

Application of the fetal alcohol syndrome facial photographic screening tool in a foster care population

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We determined the prevalence of fetal alcohol syndrome (FAS) in a foster care population and evaluated the performance of the FAS Facial Photographic Screening Tool. All children enrolled in a Washington State Foster Care Passport Program were screened for three conditions: (1) the FAS facial phenotype from a photograph, (2) evidence of brain damage with prenatal alcohol exposure from their Health and Education passport, and/or (3) other syndromes identifiable from a facial photograph. Screen-positives received diagnostic evaluations at a FAS Diagnostic and Prevention Network clinic. The prevalence of FAS in this foster care population was 10 to 15/1000, or 10 to 15 times greater than in the general population. The screening tool performed with 100% sensitivity, 99.8% specificity, 85.7% predictive value positive, and 100% predictive value negative. We conclude that the foster care population is a high-risk population for FAS. The screening tool performed with very high accuracy and could be used to track FAS prevalence over time in foster care to accurately assess the effectiveness of primary prevention efforts. (*J Pediatr* 2002;141:712-7)

Fetal alcohol syndrome (FAS), a permanent birth defect caused by maternal consumption of alcohol during pregnancy, is characterized by growth deficiency, central nervous system dysfunction, and a unique cluster of minor facial anomalies.^{1,2} FAS is the leading known cause of mental retardation in the Western world³ and is entirely preventable.

Primary prevention of FAS and prevention of secondary disabilities (eg,

school/job failure, depression, trouble with the law) among persons with FAS are paramount. With the development of the FAS Facial Photographic Screening Tool,^{1,4} the creation of the FAS 4-Digit Diagnostic Code^{2,5,6} and the establishment of the Washington State FAS Diagnostic and Prevention Network (FAS DPN) of clinics,^{7,8} FAS screening, diagnosis and prevention are now being effectively and efficiently conducted in Washington State.

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Targeting FAS prevention efforts to high-risk populations is an efficient and effective use of limited resources. Children in foster care serve as an ideal population to target. First, the risk of FAS in this population is likely to be high; as much as 75% of children in foster care have a family history of mental illness or drug or alcohol abuse.⁹ Foster children comprised 2 to 5 times the normative percent of children below the 5th percentile for height and weight.^{9,10} Devel-

95% CI	95% Confidence intervals
DCFS	Division of Children and Family Services
DPN	Diagnostic and Prevention Network
DSHS	Department of Social and Health Services
EPSDT	Early, periodic screening, diagnosis, and treatment
FAE	Fetal alcohol effect
FAS	Fetal alcohol syndrome
FCPP	Foster Care Passport Program
OFC	Occipital frontal circumference
PHN	Public health nurse

opmental disabilities and mental health diagnoses are also disproportionately prevalent in foster children.^{9,11} Second, early diagnosis helps reduce the risk of secondary disabilities.¹² 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.

The primary objectives of this project were to: (1) screen all eligible children

in out-of-home care, enrolled in the Region 4 (King County) Foster Care Passport Program (FCPP), for the FAS facial phenotype, structural or neurologic evidence of brain damage with confirmed prenatal alcohol exposure, and/or other syndromes identifiable from a facial photograph; (2) provide all children who screen positive with comprehensive diagnostic evaluations and treatment plans through the FAS DPN of clinics; (3) determine the prevalence of FAS in this foster care population; and (4) evaluate the performance of the FAS Facial Photographic Screening Tool in a population-based sample.

METHODS

This FAS screening was a collaborative effort between the University of Washington FAS DPN, the Washington State Department of Social and Health Services (DSHS), Children's Administration, Division of Children and Family Services (DCFS), Region 4, and Public Health—Seattle and King County.

Subjects

All children who were legally dependent with the state of Washington and enrolled in the Region 4 FCPP on or after March 1, 1999 in King County, Washington, were eligible to participate in this screening. To be enrolled in the FCPP, a child had to be: (1) legally supervised by DCFS; (2) 0 to 12 years of age at the time of enrollment, but were able to remain in the program after their 12th birthday; (3) dependent; and (4) in out-of-home placement. Throughout this report, the term "foster care" will refer to children in out-of-home care that includes children in foster care or in the care of their relatives. Up to 500 children enter this FCPP annually.

