HCR

31

SE''ATE COMMITTEE REPOR

DATE: 2/23/94 FURTHER:

DATE TURNED INTO OFFICE: 3/16/94

HES Committee considered HOUSE CONCURRENT RESOLUTION NO. 31

Relating to Alcohol-Related Birth Defects Awareness Week.

and recommends:

[ ] replace with ________ CS ____________________ (______)

or [ ] adopt previous_____ CS ____________________ (______)

[ ] attaches amendment(s)

[ ] same title
[ ] new title
[ ] technical title change (HB only)

[ ] adopts ________________________ Letter of Intent

[ ] further referral to the ________________________

[ ] do pass

[ ] do not pass

[ ] no recommendation

[ ] individual recommendations

NEW FISCAL NOTES

Department	Date	Zero	Fiscal

PREVIOUS FISCAL NOTES

Department	Date	Zero	Fiscal
HSS/Alcohol + Drug Abuse	2/9/94	✓	

[ ] Appropriation No Fiscal Note

DO PASS:

OTHER RECOMMENDATIONS:

Do Pass

Chair: Signature and Recommendation

House District 36
Alatna
Allakaket
Aniak
Anvik
Arctic Village
Beaver
Bettles
Birch Creek
Canyon Village
Central
Chalkyitsik
Chicken
Chistochina
Chitina
Chuathbaluk
Circle
Copper Center
Crooked Creek
Dot Lake
Eagle
Evansville
Fort Yukon
Gakona
Galena
Grayling
Gulkana
Healy Lake
Holy Cross
Hughes
Huslia
Igiugig
Iliamna
Kakhonak
Kalskag
Kaltag
Kenny Lake
Koyukuk
Lake Minchumina
Lime Village
Livengood
Lower Kalskag
Lower Tonsina
Manley
McCarthy
McGrath
Medfra
Mentasta
Minto
Nabesna
Newhalen
Nikolai
Nondalton
Northway
Nulato
Port Alsworth
Rampart
Red Devil
Ruby
Shageluk
Slana
Sleetmute
Stevens Village
Stony River
Takotna
Tanacross
Tanana
Tazlina
Telida
Tetlin
Tok
Tonsina
Tuluksak
Tyonek
Venetie
Wiseman

Representative Irene K. Nicholia

State Capitol • Juneau, Alaska 99801
Phone: 465-4527 FAX: 465-2294

Health, Education and Social Services Committee
Special Committee on Fisheries

House Concurrent Resolution 31

SPONSOR STATEMENT

HCR 31 recognizes Mother's Day week of May 8 - 14, 1994 as Alcohol-Related Birth Defects Awareness Week.

Fetal Alcohol Syndrome (FAS) related birth defects include **permanent** growth retardation, physical malformations, and permanent central nervous system damage, including developmental delays, learning disabilities, behavioral problems, and mental retardation.

Following are some additional FAS/FAE Facts:

- FAS is the number 1 known cause of **mental retardation** in the United States, and one of the three leading causes of birth defects.
- Each year over **40,000 American children** are born with defects because their mothers drank alcohol when pregnant.
- **The effects of FAS never go away.** People with FAS have the disabilities they are born with, including mental retardation, throughout their lives.
- There is **no known safe amount of alcohol** for a pregnant woman. When a woman drinks, her baby drinks because the alcohol passes directly through the placenta to the baby.
- Conservatively estimated, the lifetime cost per Alaska FAS birth is **$1.4 million**.

Attached is some additional information regarding FAS. I would encourage you to read the enclosed Economic Impact of Fetal Alcohol Syndrome in Alaska Report and "The Preventable Tragedy, Fetal Alcohol Syndrome," which appeared in the February, 1992 edition of *National Geographic*.

Today we have the opportunity to make an impact in the area of FAS by both improving quality of life and by promoting cost effective prevention. Fetal Alcohol Syndrome and Fetal Alcohol Effects are 100% preventable. Let's work together to send a message to the public about the dangers of drinking alcohol during pregnancy.

I strongly urge you to support HCR 31.

FISCAL NOTE

STATE OF ALASKA
1994 LEGISLATIVE SESSION

BILL NO. HCR 31

Revision Date:
Title: Relating to Alcohol-Related Birth Defects Awarness Week.
Sponsor: Representative Nicholia
Requestor:

Dept. Affected: Health and Social Services
BRU: Alcohol & Drug Abuse
Component: Administration

COMPONENT SERIAL NO. 302

Expenditures/Revenues: (Thousands of Dollars)

OPERATING	FY95	FY96	FY97	FY98	FY99	FY00
PERSONAL SERVICES	0.0	0.0	0.0	0.0	0.0	0.0
TRAVEL	0.0	0.0	0.0	0.0	0.0	0.0
CONTRACTUAL	0.0	0.0	0.0	0.0	0.0	0.0
SUPPLIES	0.0	0.0	0.0	0.0	0.0	0.0
EQUIPMENT	0.0	0.0	0.0	0.0	0.0	0.0
LAND & STRUCTURES	0.0	0.0	0.0	0.0	0.0	0.0
GRANTS, CLAIMS	0.0	0.0	0.0	0.0	0.0	0.0
MISCELLANEOUS	0.0	0.0	0.0	0.0	0.0	0.0
TOTAL OPERATING	0.0	0.0	0.0	0.0	0.0	0.0
CAPITAL EXPENDITURES	0.0	0.0	0.0	0.0	0.0	0.0
CHANGES IN REVENUES	0	0	0	0	0	0

FUND SOURCE (Thousands of Dollars)

1002 Federal Receipts	0.0	0.0	0.0	0.0	0.0	0.0
1003 GF Match	0.0	0.0	0.0	0.0	0.0	0.0
1004 GF	0.0	0.0	0.0	0.0	0.0	0.0
1005 GF/Program Receipts	0.0	0.0	0.0	0.0	0.0	0.0
1006 GF/MHTIA	0.0	0.0	0.0	0.0	0.0	0.0
Other	0.0	0.0	0.0	0.0	0.0	0.0
TOTAL	0.0	0.0	0.0	0.0	0.0	0.0

POSITIONS:

FULL-TIME	0	0	0	0	0	0
PART-TIME	0	0	0	0	0	0
TEMPORARY	0	0	0	0	0	0

Estimate of current year (FY9-) cost $

ANALYSIS: (Attach a separate page if necessary)

This HCR has no fiscal impact on the department.

Prepared by: Suzanne Perry
Division:
Phone: 465-2071
Date: 02/08/94

Approved by Commissioner: Margaret R. Lowe, M.Ed., Ed.S.
Agency: Department of Health & Social Services
Date: 2/9/94

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POSITION PAPER

STATE OF ALASKA ★ DEPARTMENT OF HEALTH & SOCIAL SERVICES

HCR 31

Alcohol-Related Birth Defects is the nation's leading known cause of preventable birth defects. Alcohol-related birth defects are a combination of permanent physical and mental birth defects that result from alcohol consumption during pregnancy.

May 8, 1994 is Mother's Day, and marks the beginning of the National Alcohol-Related Birth Defects Awareness Week. In addition to honoring women in our lives, we can take this opportunity to bring an important message to the members of our community. In an effort to educate the public regarding the impact of alcohol on the fetus, the Division of Alcoholism and Drug Abuse is sponsoring an Alcohol-Related Birth Defects Awareness Campaign May 8-14, 1994. This also coincides with The Annual School on Addictions which include specific sessions on alcohol-related birth defects.

The Division of Alcoholism and Drug Abuse strongly supports HCR 31 relating to Alcohol-Related Birth Defects Awareness Week. No costs will be incurred by the division as a result of this resolution.

Information regarding alcohol-related birth defects can be presented to the HESS Committee at your request.

Margaret R. Lowe — 2/9/94

Margaret R. Lowe, M.Ed., Ed.S. — Date

National Review
February 1992

THE PREVENTABLE TRAGEDY

FETAL ALCOHOL SYNDROME

Text and photographs by GEORGE STEINMETZ

"When Malcolm was born, I thought my heart would break," she said. "And, oh my God, the guilt. . . ."

Ellen O'Donovan* was losing her fight against alcoholism when she discovered she was pregnant. Months later her son was born with fetal alcohol syndrome, and his battles began.

I met them both in Dublin, where my photographic coverage had brought me. Ellen and her three-year-old son, Malcolm (left), live in a small town on Ireland's north coast; they had ridden a bus for six hours to visit Malcolm's doctor, a specialist who is treating the boy for severely defective vision, one of his many alcohol-related disabilities.

