Fetal Alcohol Syndrome — Alaska, Arizona, Colorado, and New York, 1995–1997

Fetal alcohol syndrome (FAS) is caused by maternal alcohol use during pregnancy and is one of the leading causes of preventable birth defects and developmental disabilities in the United States (*1*). FAS is diagnosed on the basis of a combination of growth deficiency (pre- or postnatal), central nervous system (CNS) dysfunction, facial dysmorphology, and maternal alcohol use during pregnancy. Estimates of the prevalence of FAS vary from 0.2 to 1.0 per 1,000 live-born infants (*2–4*). This variation is due, in part, to the small size of the populations studied, varying case definitions, and different surveillance methods. In addition, differences have been noted among racial/ethnic populations (*5*). To monitor the occurrence of FAS, CDC collaborated with five states (Alaska, Arizona, Colorado, New York, and Wisconsin*) to develop the Fetal Alcohol Syndrome Surveillance Network (FASSNet). This report summarizes the results of an analysis of FASSNet data on children born during 1995–1997, which indicate that FAS rates in Alaska, Arizona, Colorado, and New York ranged from 0.3 to 1.5 per 1,000 live-born infants and were highest for black and American Indian/Alaska Native populations. This study demonstrates that FASSNet is a useful tool that enables health care professionals to monitor the occurrence of FAS and to evaluate the impact of prevention, education, and intervention efforts.

FASSNet is a standardized, multiple-source FAS surveillance method supported by CDC through cooperative agreements with four state health departments and one university. Surveillance is conducted statewide in Arizona and Alaska and in selected areas of Colorado (Denver-Boulder Consolidated Metropolitan Statistical Area) and New York (nine counties in western New York). FASSNet participants use the same general surveillance methodology, including a common case definition for confirmed and probable FAS (Table 1); multiple sources to identify cases (e.g., hospitals, birth defects monitoring programs, genetic clinics, developmental clinics, early intervention programs, and Medicaid files); a common electronic data abstraction form; and quality assurance procedures to maintain consistency among sites (*6*). The surveillance case definition is based on criteria from the 1996 Institute of Medicine report on FAS (*1*), which were adapted for use by FASSNet by a committee of experts in dysmorphology, psychology, and public health surveillance. Each state used multiple sources to identify potential cases, including *International Classification of Diseases, Ninth Revision* (ICD-9) code 760.71 (newborn affected by alcohol via placenta or breast milk) in hospital discharge data sets or birth defects monitoring programs, specialty clinic records of prenatal alcohol exposure or suspected FAS, and health-care provider referral of children to a state FASSNet program. Case status was determined electronically through application of computer algorithms (derived from the surveillance case definition) by evaluating the combined data from all abstracted records for each child.

The analysis included only children who were born during 1995–1997 to a mother then residing in a surveillance area and who, based on medical record information abstracted during June 1998–March 2002, met the surveillance case definition for confirmed or probable FAS (Table 1). The denominator for the prevalence calculations consisted of all births to women residing in the selected surveillance area as determined by birth certificate data. For reporting purposes, the mother's race/ethnicity on the birth certificate was used to classify the child's race/ethnicity.

* Because Wisconsin uses a different surveillance methodology, its data are not included in this report.

TABLE 1. Fetal Alcohol Syndrome Surveillance Network case definition categories

Case definition category	Phenotype positive		
	Face	Central Nervous System (CNS)	Growth
Confirmed Fetal Alcohol Syndrome (FAS) phenotype with or without maternal alcohol exposure*	Abnormal facial features consistent with FAS as reported by a physician or Two of the following: • short palpebral fissures • abnormal philtrum • thin upper lip	Frontal-occipital circumference ≤10th percentile at birth or any age or Standardized measure of intellectual function ≤1 standard deviation below the mean or Standardized measure of developmental delay ≤1 standard deviation below the mean or Developmental delay or mental retardation diagnosed by a qualified examiner (e.g., psychologist or physician) or Attention deficit disorder diagnosed by a qualified evaluator	Intrauterine weight or height corrected for gestational age ≤10th percentile or Postnatal weight or height ≤10th percentile for age or Postnatal weight for height ≤10th percentile
Probable FAS phenotype with or without maternal alcohol exposure*	Required; facial features same as above	Must meet either CNS or growth criteria as outlined above	

* Documentation in the records of some level of maternal alcohol use during the index pregnancy.

Records for 1,489 children were reviewed and abstracted; information was abstracted from more than one record source (including birth certificates) for 1,338 (90%) children who might have FAS. A total of 209 children (14%) met the surveillance case definition for confirmed or probable FAS; 24 (11%) were excluded from the analysis because they were born outside the surveillance area. Of the remaining 185 children with confirmed or probable FAS, 142 (77%) met the confirmed definition, and 43 (23%) met the probable definition. Children with a probable diagnosis were included because they were likely to have FAS given that they met FAS-specific dysmorphic facial criteria and at least one other criterion (e.g., CNS abnormalities or growth retardation). Although health-care provider documentation of maternal alcohol use during pregnancy is not required to meet the confirmed or probable case definition, such documentation existed in at least one abstracted record for 170 (92%) of the 185 children.