To maximize the efficiency of the FAS Screening program, the screening was incorporated into an already established state program, the FCPP. The FCPP uses information regarding services already provided to children who receive

Medicaid-covered health services, such as early, periodic screening, diagnosis, and treatment (EPSDT) examinations, as well as other health care information, to provide a comprehensive health picture of each enrolled child. Children who remain in out-of-home placement for 90 consecutive days are automatically referred through the DSHS information system to the FCPP. A public health nurse (PHN) and a health program assistant work as a team to seek out and gather all available health history information (from birth to present) for each child enrolled in the program. The PHN interprets and enters all information into a computerized Health and Education database. A shortened summary (a Health and Education "passport") is provided with health recommendations to the social worker and the foster parent to share with the child's health care provider(s). Each child's passport is updated every 6 months. By nesting the FAS screening into an already existing program, the screening program had access to a computer-generated eligibility list, current names and addresses of all foster parents and caseworkers, and a concise summary of the child's health/educational history. When the screening was complete, the child's screening and diagnostic outcomes, as well as their electronic facial photograph, were entered into the Health and Education Database and case file. This provided immediate and broad access to this information for future medical/social service care and placement decisions. This screening activity was approved by the Human Research Review Boards of Washington State and the University of Washington.

Enrollment

The FCPP identified all eligible children, obtained written consent from the child's legal guardian (DCFS social worker), sent the child's foster parents a letter that explained the purpose and process of the FAS screening, and sent the FAS DPN the list of all newly eligible, consented children, weekly. The

FAS DPN scheduler called each foster parent to schedule a photography appointment with one of the two FAS DPN photographers.

Facial Photograph and Head Circumference

Two University of Washington students were trained to take three standardized facial photographs (frontal, $\frac{3}{4}$ view and lateral) by using a handheld, 3-megapixel, digital camera. The guidelines of Astley and Clarren¹⁶ and the FAS Tutor CD ROM¹⁷ were followed. The photographers were also shown how to measure the child's head circumference (occipital frontal circumference (OFC)). During a 20-minute photography session at the child's foster home, the photographer took the standardized photographs, one casual portrait photograph (to give to the child as a way of thanking them and assuring them they were a fine looking child) and the OFC. The photographers transferred the photographic images and OFC measures to the University of Washington FAS DPN image analysis laboratory weekly.

A small proportion (20%) of the children had foster placements with relatives who lived outside King County or outside Washington State. These families were sent a disposable camera with a one-page pictorial instruction sheet for how to take the three standardized photographs. A stamped, addressed envelope was enclosed for them to return the camera. Parents were not requested to measure their child's OFC. We relied on OFC measures in the child's passport, when available. The FAS DPN scanned the photos to generate electronic image files. On occasion, a second camera had to be sent to the family because the lower resolution of the photos from the disposable camera were not of sufficient quality to provide an accurate screen.

Review of the Foster Care Health and Education Passport

All passports were reviewed by S. J. A. The passport was used to screen for structural or neurologic evidence of