First identified about 1970, fetal alcohol syndrome (FAS) is a term used to describe the damage some unborn children suffer when their mothers drink during pregnancy. Alcohol in the mother's bloodstream can be toxic to the developing fetus depending on the stage of pregnancy and how much she drinks. Damage can range from subtle to severe, causing clumsiness, behavioral problems, stunted growth, disfigurement, mental retardation.

Ellen's doctor had told her that an American journalist wanted to photograph her with her son. She consented in hopes that others could learn from her mistake, but when I began unpacking my cameras, she hesitated. Then she took a deep breath and began to talk.

"I was drinking a bottle of vodka a day that December," she said grimly, "so out of touch that I didn't even know I was two months pregnant. When I found out, I quit there and then, but the damage was done."

The O'Donovans are not alone. Thousands of babies are born with alcohol-related defects each year, ranking FAS as one of the leading known causes of mental retardation.

According to his doctors, Malcolm was undersized at birth, with kidneys and a stomach that didn't work properly; he had to be tube-fed until he was 14 months old.

His head is smaller than normal, and he also has facial abnormalities typical of FAS children—small wide-set eyes, a thin upper lip, a short upturned nose, and a receding chin. He was born with damaged corneas, and his eyelids drooped. Surgery later gave him limited sight in his right eye.

FAS is irreversible, and during our session it became clear to me that Ellen has dedicated her life to caring for her son. "He doesn't seem retarded, thank God," she said. "He's even starting to talk a little. I'm working with him every day, helping him learn to do the things normal kids do."

I was moved by the way she held him and comforted him in Gaelic when he started to cry. "If this little boy hadn't come along, I might have drunk myself to death," she said quietly. She hasn't taken a drink, she added, in three and a half years.

Still, it isn't going to be easy. Unemployed and living with her mother, Ellen plans each day around Malcolm and the frequent trips they make to his doctors in Dublin. When I offered to reimburse her for the bus fare, she declined. "Just tell women out there that if they want to have a baby, leave the drink out of it," she said. Then she kissed her son on the top of his head and they were gone.

**Real names are not used.*

A large dose of alcohol given to a pregnant mouse produced severe abnormalities in the developing fetus (bottom), according to doctors at the University of North Carolina studying effects of alcohol in early pregnancy.

Compared with a normal fetus (top), the one exposed to alcohol suffered eye damage, a stunted brain, and facial deformities similar to human babies with FAS, particularly those affected during the first trimester, when bones and organs are forming.

Blood-alcohol levels reached during the experiment approximate those that could occur in a woman of average size if she drank a quart of vodka within a 24-hour period.

E. C. SULIK, UNIVERSITY OF NORTH CAROLINA, CHAPEL HILL

I met them in every country I visited—some with tiny, twisted bodies, others with faces tragically skewed. Some were agitated, while others seemed quite normal. Each encounter was disturbing, for few things compare to the sadness of a child stunted by FAS, or made miserable by a group of more subtle abnormalities known as fetal alcohol effect (FAE).

"What's really sad is how many FAS and FAE kids go through life undetected," says Ann Streissguth of the University of Washington, a specialist in FAS behavior. "It takes a trained eye to spot FAS, even in the severely retarded. And in FAE, mildly retarded kids are often misjudged because they tend to be talkative and outgoing. No one dreams their nervous systems are impaired."

As the FAE child grows, such positive traits are often muted by alcohol-related shortcomings—impaired memory, brief attention span, poor judgment and capacity to learn from experience. Some victims drop out of school in frustration or wind up on the margins of society.

Fetal alcohol damage shows itself differently in every child. In the Soviet Union I met a boy, a teenager, who was continually trying to stab his playmates with scissors; in Sweden I met a wonderful little girl who was so sweet and beautiful that I felt I was photographing an angel.

Little is known about the

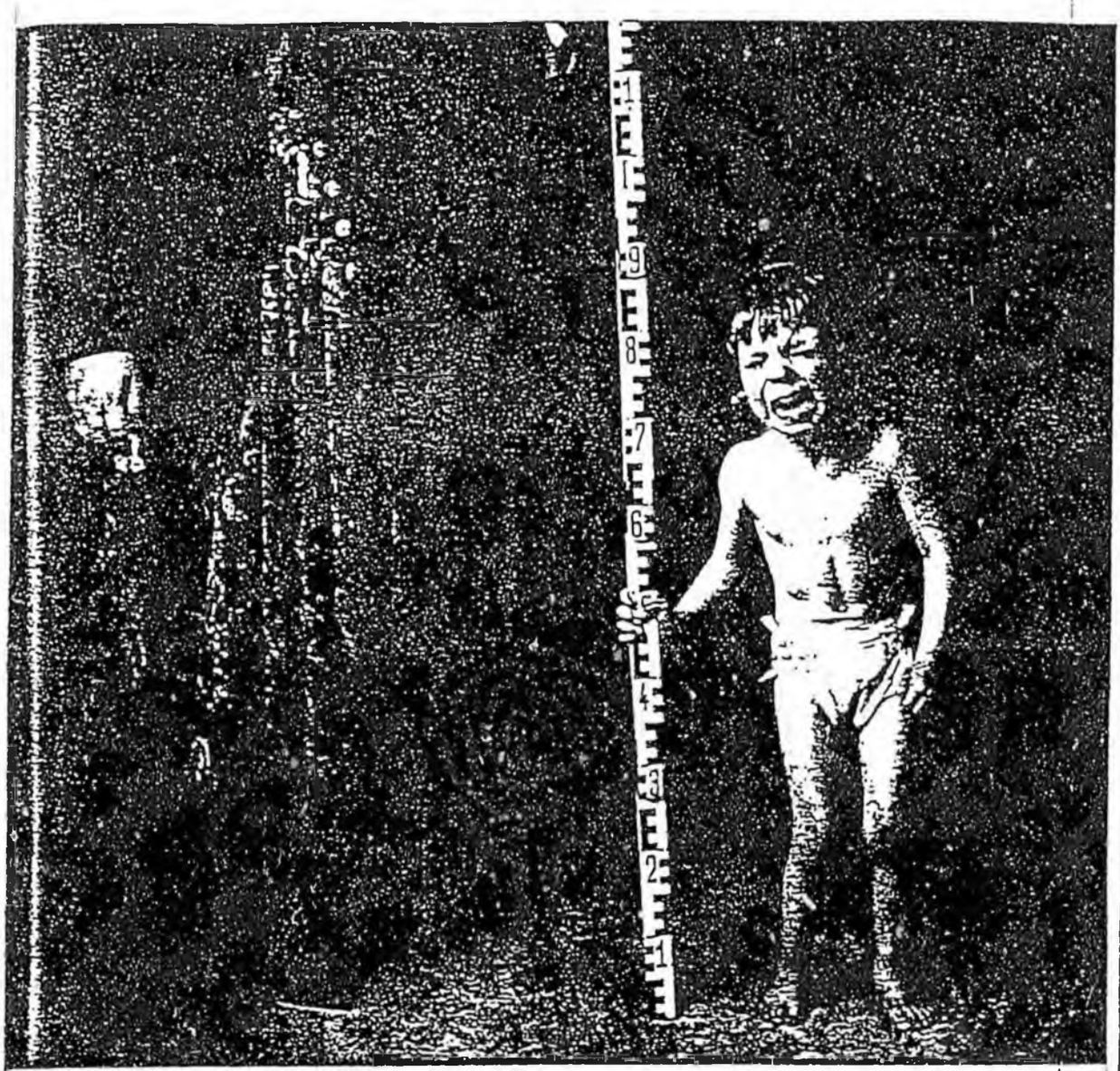
FRATERNAL TWIN GIRLS, FIVE MONTHS OLD; FRANCE

FIFTEEN-YEAR-OLD BOY WITH FATHER; SWEDEN

THREE-YEAR-OLD GIRL; SWEDEN

TEN-YEAR-OLD GIRL; CHICAGO

SIX-YEAR-OLD BOY; SEATTLE



FOUR-YEAR-OLD GIRL; GERMANY

SEVENTEEN-YEAR-OLD BOY; SEATTLE

thresholds of alcohol that cause FAS. Genetics may also be a factor. Even with fraternal twins one might have severe FAS, while the other is mildly affected. Not all mothers who drink have FAS babies. Some doctors believe that any alcohol puts the baby at risk, while nearly all agree that binge drinking is perilous, especially during the first 12 weeks, when signs of pregnancy are few. As Ellen O'Donovan lamented, "I didn't even know I was pregnant. That's the tragedy of it." □

Symptoms of Fetal Alcohol Syndrome

For more information on Fetal Alcohol Syndrome call the Information Center for New Mexicans with Developmental Disabilities at 1-800-552-8195.

