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Fetal Alcohol Syndrome

Prevalence

Risk Factors

Prevention

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Preface

This report summarizes six and a half years of work towards the characterization and prevention of fetal alcohol syndrome in Alaska. We compiled key findings from Alaska's surveillance efforts, analytic studies and alcohol-related surveys to help guide the state's future FAS prevention and research efforts directly from previous publications. This monograph would not have been possible without the energy and dedication of the many individuals whose original work advanced our knowledge of FAS.

We have tried to present accurately the major findings and recommendations from original works conducted in Alaska by the AFASPP and others. We were unable to have this document reviewed prior to publication by all of the AFASPP participants or by other primary authors. The Section of Epidemiology accepts responsibility for the content of this document.

Executive Summary

Birth defects are the leading cause of infant mortality on the United States, accounting for more than 20 percent of all infant deaths. In addition, birth defects are the fifth leading cause of years of potential life lost and contribute substantially to childhood morbidity and long-term disability. Fetal Alcohol Syndrome (FAS) is a leading birth defect that causes significant lifetime disability. Unlike many other birth defects, however, FAS has a known etiology and is preventable.

In 1990, the Centers for Disease Control and Prevention, Indian Health Service, and Department of Health and Social Services established the Alaska Fetal Alcohol Syndrome Prevention Project (AFASPP). As a result of the work done by the AFASPP, Alaska is recognized for its leadership in developing science-based, FAS prevention programs.

PREVALENCE

The overall minimum prevalence of FAS in Alaska ranged from 0.8-1.3 cases per 1,000 live births. The prevalence of FAS among Alaska Natives was 3.0 - 5.2 per 1,000 live births compared to 0.2 - 0.3 per 1,000 live births among non-Natives.

While the higher FAS rates among Alaska Natives compared to non-Natives may be due in part to extensive case finding by the IHS and underascertainment of FAS among non-Natives, Alaska Natives are at higher risk of FAS than non-Natives.

RISK FACTORS

- A large proportion of Alaska's identified FAS children were either adopted or in foster care.
- There is a real risk of mothers of FAS children having multiple FAS children -- 14 mothers had 32 FAS children; one woman gave birth to 4 FAS children and to 3 other children who had a physician notation of FAS in their medical charts. Among the noted problems in their records were physical and sexual abuse, partners with alcohol problems, denial of alcohol problems, alcohol-related emergency room visits, sexually transmitted diseases, involvement with law enforcement officers, suicide gestures, and multiple refusals of alcohol treatment.
- The high prevalence and the characteristics of alcohol consumption among Alaskan women of child-bearing age have important implications.
- Of mothers of FAS children, the majority were unmarried at the time of delivery, many had not completed high school, and most either had no prenatal care or began prenatal care after the first trimester.

PREVENTION RECOMMENDATIONS

- Population-based surveillance of FAS is essential to document the magnitude of the problem, to monitor trends in the occurrence of FAS, and to document the impact of prevention efforts.
- The more that is understood about the women who give birth to FAS and other alcohol-affected children, the better is our ability to target prevention activities to them before they give birth to an alcohol-affected child. The top priority for developing effective prevention is to conduct a risk factor analysis of the women who have given birth to FAS children and the fathers by examining their medical, social, and reproductive histories. DHSS should conduct a maternal risk factor analysis of the biological mothers and fathers of the FAS cases identified through the AFASPP.
- Programs should be targeted at two major strategies:
    1) Reduce alcohol consumption among women of child-bearing age and especially among pregnant women, and
    2) Postpone pregnancy among women who are unable or unwilling to reduce substantially or stop completely alcohol consumption.
- Improve coordination of services and target services to families who are identified through having a child diagnosed with FAS.
- Determine the barriers to treatment for women who have had an alcohol-affected pregnancy.
- DHSS and DOE should conduct an analysis of the relationship of a medical diagnosis of FAS to the need for special education services.

I. Background

Overview

Fetal alcohol syndrome (FAS) is a preventable birth defect which causes a spectrum of lifetime central nervous system impairments including mental retardation, developmental delay, and other cognitive and behavioral abnormalities.

Over 20,000 Alaskan women of childbearing age are self-reported heavy drinkers, and 7% of new mothers in Alaska report having drunk during the third trimester of pregnancy. This has important implications for Alaska, because no universally safe level of alcohol consumption has been determined for pregnant women. Among Alaskan children born 1989-92, at least 18 per year were suspected of or received a clinical diagnosis of FAS.

High economic and societal costs are associated with FAS. In Alaska, minimum Medicaid claims are estimated at $9,000 annually per FAS child. In addition to medical costs, many FAS patients are eligible for Supplemental Security Income (SSI). The 20-year projected SSI cost in Alaska is estimated at $103,000 per person (1993 reimbursement rate). It is believed that these figures represent only a fraction of the total economic burden. A comprehensive study completed outside of Alaska estimated the lifetime cost of both medical treatment and long-term care at $1.4 million per person with FAS (Abel and Sokol, 1987).

Caring for individuals with FAS requires more than tax dollars. The neurological impairments associated with the syndrome often manifest themselves in cognitive and behavioral disabilities which can lead to maladaptive behaviors such as poor judgment, attention deficits, difficulty understanding the relationship between cause and effect, and difficulties in interpreting social cues (Streissguth, et al., 1991). Such outcomes suggest a substantial impact on the state's educational and judicial systems.

Because FAS is a completely avoidable disease with serious individual and societal impacts, a prevention plan is essential. Such a plan must have multiple components. The magnitude of the FAS problem in Alaska must be further assessed and continually monitored. Women at high risk of delivering FAS children must be identified and reached *before* they give birth. The FAS awareness levels of both the general public and health care professionals must be raised. Individuals with FAS must receive the special treatment and attention they need to function productively in Alaskan society. And, appropriate research and programmatic resources must be set to ensure accomplishment of all of the above. This document, and the information it assembles, provides the foundation upon which such future programs can be built.

History of FAS

FAS was first identified as a clinical entity in the United States in 1973 with the publication in LANCET of "Pattern of malformation in offspring of chronic alcoholic mothers," by Jones and Smith who coined the term "fetal alcohol syndrome."

In 1980 the Research Society on Alcoholism through its Fetal Alcohol Study Group standardized the definition for FAS. It had become clear by 1985, however, that the diagnostic criteria or terminology for FAS had not been consistently applied by clinicians or researchers. Therefore, in 1987 the Fetal Alcohol Study Group reevaluated the definition.

In 1989 the Group modified the definition slightly to specify that a child with FAS must manifest signs of abnormality in each of the following categories:

- Prenatal and/or postnatal growth retardation (weight and/or length or height below the 10th percentile when corrected for gestational age);
- Central nervous system impairment, including neurological abnormality, developmental delay, behavioral dysfunction or deficit, intellectual impairment and/or structural abnormalities such as microcephaly;
- A phenotypic face including short palpebral fissures (eye openings), an elongated midface, a long, flat philtrum (groove in the median portion of the upper lip), thin upper lip, and a flat midface.

While these attempts have been made to clarify the terminology used to describe the impact of alcohol on offspring and to enhance the comparability of the results of clinical observations, the diagnosis of FAS remains highly subjective and the application of clinical criteria inconsistent.

Less severe or incomplete expressions of the FAS phenotype have also been classified as Fetal Alcohol Effects (FAE) (Clarren and Smith, 1978). Variations in the amount (or dose) and timing of a fetus'

exposure to alcohol may impact its development of alcohol-related defects. Multiple other factors, including genetic susceptibility, nutritional status and the presence of other toxins (e.g., caffeine, nicotine, marijuana) in the placenta, may also influence the severity of the effects. The existence of FAE is debated, and use of the term as a diagnosis has been discouraged by the Fetal Alcohol Study Group and many of the country's top dysmorphologists.

The most recent attempt to clarify the terminology used came in 1995 when the Institute of Medicine convened a committee to study FAS which issued its report in 1996. One of the committee's key charges was to review and evaluate the diagnostic criteria and terminology used for FAS and related conditions. It recommends the use of five diagnoses for describing FAS and alcohol-related effects:

1. FAS with confirmed maternal alcohol consumption,
2. FAS without confirmed maternal alcohol exposure,
3. partial FAS with confirmed maternal alcohol exposure,
4. alcohol-related effects (ARBD), and
5. alcohol-related neurodevelopmental disorder (ARND).

Challenges

Exposure to alcohol *in utero* can have a wide variety of cognitive, behavioral and morphological effects on the fetus; FAS represents a specific constellation of these defects. Presently, there is no objective test by which FAS cases can be ascertained. Trained dysmorphologists rely on "gestalt", or a general clinical impression, to diagnose the physical expression of FAS (Clarren and Astley, 1995). (This approach becomes increasingly unreliable as less experienced individuals attempt the FAS diagnosis.) Furthermore, CNS involvement and the characteristic facial dysmorphology may not always be evident in FAS cases. Diagnosis in newborns—even ones born intoxicated—is rarely possible since FAS children often do not have the opportunity to display their behavioral abnormalities or mental deficits until they reach school age. By adolescence many FAS children outgrow their characteristic facial features and growth deficits.

Exacerbating the diagnostic challenge is the fact that the normal facial morphology of several racial groups (Asians, Alaska Native) includes some of the features present in FAS (epicanthal folds, wide intercanthal distance, and flattened midface). Also, the severity of FAS conditions (physical and neurological) is not uniform across cases. Critical to accurately diagnosing FAS is a detailed, objective case definition and the ability to examine children during a very specific time period, ideally between the ages of 3 and 10. While the *International Classification of Diseases, 9th Revision* (ICD-9*)* now includes a code for alcohol effects on the fetus, the code is not limited to the specific grouping of effects which constitutes FAS.