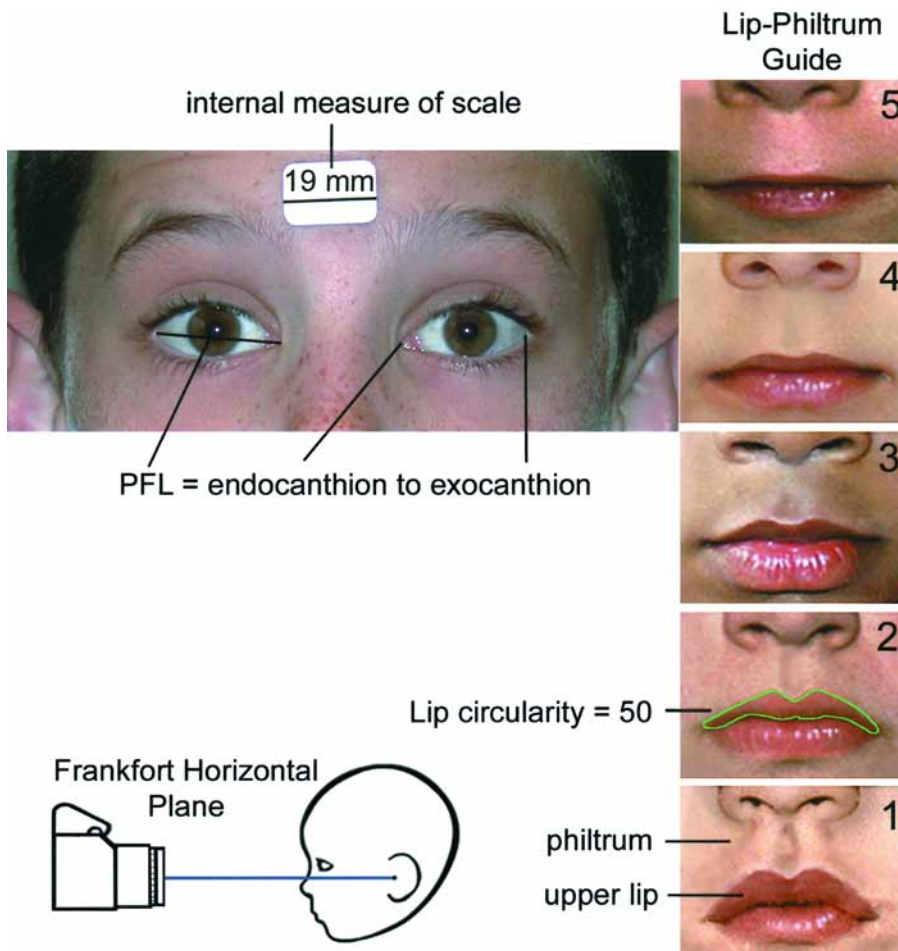


Figure. A standardized, digital, frontal facial photograph is taken while aligning the center of the camera lens in the patient's Frankfort horizontal plane (a plane extending from the patient's upper margin of the external auditory meatus [porion] through the lowest margin of the lower bony orbital rim [orbitale]). An internal measure of scale (19 mm paper sticker) is placed between the patient's eyebrows to serve as a ruler or internal measure of scale in the photo. Three facial features are measured: (1) the palpebral fissure length (PFL) or distance between the endocanthion and exocanthion landmarks, (2) philtrum smoothness, and (3) upper lip thinness. The PFL is converted to a Z score (or number of SD above or below the norm) by using appropriate normal anthropometric tables.¹⁹ The philtrum is ranked using the 5-point Likert scale depicted on the Lip-Philtrum Guide. The upper lip is first outlined with the computer mouse to generate a quantitative measure of thinness called circularity ($\text{perimeter}^2/\text{area}$). It is then ranked on the 5-point Likert scale depicted on the Lip-Philtrum Guide by using circularity as a guide. The circularity of each upper lip pictured on the Lip-Philtrum Guide is: Rank 5 = 178, Rank 4 = 85, Rank 3 = 65, Rank 2 = 50, and Rank 1 = 35.

brain damage (seizures, microcephaly, abnormal brain magnetic resonance imaging/computed tomography/positron emission tomography scans, neurologic disorders) and documentation of prenatal alcohol exposure, and to generate a clinical profile of the screened population. The clinical profile served to describe the study population and assess the performance of the photographic screening tool. When screening a population-based sample, one rarely gets the opportunity to assess the screen-negative

subjects to confirm they were truly negative. The passports provided an invaluable opportunity to review the medical histories and prenatal exposures of all screen-negative children to determine if any of the three remaining key diagnostic features of FAS (growth deficiency, brain dysfunction, and prenatal alcohol exposure) were present in a child.