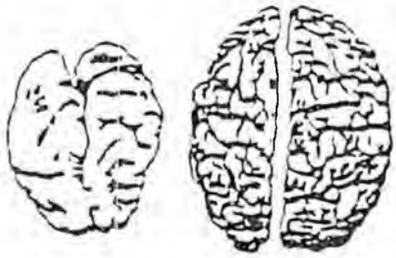
Fetal Alcohol Syndrome (FAS) is a group of physical and mental birth defects resulting from a mother's alcohol consumption during pregnancy. Although more and more cases of the syndrome are being diagnosed in the U.S. every year (approximately 5000 per year), medical personnel are often unfamiliar with FAS, which was only identified as a birth defect in 1973. A complete diagnosis of fetal alcohol syndrome in children involves the identification of as many as 38 characteristics. Here are a few of the most common features of babies born with FAS.

Normal
8 year old

FAS
8 year old

Slow growth before and after birth

- Birthweight of newborns is usually in the lowest 5%
- Growth remains slow throughout childhood
- Small head circumference (microcephaly) persists throughout adult life



FAS brain Normal brain

Brain damage resulting in a smaller and abnormally developed brain. This results in low IQs (average FAS child's IQ is low 70s) and mental retardation as well as behavioral problems.

Abnormal facial features

- flat facial profile
- small eye openings
- small nose with nostrils which are often aimed forward
- poorly developed nasal bridge
- abnormal ears with "railroad track" ridges
- long and flattened upper lip

over please

A pregnant woman never drinks alone.

New Mexico's Campaign to Stop Fetal Alcohol Syndrome

A project of the N.M. Developmental Disabilities Planning Council
435 Saint Michael's Dr.
Building D
Santa Fe, NM 87501

505 827-7590

Bodies are hairy at birth, although the hair disappears

Joint abnormalities in the hands, elbows and hips

High risk for congenital heart disease, cleft lip, cleft palate & seizures

Braces often required for misaligned teeth

Poor eyesight requiring glasses

As FAS children grow, the syndrome is less visible but behavioral difficulties are apparent. Among the most common behavioral difficulties are:

delayed toilet training
irritability
hyperactivity
attention deficits
poor coordination
poor judgement & logic
temper tantrums & disobedience
easily manipulated
failure to understand consequences of actions
anti-social behavior

FAS is completely preventable if a woman abstains from drinking during pregnancy, while nursing or attempting to conceive. Therefore, it's important for doctors, nurses and other medical personnel to discuss alcohol consumption with pregnant patients. While most FAS babies are born to women who drink enormous quantities of alcohol, it is not clear whether there is a threshold amount of alcohol that must be consumed before damage occurs. Even moderate amounts of alcohol, or a pattern of binge drinking, can lead to low birthweight babies, depressed IQs, behavioral problems and other symptoms of Fetal Alcohol Effect (FAE), a less severe version of FAS.

A pregnant woman never drinks alone. Until more data are available, it's best to advise patients to follow the Surgeon General's advice and avoid alcohol during pregnancy.

Fetal Alcohol Fact Sheet

"If women didn't drink anymore during pregnancy, there would **never** be another baby born with Fetal Alcohol Syndrome or Fetal Alcohol Effect."

– Ann P. Streissguth, Ph.D., University of Washington

What are FAS and FAE?

When mothers drink alcohol while pregnant, their babies could have **Fetal Alcohol Syndrome (FAS)** or **Fetal Alcohol Effect (FAE)**. FAS and FAE are a group of birth defects that have no cure. People with FAS and FAE have a range of problems as severe as being mentally retarded to less visible problems like difficulty paying attention in school. Alcohol might cause a child to:

...be slow or mentally retarded
...look different than other children
...be small for his or her age
...have learning problems, with a lower IQ
...be hyperactive, with a short attention span
...have many health problems

Facts...

- FAS is the #1 known cause of **mental retardation** in the United States, and one of the three leading causes of birth defects.
- Each year over **40,000 American children** are born with defects because their mother drank alcohol when pregnant.
- **The effects of FAS never go away.** People with FAS have the disabilities they are born with, including mental retardation, throughout their lives.

Can FAS and FAE be prevented?

Yes, they are both 100% preventable! When a woman stays away from alcohol (beer, wine, hard liquor and wine coolers) during pregnancy, her baby **will not** have FAS or FAE.

- Women **planning a pregnancy** should stop drinking alcohol before trying to conceive and should not drink throughout pregnancy and breast feeding.
- Women who drink and have an **unplanned pregnancy** should quit drinking as soon as they suspect they are pregnant.
- **Heavy drinkers** should avoid pregnancy until they think they can stay away from alcohol for the nine months from conception to birth, and longer, if they plan to breast feed their babies.

How much is too much?

There is **no known safe amount** of alcohol for a pregnant woman. When a woman drinks, her baby drinks because the alcohol passes directly through the placenta to the baby.

For more information about...

Alcohol use: National Council on Alcoholism and Drug Dependence Helpline:		1-800-622-2255
	or:	1-800-475-4673
Drug use: National Clearinghouse on Alcohol & Drug Information:		1-800-729-6686
Birth Defects: March of Dimes, Washington State Chapter		1-800-345-5188
If you want to talk to someone about a problem with alcohol or other drugs call		1-800-662-4357

10 COMMON MISCONCEPTIONS ABOUT FETAL ALCOHOL SYNDROME (FAS) AND FETAL ALCOHOL EFFECTS (FAE)

Ann P. Streissguth, Ph.D.
Fetal Alcohol & Drug Unit, Department of Psychiatry & Behavioral Sciences
School of Medicine, University of Washington
Seattle, WA 98195

1. **That FAS means mental retardation.**
   - Some people with FAS are mentally retarded, others are not.
   - People with FAS can have normal intelligence.
   - They are brain damaged and have specific areas of strengths and weaknesses.
     - It's more like people who have sustained brain injury from an auto accident.

2. **That the behavior problems associated with FAS/FAE are all the result of poor parenting or a bad environment.**
   - No, being brain damaged can lead to behavior problems because brain damaged people don't process information the same way that other people do, so they don't always behave like others expect them to.
   - Brain damaged children are hard to raise in the best environments.
   - Their parents need help and support, not criticism.

3. **That they will outgrow "it" when they grow up.**
   - Unfortunately, they do not. FAS lasts a lifetime, but the manifestations and type of problems change with each age.
   - It takes a longer period of sheltered living for brain damaged children to grow up.

4. **That to admit they are brain damaged is to give up on them.**
   - Have we given up on children with other defects?
   - We need research to understand the needs of patients with FAS and how to help them. We haven't invested in that area yet. We will learn how to help them when we decide to invest in the problem.

5. **That diagnosing them will brand them for life.**
   - A diagnosis tells you what the problem is, helps you figure out how to treat the problem and relieves the person of having to meet unrealistic expectations.

6. **That they are unmotivated when they don't keep appointments or act in a way that we consider responsible.**
   - Probably the explanation lies in memory problems, inability to problem solve effectively, or simply being overwhelmed.
   - Sometimes they misconstrue reality.

7. **That one agency can solve any or all of the problems alone.**
   - The multiple needs of patients with FAS/FAE require multiple fronts of intervention and intense interagency cooperation.

8. **That this problem will be solved with existing knowledge.**
   - Research is desperately needed, and the magnitude of the problem will necessitate.

9. **That the problem will go away.**
   - FAS is preventable, but alcohol is so much a part of our culture and so aggressively marketed to those least able to resist, that active prevention activities must continue on all fronts to safeguard our children's future and the future of our people.

10. **That their mothers had an easy choice not to drink during pregnancy, and through callousness or indifference, permanently damaged their children.**
    - Biologic mothers of children with FAS need help with their alcoholism and/or with birth control.
    - Pregnancy is an excellent time for alcohol abusing mothers to stop drinking, but they need help.