In summary, FAS diagnosis remains subject to five major constraints:

- subjectivity inherent in the diagnosis;
- difficulty of diagnosing the syndrome in newborns;
- age difference in the expression of the phenotype;
- variability of the severity of conditions associated with the syndrome; and
- the lack of specificity in the ICD-9 code assigned to FAS.

These diagnostic constraints hinder FAS surveillance efforts, essential for ascertainment of the frequency and distribution of the syndrome as well as for the assessment of and ability to target prevention efforts. No detailed, objective, national case definition or surveillance methodology exists for FAS. Calculating rates, much less comparing these rates across years, geographies or populations, is extremely difficult. The lack of any single data source for case finding further compounds the problem.

Surveillance History

Until the methodology of linking multiple data sources for FAS surveillance was developed in Alaska, no surveillance system had been designed to enumerate the occurrence of the condition in the population. However, the Centers for Disease Control and Prevention (CDC) had been monitoring birth defects since 1976 through the Metropolitan Atlanta Congenital Defects Program (MACDP) and since 1974 through the Birth Defects Monitoring Program (BDMP). Both programs are administered by the Division of Birth Defects and Developmental Disabilities (DBDDD) in the National Center for Environmental Health (NCEH).

In 1974, shortly after FAS had been identified as a clinical entity in the U.S., MACDP added the condition to the list of defects it monitored. MACDP collects information on all live-born and stillborn infants born in the five-county metropolitan Atlanta area. It is designed to track infants with a least one major defect diagnosed within the first year of life. It was not designed to track infants with less distinct anomalies such as FAS.

In 1979 the ICD-9 added the code--760.71--that could be used for FAS. ICD-9 was the first revision of the Code since FAS was recognized as a clinical entity in the U.S.

In 1979, BDMP began collecting information on infants assigned the 760.71 code. BDMP is not a population-based surveillance system. It uses hospital discharge data on newborns in approximately 1,200 participating hospitals nationwide.

The limitations on FAS surveillance by both MACDP and BDMP were not apparent until the Alaska methodology of linking multiple data sources was developed.

The Alaska Fetal Alcohol Syndrome Prevention Project

During the 1980s, clinical and epidemiological interest in FAS increased greatly. While at the time there existed no state-based methodology for the surveillance of FAS, DBDDD sought to improve the surveillance and thereby the prevention of FAS and other alcohol-related birth defects.

Alaska provided the opportunity to develop a comprehensive FAS prevention program addressing the entire population of a state. First, the Alaska Area Native Health Service (AANHS) of the U.S. Indian Health Service (IHS) had developed a statewide FAS prevention program targeting Alaska Natives, and secondly, the Alaska Department of Health and Social Services (DHSS) showed considerable interest in developing an FAS prevention program. (Alaska has one of the highest per capita alcohol consumption levels in the nation, the highest rate of alcohol-related hospitalizations in the country, and has one of the highest rates of heavy drinking among women of reproductive age.)

In 1990 DBDDD conducted a site visit to Alaska to determine the level of commitment by AANHS and DHSS to collaborating with NCEH in the development of a statewide FAS surveillance methodology and prevention program to be used as a model for other states. Out of that site visit came separate Agreements to Cooperate between NCEH and IHS and between NCEH and DHSS. These formal five-year agreements established and funded the Alaska Fetal Alcohol Syndrome Prevention Project (AFASPP). The parties formed a steering committee with representatives from AANHS, DBDDD, DHSS and the Alaska Department of Education (DOE) to provide policy oversight and direction to the Prevention Project.

The AFASPP's charge was to develop a surveillance methodology for monitoring the occurrence of FAS. In doing so, it pioneered the methodology of linking multiple data sources. It identified several constraints on FAS surveillance. It documented that the ICD-9 code of 760.71 lacked specificity for FAS surveillance, and demonstrated the need for a surveillance case definition for FAS. The Project also evaluated the usefulness of the 16 different data sources it utilized, demonstrating that birth certificates and hospital discharge data are unreliable sources for surveillance of FAS.

Additional AFASPP efforts have included the demographic and clinical characterization of FAS children and their mothers, the administration of a public awareness survey, and the administration of a survey of health care professionals' alcohol and FAS-related knowledge, attitudes, beliefs and behaviors. A joint DHSS/DOE study of the FAS diagnosis' ability to predict children's special education needs is currently underway.

II. Descriptive Epidemiology of FAS

FAS Case Definition

Establishing a case definition enables the objective and reproducible collection of epidemiologic information. Once explicit and objective diagnostic criteria for a disease have been established, the actual number of cases can be tracked over time and populations. Since no operational, nationwide case definition for FAS surveillance exists, the AFASPP, in consultation with FAS experts, developed its own surveillance definition. Adding to the Research Society on Alcohol's criteria, the AFASPP specifies an FAS case must have medical chart mentions of each of the following:

- any chart notation of FAS by a physician;
- prenatal alcohol exposure or a maternal history of alcohol abuse;
- medical chart notation of at least one characteristic fetal alcohol syndrome facial feature or a comment "stigmata";
- growth deficiency; and
- central nervous system impairment.

The AFASPP definition further details that characteristic facial features include a physician notation of fetal alcohol syndrome stigmata or any of the following: short palpebral fissures, long or flat philtrum, thin upper lip, hypoplastic maxilla (underdeveloped/flattened upper jaw/midface), short nose relative to normal length midface, or flat nasal bridge. Growth deficiency is defined as height or weight less than or equal to the tenth percentile for a given age. Evidence of central nervous system impairment includes any of the following: structural abnormalities (microcephaly or hydrocephaly), other neurologic anomalies (seizures, abnormal EEG, hypertonia, cerebral palsy, tremors, hearing deficits of neurosensory origin, or microphthalmia), or behavioral or cognitive anomalies (mental retardation, hyperactivity, short attention span or attention deficit disorder, learning disability, developmental delay [including fine or gross motor delay or speech or language delay], behavior or conduct problems, or school failures).

Limitations

Underdiagnosis, underreporting of diagnosis and the potential for differentially diagnosing FAS across populations can lessen a case definition's specificity, or ability to capture all true cases (Cordero et al., 1994). The possibility of all three of these limitations should be recognized in the AFASPP case definition. As discussed, the diagnosis of FAS is problematic and may often depend on subjective impression or "gestalt". Also, the ICD-9 code is non-specific, further complicating surveillance based on medical record systems. The potential stigma associated with the FAS diagnosis may contribute to underdiagnosis. The inclusion of documented prenatal alcohol exposure in the FAS case definition may also impact the specificity of the definition: the AFASPP provider survey revealed that a significant portion of doctors do not always report maternal alcohol use, even when alcohol abuse is known or strongly suspected.

FAS in Alaska, due to IHS's efforts, has been a focus in the Native population longer than it has been among non-Native practitioners. Consequently, differing awareness levels among practitioners could lead to a different likelihood of FAS diagnosis among Native and non-Native children. Since the AFASPP case definition relies on available medical charts and the thoroughness of physicians' notations within them, it is almost certain that the actual number of cases detected represents a *minimum* count. While this result is not ideal for total cost or total prevalence estimates, it does permit, as much as possible, a consistent comparison of relative rates over time and peoples. A more lenient case definition may capture a greater number of FAS cases, but it would simultaneously capture more noncases, reducing the diagnostic accuracy, or positive predictive value, of the definition.

A common limitation of surveillance case definitions is that they do not capture all of the true cases of the condition in a particular population of interest (Cordero et al., 1994). The AFASPP utilized multiple datasets plus screening activities to assure a population-based effort attempting to identify all cases within the population rather than extrapolating from a sample of datasets. FAS rates reported for Alaska should be more representative than current surveillance activities in other states, the BDMP, and the MACDP.

FAS-Noted

Bearing in mind the potential limitations of a chart-verified FAS case definition, the AFASPP also cataloged all individuals who had any chart mention of fetal alcohol syndrome (whether or not they had the other FAS criteria). These cases are classified as "FAS-noted," and may represent the upper-bound of the actual FAS case count.

Data Sources and Collection Methods

In the rigorous AFASPP surveillance effort begun in 1991, FAS and FAS-noted cases were actively sought from three major sources: the private medical sector, the State of Alaska programs and services, and Alaska Native-specific services and corporations (Table 1). Overall, sixteen individual practices, services and corporations were examined. (Non-Native sources were eligible to be identified in 13 of the 16 data sources.) Where sources had computerized ICD-9 data, searches were made for code 760.71 (noxious influence of alcohol on fetus or newborn via placenta or breast milk) or, if categorized on a more aggregate level, code 760.7 (any noxious influence affecting fetus or newborn). The range of years searched varied by source due to different program initiation dates or variability of data.

