence quotient.

This high-risk population of women was diverse in racial, educational and economic background, was often victims of abuse, and was challenged by multiple mental health disorders. Despite their harsh psychosocial profile, many demonstrated the ability to overcome their alcohol dependence over time.

The women who had achieved abstinence had significantly higher I.Q.s, higher household incomes, larger more satisfactory social support networks, were more likely to report a religious affiliation and were more likely to be receiving mental health treatment for their mental health disorders than the women who had not achieved abstinence. The rate of unintended and alcohol-exposed pregnancies was substantial. Key barriers to effective family planning were alcohol and drug use, lack of access to birth control and lack of support by their partner to use birth control.

This study demonstrated women at high risk for producing children damaged by prenatal alcohol exposure can be identified through a FAS DPN clinic. Primary prevention programs targeted to this population could lead to measurable reductions in the incidence of FAS. This study led to the establishment of the FAS DPN First Bridges Program that provides birth mothers with linkage to community primary prevention services.
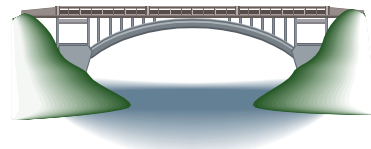
Evidence of Success

FAS was first identified in Washington State in 1973. Statewide prevention efforts over the past 30 years have spanned the full continuum from public health education to drug/alcohol treatment for high-risk women. There is now evidence that these efforts are paying off. PRAMS data confirms the prevalence of maternal drinking during pregnancy in Washington State has significantly declined from 1993 through 1998. The FAS DPN FAS Screening Program has also documented a significant decline in the prevalence of FAS among children in foster care born between 1993 to 1998.

Training & Education

*T*he University of Washington FAS DPN

Core Clinic serves as a training and education center for professionals nationwide. The Core Clinic provides two formal training programs.

1. One-Day Training: This training is conducted weekly and provides an overview of current assessment, diagnostic and treatment strategies for the full spectrum of fetal alcohol disorders. The day begins with a didactic lecture followed by direct observation of two diagnostic evaluations at the Center on Human Development and Disability. This training is targeted to community health and social service professionals. Participants learn what FAS is, how it is diagnosed, who benefits from a diagnostic evaluation, what services the Washington State FAS DPN provides and how to utilize them, and what their role is in the referral, diagnostic and service provision process for these patients and their families. This training is provided at no cost. Several thousand students and professionals have been trained to date.

2. Two-Day Training: The two-day training course is conducted biannually and introduces multidisciplinary clinical teams to the methods used by the Washington State FAS DPN to screen, diagnosis and prevent FAS. A typical multidisciplinary team includes a physician, psychologist, speech/language pathologist, occupational therapist, and family/maternal advocate. The training includes didactic lectures, observation of a diagnostic evaluation and hands-on practice sessions. The clinical teams learn how to conduct a multidisciplinary clinic using the FAS 4-Digit Diagnostic Code. Over 70 clinical teams have been trained across the U.S. and Canada.
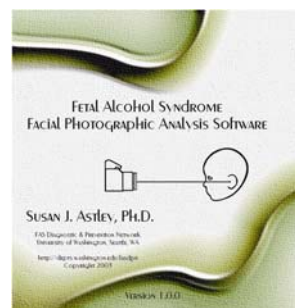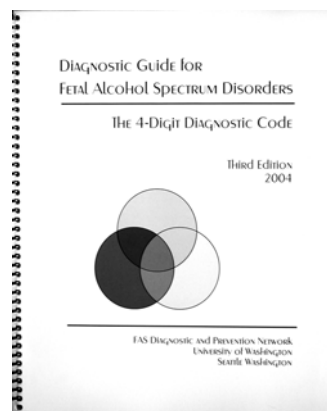

FAS DPN multidisciplinary diagnostic teams

Training Materials

The FAS DPN has created and distributes the following training/educational materials:
- FASD Diagnostic Guide
- Lip-Philtrum Pictorial Guides
- FAS Tutor CD-ROM
- FAS Facial Photographic Analysis Software

These materials and further information on training are available on the FAS DPN website
   http://depts.washington.edu/fasdpn

Research

*T*he FAS DPN is committed to the practice of evidence-based medicine and establishment of best practices. The research staff at the FAS DPN have been engaged in laboratory, clinical, and public health research for over 20 years. Key FAS DPN research publications can be downloaded directly from the FAS DPN website:

http://depts.washington.edu/fasdpn

Database / Research Registry

The FAS DPN core site at the University of Washington maintains one of the world's largest and most comprehensive, confidential databases on all patients evaluated at the FAS DPN. This database was established with patient consent and Human Subjects Review Board approval. Over 1,000 fields of data have been collected on several thousand patients. The data allows the FAS DPN to:

1. Track regional demand for services and diagnostic outcomes over time.

2. Develop new state-of-the-art screening and diagnostic tools.

3. Support intervention research that could directly benefit patients and their families.

Facial Photographic Image Analysis Lab

The FAS DPN Photographic Image Analysis Laboratory provides computerized facial photographic analysis for clinical and research teams around the world. The photographic archive contains over 13,000 fully-analyzed digital facial photographs on over 4,200 individuals.

Intervention Research

The FAS DPN is currently funded by the CDC to evaluate the effectiveness of two interventions targeted to school-aged children with cognitive/behavioral problems and prenatal alcohol exposure. One study will provide individualized, supportive, behavioral consultation intervention for the parents and school staff of these children. The second study will provide a school-based, social communication intervention for children targeting critical deficits in their social communication and peer relations. The effectiveness of these interventions will be assessed through two randomized control trials on a total of 128 children.

Brain Research

The FAS DPN is currently funded by the NIAAA to use magnetic resonance imaging (MRI), magnetic resonance spectroscopy (MRS) and functional magnetic resonance imaging (fMRI) to determine if prenatal alcohol-exposed children, with and without FAS, who present along the full continuum of mild to severe cognitive/behavioral dysfunction, have alterations in brain structure, chemistry and metabolism. Such alterations would serve as irrefutable evidence of organic brain damage. If non-invasive techniques such as MRI/S or fMRI can be used to confirm the presence of organic brain damage in these patients, then diagnostic accuracy would be substantially improved especially among alcohol damaged individuals who do not meet the criteria for FAS.

Meeting the Challenge

*T*he FAS DPN is committed to working

with families and professionals in the worldwide effort to prevent FAS.

While the challenges may be great, the benefits to the children, their families and society are immeasurable.

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