03/05/92

WHAT YOU CAN DO TO MAKE A DIFFERENCE

Suggested Steps to Take to Address FAS in Your Community

- Educate yourself. Learn all you can about FAS. Be sure you understand the facts. Remember that FAS is multi-faceted. There are persons with FAS in every age group and every age has different needs. In addition there is the whole area of prevention. No one strategy will address all the needs.

- Educate the community. The following are 2 examples of how communities have done this in Washington:

  - Woodinville had a town meeting sponsored by the Woodinville Kiwanis Club and the March of Dimes.
    - The meeting was widely advertised. Notices went home with every child in the school district.
    - They arranged for a panel of speakers including:
      - The FAS Coordinator for the state Department of Health who gave an overview of FAS.
      - The biological mother of a child with FAS from Woodinville who talked about her experience as a parent of a 9 year old with FAS and what support she needs.
      - The teacher of the above child, who talked about how she deals with him in the classroom.
      - A counselor who works with children with FAS in a grade school, who talked about techniques she uses with them.
      - An adoptive parent who talked about her experience as the parent of an adolescent with FAS and what support she needs.
      - A probation counselor supervisor who talked about how the criminal justice system is beginning to recognize clients with FAS.
    - A sign-up was available for persons interested in pursuing the issue. The plan was to get a working group formed.
    - The meeting was in the evening in the school gym and about 80 people were in attendance.

  - In Chehalis the Lewis County Hotline and C.A.R.E. Services coordinated with the Lewis County Health Department and set up an informational evening meeting on FAS.
    - The state FAS Coordinator for the Department of Health gave a 45 minute talk describing FAS.
    - An adoptive mother spoke about being the parent of a 9 1/2 year old with FAS.
    - A local parent who has adoptive and foster children with FAS spoke about her experiences.
    - A panel of local people was present to speak about their interest in FAS, what they know, and what they are trying to learn. The panel included:

- Talk to your legislator and senator. Are they knowledgeable about FAS? One way to educate them is to have parents in their district with children with FAS tell them their story.

- Get in touch with the FAS Adolescent Task Force, Jocie DeVries, (206) 778-4048, to learn about what they are doing. They may be involved is testifying before the legislature or any number of other activities. They welcome active support.

- Subscribe to ICEBERG, a quarterly newsletter for parents and professionals who care about persons with FAS.

- Be an advocate for one family or one child.

Prepared by: Sandra P. Randels, Coordinator
Fetal Alcohol Syndrome Program
Washington State Department of Health
(206) 368-4473

May 29, 1992

ICPA dispatch INTERNATIONAL

What We Can Do About Fetal Alcohol Syndrome

Ann Pytkowicz Streissguth, PhD

When a pregnant woman drinks alcohol, within minutes the blood alcohol level in the fetus becomes about the same as that in the mother. The embryo and fetus are growing and changing so rapidly that their development can be altered by exposure to certain toxic drugs, like alcohol. Amounts of alcohol that have no perceptible long-term effect on the mother can produce long-lasting effects on the offspring.

The birth defect caused by heavy prenatal exposure to alcohol *in utero* is called Fetal Alcohol Syndrome (FAS). FAS is the most common known cause of mental retardation in the western world. Yet FAS is entirely preventable.

FAS is the most common known cause of mental retardation in the western world.

Lemoine, a French pediatrician, noted a characteristic appearance and behavior among children of alcoholic mothers. He concluded in a 1968 paper that the characteristics were so distinctive that alcoholism in the mothers could be diagnosed by observing the children. In 1973 Jones, Smith, and colleagues independently made similar observations and termed this characteristic pattern of physical abnormalities *Fetal Alcohol Syndrome*.[1,2] Since then, hundreds of reports of patients from all racial groups have been published.

Fetal Alcohol Syndrome (FAS) is a specific birth defect manifest by a cluster of specific features in each of three categories: (1) facial abnormalities; (2) growth deficiency; and (3) central nervous system effects.

The facial abnormalities include a cluster of characteristics: small eyes; thin upper lip; flat midface; short upturned nose; small chin; other eye problems, including drooping eyelid and crossed eyes; and some minor abnormalities of the external ear. Not all of these are found in all cases of FAS, and the individual characteristics have no diagnostic significance when found in isolation. A higher frequency of major congenital malformations (heart defects, cleft lip and palate, and so forth) occurs in children with FAS, but no particular major malformation is necessary for the diagnosis.[3] Malformations of the fingers, toes, and other joints and limbs also occur with increased frequency. Auditory problems (primarily inflammation of the ear) and vision problems (primarily nearsightedness) are also frequently observed, along with malformed and misaligned teeth.

Growth deficiency for height and/or weight is present at birth and continues during childhood. The low birth weight and short birth length show a direct effect of alcohol on fetal growth. Except in unusual circumstances the continuing growth deficiency is a permanent condition arising from the prenatal trauma, and usually not the result of postnatal nutritional status. Hormonal changes may result in weight gain among females, so the characteristic thin appearance may not be observed after puberty. Shortness of stature remains characteristic into adulthood in most patients.

Central nervous system manifestations usually include some degree of mental handicap, ranging from mild to severe. Small head circumference is usually present and it reflects smaller brain size. Large head circumference may be present. In infancy, tremulousness and jitteriness, poor sucking reflex, high or low muscle tension, and/or delayed development are often observed. Childhood manifestations include hyperactivity, short attention span, borderline to moderate mental retardation, and/or learning and behavioral problems.

Certain postpubertal changes should be considered in diagnosing FAS in adolescents and adults.[4] After puberty the general appearance may not be as striking. Growth of the nose and chin may increase; growth deficiency for weight may no longer be relevant (particularly in females), although small head circumference and/or short stature may remain as

markers. Hyperactivity and short attention span may become less prominent, although specialized memory deficits, difficulty with adaptive behavior, and poor judgment become increasingly noticeable.

In general, the older the child, the less distinguishing are the physical features associated with FAS. Diagnosis is easiest within the first two or three years of life. Not all newborns are readily diagnosed, although by eight or nine months the diagnostic picture is usually clear.

FAS, or the effects of prenatal alcohol in general, do not diminish as the child grows older. Different aspects, however, are conspicuous at different ages. The newborn shows effects on growth and development and subtle central nervous system abnormalities. During the pre-school years, hyperactivity and language and motor problems are noted. The school-age years show learning and behavior problems, and attentional and memory deficits. In adolescence psychosocial problems and aggressive anti-social behavior are often observed. Adults exhibit difficulties with adapting and self-sufficiency. Intellectual deficits associated with FAS remain fairly constant into adulthood in most patients.

Fetal Alcohol Effects (FAE) is a term used when a child has had prenatal alcohol exposure and some characteristics of FAS, but not enough for diagnosis of the full syndrome.[3] FAS is clearly defined and known to be caused by heavy *in utero* alcohol. FAE covers a wide range of disabilities and aberrations from which prenatal alcohol exposure can only be inferred. With FAE, symptoms are less specific to alcohol.

The impact on the child can be just as debilitating whether the diagnosis is FAS or FAE. All such children should be considered at risk for developmental problems, particularly at key ages such as the onset of normal schooling, the onset of puberty, and the end of formal schooling. Although children diagnosed with FAS, as a group, have lower IQ scores than those with FAE, they may be equally at risk as adolescents and adults for learning disability, behavioral problems, mental illness, and psychosocial disorders as adolescents and adults.

Children with the full FAS are usually born to women who clearly consumed a lot of alcohol during pregnancy. One problem with research on the effects of alcohol on the fetus, however, is that assessment of exposure comes primarily from self-report.

The duration of maternal alcoholism is highly related to severity and frequency of FAS among offspring. Women are more vulnerable to alcohol than men, developing cirrhosis and dying from alcoholism after fewer years of and much less lifetime alcohol consumption. Gynecologic problems increase with increasing drinking levels. Miscarriage or stillbirth, premature birth, birth defects, and infertility are all associated with higher levels of alcohol consumption.[5,6]

Prenatal alcohol exposure is associated with a continuum of risks. At the heaviest exposure end are children who are clinically abnormal and diagnosed FAS. At the lighter end effects may not be observed in individual offspring but are detected by epidemiologic studies of more or less normal individuals in population-based studies.

Amounts of as low as two drinks per day increase risk of spontaneous abortion, lowered birth weight, and neurobehavioral effects on offspring as old as seven years. Three or more drinks per day increase risk of stillbirths, reproductive system disorders, and neurobehavioral deficits.