Table 1. Sources of data and methods of identifying potential FAS cases in AK

Source of Data	Method of Identifying Potential FAS Cases
Private Sector	
Hospitals	
Anchorage and Fairbanks	ICD-9 code 760.71 on discharge data tapes from 1988-1992. (Largest and fourth largest hospitals in the state.)
Pediatricians	
Anchorage	List of potential FAS patients served in 1993.
Fairbanks	List of FAS/alcohol-exposed patients served from 1990-1992.
State of Alaska[a]	
Infant Learning Program	Potential FAS children 0-3 years of age seen in 1991-1992.
Health Care Program for Children w/Special Needs (HCP-CSN)	ICD-9 code of 760.71 on data tape of program recipients age 0-21 years served in 1992.
Clinic, Cleft lip & palate	Potential FAS children evaluated from 1983-1993.
Clinic, Genetics	Potential FAS children evaluated from 1977-1992.
Clinic, Alcohol-exposed children	Children evaluated from 1992-1993.
Rural Nursing Station	Potential FAS children identified in a public health nursing caseload in 1993.
Medicaid Claims	ICD-9 code of 760.71 on tapes from 1989-1990.
Birth Certificates	FAS check box on certificates filed from 1989-1990.
Death Certificates	ICD-9 code 760.7 as contributing/underlying cause of death from 1977-1990.
Alaska Native Data Sources	
IHS[b] Case File	Patients seen for an alcohol-related diagnosis during 1985-1993. Statewide active screening in 1986 followed by ongoing active screening in Anchorage area and passive reporting from 12 autonomous regional Native Health Corporations.
2 Regional Native Health Corporations (serving the Interior and Southeast regions of Alaska)	ICD-9 code 760.71 on discharge data tapes from 1989-1990 for Interior Alaska, and 1986-1992 for Southeast Alaska.
Native Medical Center, Anchorage	ICD-9 code of 760.71 on discharge data tapes from 1985-1992. (Third largest hospital in the state.)

[a] Alaska Department of Health and Social Services
[b] Indian Health Service

After all potential FAS cases were identified (630), all available medical charts (568) were obtained. An FAS data abstraction form was developed to gather diagnostic information from the medical charts. All information was extracted with appropriate attention to confidentiality as established under state law and through memorandums of agreement.

While no single source identified all of the recorded FAS cases, the use of sixteen different sources did not prove necessary. Screening and referral programs to diagnostic clinics (state genetics and alcohol-exposed children clinics and the Indian Health Service case file), for example, identified 70% of all recorded cases, and 65% of all cases were uniquely identified by these sources. Passive reporting data systems, most notably birth certificates and hospital discharge summaries, did not prove sufficiently "high-yielding." Due to Alaska's unique structure where Native Medicaid claims are billed directly to the federal government, this source was less useful for FAS surveillance than it may prove to be in other states.

Overall, the Indian Health Service case files identified the largest proportion of cases (56%), followed by the Native Health Corporations (19%) and the state's genetics clinic (12%) (Table 2). Interestingly, 57% of all non-Native cases were *not* identified by the private medical sector while only 13% of the Alaska Native cases were not found in the Native-specific sources. This discrepancy may be due to a lower awareness level and/or the stigma associated with an FAS diagnosis in the non-Native population.

Table 2. FAS case ascertainment by source of data, born 1977-93, AK

	Potential cases identified	Charts Abstracted		FAS-noted[a]		FAS cases		% Total FAS Cases
Source of Data	N	N	(%)[b]	N	(%)[c]	N	(%)[c]	
Private Sector								
Hospital, Fairbanks	16	16	(100)	12	(75)	4	(25)	3
Hospital, Anchorage	34	29	(85)	21	(72)	11	(38)	8
Pediatrician, Fairbanks	117	116	(99)	25	(22)	17	(15)	12
Pediatrician, Anchorage	44	38	(86)	10	(26)	7	(18)	5
ADHSS[d]								
Program, Infant Learning	31	24	(77)	17	(71)	14	(58)	10
Program, HCP-CSN[e]	3	3	(100)	3	(100)	3	(100)	2
Clinic, Cleft lip & palate	9	9	(100)	4	(44)	3	(33)	2
Clinic, Genetics	50	50	(100)	23	(46)	18	(36)	12
Clinic, Alcohol-exposed children	41	41	(100)	11	(27)	8	(20)	6
Rural nursing station	15	15	(100)	11	(73)	8	(53)	6
Medicaid claims	46	38	(83)	22	(58)	16	(42)	11
Birth Certificates	20	17	(85)	4	(24)	2	(12)	1
Death Certificates	3	1	(33)	1	(100)	1	(100)	1
IHS[f]/Regional Native Health Corporations								
IHS case file	218	190	(87)	124	(65)	81	(42)	56
Regional Native Health Corps (serving Interior & Southeast AK)	94	92	(98)	53	(58)	28	(30)	19
Native Medical Center, Anchorage	31	30	(97)	19	(63)	12	(40)	8
Total Unduplicated Count	**630**	**568**		**248**		**145**		

[a] Denotes individuals with a physician chart notation of FAS suspected or diagnosed
[b] % of potential cases identified
[c] % of charts abstracted
[d] Alaska Department of Health and Social Services
[e] Health Care Program for Children with Special Needs
[f] Indian Health Service

FAS Prevalence

Prevalence rates quantify the proportion of individuals in a population who have a disease (or syndrome) at a specific point in time. Birth defects are traditionally measured by a prevalence rate which compares the number of individuals born with a given abnormality to the number of live births during the period of time in which the cases were born.

During the first six years of the AFASPP, the team completed a two-phased FAS prevalence assessment based on their surveillance findings (Table 3):

Phase I (documented in the AFASPP Interim Report, March 24, 1993, and MMWR, 1993): presents minimum Native prevalence rates using 83 cases identified from the first five data sources reviewed (birth certificates, death certificates, Medicaid claims, IHS case files and one pediatric practice).

Phase II (documented in "Fetal Alcohol Syndrome in Alaska, 1977-1992: An Administrative Prevalence Derived from Multiple Sources" [*American Journal of Public Health*, in press]): presents comprehensive prevalence rates (Native and non-Native) using the 248 cases identified from the sixteen data sources.

Between these two phases of active case finding, an applied analysis was performed to evaluate and bound the Phase I prevalence estimates. This applied analysis used a technique called capture-recapture[1].

[1] Capture-recapture is a statistical technique used most frequently in the enumeration of wildlife populations. In an epidemiologic setting, capture-recapture measures the amount of overlap between two independent samples (or data sources) to estimate the true disease prevalence. It assists in determining the extent to which observed rates reflect differences in completeness of case ascertainment.

Table 3. Fetal Alcohol Syndrome (FAS) Prevalence Studies, Alaska

Analysis	Birth Years Covered	No. FAS Cases	Minimum Alaska FAS Prevalence Rates (per 1,000 live births)			Key Finding(s)
			Overall	Native	Non-Native	
Phase I	1978-1991	83	0.5 (FAS) (range of 0.4 - 0.6)	2.1 (FAS) (range of 1.4 - 2.9)	insufficient data	• high prevalence of FAS among Native Alaskans • underascertainment of cases likely (only 14% overlap btw. sources)
		129 FAS-noted		3.3 (FAS-noted)		
Capture-Recapture	1982-1989	50	N/A	*3-6 yrs old:* 2.0 (observed) 3.1 (predicted) *7-10 yrs old:* 3.1 (observed) 3.8 (predicted)	N/A	• poorer case ascertainment among the younger cohort • multiple sources necessary — even for Native ascertainment
Phase II (detailed further in Table 4)	1977-1993	145	0.8 (FAS)	3.0 (FAS) (range of 1.4 - 4.1)	0.2 (FAS) (range of 0.1-0.3)	• high FAS prevalence among Natives confirmed • appears case ascertainment improving among non-Natives
		248 FAS-noted	1.3 (FAS-noted)	5.2 (FAS-noted) (range of 2.4 - 6.6)	0.3 (FAS-noted) (range of 0.2-0.4)	

Case Ascertainment

Closer analysis of the Phase II findings suggests that FAS rates vary among different birth cohorts (Table 4). Rather than represent a change in actual rates, these differences (particularly in the Native population) may reflect poorer ascertainment in the oldest and youngest cohorts: children grow out of the facial dysmorphology of FAS during adolescence, and young children have not had the same opportunity to be diagnosed (i.e., demonstrate behavioral or cognitive abnormalities). This hypothesis is supported by the capture-recapture analysis which found that half of the difference in rates between the two Native birth cohorts could be attributed to a lower case ascertainment rate among the youngest cohort (Table 3).

The greater FAS rates among Alaska Natives relative to non-Natives may be attributed, in part, to the extensive case finding activities of the Indian Health Service, and to underascertainment of FAS among non-Natives. The rate of non-Native cases in the most recent birth cohort (1989-1992) was nearly twice that in the previous birth cohorts, and non-Native children in the younger birth cohorts had median ages at the time of first chart mention of FAS that were comparable to those of Alaska Natives, suggesting that case ascertainment may be improving for non-Natives. However, the large discrepancy between Native and non-Native FAS prevalence rates cannot likely be attributed entirely to differences in ascertainment between the two populations. Alaska's Native population appears at higher risk of FAS than the non-Native population.

US Prevalence Comparison

The national BDMP, which estimates FAS prevalence rates based on sampled hospital birth records, reports an FAS prevalence rate for the U.S. of 0.5 cases per 1,000 live births. Low socioeconomic status appears to be associated with higher FAS rates as the BDMP reports rates among Native American, black and white U.S. populations at 3.0, 0.6 and 0.1 cases per 1,000 live births. Direct comparison with the U.S. estimates is difficult due to differences in the case finding methodologies, but Alaska's findings do support the inverse socioeconomic relationship. The national health goal for the year 2000 is an overall FAS prevalence rate of .12 cases per 1,000 live births and a rate of 2.0 cases per 1,000 live births among Alaska Natives/American Indians. Achieving these goals in Alaska will require a concerted focus on FAS prevention across the state.