The overall 3-year prevalence of FAS varied only slightly in three of the four sites, from 0.3 to 0.4 per 1,000 live-born infants; the prevalence in Alaska was 1.5 (Table 2), due primarily to a high rate among American Indians/Alaska Natives. The highest prevalence rates observed during the surveillance period were among blacks in two states (range: 0.9–1.6) and among American Indians/Alaska Natives in two states (range: 2.5–5.6).

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Editorial Note: This report demonstrates that maternal alcohol use during pregnancy continues to affect children. Recent data indicate that the prevalence of binge (i.e., >5 drinks on any one occasion) and frequent drinking (i.e., >7 drinks per week or >5 drinks on any one occasion) during pregnancy reached a high point in 1995 and has not declined (*7*).

FASSNet prevalence rates are similar to rates published previously from population-based prevalence studies, despite different case definitions and surveillance methods (*2*). These data indicate that children born to mothers in certain racial/ethnic populations have consistently higher prevalence rates of FAS. For example, FAS prevalence was 3.0 per 1,000 live-born infants for American Indians/Alaska Natives during 1977–1992 compared with 0.2 for other Alaska residents during the same period (*4*). FASSNet findings confirm higher prevalence rates among black and American Indian/Alaska Native populations. Alaska health authorities have increased

TABLE 2. Number and prevalence rate* of fetal alcohol syndrome cases, by race/ethnicity — Alaska, Arizona, Colorado†, and New York§, Fetal Alcohol Syndrome Surveillance Network, 1995–1997

	Alaska			Arizona			Colorado			New York			Total		
Race/ethnicity¶	No. births	No. cases	Rate	No. births	No. cases	Rate	No. births	No. cases	Rate	No. births	No. cases	Rate	No. births	No. cases	Rate
White, non-Hispanic	19,007	5	0.3	114,851	15	0.1	63,653	11	0.2	68,932	18	0.3	**266,443**	**49**	**0.2**
Black	1,341	0	—	7,054	4	**	5,508	5	0.9	13,455	21	1.6	**27,358**	**30**	**1.1**
Hispanic	1,287	0	—	80,626	16	0.2	21,579	8	0.4	3,635	0	—	**107,127**	**24**	**0.2**
Asian/Pacific Islander	1,493	0	—	4,371	1	**	2,556	0	—	1,693	0	—	**10,113**	**1**	**
AI/AN††	7,117	40	5.6	15,685	39	2.5	1,744	1	**	627	1	**	**25,173**	**81**	**3.2**
Other/unknown§§	39	0	—	456	0	—	96	0	—	447	0	—	**1,038**	**0**	**—**
Total	**30,284**	**45**	**1.5**	**223,043**	**75**	**0.3**	**95,136**	**25**	**0.3**	**88,789**	**40**	**0.4**	**437,252**	**185**	**0.4**

* Per 1,000 population.
† Denver-Boulder Consolidated Metropolitan Statistical Area.
§ Nine counties in western New York.
¶ Black includes black Hispanic and non-Hispanic; Hispanic excludes black Hispanic.
** Rates were not calculated when the number of cases was <5.
†† American Indian/Alaska Native.
§§ Other non-Hispanic and unknown.

efforts to address this health problem. Increased awareness of maternal alcohol use and more complete documentation by Alaska Native health organizations might result in more vigilant reporting of potential cases of FAS, which could contribute to high reported FAS prevalence in this population (*4*).

The number of children affected adversely by in-utero exposure to alcohol is probably underestimated for at least four reasons. First, some FAS cases might not be diagnosed because of the syndromic nature of the condition, the lack of pathognomonic features, and the negative perceptions of FAS diagnosis. Second, medical records of children with FAS often lack sufficient documentation to determine case status. For example, 10 children diagnosed with FAS by a clinical geneticist, dysmorphologist, or developmental pediatrician did not meet the surveillance case definition for confirmed or probable FAS because documentation in the abstracted medical records was insufficient or the child did not meet FASSNet surveillance case definition criteria. However, adding these 10 children to the total case count would change the overall prevalence only slightly, from 0.43 to 0.45 per 1,000 live-born infants. Third, some children might not be identified as having FAS until they reach school age, at which point CNS abnormalities and learning disabilities are recognized more easily. Because only part of the cohort under surveillance was of school age and education records were not used in this surveillance system, the actual number of cases might have been underestimated. Finally, an unknown number of persons with FAS left the surveillance area before being identified by the surveillance system. Because of the small numbers and differences in sources and awareness among clinicians, prevalence rates across racial/ethnic populations and across states should be compared with caution.

Ongoing, consistent, population-based surveillance systems are necessary to measure the occurrence of FAS and the impact of FAS prevention activities. These systems also are useful in evaluating the need for early intervention and special education services for children with birth defects such as FAS. One of the national health objectives for 2010 is to reduce the occurrence of FAS (objective no. 16-18) (*8*); however, no national surveillance program exists to evaluate progress in achieving this objective. FASSNet data can be used in conjunction with maternal alcohol exposure surveillance system data to monitor trends and identify high-risk populations for targeted prevention efforts.

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