One recent study shows an association between drinking one or two drinks per day during lactation and a decrease in psychomotor function in year-old babies, even after adjusting for variables. Advice to breast feeding mothers may also need to be modified.

Much information on long-term neurobehavioral effects of social drinking in pregnancy has come from the 15-year Seattle Longitudinal Prospective Study on Alcohol and Pregnancy.[7,8] Starting on the first day of life, alcohol-related deficits were observed on neurobehavioral tests and on physical examination. Subtle alcohol-related decreases were also noted on mental and motor development at eight months. By four years statistically significant IQ deficits were observed, as well as decreases in fine and gross motor function (mostly balance), and sustained attention. Poor reaction time was one of the strongest deficits at the four-year exam.

Of course these studies do not indicate that drinking during pregnancy is the *only* cause of these outcomes. But after other known causes have been statistically adjusted for, prenatal alcohol exposure remains a significant predictor of later neurobehavioral effects in children. These studies on the children of social drinkers confirm that there is no known safe level of alcohol exposure *in utero* and no known safe time for exposure during gestation.

The prevalence of FAS is about one in 600 to 750 live births in studies conducted in northern France; Gothenburg, Sweden; and Seattle, Washington. The risk of FAE is about twice that of FAS.

The cost to the United States of Fetal Alcohol Syndrome has been conservatively estimated at $321 million per year for only some of the disabilities associated with it.[9] Many patients with FAE are unable to live independent productive lives even though they may not technically be classified as mentally retarded. Current residential and support services for mentally retarded persons in the United States are about $11.7 billion per year; 11 percent of these costs are estimated to be from FAS alone.[9] These are probably underestimates as the extent of disability in adolescents and adults with both FAS

and FAE is only now being recognized.

In the Seattle Longitudinal Study on Alcohol and Pregnancy, "blind" clinical examinations were given to newborn infants whose mothers' alcohol use had been previously measured by self-report during pregnancy. The higher the mother's drinking during pregnancy, the higher the risk of having a baby with fetal alcohol effects (defined here as growth deficiency, small head circumference, and minor physical abnormalities). The risk for an offspring with FAE was 10 percent for those reporting one to two ounces of absolute alcohol per day, and 19 percent for those averaging over two ounces (over four drinks of wine, beer, or hard liquor per day, on the average).[10]

At four years of age, children classified FAE at birth on these criteria had IQ scores over 2/3 of a standard deviation (10.5 IQ points) below the rest of the sample *after* adjusting for the other know influences on IQ in this population.[11] These subtle newborn characteristics of FAE were good predictors of children who were clearly at risk for long-term neurobehavioral deficits. Irrespective of neonatal FAE characteristics, mothers who had three or more drinks per day on the average had children with an average of five IQ points lower than the rest of the group at four years.[11] Mothers who reported a binge pattern of alcohol (five or more drinks per occasion) had more children at risk for learning disabilities. By the second grade of school, 24 percent of their children were already in special programs or classes, versus 14 percent for the rest.

The harm alcohol causes to the fetus has been established with hundreds of studies on laboratory animals where alcohol, as the primary cause, can be separated from the other factors that may vary with alcohol in the human condition and which in human studies must be statistically controlled. These include smoking, use of illicit drugs, poor nutrition, poverty, and adverse child-rearing conditions. Prenatal alcohol, in the absence of these variables, has been shown to produce growth deficiency, physical malformations, and disruptions in the central nervous system in a variety of animal species ranging from rodents to nonhuman primates. The studies of perhaps the greatest interest are those documenting alcohol-related disruptions in brain development *in utero*. Early work in this area documents alcohol-related disruptions in several regions of the brain.[12] Several more recent studies extend this work to low-dose effects of alcohol, showing behavioral and neurochemical effects at doses too low to produce deviations in physical structure or growth that last well into adulthood. Noble reports evidence that prenatal alcohol exposure alters activity of excitatory amino acids (EAAs) in the brains of adult rats.[13]

The behavioral problems observed in animal models of FAS may derive in part from brain disruption *in utero*, the lifetime consequences of which are played out as the offspring develops.[12] A wide variety of lifetime behavioral deficits of the rat that are produced by prenatal alcohol exposure have been documented. These behaviors—also observed in patients with FAS and/or documented in the Seattle social drinking study—include: early sucking difficulty, weak reflexes, early gait problems, difficulty with response inhibition, increased activity, learning problems, and visual spatial problems. Animal and human studies show fairly good agreement when compared in terms of estimated blood alcohol levels (BALs), and both show a dose response relationship.

Other mechanisms that may show the harm alcohol causes to the fetus have included prenatal oxygen deficiency from alcohol-induced constriction of fetal circulation; alcohol-induced inhibition of essential amino acids across the placenta and blood/brain barrier; direct toxic effects of acid aldehyde or other primary metabolites of alcohol; disruption of prostaglandin synthesis; and/or disruption of the hypothalamic-pituitary-ovarian-adrenal axis.

The 1985 National Household Survey on Drug Abuse found that 89 percent of women in the childbearing years had had alcohol in their lifetimes, 61 percent in the past month. The 1987-88 National Adolescent Student Health Survey showed that 50 percent of 10th grade girls were using alcohol and 50 percent thought it was acceptable to have sex with a steady friend. In Seattle, recent studies at the University Hospital revealed that 52 percent of women had used alcohol during pregnancy and 13 percent had an alcohol use pattern involving five or more drinks per occasion.

Children classified FAE at birth had IQ scores 10.5 points below the rest of the sample.

Organized prevention activities are clearly warranted. The best start is a pronouncement from a country's public health officer, recommending that women abstain from alcohol during pregnancy and when planning a pregnancy.

The next step is to get that message to the entire community, not just pregnant women. Although it may be difficult for an individual woman on her own to overcome alcohol use, the support from family and friends can help her attain and maintain abstinence.

Strategies for raising public awareness about abstinence during pregnancy can include warning labels on alcohol beverage containers; signs at places where people purchase alcoholic beverages; brochures distributed throughout the community; continued media coverage; and a crisis line for information and referral. The crisis phone line becomes the link between the information transmitted in the public awareness campaign and the services available in the community. One without the other will not solve the problem.[14, 15]

Increasing professional education about alcohol-related birth defects (ARBD) is another important activity. Medical schools, nursing schools, psychology departments, schools

of education and social welfare, schools for public administration and policy—all training programs for human services personnel should have specific curriculum materials on alcohol-related birth defects. But to prevent alcohol related birth defects, we will have to rely on a broader campaign than one just oriented to public health nurses, obstetricians, and midwives. It should be a community activity, and a broad range of community service professionals need to be trained at two levels: curriculum additions for those currently in training, and on-going in-service training for those who are already operating as professionals in the field.

Teachers without knowledge of FAS/FAE are often annoyed at the behaviors of such children in the classroom and frustrated by their inability to help them. When the cause of these problems is not recognized, they are often expected to perform to unrealistic expectations, often find school frustrating and unrewarding, often develop undesirable behaviors, and often end up dropping out of or being expelled from school. They are usually even less well-equipped for survival outside of school. Use of alcohol and other drugs and a life on the streets often awaits them once they leave institutional supports.

All women in prenatal care should be asked about their use of alcohol before and during pregnancy, told about the risks associated with such drinking, and advised to stop drinking. Although the best outcome is obtained by abstaining throughout pregnancy, stopping during pregnancy is related to better outcome than drinking throughout pregnancy.

Routine screening of all delivering mothers for alcohol use and of all newborns for FAE is extremely important to target these high-risk families. Appropriate services are needed not only for women who are using alcohol during pregnancy, but also for intensive post-delivery follow-up for mothers and babies. The range of services should include both inpatient and outpatient services, oriented to the special needs of alcohol-dependent women and dealing with the myriad of associated problems, including social support, financial support, self-image and job-skills training, as well as the obvious detoxification and alcohol treatment aspects.

Finally, it is important to properly educate learning-disabled individuals about ARBD and the risks of alcohol use and to provide concrete help with appropriate methods of birth control and treatment for alcohol and drug abuse problems, particularly among the handicapped. Pregnancy has been a frequent problem among adolescent girls with FAS. Although FAS is not genetically transmitted, it can occur in successive generations when women who themselves have ARBD drink heavily during pregnancy. Even in the absence of drinking during pregnancy, these developmentally-disabled mothers are clearly at high risk for parenting difficulties.