Table 4. Rates for FAS-noted individuals and FAS cases per 1,000 live births, for Alaska Natives and non-Natives

	Native				Non-Native			
	FAS-Noted[a]		FAS Cases[b]		FAS-Noted[a]		FAS Cases[b]	
Birth Years	(N cases/live births)	Rate	(N cases)	Rate	(N cases/live births	Rate	(N cases)	Rate
89-92	(57 / 11,262)	5.1	(28)	2.5	(16 / 35,695)	0.4	(11)	0.3
85-88	(68 / 10,346)	6.6	(42)	4.1	(7 / 37,716)	0.2	(6)	0.2
81-84	(53 / 8,968)	5.9	(34)	3.8	(7 / 37,098)	0.2	(4)	0.1
77-80	(17 / 7,160)	2.4	(10)	1.4	(5 / 28,686)	0.2	(2)	0.1
Total	**(195 / 37,736)**	**5.2**	**(114)**	**3.0**	**(35 / 139,195)**	**0.3**	**(23)**	**0.2**

[a] **Denotes individuals with a physician chart notation of FAS suspected or diagnosed.**
[b] **Case meets 5 criteria case definition for FAS.**

Demographic Characteristics of FAS Cases

FAS is a permanent condition. Familiarity with clinical and demographic characteristics of FAS can help health care providers, social service workers and educators to recognize suspected FAS cases. Only through diagnosis will these individuals have an opportunity to receive the special assistance they may need. Recognition of FAS in one child also may help prevent the subsequent birth of similarly affected siblings.

The AFASPP findings suggest that FAS occurs disproportionately in Alaska Native children, but there does not appear to be a favoring of one sex over the other. Among the 145 identified FAS cases, 83% were Alaska Native, 12% were white and 4% were black (compared to 22%, 68% and 5% of all live births in 1994). Fifty-three percent of the cases were male. Median age at the time of the first chart mention of any alcohol-related diagnosis (i.e., fetal alcohol syndrome, fetal alcohol effects, or alcohol-related birth defects) was quite young, averaging 8.4 months of age with a range from birth to 16 years of age[2] (Table 5).

The largest number of cases (33% of FAS and 30% of FAS-noted) was identified in the cohort born between 1985 and 1988, the group entirely within the 3-7 year age window at the time of the study. Seventy-five percent of all cases had an alcohol-related diagnosis mentioned in their chart by age three. Only 43% of the cases had been diagnosed as fetal alcohol syndrome or "possible fetal alcohol syndrome" by a dysmorphologist.

Sixty-seven percent of those with known custody status (127) were either adopted or in foster care. A similar custody status profile was described in the AFASPP's Interim Report (Figure 1). This finding, along with the high prevalence of physical/sexual abuse and neglect noted among alcohol-exposed children in the Alaska clinics, suggests a strong role for social services in the recognition and proper referrals of both FAS cases and families.

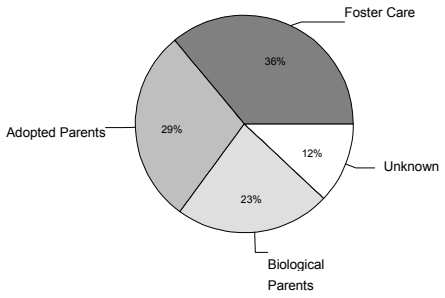
[2] The median age at first chart notation was comparable for Natives and non-Natives by birth cohort with one exception: non-Native children born in the eldest cohort (1977-1980) had a significantly older age at time of syndrome recognition in medical charts (median age of 12.7 years) than natives (median age of 2.8 years) (Kruskal -Wallis one-way analysis of variance, $p < .05$) (Table 5). Again, this variance may represent a waning reluct-ance to diagnose FAS in non-Native children.

Table 5. Median age and year at first medical chart notation of FAS, by birth cohort for FAS-noted cases

Birth Years	(N)	First Chart FAS Notation Age (years) Median (Min, Max)	Year Median
89-92			
Native	(57)	0.0 (0, 2.8)	90.8
Non-Native	(16)	0.5 (0, 2.8)	91.1
85-88			
Native	(68)	0.6 (0, 7.0)	87.8
Non-Native	(7)	0.4 (0, 7.0)	88.1
81-84			
Native	(53)	2.1 (0, 9.0)	85.4
Non-Native	(7)	2.9 (0, 8.6)	87.3
77-80			
Native	(17)	2.8 (0, 16.1)*	84.0
Non-Native	(5)	12.7 (7.5, 13.9)	89.6
Total	(230)	0.6 (0, 16.1)	88.0

*Kruskal Wallis One-Way Anova test, $p<.05$

Figure 1. Custody status of Alaskan FAS cases



- 65% were either adopted or in foster care
- Custody Status of Alaskan Chart-verified FAS Children (N=83)

Clinical Features of FAS Cases

The most prevalent facial features noted among the FAS cases were long or flat philtrum (70%), short palpebral fissures (66%), and thin upper lip (Table 6). Two or more of the characteristic facial features were noted in 79% of the cases. The most prevalent central nervous system impairments were developmental delay (76%), and microencephaly (37%). Eighty-one percent of the cases had some type of delay or learning disability. With regard to growth deficiencies, 64% of cases had both a birth-weight or -height measurement and a postnatal-weight or -height less than or equal to the tenth percentile. Fifty percent were born at <= 37 weeks gestation (i.e., preterm deliveries).

Table 6. Facial features, central nervous system impairments, growth characteristics and other conditions among FAS cases, born 1977-1992, Alaska, based on notations in medical chart.

Facial Features	n	%
Long, flat philtrum	102	70
Short palpebral fissures	96	66
Thin upper lip	75	52
Hypoplastic maxilla	56	39
Flat nasal bridge	45	31
Short nose relative to normal length face	34	23
2 or more features	115	79
4 or more features	51	35
Central Nervous System Impairment		
Developmental delay	110	76
Speech/language delay	59	41
Gross motor delay	32	22
Fine motor delay	30	21
Microcephaly	54	37
Short attention span or attention deficit disorder	40	28
Learning disability or mental retardation	29	20
Seizures	29	20
Any delay or learning disability	118	81
Growth Characteristics	**n**	**%**
Failure to thrive	32	22
Birth weight (≤ 10%ile)	107	74
Birth length (≤ 10%ile)	68	47
Preterm delivery (≤ 37 wks)	72	50
Small-for-gestational-age	62	43
Postnatal weight (≤ 10%ile)	106	73
Postnatal height (≤ 10%ile)	99	68
Malformations and Other Conditions		
Palmar crease anomalies	45	31
Digital or limb anomalies	43	30
Strabismus	33	23
Congenital heart disease	26	18

Characteristics of FAS Mothers

Critical to the prevention of future FAS cases is the ability to identify those women at risk of drinking during pregnancy. Birth certificates obtained for 102 cases (70%) showed that 63% of FAS mothers were not married at delivery. Forty-one percent had not completed high school, and 69% either had no prenatal care (33%) or began prenatal care after the first trimester (36%). (In contrast, for the general population only 15% of Alaska mothers delivering between 1989 and 1993 had not finished high school and only 18% had no or late prenatal care.) These women are older mothers who frequently have had previous children. Medical charts and birth certificates documented an average maternal age at delivery of 29 years (SD=5.0, Range=[15,45]). The average number of living children born prior to the child with FAS was 2.4 (SD=2.0).

There also appears a real risk of FAS mothers producing multiple FAS children. Thirteen percent of the women (14/111 identified mothers) had multiple FAS births, averaging 2.3 FAS children each. One woman alone gave birth to four cases and to three other children who had physician mentions of fetal alcohol syndrome in their charts. In addition, one FAS-noted individual was the mother of another FAS case. Medical charts also mentioned prenatal tobacco use among 39% of the FAS mothers, cocaine use in 8%, and marijuana use in 8%.

A profile of six FAS mothers completed during Phase I of the AFASPP suggests additional commonalties among mothers of multiple FAS children. The women were prone to report histories of physical and sexual abuse, have partners with alcohol problems, deny alcohol problems, alcohol-related emergency room visits, have psychiatric illness, and refuse alcohol treatment.

A study outside of Alaska correlated continued drinking during pregnancy (despite information on the risks and referral for intervention) with early onset of drinking, heavy drinking in parents and siblings (especially female relatives), evidence of alcohol-related physical problems, and qualifying for a diagnosis of alcohol dependence (Institute of Medicine, 1996). The Institute of Medicine suggests an even broader list of psycho-social predictors for drinking among women in general including familial and genetic factors, demographic and social role variables (lack of social roles, unemployment, cohabitation, divorce or separation), individual psychological factors (depression, anxiety, eating disorders), relationship variables (partner's drinking habits, relationship conflict/violence), physical and sexual victimization, and drinking contexts (behavior of coworkers and significant others). While the AFASPP findings do not constitute a scientifically based psychosocial profile of Alaskan FAS mothers, they are supported by the results of these other studies.

Little information is available from the AFASPP to characterize FAS fathers, who may be influential in encouraging or ensuring an alcohol-free pregnancy. A study outside of Alaska by Abel (1983) found that FAS fathers also tended to abuse alcohol, suggesting effective prevention may need to target both the mother and her partner (Institute of Medicine, 1996).

III. Statewide Drinking Trends and FAS Awareness

Crafting an effective FAS prevention strategy requires an understanding of the current drinking habits and FAS-awareness levels of all Alaskans.

Adult Alcohol Consumption

Behavioral Risk Factor Survey

The prevalence and characteristics of alcohol consumption among Alaskan Natives and women of childbearing age are of particular interest in the effort to prevent FAS. Such behavioral information is gathered on an ongoing basis through the Behavioral Risk Factor Surveillance System (BRFSS). This national system surveys adults (18 years of age and older) by a random-digit-dialed telephone method.

While overall alcohol use from 1991-1993 was reported less frequently among Natives than non-Natives, statewide binge rates (consuming 5 or more drinks on a single occasion) were higher among Natives (Figures 2 & 3). Geographically, Southeast Alaska reported the highest binge rates overall (32% Natives, 25% Non-Natives). As of 1994, Alaskan women most likely to binge were aged 25-34, a range which captures the age of most FAS mothers (Figure 4). These statistics, combined with the previously described maternal risk profiles, may imply that FAS prevention should focus heavily on the reduction of binge drinking during pregnancy. Toxicological studies of animals also support this idea. A high dose of alcohol delivered during a concentrated time period (binge drinking) interferes with brain development more than the same dose delivered over a longer period of time (Institute of Medicine, 1996).