Facial Photographic Assessment

Image analysis software¹⁸ was used to measure the magnitude of expression of

the FAS facial phenotype (short palpebral fissure lengths, smooth philtrum, and thin upper lip) from the digital images (Figure). Briefly, the image is presented on a computer monitor, the three facial features are measured, and the magnitude of expression of the FAS facial phenotype is classified into one of 4 case-defined categories; normal, mild, moderate, or severe.¹⁶ The photographs were also reviewed by a dysmorphologist for the presence of other minor and/or major anomalies that may or may not be part of another syndrome. Assessment of the photographs took approximately 10 minutes per child.

Screen-Positive Definition for FAS

A child was screened positive for FAS if all three of the following features were present in their facial photograph: (1) palpebral fissure lengths were >2 SD below the mean,¹⁹ (2) the philtrum was smooth (Likert rank 4 or 5 on the 5-point Lip-Philtrum Guide), and (3) the vermilion border of the upper lip was thin (Likert rank 4 or 5 on the 5-point Lip-Philtrum Guide [circularity ≥ 75]) (Figure).^{4,16} Confirmation of prenatal alcohol exposure was not required at the time of the screening because this facial phenotype is so highly specific to prenatal alcohol exposure.⁴ Confirmation was sought at the time of diagnosis. This case-definition of the facial phenotype was derived analytically by Astley and Clarren⁴ and matches the original 1979 definition by Smith.²⁰

Screen Positive Definition for Structural or Neurologic Evidence of Brain Damage with Prenatal Alcohol Exposure

A screening tool to accurately identify persons at risk for fetal alcohol effects (FAE) does not exist because cognitive/behavioral dysfunction associated with prenatal alcohol exposure is not sufficiently specific to prenatal alcohol exposure to clinically label the outcome as a specific FAE. It is for that reason that FAE is not a medical-

ly recognized diagnosis.^{21,22} The number of persons with brain damage caused by prenatal alcohol exposure who do not have FAS far exceeds the number of persons with FAS. Current medical technology simply cannot confirm that a patient's brain damage/dysfunction was caused by their prenatal alcohol exposure when the patient does not have the FAS facial phenotype. But identification and treatment of persons with brain damage does not require confirmation of etiology. Prenatal alcohol exposure and structural/neurologic evidence of brain damage are clear risk factors for brain damage/dysfunction. If prenatal alcohol exposure *and* structural or neurologic evidence of brain damage (microcephaly, seizures of unknown origin, abnormal brain image) were present, the child was screened positive for static encephalopathy/alcohol exposed. Confirmation of prenatal alcohol exposure at the time of the screening was required because a secondary goal of this study was to identify birth mothers at high risk of exposing future children to damaging levels of prenatal alcohol exposure.

Procedure Followed When a Child Screened Negative

An FAS screen-negative medical note and the child's portrait photographs were sent to the FCPP and the foster parents. The medical note included the statement that a child could still have problems related to prenatal alcohol exposure that will not show up in a facial photograph; thus if they had concerns about the child's growth or development, they should talk with the child's health care provider.

Procedure Followed When a Child Screened Positive for FAS and/or Brain Damage/Alcohol Exposed

When a child screened positive for either FAS or structural/neurologic evidence of brain damage with confirmed prenatal alcohol exposure, the follow-

ing documents were sent to the FCPP: (1) a standardized screen-positive medical note, (2) an FAS DPN clinic registration packet, and (3) copies of the child's portrait photograph. The FCPP notified the social worker, entered the screen-positive results in the Health and Education database, updated the passport and health recommendations, completed the FAS DPN registration packet, and provided the social worker with an updated passport packet for the DCFS file, along with the FAS DPN registration packet. The foster parents were initially informed of the screen-positive outcome by the FCPP PHN. The foster child, accompanied by his/her foster parents and caseworker, was subsequently scheduled for a diagnostic evaluation at the FAS DPN clinic where he/she received a comprehensive diagnostic evaluation and treatment plan by the multidisciplinary team using the 4-Digit Diagnostic Code.^{2,23}

Procedure Followed When a Child Screened Positive for Other Facial Anomalies/Syndromes

When the dysmorphologist identified other minor/major craniofacial anomalies that were either consistent with another syndrome or warranted further follow-up, the child's medical record was reviewed and the child was referred to a clinical geneticist or craniofacial clinic, if appropriate. Information, in the form of a medical note, was sent from the FAS DPN to the FCPP. All information received by the FCPP was entered into the database. Updated passports and health recommendations were supplied to the foster family as well as the assigned social worker, including any recommendations for further evaluation.