Safeguarding the future generation should be a primary goal for public health officials and for private citizens. Our children are our most precious resource.

Ann Pytkowicz Streissguth, PhD, is professor of psychiatry and behavioral sciences at the University of Washington School of Medicine in Seattle.

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Fetal Alcohol Syndrome (FAS) is a birth defect caused by a woman drinking during her pregnancy.

44-50% of women who drink heavily during pregnancy will have children with FAS.

11% of women who drink moderately during pregnancy will have children with FAS.

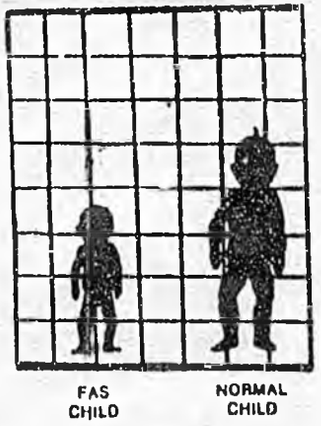
Alcohol passes freely through the placenta to the baby. The baby's blood alcohol level is the same as the mother's. The baby drinks with the mother - drink for drink.

No amount of alcohol during pregnancy is safe for the baby.

Children with FAS have:

1. Abnormal, Deformed Facial Features
   * small, widely spaced eye openings
   * small head
   * short, upturned nose
   * indistinct or no groove between the nose and upper lip
   * thin upper lip
   * flat midface
   * small jaw

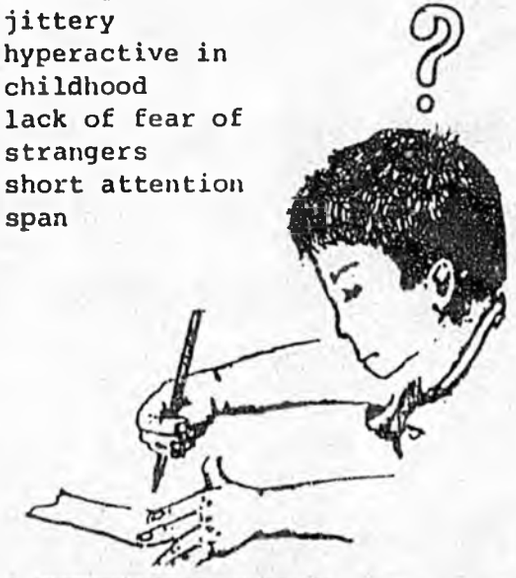
2. Growth Retardation
   * at birth they are smaller than normal children in weight, length and/or head circumference
   * FAS children do not "catch-up", they will always be below normal



3. Poor Brain Development
   * mental retardation
   * small, incompletely formed brain
   * developmental delays
   * learning disabilities
   * poor fine and gross motor coordination
   * seizures

4. Physical Deformities
   * heart defects needing surgery
   * vision and hearing defects
   * kidney defects
   * abnormal liver functioning
   * cleft lip or cleft palate
   * joints (fingers, toes, hips, elbows, knees, etc.) that do not work right
   * immune deficiencies - are sickly children
   * failure to thrive

5. Behavior Problems
   * irritable in infancy
   * poor mother-child bonding
   * jittery
   * hyperactive in childhood
   * lack of fear of strangers
   * short attention span



Drinking is harmful all through the pregnancy. It is especially harmful to the baby during the first three months, a time when many women do not know they are pregnant.

FAS is a totally preventable birth defect which only YOU can prevent.

FETAL ALCOHOL SYNDROME

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Economic Impact of Fetal Alcohol Syndrome in Alaska

February 1989

by

Maureen Weeks
Senate Advisory Council

for

Senator Johne Binkley

Alaska State Legislature

Senate Advisory Council

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MEMORANDUM

TO: Senator Johne Binkley
Alaska State Senate

FROM: Maureen Weeks MW
Senate Advisory Council

DATE: February 17, 1989

SUBJECT: Economic impact of Fetal Alcohol Syndrome; IR # 89-100015

An estimated 29 babies with Fetal Alcohol Syndrome (FAS) are born in Alaska annually; of these 26 survive the first year. Two to 15 times this many babies are born with a lesser set of symptoms known as Fetal Alcohol Effects (FAE). Babies exposed to alcohol before birth may be too small when they are born. Just ten years ago almost all low birthweight babies died at birth. Today, increasingly expensive medical technology saves the lives of four out of five but cannot correct many defects already caused by alcohol. Fifty-eight percent of both FAS and FAE patients have IQ's below 70 (classified as Developmentally Disabled). Conservatively estimated, the lifetime cost per Alaska FAS birth is $1.4 million. Lifetime cost for Alaska FAS babies born each year is $39.8 million.

These are selected medical and social costs only; they do not include, among other things, costs of welfare, the justice system, mild physical problems, mild learning disabilities or loss of a useful member of society.[1]

A table of costs associated with FAS and FAE follows page 18 of this report.

I. BACKGROUND.

Fetal Alcohol Syndrome (FAS) is caused when the alcohol which a pregnant woman drinks damages the brain and body of the fetus as it develops. Until 1973, alcohol was not suspected as toxic to an unborn baby. Respected medical authorities told pregnant women that the placenta protected their fetuses from harmful substances. Today we know these authorities were wrong. Babies who are exposed to alcohol before they are born can be irreversibly harmed for the rest of their lives.

The damage done by alcohol has profound implications for the victim and society. The harmful effects of alcohol on the fetus last a lifetime. A common problem is mental retardation. The average IQ of FAS patients is 66. Almost every child

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[1] Harwood and Napolitano estimate direct average lifetime costs at $405,000 per person and indirect costs at $191,000, in 1980 dollars. Adjustment for inflation and cost of living differences (3 percent per year and 30 percent) yields direct costs of $528,000 and indirect costs of $249,000, for a total of $1,010,000/person, Alaska 1989. Total costs for 29 Alaska FAS births would be $29,290,000. (A 30 percent increase is conservative; the Bureau of Labor Statistics reports that medical services increased by 83.5 percent in Anchorage between 1980 and 1988.) It should be noted that some costs in the Harwood study are much less than Alaska costs. For example, intensive care hospitalization is estimated nationwide at $2,500 per infant v. $120,000/year per infant in Alaska; institutionalization is estimated at $25,000/year nationwide v. $109,000 in Alaska.

or adult with FAS needs lifelong care, supervision or support from family and society. Those most severely affected may spend their lives in institutions. Some suffer physical anomalies such as heart problems, cleft palate, kidney problems, blindness and deafness.

Few, if any, families can pay the enormous costs of supporting an FAS child or adult. Babies born with FAS may need intensive hospital care at birth at an average cost of $2,400 a day. One in eight children born with FAS have cleft palates, requiring surgeries costing up to $75,000 and long term speech therapy twice or three times a week at $96 an hour. Fifty-eight percent of patients with FAS have IQ's below 70 and as such are classified as developmentally disabled. Cost of special education for a severely retarded child is $20,000 a year. Average annual cost for each FAS patient in an institution is $109,000.

Two national studies of the economic impact of Fetal Alcohol Syndrome have been published since the syndrome was discovered in 1973. Harwood and Napolitano in 1985 found the U.S. spends up to $108.8 million a year on FAS births; Abel and Sokol in 1986 found annual costs of $321 million a year. This report adapts the more conservative Harwood and Napolitano study to Alaska.

II. INCIDENCE OF FAS AND FAE

An estimated 29 Alaska babies are born a year with FAS. Experts believe between two and 15 times that many FAE babies are born annually.

A diagnosis of FAS requires signs in three areas:

(1) Pre and/or post natal growth retardation (weight, length, and/or head circumference below the tenth percentile).

(2) Central nervous system problems (neurological abnormality, developmental delay, or intellectual impairment.

(3) Characteristic facial features (including small eyes, crossed eyes, short nose, or abnormalities of the mouth such as cleft palate).

FAS may be difficult to identify, especially among newborns. The identifying facial features may not be easily recognized and mental retardation may not be identified until years after birth.

U.S. researchers speculate that some racial groups, such as certain American Indian tribes, may be at greater risk for FAS than the population as a whole. A 1982-83 study of Indians on 26 reservations in New Mexico, Colorado, Utah and Arizona showed a wide variation in prevalence of FAS among cultural groups. For example, among Navajo Indians, the incidence was 1.4 FAS cases per 1,000 births; among Pueblo Indians it was 2 per 1,000 births and among Plains Indians it was 9.8 per 1,000 births.