Figure 2. Alcohol Use in Past Month by gender and race, 1991-1993, BRFSS

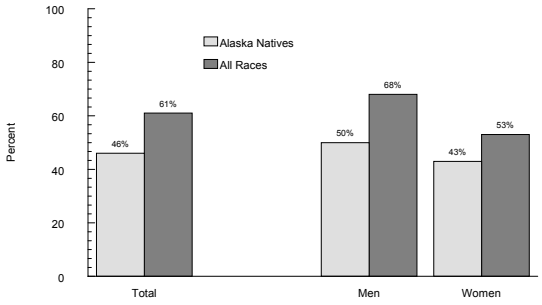


Figure 3. Binge Drinking (five or more drinks at one time in the past month) by gender and race, 1991-1993, BRFSS

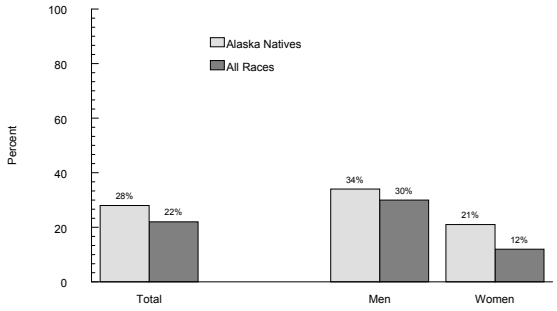
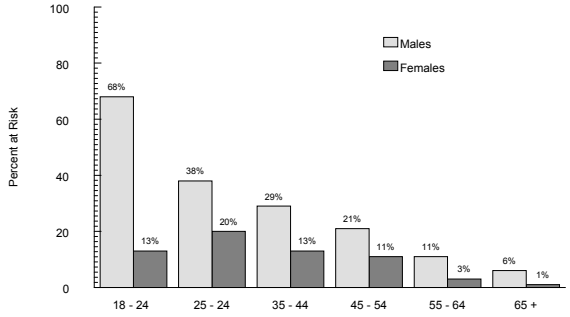


Figure 4. At Risk for Acute Binge Drinking in Alaska by age and gender, 1991-1993, BRFSS



Weighted results for the 1991 BRFSS found that 55% of Alaska women of childbearing age (18-44) reported drinking during the previous month: 38% classified as light drinkers (<31 drinks a month) and 17% classified as heavy drinkers (>30 drinks in a month or 5 in on a single occasion). While non-Native women were over two times more likely to report light drinking than Native women (41% vs. 17%; PR=2.4, 95% CI=1.6-3.8), the prevalence of heavy drinking among non-Native women was half that among Native women (15% vs. 32%; PR=0.5, 95% CI=0.2-0.9).

Because heavy drinkers are most likely to continue drinking during pregnancy, determining ways to identify or predict heavy drinking behavior may become an important element of the FAS prevention strategy (Institute of Medicine, 1996). Smoking and education level may be two such predictors. Women who smoked were more likely to report heavy drinking than were nonsmokers (29% vs. 13%; PR=2.2, 95% CI=1.2-3.9), and women with at least a college degree were less likely to report heavy drinking than were women with less education (6% vs. 20%; PR=0.3, 95% CI=0.2-0.6). Unweighted analysis of the data also associated heavy drinking inversely with both marriage and children in the household (Epidemiology Bulletin, March 24, 1993). This analysis did not find an association between women's drinking habits and their employment type.

Pregnancy Risk Assessment Monitoring System

The Alaska Pregnancy Risk Assessment Monitoring System (PRAMS) is an ongoing mail survey of mothers of newborns which gathers information on health risk behaviors and circumstances of pregnant and post partum women[3]. Data collected during 1990-1991 revealed that third trimester drinking, while relatively uncommon overall, was strongly associated with older age and drug (cocaine or marijuana) use. Women who were older than 30 were 3.5 times more likely to report drinking during the third trimester than were women under 20 (14.7% compared to 3.9%). Third trimester drinkers were 5 times more likely than non-drinkers to use drugs (13.9% compared to 2.8%).

[3] PRAMS data is stratified by mother's race (Native or non-Native) and the amount of prenatal care she received (adequate or inadequate). Drinking behavior is classified by non-drinkers (no reported drinking the 3 months before and the last 3 months of pregnancy), drinkers who quit (drinking reported the 3 months before but not the final 3 months of pregnancy) and 3rd trimester drinkers (drinking reported during the final 3 months of pregnancy). Many of the figures presented display results across all of these categories while the text reports more aggregate findings.

Additional factors associated with any third trimester drinking were non-Alaska Native race, domestic violence, post-high school education, prenatal cigarette smoking, and exposure to more than one significant life stressor. Non-Native mothers reported third trimester drinking 1.4 times as often as Native mothers (11.4% overall vs. 8.3%), but Native women were more than twice as likely to have experienced domestic violence (26.7% overall vs. 11.4%) (Figures 5 and 6). Across both races, mothers who drank were more likely to have experienced domestic violence.

Figure 5. Percent of Mothers by Drinking Category, Alaska, 1990-1991, PRAMS data

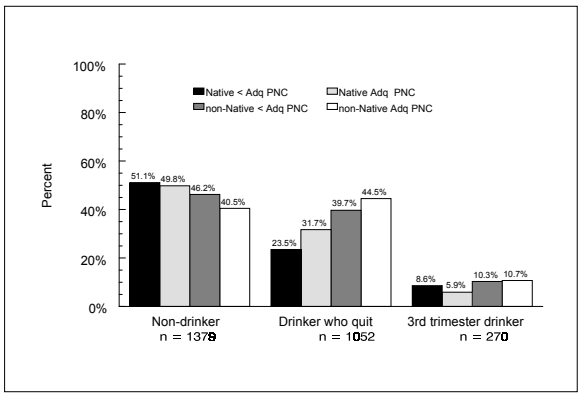
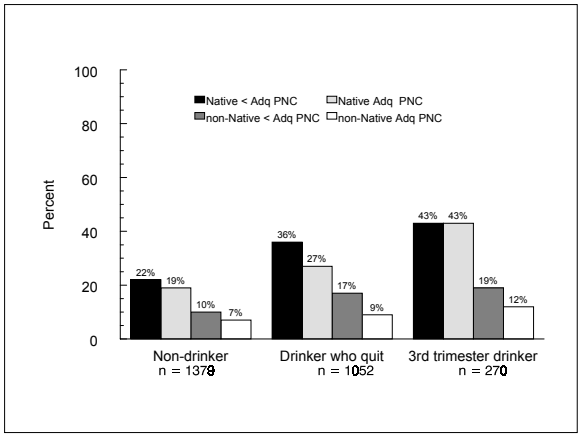


Figure 6. Percent of Mothers Experiencing Domestic Violence by Drinking Category and Stratum, Alaska, 1990-1991, PRAMS data



Women with greater than a twelfth grade education reported any drinking during the third trimester of pregnancy more often than women with less than a twelfth grade education (12% vs. 5.3%). Third trimester drinkers were also twice as likely to smoke as non-drinkers (36% vs. 20%) (Figure 7). Geographically, Southeast Alaska reported the highest percentage of third trimester drinkers, the Yukon-Delta region the lowest (Figure 8).

Figures 7. Percent of Mothers (Postpartum) Currently Smoking by Drinking Category and Stratum, Alaska, 1990-1991, PRAMS data

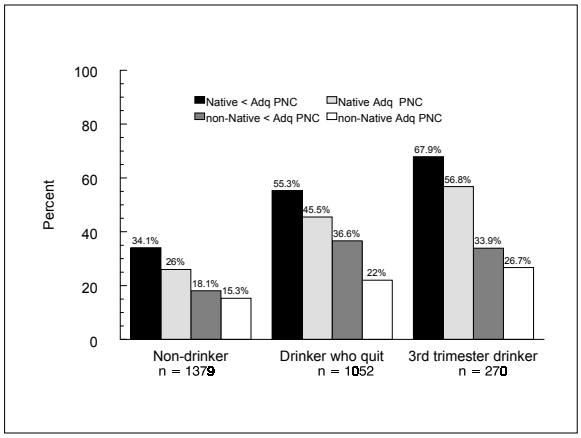
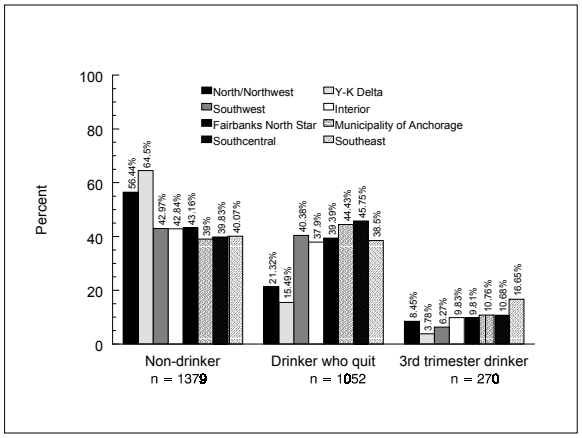


Figure 8. Percent of Mothers within a Region by Drinking Category, Alaska, 1990-1991, PRAMS data



The mothers reporting third trimester drinking tended to report a greater prevalence of life stressors during the 12 months prior to delivery (someone close with a drinking or drug problem, separation from a partner, getting into debt, etc.) than other women (Table 7). The PRAMS data reinforce the idea that prevention efforts should target not only the behaviors of pregnant women (binge drinking, smoking, etc.) but their environments (support systems—or the lack thereof, familial/social influences, etc.).

