Fetal Alcohol Syndrome (FAS) and other effects of maternal drinking during pregnancy are 100% preventable – if a woman does not drink any alcohol while she is pregnant. FAS is the leading non-hereditary cause of mental retardation. Many children born affected by maternal drinking during pregnancy have irreversible conditions including severe brain damage that causes permanent, lifelong disability – even if they don’t meet the criteria for full FAS (see Notes for definition).

A University of Washington study showed that across the full age spectrum of 415 individuals with FAS/FAE, 94% had mental health problems, 45% had inappropriate sexual behavior, 43% had disrupted school experience, and 42% had trouble with the law.2

Urgency
• Compared to the baseline for birth years 1995-1997, the 1996-1998 prevalence of FAS in Alaska was similar with 1.6 per 1,000 live births.

Children with FAS are only about 10% of the entire group of children living with some effect from maternal drinking during pregnancy.
• The Alaska FAS Surveillance Project estimates that approximately 163 Alaskan children are born every year with some effect from maternal drinking during pregnancy (16.3 per 1,000 live births), including FAS.
• Extrapolation of Alaska’s estimated prevalence provide an estimate of 6,500 people under the age of 45 living in Alaska who may have a disability as a result of maternal drinking during pregnancy. Of these, there are an estimated 2,000 women of childbearing age and 2,500 school-aged children; approximately 600 could have full FAS.

Disparities
Race-specific FAS prevalence estimates should be interpreted with caution. Increased awareness of maternal alcohol use and careful documentation by Alaska Native health organizations may result in more complete reporting of potential cases of FAS among Alaska Natives than other races.
• Infants born to Alaska Native women have higher rates of FAS than other races. For birth years 1995-1999, FAS prevalence among Alaska Natives was approximately 5 per 1,000 live births – more than 15 times that of whites.

Seriousness

Healthy People 2010 Targets and National Data

<table>
<thead>
<tr>
<th>Indicator</th>
<th>Alaska 1995-97</th>
<th>Nation 1995-97</th>
<th>Healthy People 2010 Goal</th>
</tr>
</thead>
<tbody>
<tr>
<td>Prevalence of Fetal Alcohol Syndrome per 1,000 live births</td>
<td>1.5</td>
<td>0.3-1.5</td>
<td>Developmental</td>
</tr>
</tbody>
</table>

*Range represents prevalence rates from 1995-1997 for 4 states participating in FASSNet. Refer to Data Sources and Notes for more information.

• Reducing the prevalence of FAS is a developmental Healthy People objective, and national goals have not yet been defined. However, the Healthy Alaskan 2010 target is 0.5 per 1,000 live births – much lower than the current rate in Alaska.

• Since surveillance is not conducted in all states there is no reliable national rate for FAS, however, among the four states in the FAS Surveillance Network (FASSNet) that use similar methodology for surveillance, Alaska reported the highest prevalence of FAS – 3.8 to 5 times higher than all other reported rates.

Severity

For birth years 1995-1999, more than one-third of children who were diagnosed with FAS were born preterm and with low or very low birth weight.

Children with FAS and other effects of maternal drinking during pregnancy do not catch up with their peers or outgrow their disabilities. Some problems that occur frequently are poor judgment (easily victimized), attention deficits (unfocused/distractible), arithmetic disability (difficulty handling money), memory impairment (difficulty learning from experience), difficulty abstracting (difficulty understanding consequences), disorientations in time and space (difficulty perceiving social cues), and impulsivity (poor frustration tolerance).1 Many of these problems may not be identified at birth, and may not become obvious until the child reaches school age or later.
Economic Loss
Based on a lifetime cost of $1.5 million, the expected lifetime costs of 1999 births with FAS in Alaska were estimated to be $21 million to $42 million (cost estimates include medical costs, behavior management, and residential services, which include special education, home care, speech therapy, and institutional care.2

Interventions & Recommendations
Primary Prevention
Abstinence Education: The Office of FAS and the Office of the Governor have undertaken a variety of primary prevention projects to reduce maternal drinking during pregnancy. Among these are public education media campaigns warning about the dangers of drinking any alcohol during pregnancy – that no amount is known to be safe.