Dr. James Berner of the Native Health Service, and Vicki Hild, FAS Coordinator for the Alaska Native Health Board, report statewide incidence of FAS between

1981 and 1988 at 4.2 per 1,000 live births. At an average of 2,700 deliveries annually, this would be about 12 FAS Native births a year.

The estimate comes from an Alaska Area Native Health Service survey of Alaska Native children born between 1981 and 1988. The study shows that the highest recorded FAS rate among any population in the world is in the Copper River area of Alaska: 250 FAS cases per 1,000 births (or one in every four births). Estimated incidence among Alaska Natives in other areas:

Sitka region:	2.1 FAS cases per 1,000 births
Bethel region:	3.5 FAS cases per 1,000 births
Anchorage:	3.8 FAS cases per 1,000 births
Nome region:	4.0 FAS cases per 1,000 births
Tanana Chiefs:	5.9 FAS cases per 1,000 births

It would be a mistake to ignore FAS among non-Native Alaskans. Data shows, for example, that one non-Native woman in Southcentral Alaska has produced seven children with FAS. No one has studied the incidence of FAS among non-Native Alaskans. Indeed, relatively few studies of the incidence of FAS among the general population have been done in the U.S. The literature commonly estimates overall FAS prevalence at from 1 to 3 cases per 1,000 live births (see Sixth Special Report to the U.S. Congress on Alcohol and Health, January 1987). Estimates in U.S. cities show:

Cleveland (1973-79)	.4 FAS cases per 1,000
Cleveland (1979-82)	3.0 FAS cases per 1,000
Seattle (1978)	1.3 FAS cases per 1,000
Boston (1977)	3.1 FAS cases per 1,000
Boston (1983)	2.1 FAS cases per 1,000

Estimates from Europe include:

Sweden (1979)	1.6 FAS cases per 1,000 births
	1.4 cases per 1,000 births
France (1977-79)	1.3 cases per 1,000 births
	2.9 cases per 1,000 births.

Abel and Sokol added together all FAS births reported worldwide in text or by personal communication and found a worldwide incidence of 1.9 FAS cases per 1,000 live births. Rates were higher in North America (2.2 cases per 1,000 live births) than in Europe and other countries (1.8 cases per 1,000 live births). They believe site, economic class and culture affect the reported FAS rate. Hild and Berner place national incidence at 1.7 per 1,000 live births. This study will use that conservative estimate. At an average of 10,000 deliveries annually, this would be about 17 non-Native babies born with FAS in Alaska a year. Added to the estimated 12 Native births, this brings the total Alaska FAS births per year to 29 babies. Of these, 26 babies survive their first year. See Table 1.

In the 16 years since U.S. doctors recognized that alcohol harms the fetus, researchers have concentrated on the more serious illness, FAS. However, patients with FAE have an average IQ of 73 and researchers now believe that in addition to lowered IQ, FAE causes hyperactivity, learning disorders, speech and hearing problems, perceptual problems and short attention span, among other problems. In some cases, these signs may not become evident until the child has trouble in school. Educators faced with a "difficult" child may not associate school problems with prenatal exposure to alcohol.

Researchers disagree on the incidence of FAE. Ann Streissguth of the University of Washington Medical School, an associate of the U.S. discoverers of FAS, estimates that FAE occurs twice as often as FAS. The National Institute on

Table 1

Incidence of FAS births in Alaska, 1988

Native births:	
Deliveries (a)	2,736
Incidence of FAS births (b)	4.2/1000
Number of FAS births (2736 x .0042 = 11.5)	12
Non-Native births:	
Deliveries (a)	10,163
Incidence of FAS births (b)	1.7/1000
Number of FAS births (10163 x .0017 = 17.3)	17
Total FAS births:	29
First-year survivors:	
Neonatal mortality rate, Alaska: (c)	5.1%
Neonatal survivors:	28
Postneonatal mortality rate: (c)	5.9%
FAS first-year survivors	26

(a) Alaska Vital Statistics 1985, Department of Health and Social Services, Juneau, 1988.

(b) J.E. Berner, "Update: Incidence of Fetal Alcohol Syndrome (FAS) In Alaska Natives", February 3, 1989.

(c) Alaska Vital Statistics 1985, p. 7.

Alcohol Abuse and Alcoholism reports a ten times increase and Sokol estimates much as a 15 times increase. Hild believes the incidence of FAE in Alaska is ten times that of FAS, or higher. In an effort to be conservative, this report will use the lowest estimate (twice FAS). At this rate, 58 Alaska FAE babies are born a year.

Table 2 shows the number of FAE births per year at each estimate.

Table 2

Incidence of FAE, Alaska 1985 (a)

Estimate of times increase over FAS	Number of FAE born/year (FAS = 29/yr)
2	58
10	290
15	435

(a) Three estimates of the frequency of FAE are quoted in the literature:

* 2 times FAS: Ann P. Streissguth, Ph.d, of the University of Washington Medical School. (Manual on Indian Adolescents and Adults with Fetal Alcohol Syndrome, July, 1986, p. 4)

* 10 times FAS: National Clearinghouse for Alcohol Information at Rockville Maryland. (Fact Sheet, December 1985). V. Hild, FAS coordinator for the Alaska Native Health Board, estimates the FAE incidence in Alaska exceeds 10 times that of FAS.

* 15 times FAS: R.J. Sokol. ("Alcohol Abuse During Pregnancy: An Epidemiologic Study", Alcoholism: Clinical and Experimental Research, April 1980, p. 135-145.

B. Medical costs associated with FAS and FAE.

FAS patients commonly require medical care for cleft palate, heart defects, kidney defects, visual and hearing defects, dental problems and skeletal and postural problems. When estimates of the prevalence of these anomalies are available, this report relies on Abel and Sokol, Harwood and Napolitano and Hild for accurate statistics. Unfortunately, the prevalence for the majority of physical problems has not been established and these costs are not be included in this report. Table 6 shows costs of selected physical disorders. Hospital costs are explained below.

Alcohol can lower birthweight even in babies who do not have FAS. Ruth Little reports that when a pregnant woman drinks one ounce of alcohol a day, birthweight can fall by 160 grams. Alcohol also lowers birthweight in the majority of FAS births. Low birthweight babies are at risk to need intensive care. Just ten years ago almost all low birthweight babies died at birth. Today, newborn intensive care saves the lives of four out of five. This intense early care is increasingly expensive and cannot correct the lifelong and expensive defects already caused by prenatal exposure to alcohol. In some cases, the desperate effort to save a too-small baby's life adds to the irreversible burden of harm the child will carry with it for the rest of its life.

Abel and Sokol report that 79.8 percent of FAS babies are low birthweight (see Table 3). Of 29 Alaska babies born annually with FAS, 23 babies would be low birthweight. Alaska vital statistics records show that 4.6 percent of babies are born low birthweight despite their prenatal care. Thus, one Alaska baby would be low birthweight despite the best prenatal care, leaving 22 Alaska babies whose low birthweight is due to FAS. Abel and Sokol report that 74.3 percent of FAS low birthweight babies are moderately low birthweight, weighing between 1500 and 2500 grams. At this rate, 16 Alaska FAS babies would be

moderately low birthweight. The rest (six babies) are very low birthweight, weighing less than 1500 grams.

The National Institute of Medicine reports that 32.8 percent of moderately low birthweight babies need intensive care (see Table 4). Of the 16 moderately low birthweight Alaska babies, five would need intensive care. All of the very low birthweight babies (six babies) would need intensive care. The total number of FAS low birthweight babies needing intensive care is 11 per year. This estimate is corroborated by Dr. Jack Jacob, Providence Hospital neonatologist, who reports between ten and 15 FAS infants are treated in the intensive care unit each year.

Providence Hospital records show that in 1987, the average length of stay in intensive care for an FAS baby was 27 days and in 1988, it was 65 days.[2] Average FAS hospital costs in 1987-88 were $99,740 per FAS child; average neonatal physician fees for FAS infants were $11,065. These costs include all hospital costs except transport, other physicians and anesthesiology. Total average cost of intensive care for one FAS baby is $110,805 per year. For 11 low birthweight babies, it is $1,218,855 per year.