Table 7. Percent of Mothers Citing Top 5 Life Stressors During the 12 Months Before Delivery, 1990-1991

Lifestyle Stressor	Non-Drinker	Drinker-Who-Quit	3rd Trimester-Drinker	Total (weighted)
1. Family member very sick	25.8	24.7	25.5	25.4
2. Someone close drinking/drugs	17.5	19.9	25.8	20.3
3. Separated from partner	13.5	16.9	19.2	16.0
4. Got into debt	13.5	15.2	18.2	15.1
5. Family member died	13.6	14.9	14.1	14.5

Table 8. Rate of drinking during the third trimester of pregnancy, 1991-94, Alaska

Any drinking of alcoholic beverages during the third trimester:				
1991	1992	1993	1994	1991-1994
10.3%	10.9%	7.7%	7.4%	9.2% (statistically significant trend)

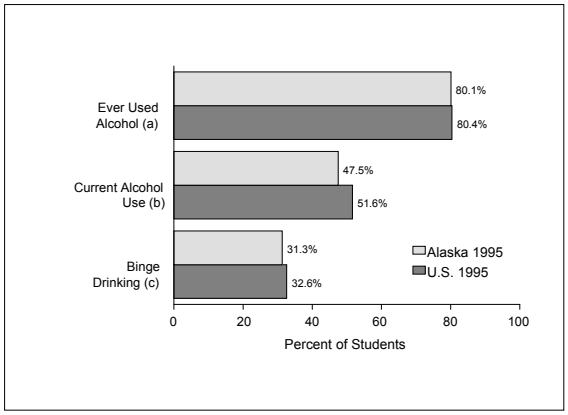
Note that PRAMS estimates of "Prenatal use of alcohol" are limited to any amount (starting from less than a drink a week [dose] and are indicated for third trimester use only [timing] and as such are considered to be minimal prevalences of prenatal alcohol use in general. PRAMS surveillance is limited to mothers who delivered a live birth.

Youth Alcohol Consumption

The optimal timing for any behavioral intervention is before the deleterious behavior is established. An important FAS prevention question is "when are (heavy) alcohol drinking behaviors first apparent in FAS parents?" Unfortunately, this information is not presently available. However, the Youth Risk Behavior Survey (YRBS), a nationally administered in-school survey of health risk behaviors, provides a means of addressing this question by evaluating the drinking patterns of Alaska's public high school students.

Unlike the adult population, Alaska's high school students do not report significant differences in drinking behaviors by race nor do the Alaskan rates differ much from National averages (Figure 9). The 1995 YRBS found that 80.4% of U.S. high school students reported ever drinking. In Alaska, 80.1% of high school youth (83.2% of Natives) reported this behavior. When asked about drinking within the last 30 days, 51.6% of U.S. youth responded affirmatively while only 47.5% of Alaska youth (43.9% of Natives) reported this behavior. Alaska youth were also slightly less likely to report binge drinking within the past 30 days (31.3% overall, 31.3% Natives) than the US average (32.6%). In an unweighted analysis of female responses, Native females were even less likely to binge than their non-Native peers (26% vs. 30%). The one alcohol-related question to which Alaska youth reported consistently higher rates than the U.S. average was drinking before the age of 13 (36.7% Alaska, 35.7 Alaska Natives, 32.4% U.S.).

Figure 9. 1995 AK and 1993 U.S. YRBS--Alcohol Use Among High School Students



a) Ever had at least one drink.
b) Had at least one drink in the 30 days prior to the survey.
c) Had five or more drinks within a couple of hours, in the 30 days prior to the survey.

Overall these findings suggest that adult drinking patterns, particularly differences between Native and non-Native behaviors, are not necessarily patterned in Alaska's high school students, underscoring the opportunity for comprehensive in-school education on the effects of alcohol during pregnancy. What is not clear is the relation of these rates to those of youth who become FAS-parents or who are not members of the regular public school system (i.e., drop outs and students in correctional schools). As has been discussed, individuals with less education are already at greater risk of drinking during pregnancy, thus their behaviors may differ from the average. This possibility further encourages the inclusion of alcohol-related education early in children's schooling.

Drinking Trends

Heavy drinking among Alaska women may be declining. Between 1991 and 1995, the percentage of Alaska women of childbearing age drinking heavily dropped from 17.6% to 15.0% (BRFS). PRAMS also suggests women in Alaska may be drinking less during pregnancy. Between 1991 and 1994 the system reported a statistically significant decline in the percent of women drinking any alcohol during the third trimester of pregnancy (from 10.3% to 7.4%) (Table 8). During the same time, however, the national rate of frequent drinking among pregnant women increased 4 times (from 0.8% to 3.5%, $p < .01$) (MMWR, vol. 46, no. 16). The impact and validity of a declining drinking trend in Alaska remains to be determined.

Community Awareness of FAS

While youth education may offer an ideal component of the long-term FAS prevention effort, alcohol- and FAS-related information needs to be disseminated to the group most actively procreating. Many Alaskan adults do not have accurate or sufficient knowledge about the syndrome.

In March of 1993, the AFASPP conducted a statewide survey to determine the FAS awareness level of Alaskans and to help identify segments of the public which need to be reached in educational campaigns. Using a simple random-digit dialed phone survey, 400 adults (age >=18) were interviewed between March 12th and 15th.

Most Alaskans (91%) had heard about FAS, but only 41% were able to answer accurately 7 true or false questions about the syndrome. Educational level directly related to individuals' FAS knowledge: 28% of high school educated respondents scored correctly on the 7 questions compared to 35% for those with 1-2 years of college, 56% for those with 3-4 years of college, and 65% for those with post-college education.

Geographic location also seemed to impact FAS knowledge. While 35% of Anchorage respondents were "knowledgeable", 40% of rural respondents, 42% of Fairbanks respondents, 47% of Valdez/Kenai-Mat-Su respondents, and 53% of Southeast respondents answered all 7 questions correctly. Race also predicted FAS knowledge: 43% of non-Natives vs. 27% of Natives answered the 7 questions correctly. Knowledge levels did not vary significantly by sex, marital status, age, or number of children in the household. Importantly, individuals who were knowledgeable about FAS were also more likely to report they would be very likely to talk to a pregnant friend or family member about the harmful effects of alcohol on the fetus (93% vs. 75%, respectively).

Slightly fewer respondents expressed a willingness to talk to the individual about seeking professional services to help her quit (80% vs. 63%). The low FAS knowledge levels among less educated individuals and Alaska Natives again support the selection of these groups as primary targets for FAS education and reinforces the need to target middle and high schools for educational programs.

Health Professionals' Alcohol-Related Knowledge, Attitudes Beliefs and Behaviors...and Needs

One of the most effective conduits for FAS education and prevention may be health care. Healthcare professionals, however, are often not prepared to deliver the type of information and support that drinking women of child-bearing age require.

During 1992 and 1993, the AFASPP conducted a survey of 467 health care professionals throughout the state to assess their knowledge, attitudes, beliefs and behaviors (KABB) related to alcohol abuse issues and FAS. The overall response rate was 66% (306 surveys), but it varied by profession: 76% for public health nurses, 58% for pediatricians, 67% for ob/gyns, and 61% for family practitioners.

The majority of providers (95-100%) believed it was their role to address alcohol abuse problems among their patients and their patients' families (Table 9). Considerably fewer, however, reported always referring a patient to an alcohol abuse or outpatient service when they knew or suspected an alcohol abuse problem (19-64%), and almost 50% of public health nurses and pediatricians felt minimally prepared or unprepared to deal with a patient/parent in the area of alcohol abuse. The providers who felt very or somewhat prepared to deal with alcohol issues were more than 2 times as likely to also report that they always refer alcohol-abusing patients to treatment programs (PR=2.2, 95% CI=1.4,3.5). The survey identified the need to facilitate referrals from health care providers and to enhance providers' levels of preparedness in dealing with patients in the area of alcohol abuse.

Table 9. Health care provider beliefs on alcohol-abuse and FAS

"Belief/Behavior"	Public Health Nurses (n=107)	Pediatricians (n=38)	Family Practice Physicians (n=132)	OB/Gyns (n=29)
Agree that it is the role of their profession to address alcohol abuse issues among patients and their families	98	95	97	100
Believe FAS is an identifiable & diagnosable syndrome	94	97	92	90
Believe making a diagnosis of FAS can improve treatment plans for the affected child	88	63	81	79
Believe discussing alcohol abuse will frighten or anger patients/parents and/or deter them from continuing to see the provider	10	11	11	10
Felt minimally prepared or unprepared to deal with patients/parents in the area of alcohol abuse	47	47	8	11
Always referred a patient to alcohol abuse inpatient or outpatient services when they knew or strongly suspected an alcohol abuse problem	34*	19*	64	63

*Pediatricians and public health nurses were asked about parents of pediatric patients.

Although 92% of the 1991 PRAMS respondents reported that a doctor or nurse had asked them about their alcohol consumption, only 77% reported that a doctor or nurse had counseled them about the effects of drinking on their fetus. These statistics match those reported by the OB/GYNs in the KABB survey (Table 10). Ninety-three percent of the doctors reported always asking patients if they use alcohol, but only 79% indicated they always informed their patients about the dangers of alcohol on the developing fetus. Of particular concern for FAS surveillance and prevention is the fact that 50% or less of delivering doctors reported always noting alcohol use on the birth certificate in cases where alcohol abuse was known or strongly suspected. Education regarding the benefits (as opposed to the stigma) of diagnosing FAS is strongly indicated. Supporting this conclusion is the fact that only 63% of pediatricians (vs. almost 80% of other providers) believed making an FAS diagnosis could improve the treatment plans for the affected child.