Data Analysis

The prevalence of FAS (number of children with FAS/number of children screened) with 95% confidence intervals (95% CI) was computed. A binomial test was used to determine if the

observed prevalence of FAS in this foster population was significantly different from the estimated prevalence of 1 to 3 per 1000 live births reported in the general population.²⁴

RESULTS

Sociodemographics and Participation Rate

In this ongoing screening activity, 793 children were eligible to participate between March of 1999 and September of 2001. Of these 793 children, 592 have been screened to date, 8 had already received an FAS diagnostic evaluation before the screening program, 129 are in the process of being screened, 10 chose not to participate, and 54 left foster care before completing the screening. The diagnostic outcomes of the 8 children were combined with the screening outcomes of the 592 children to serve as the study population of 600 children for this first screening program assessment. The 600 children were on average 5.8 ± 4.1 SD years of age at the time they were screened, 48% were female, 48% were white, 32% were black, 12% were Native American, 15% had documented prenatal alcohol exposure, and 32% had documented prenatal drug exposure. The 64 children who did not participate in the screening were nearly identical in profile to the 600 who did participate. The participation rate to date is 98.6%. Only 10 families of 739 chose not to participate.

FAS Screen-Positive Outcomes

Of the first 600 children screened to date, 10 screened positive for FAS. They were 5.5 ± 3.1 years of age (range, 1.1-11.4 years), 30% female, 40% white, 20% black, and 10% Native American. Nine of the children had confirmed prenatal alcohol exposure; one, still pending review, has a family history of alcohol abuse. Four of the 10 children who screened positive for FAS had microcephaly and only one was significantly growth deficient

(height and weight <3rd percentile). Six had documented prenatal exposure to illicit drugs. Diagnostic evaluations have been conducted on 7 of the 10 children to date in this ongoing screening. Six of the seven received a diagnosis of FAS. The 7th child had the full facial features, attention deficit-hyperactivity disorder, poor adaptation skills, borderline concerns in visual-motor integration and soft neurologic signs, significant impairment in academics, and prenatal alcohol exposure. This profile fell just short of a full diagnosis of FAS using the 4-Digit Diagnostic Code. He received a diagnosis of sentinel physical findings/neurobehavioral disorder/alcohol exposed. None of these 7 children had been previously diagnosed with FAS. A one-year old child who screened positive for the FAS facial phenotype also had Down syndrome. This child was subsequently diagnosed with FAS (4-Digit Diagnostic Code 4444), presenting with height and weight <1% when plotted on a growth chart for children with Down syndrome, microcephaly and daily exposure to alcohol throughout gestation.

Estimated Prevalence of FAS

Due to the ongoing nature of this screening, 3 of 10 screen-positive children have not yet received diagnostic evaluations. Thus, the prevalence of FAS will fall between the following minimum and maximum estimates. If none of the three remaining children receive a diagnosis of FAS, the prevalence of FAS in this foster care population will be 6 of 600 or 10 of 1000 (95% CI, 5-22 per 1000). If all three receive a diagnosis of FAS, the prevalence of FAS will be 9 of 600 or 15 of 1000 (95% CI, 8-28 per 1000). Both of these FAS prevalence estimates are statistically significantly greater (binomial test: P values < .001) than the FAS prevalence estimate of 1 to 3 per 1000 live births in the general population reported by the National Institute of Alcohol Abuse and Alcoholism.²⁴