In a recent advisory on alcohol use during pregnancy, the Surgeon General recommended that health professionals regularly ask women of childbearing age about alcohol use and to inform them of the risks of drinking alcohol during pregnancy. It is further recommended that they advise them not to drink alcohol during pregnancy.3 In 2002, a survey of FAS Knowledge, Attitudes, Beliefs and Behaviors (KABB) found that 36% of obstetrician/gynecologists responded that it was OK for a pregnant woman to drink alcohol occasionally, more than double the percent of either Pediatricians or Family Physicians. Over 90% of physicians strongly agreed that FAS is preventable.

Ongoing Surveillance: FAS surveillance is the only reliable and scientifically defensible means of gathering annual, population-based information on the occurrence of FAS statewide. These data are necessary for tracking the effect of prevention efforts.

Secondary Prevention
Education: Preliminary data from the KABB survey indicated that although nearly 90% of educators believed that a teacher can develop successful classroom interventions to help students who have FAS, nearly half felt they do not have the appropriate skills and knowledge to deal with students who have FAS and just over 75% do not feel they have the skills and knowledge to deal with families of those students who have FAS.

The Office of FAS has developed FASD curricula, which, along with other educational efforts, have been provided for many people throughout the State.

Intervention Effectiveness
The Office of FAS will be conducting a follow-up KABB survey to evaluate the effectiveness of these and other educational efforts.

The FAS Diagnostic and Prevention Network (DPN) at the University of Washington is currently evaluating the effectiveness of two interventions targeted to children with the full spectrum of disorders associated with prenatal alcohol exposure, and their families.

Capacity
Propriety
Ongoing surveillance of FAS and other effects of maternal drinking during pregnancy falls within the overall mission of the Women’s, Children’s, and Family Health (WCFH) Section.

Economic Feasibility
The economic and social consequences of not continuing prevention, education, diagnosis and evaluation (including FAS Surveillance) are serious (see Economic Loss). In addition, an expansion of this work to strengthen intervention resources is indicated for children already living with effects of maternal drinking during pregnancy. Prevention, evaluation and intervention efforts combined could have an important impact on reducing both annual and lifetime costs.

Acceptability
In general, the FAS Surveillance Project and the Office of FAS have found legislators, families, professionals and communities to be welcoming and encouraging of continued and expanded efforts in this area.

Resources
Funding: Starting in 2003, the Office of FAS agreed to fund the FAS surveillance program (through SAMSHA funds) through June 2005. If the 2005 AK Legislature approves the proposed budget, the FASSP will be funded through the Office of FAS by the state general fund for FY 05-06. Efforts are underway to identify ongoing funding.

SAMHSA funding for the Office of FAS is ending in June of 2005. The Governor has asked the legislature to approve $7.1 million for Alcohol and Substance Abuse Prevention, targeting $1.1 million of that specifically for FAS/D prevention. This $1.1 million will go to the Office of FAS and will allow continuation of some services for one year. A portion of that funding is likely to go toward evaluation and other wrap-up activities with some funding directed for one year to FAS Surveillance activities.

Legality
Effects of maternal drinking during pregnancy (ICD-9 code 760.71) is among the birth defects that require mandatory reporting to the Alaska Birth Defects Registry under the Alaska Administration Code (7 AAC 27.012).

References

Data Sources
† Alaska Fetal Alcohol Syndrome Surveillance Project (FASSP), 1995-1997 Data: State of Alaska, DHSS, DPH.


Notes
Prevalence estimates for FAS in Alaska are based on 3-year averages due to the small number of events experienced in Alaska.

The range used for the national prevalence of FAS is from four states (Alaska, Arizona, Colorado, and New York) participating in the FAS Surveillance Network (FASSNet) that used a comparable methodology for surveillance.

Fetal Alcohol Syndrome (FAS) is the only condition within Fetal Alcohol Spectrum Disorders (FASD) for which a clinical or surveillance case definition exists. A diagnosis of FAS includes central nervous system damage (developmental delays, mental retardation, learning disabilities, behavior and reasoning problems and other intellectual impairments), growth deficiency, characteristic facial features and information that the child’s mother drank during pregnancy.