Many health care providers reported not having the information they need to educate effectively—or identify—FAS patients and families. Resources most frequently requested by the KABB respondents were:

- lists of referral resources for children with FAS (family practitioners, PHNs)
- materials on identifying FAS (family practitioners)
- lists of resources for parents with alcohol problems (pediatricians, PHNs, ob/gyns)
- FAS literature for parents (pediatricians, PHNs, ob/gyns)
- support group referral resources for FAS parents (pediatricians)
- registry of specialists for consultation for children suspected of FAS (PHNs)
- registry of specialists in women's treatment issues available for consultation (ob/gyns)

Table 10. Delivering Physician Beliefs on Alcohol-abuse and FAS

Percent of survey respondents* for belief and behavior questions regarding alcohol abuse among obstetric patients by health care provider, Alaska 1993.

"Belief/Behavior"	Family Practice Physicians (n=132)	OB/Gyns (n=29)
Always ask obstetric patients if they use alcohol	86	96
Always inform obstetric patients about the dangers of alcohol on the developing fetus	82	79
Ever referred a woman to an alcohol treatment/counseling program	90	90
Always approached the topic of alcohol abuse with the patients seen in the last year with a known or suspected alcohol abuse problem	83	96
Always noted alcohol use on the birth certificate, in cases where alcohol abuse was known or strongly suspected	46	50

* For any question, the proportion of respondents with missing data was no greater than 8 percent.

IV. Prevention: Approaches and Recommendations

Summary of Key Findings and Implications

The AFASPP's efforts to date have focused on characterizing FAS in Alaska. Key findings and implications to be considered in the creation of an FAS prevention plan include:

- active, multi-source surveillance (using an objective case definition) is essential for accurate FAS case ascertainment and rate determination and to measure trends over time.
- Alaska's prevalence rates for drinking among women of childbearing age are among the highest in the country.
- Alaska Natives are at the highest risk of delivering FAS children and the public awareness survey indicates that their knowledge level about the disease could be greatly improved.
- in addition to race, education level attained and smoking behavior (both indicators of heavy drinking risk) are potential indicators of a woman's likelihood to drink during a future/current pregnancy.
- older age and drug use are the strongest identified risk factors for drinking during the third trimester of pregnancy.
- marital status, and birth of a previous FAS child predict women at highest risk.
- a clear psychosocial profile of Alaska's FAS mothers does not currently exist, but the suggestion of an association between maternal drinking and other life stressors does.
- little is known about the characteristics of FAS fathers.
- effective prevention may require a focus shift from simply changing maternal drinking behaviors to ameliorating at-risk women's social environments.
- public knowledge about FAS is generally low and could be improved.
- many health care professionals are not effectively prepared to address alcohol abuse in women of child-bearing age.
- Alaska's youth drinking behavior does not differ significantly by race, suggesting (along with the maternal risk characteristics) that the public school system may be an important conduit for FAS education.
- a broad range of professions, organizations and lay people touch FAS parents and children and need to be involved in the FAS prevention plan (e.g., health care providers, social service providers, educators, friends and families)
- knowledge of FAS seems to correlate with a willingness to take preventative action on the part of both lay people and health care professionals.

Prevention Approaches

Disease prevention is frequently discussed in terms of three levels: primary, secondary and tertiary. Primary prevention, reducing the number of new cases of disease, represents the ultimate goal of most prevention efforts. Primary prevention does not address those individuals who already have or are developing the disease. Primary FAS prevention would include very broad, population- or risk group-based programs geared towards preventing maternal drinking prior to and during pregnancy, or postponing pregnancy in women who are unable to stop drinking. Its success depends on the ability to reach and influence at-risk women.

Secondary prevention, reducing the prevalence of existing cases, generally requires effecting some sort of cure or clinical turnaround. In the case of FAS, secondary prevention necessitates an ability to reduce or ameliorate the effects of alcohol on an already exposed fetus/child. While there is no known "cure" for FAS, preliminary research described by the Institute of Medicine suggests that certain chemicals or dietary supplements may modulate the effects of alcohol on a growing fetus. Reducing the dose of alcohol that a fetus receives may also reduce the extent of neonatal damage. To implement secondary prevention, women drinking during pregnancy would have to be identified and an effective treatment established.

Tertiary prevention focuses on reducing the ultimate consequences of disease through treatment and rehabilitation. It focuses on the FAS child instead of its mother. Again, FAS therapy is a largely unexplored area. The Institute of Medicine reports that the combination of stable family environment, good diet, and intervention programs has met with some success in enabling FAS children to better function in their families and schools. Success of a tertiary FAS prevention program would, therefore, depend on enhanced FAS diagnostic ability and the development of FAS treatment programs.

Future Prevention Recommendations

FAS prevention is challenging. The FAS prevention strategy needs to combine elements of all three prevention levels (primary, secondary, and tertiary), requiring the involvement of a large number of individuals and professional organizations. As summarized in the FAS Prevention Program Matrix (Table 11), each prevention level can be applied to different approaches (educational, interventional, legal) and targets (the general public, specific age/race/professional groups, FAS parents). Many of the resulting program options overlap in terms of the individuals and resources involved, but it is unrealistic to assume all prevention alternatives can—or should—be implemented.

The FAS prevention strategy will need to balance the anticipated impact/benefit of each approach with its estimated costs and feasibility of implementation. The appropriate chronological order for the efforts may also need to be considered. Regardless of the ultimate programs selected, the FAS prevention plan will need to include surveillance and research activities, not explicitly means of prevention themselves, but essential to the continued evaluation and development of prevention programs.

Table 11. FAS Prevention Program Matrix

Approaches:	Primary Prevention preventing women from drinking during pregnancy	Secondary Prevention preventing/ameliorating the effects of alcohol on a growing fetus	Tertiary Prevention ameliorating the lives of FAS victims and their families
Professional Education/ Training	• *Targets*: health care (ob/gyns, ER physicians, family practitioners, PHNs, Native Health Corps.), social services (mental health, MCH, family services, alcohol/drug abuse, WIC, etc.), educators (middle/high school) • *Programs*: the basic facts about FAS/FAE, maternal risk characteristic identification, resources available for individuals with alcohol problems, resources offering free/accessible birth control, how to approach a patient/client intervention (less for educators)	• *Targets*: health care (ob/gyns, ER physicians, family practitioners, PHNs, Native Health Corps.), social services (mental health, MCH, family services, alcohol/drug abuse, WIC, DFYS, etc.), justice (municipal police, state troopers) • Programs: resources available for parents with alcohol problems, value of secondary prevention efforts, legal rights/bounds of intervention, resources available for counseling mothers and their partners/families, potential treatment options-primarily for health care professionals (diet, medication), how to approach a patient/client/civilian intervention	• *Targets*: health care (pediatricians, PHNs, family practitioners, ob/gyns, Native Health Corps.), social services (child protective, DFYS, youth corrections, family services, mental health, MCH, healthy baby, nursing, WIC, Head Start, etc.), educators (special education) • *Programs*: value of diagnosing/ treating FAS individuals, clinical/behavioral/ demographic FAS characteristics (ability to diagnose or refer cases), resources available to FAS individuals, appropriate follow-up guidelines, resources available to FAS parents/ families, legal rights of FAS parents, treatment options/approaches for FAS children (as are developed)
Public Education/ Awareness	• *General Targets*: women and men of childbearing age, general public, middle and high school students • *Programs*: basic facts about FAS, maternal risk characteristic identification--simplified, how to prevent FAS (what you can do) • *Selective Targets:* Native Alaskans of childbearing age, Women in halfway houses/ shelters/alcohol-drug treatment programs, women/men with previous FAS children • *Programs:* basic facts about FAS, maternal risk characteristic identification--simplified, resources available for individuals with alcohol problems, resources available for free prenatal care, resources offering free/ accessible birth control/ family planning assistance		
Interventions	• *Target*: women at-risk, their partners and families • *Programs:* circles of care, adopt an at-risk mom/ family, community pledges, alcohol treatment centers *Active option:* seek out women with multiple FAS children (birth defects registry, AFASPP surveillance) *Passive option:* screen/refer women with high risk characteristics (when they seek medical or social services)	• Target: pregnant women who are drinking, their partners and families • *Programs:* circles of care, adopt an at-risk mom/ family, alcohol treatment centers, and anti-toxicity therapy(as developed) *Passive:* screen/refer pregnant women with high risk characteristics (when they seek medical or social services)	• *Target: FAS* children and their families • *Programs:* diagnostic clinics with care assessment and coordination, active case management, respite care, special education, FAS parent/sibling support groups *Active:* have health care professionals refer all patients with documented in utero alcohol exposure *Passive*: offer to FAS/FAE parents trying to learn how to teach/nurture their children

Legal Actions	• *Target*: general (drinking) public • *Program*: decrease availability of alcohol (e.g., limited selling hours)	• *Target*: women continuously abusing alcohol during pregnancy and their partners/families • *Programs*: force hospitalization for alcohol abuse treatment, threaten removal of child/children	• *Target*: FAS children whose parents are unable to provide necessary care • *Program*: force removal of FAS child/children from mother/parents
Economic Actions	• *Target*: general (drinking) public • Program: increase the cost of alcohol (e.g., additional tax)		
Research	• characteristics of FAS fathers • additional maternal risk factor detail, clarification (motivations, beliefs, drinking histories, etc.) • effectiveness of professional education/ training programs • effectiveness of public education/awareness programs • effectiveness of intervention programs, particularly ability to involve partners and family members • access of AK populations to FAS resources: alcohol treatment centers, well woman care, family planning, prenatal care, etc. • biomarkers for alcohol abuse detection	• ability of certain co-factors to increase or decrease the effect of alcohol on the fetus • better understanding of the dose-response relationship of alcohol on human fetal development	• effectiveness of FAS programs/ treatments (for children and adults) • more detailed estimates on the economic and social costs of FAS • biomarkers for FAS diagnosis
Disease Surveillance	• drinking behaviors/ trends (especially among women of childbearing age and Native Alaskans) • public awareness of FAS professional awareness of/preparedness for alcohol-related issues and FAS	• drinking behaviors/trends of pregnant women and their families • characteristics of women who drink during pregnancy, including partner and familial profiles	• trends in FAS and FAS-noted rates (geographic as well as racial/ethnic changes) • characteristics of FAS cases and parents

Primary FAS Prevention

Primary FAS prevention is complex, but essential. The goals of primary FAS prevention are to change the drinking behavior of women prior to conception, change drinking women's childbearing behavior, or both. Three different target groups need to be involved: the health care and social services providers who can influence women of childbearing age and identify those women at-risk; the women at risk of drinking during pregnancy, their partners, and their families; and the general public who (with the media's assistance) determine acceptable social norms. Each target group requires different programmatic approaches, all of which focus on the at-risk women and their environments (Figure 10).