Screen Positive for Structural or Neurologic Evidence of Brain Damage with Prenatal Alcohol Exposure, But Did Not Have the FAS Facial Phenotype

Fifteen (2.5%) of the 600 children screened positive for structural or neurologic evidence of brain damage with prenatal alcohol exposure, but did not have the FAS facial phenotype. They were 5.0 ± 3.6 years of age (range, 0.7-13.3 years), 47% female, 40% white, and 20% black. Three had seizure disorders of unknown origin and 12 had microcephaly. Nine of the 15 children have been diagnosed to date. All 15 currently meet the FAS DPN diagnostic criteria for static encephalopathy/alcohol exposed. Four of the 9 currently diagnosed also have growth deficiency.

Other Anomalies/Syndromes

Eight of the 600 (1.3%) children presented with other clusters of minor and/or major facial anomalies (including two with Down syndrome). They were 38% white, 38% black, 24% Native American, 63% female, and ranged in age from 0.6 to 10.1 years. All but two of the children had been previously identified and were receiving appropriate care. Two of the 8 had prenatal alcohol exposure, including one of the two with Down syndrome. The FAS facial analysis system clearly differentiated the two children with Down syndrome who did and did not have FAS.

Performance of the FAS Facial Photographic Screening Tool

Based on the seven screen-positive children with completed diagnostic evaluations and the 590 screen-negative children, the predictive value positive for the FAS photographic screening tool is 6 of 7 or 85.7%.²⁵ The predictive value negative for the screening tool is 590 of 590 or 100%. The sensitivity of the screening tool in this population-based sample is 6 of 6 or 100%. The specificity of the screening tool in this population-based sample is 590 of 591 or 99.8%. The accuracy of the tool is

596 of 597 or 99.8%. Unlike most population-based screening programs, this program had the unique ability to confirm that the 590 screen-negatives were true negatives. This confirmation was possible because the tool used to screen for the FAS facial phenotype is the same tool used to diagnose the facial phenotype in clinic.

DISCUSSION

This FAS screening program confirmed that foster care is a high-risk population for FAS, that screening for FAS in this population can be done accurately, efficiently, and with direct benefit to the children and their families, and that the FAS DPN Facial Photographic Screening Tool performs with high accuracy in a population-based sample.

During the course of this screening activity, several additional observations were made that further support the merits of FAS screening in a network of affiliated clinics. First, there was an unexpected opportunity to demonstrate that screening can lead to both primary and secondary prevention intervention for FAS. One child who screened positive for FAS returned to the care of their birth mother before the diagnostic evaluation. The birth mother willingly accompanied her child to the diagnostic appointment and received support and treatment referrals tailored to meet her needs as well as those of her child. Second, if a child's disabilities are fully known and disclosed at the time of placement, the risk of multiple failed placements could be reduced. This was observed in two children who screened positive for FAS, both of whom had multiple failed placements before diagnosis and have maintained a single successful placement since receipt of their diagnoses. Third, although the primary focus of this screening was on FAS, this activity led to increased awareness and understanding by foster parents and caseworkers of the risks of prenatal al-

cohol exposure among all children, not just children with the FAS facial features. This, in turn, led to an increase in appropriate referrals of children to the FAS DPN clinics who had prenatal alcohol exposure, cognitive/behavioral problems, but screened negative for FAS. Finally, the value of a national network of FAS DPN clinics was demonstrated when one child who screened positive for FAS lived 1600 miles outside Washington State, but was readily diagnosed by an affiliated FAS DPN multidisciplinary clinical team just a few miles from where the child lived.

The next step for the FAS DPN screening program will be to track the annual change in prevalence of FAS in this foster care population to assess the effectiveness of community FAS primary prevention efforts. Statewide expansion of the screening is also being explored. The screening program was both cost-effective and time efficient in large part because of nesting it into an already existing state-run program. Expansion of the screening program will be facilitated by FAS Facial Photographic Analysis software¹⁸ developed by the FAS DPN. The software will allow the user to measure the key facial features from digital photographs and generate a hard copy or electronic outcome report within minutes.

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