As demonstrated by the KABB survey of Alaska's health care providers, education and training programs are strongly indicated for this group. Resource materials and lists will need to be developed. The demographic profile of FAS mothers also indicates a strong need for social service providers to be educated about FAS and trained to refer women (and their families) to appropriate resources and to make these resources available and accessible.

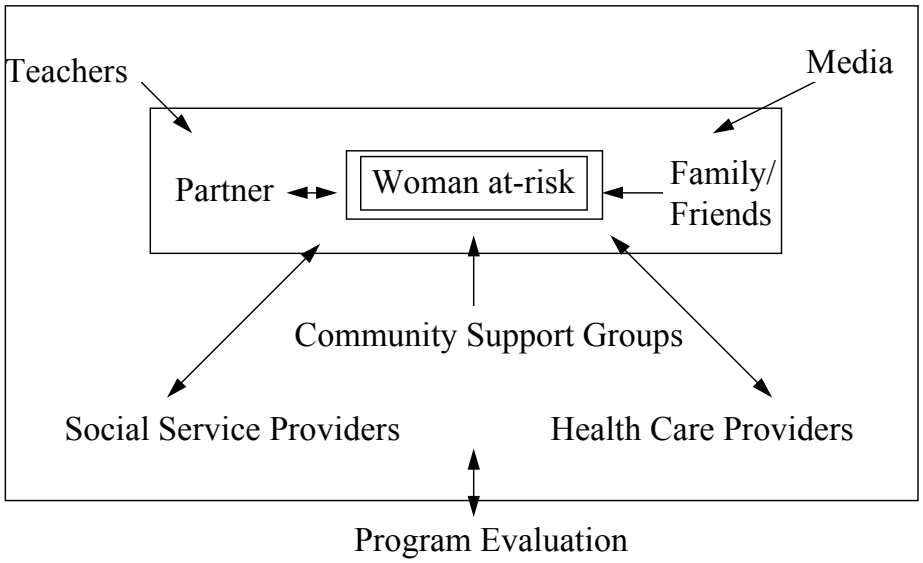
Programs to reach women at risk need to be developed or expanded. Such programs can range from the establishment of "circles of care" or "adopt an at-risk mom" coalitions, to the establishment of community-wide pledges of support,[4] to the founding of alcohol treatment centers. Regardless of the precise programs implemented, research strongly suggests that these efforts need to include an emphasis on the partner and family/friends of the at-risk woman. Also essential to the effectiveness of primary prevention efforts will be their economic, cultural and logistic accessibility to at-risk women and the complement of support services they offer (family planning, domestic violence counseling, nutritional planning, etc.)

Programs geared towards educating the general public could include media campaigns which discuss the outcomes of drinking during pregnancy *and* the means to help someone stop drinking. Public education should focus on the role of men as well as women in the prevention of FAS in their children. The most effective messages and communication channels need to be determined. These general awareness efforts should also include the development/enhancement of alcohol-related health curriculum for middle and high school students.

Legal and economic actions, such as decreasing the availability of alcohol or increasing its price, may also be considered. However, these programs, may meet with significant resistance.

[4] The Pueblo of Zuni have written a vision statement and the Spokane Tribal Community has implemented family pledges supporting FAS prevention efforts in their communities (IOM, 1996).

Figure 10. Primary FAS Prevention Model



Secondary FAS Prevention

Secondary FAS prevention offers the most difficult and limited prevention options. Until the development of treatments to moderate or reverse the effects of fetal alcohol exposure, secondary prevention efforts will focus on reducing or eliminating fetal alcohol exposure. Its goal, then, is to change the drinking behavior of women who are continuing to drink during pregnancy. Targets are the health care and social services providers who can influence and identify pregnant women who are drinking, the women themselves, their partners, and their families. Programs basically include the extension of primary prevention efforts: provider education and training; and community outreach or intervention programs for pregnant women, their partners, and families.

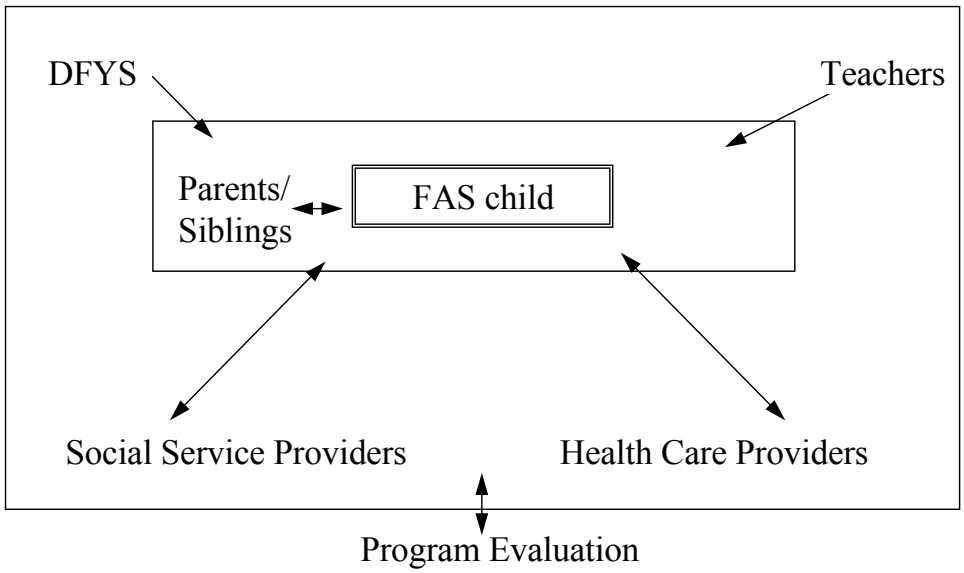
Tertiary FAS Prevention

Tertiary FAS prevention shifts the emphasis from mother to child. Its goal is to improve FAS children's ability to function and develop in their families and communities. The targets for tertiary prevention programs are the health care and social/educational providers who may come in contact with alcohol affected children, the FAS children, and their families. As with primary prevention, a very large number of organizations and individuals may be involved in the tertiary prevention model (Figure 11).

The AFASPP research revealed that educational programs about FAS diagnosis and treatment and resource lists of services available to both FAS children and parents are needed. Programs for FAS children and families also need to be developed or expanded. Such programs may range from diagnostic clinics to assess children's needs, to case management to assure care plans are being followed, to family support groups to help FAS parents and siblings, to respite care facilities designed specifically for children with FAS-type disabilities. Special education classes (and teacher training) may also factor into tertiary care efforts. Again, economic and logistic accessibility to these programs is required for their effectiveness. Qualification for special social services (SSI, ILP) may reduce the economic burdens; physical proximity may prove more of a challenge in Alaska. An ongoing DHSS/DOE study should prove helpful with the development of special education materials and approaches.

As with secondary prevention, the legal (or voluntary) removal of a child from its mother/family may be a necessary consideration. Based on the custody status of most of Alaska's FAS cases, this event is the norm rather than the exception.

Figure 11. Tertiary FAS Prevention Model



Policy Implications

Ensuring an effective FAS prevention plan should not require any major federal or state policy changes. The AFASPP's research, however, has suggested at least one legislative consideration:

- reevaluate the Maternal Child Health Block Grant requirement that grant recipients monitor and annually report the proportion of live births with FAS (House Resolution 2651) since the use of birth records alone substantially understates the prevalence of FAS in a population.

Prevention Recommendations

- Population-based surveillance of FAS is essential to document the magnitude of the problem, to monitor trends in the occurrence of FAS, and to document the impact of prevention efforts.
- The more that is understood about the women who give birth to FAS and other alcohol-affected children, the better is our ability to target prevention activities to them before they give birth to an alcohol-affected child. The top priority for developing effective prevention is to conduct a risk factor analysis of the women who have given birth to FAS children by examining their medical, social, and reproductive histories. DHSS should conduct a maternal risk factor analysis of the biological mothers and fathers of the FAS cases identified through the AFASPP.
- DHSS and DOE should conduct an analysis of the relationship of a medical diagnosis of FAS to the need for special education services.
- Programs should be targeted at two major strategies:
  1) Reduce alcohol consumption among women of child bearing age and especially among pregnant women, and
  2) Postpone pregnancy among women who are unable or unwilling to reduce substantially or stop completely alcohol consumption.
- Improve coordination of services and target services to families who are identified through having a child diagnosed with FAS.
- Determine the barriers to treatment for women who have had an alcohol-affected pregnancy.

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