The Institute of Medicine estimates that 19 percent of all moderately low birthweight babies and 38.3 percent of very low birthweight babies must be rehospitalized during their first year. Streissguth of the University of Washington reports that it is "usual" for FAS babies to be rehospitalized for pneumonia and problems such as hip dysplasia; applying statistics for all low birthweight babies to FAS births may result in conservative estimates.

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[2] To compare, average length of stay for all low birthweight babies in the intensive care unit at Providence was 19.7 days in 1987 and 23.7 days in 1988.

Using the Institute of Medicine averages for all low birthweight babies, one FAS moderately low birthweight baby would be rehospitalized for 12.5 days and two very low birthweight babies would be rehospitalized for 16.2 days. Hospitalization for children not in intensive care was about $900 a day at Providence Hospital in Anchorage in 1988. Rehospitalization for one baby for 12.5 days is $11,250 and for two babies at 16.2 days it is $29,160. Total cost of rehospitalization for low birthweight FAS babies: $40,410. This does not include physicians, surgery, special procedures or transportation. See Table 5.

Table 3

Low birthweight of FAS births,
Alaska 1985

Alaska Low Birthweight Births (under 2500 grams) due to FAS.

FAS births which are Low Birthweight:	
Total FAS births:	29
% FAS births which are under 2500 grams (a)	79.8%
LBW babies in 29 FAS births:	23
(29 x .798 = 22.9)	
Low Birthweight births not due to FAS:	
% Alaska LBW births under 2500 grams not due to FAS (b)	4.6%
4.6% x 23 = 1 LBW birth not due to FAS	
LBW births due to FAS:	22
(23 x .046 = 1.1)	

Weight distribution of Alaska FAS Low Birthweight births:

1500-2500 grams (MLBW):	
% FAS births between 1500-2500 grams (a)	74.3%
FAS MLBW babies:	16
(22 x .743 = 16.4)	
Under 1500 grams (VLBW):	
All other LBW babies are VLBW (under 1500 grams)	6

(a) Abel and Sokol, "Incidence of Fetal Alcohol Syndrome and Economic Impact of FAS-Related Anomalies", Elsvier Scientific Publishers, Ireland, August, 1986, p. 58.

(b) If FAS were eliminated from Alaska, 4.6 percent of all births would still be low birthweight. Although they would still need treatment, the costs of their treatment should not be attributed to FAS. This number is the solution to the following equation: 4.8% x 12,900 births = 79.8% x 24.6 FAS births + p x 12,869 non-FAS births, where 4.8% is low birthweight rate in Alaska; 12,900 is number of Alaska births in 1985; 79.8% is U.S. LBW rate for FAS births; 24.6 is FAS births in Alaska in 1985. Formula devised by J.W. Senner, Oregon State Health Division, "Revised Annual National Cost Estimates" (Portland), p. 2.

Table 4

Costs of intensive care hospitalization for FAS LBW babies
Alaska 1985

Moderately LBW (1500-2500 grams) Intensive Care hospitalization:	
% MLBW babies requiring intensive care (a)	32.8%
MLBW FAS babies requiring intensive care (16 x .328 = 5.4)	5
Very LBW (under 1500 grams) Intensive Care hospitalization:	
% VLBW babies requiring intensive care (a)	100%
VLBW FAS babies requiring intensive care	6
Total	11 babies
Hospital cost for 11 babies at $99,740 (b)	$1,097,140
Physician cost for 11 babies at $11,065 (b)	$ 121,715

(a) The Institute of Medicine reports that 32.8% of LBW infants and 100% of VLBW infants require newborn intensive care. Preventing Low Birthweight, Institute of Medicine, (Washington, D.C.), 1985. This may be an underestimate for FAS babies who show a longer average length of stay in intensive care, an indication that they may be sicker than other low birthweight babies. Providence Hospital reports the following average lengths of stay in the newborn intensive care unit in 1987 and 1988.

	1987	1988
Low Birthweight	19.7 days	23.7 days
FAS Low Birthweight	27 days	65 days

(b) Costs do not include transportation, other physician or anesthesiology fees. Neonatologist Dr. Jack Jacob estimates between 10 and 15 FAS infants a year enter the unit (Lisa Wolf, pers. comm.).

Table 5

Cost of first-year rehospitalization for FAS LBW babies
Alaska 1985

LBW rehospitalization.	
FAS MLBW babies in intensive care	5
Neonatal mortality rate (a)	5.1%
FAS MLBW babies who survive intensive care (5 x .051 = .25)	5
Percent LBW babies rehospitalized (b)	19%
Number of LBW babies rehospitalized (5 x .19 = .95)	1
Cost of rehospitalization: 1 x $11,250 (c)	$11,250
VLBW rehospitalization:	
FAS VLBW babies in intensive care	6
Neonatal mortality rate (a)	5.9%
FAS VLBW babies who survive intensive care (6 x .059 = .35)	6 babies
Percent VLBW babies rehospitalized (b)	38.3%
Number of VLBW babies rehospitalized (6 x .383 = 2.3)	2
Cost of rehospitalization: 2 x $14,580 (c)	$29,160
Total cost of first-year rehospitalization:	$40,410

(a) Alaska 1985 Vital Statistics, Department of Health and Social Services, (Juneau), p. 7.

(b) The National Institute of Medicine reports that 19% of 2500-1500 gram babies are rehospitalized during the first year, as are 32.8% of babies under 1500 grams. Preventing Low Birthweight, National Institute of Medicine, (Washington, D.C.), 1985. This may be an under-estimate for FAS births. Streissguth reports that it is "usual" for FAS babies to be rehospitalized during the first few months of life for pneumonia, failure to thrive, hip dysplasia and other problems. A Manual on Indian Adolescents and Adults with Fetal Alcohol Syndrome, University of Washington Medical School, July 1, 1986.

(c) Providence Hospital charges for pediatric admission, 1988: $900/day (MLBW average length of stay, 12.5 days; VLBW stay, 16.2 days).

C. Costs associated with mental retardation.

Streissguth in a 1986 study of 61 FAS/FAE diagnosed patients between the ages of 12 and 40 shows that more than half (58 percent) of both FAS and FAE patients were developmentally disabled (IQ's below 70). Hild finds the 58 percent estimate likely in Alaska. This report will rely on that estimate. At this rate, 15 FAS first-year survivors and 34 FAE patients have IQ's below 70. (Note that computing the incidence of FAE at 10 times that of FAS, the percentage used by Alaska experts, there would be 336 developmentally disabled FAE patients born every year.) Social service costs for the average moderately to mildly retarded child are $25,000 a year (not including education). For adults, these costs are as high as $45,000 a year (including vocational rehabilitation). About five FAS children currently are part of the Alaska Youth Initiative program for severely troubled youth at an average cost of $50,000 a year each.

If 58 percent of FAS and FAE patients are developmentally disabled, an estimated 42 percent have minimal brain dysfunction. In this report, costs for this portion of patients are estimated at $4,000 each, the additional cost of special education for mildly disabled persons (above regular education operating costs). State officials caution that FAS/FAE patients with IQ's between 70 and 100 may actually be more expensive than those with lower IQ's because of added counselling, legal and corrections costs. This is not reflected in this report.

Streissguth's study of 61 FAS/FAE patients from the Southwest U.S., Seattle and Vancouver, B.C. showed the following patient characteristics:

(1) IQ's ranged from a score of 20 to 105. Average IQ of patients with FAS was 66 and of patients with FAE, 73. No patient with FAS showed

an IQ above 90. Streissguth concludes it is impossible to predict from a diagnosis alone how handicapped an individual patient with FAS/FAE will be as an adolescent or adult.

(2) 58 percent of both FAS and FAE patients had IQ's below 70, (generally classified as developmentally disabled).

(3) The average reading, spelling and arithmetic level of these patients (ages 12 to 40) was 4th grade, 3rd grade and 2nd grade, respectively.

(4) Average level of general adaptive functioning was 7 years 5 months. (Median age of those tested was 16 years 5 months.)

(5) There was no indication of general improvement in IQ, achievement or adaptive living scores as patients got older.

(6) None of the patients were able to live independently.

Vicki Hild of the Alaska Native Health Board has tabulated living situations for 118 Alaska Natives with FAS. She found that 20 percent had been adopted and 10 percent had died. The remaining children shuttled back and forth between their biological parents and state custody. It is state policy to keep children with their biological parents if possible; children move in and out of state custody as a parent's condition improves or worsens. Among biological parents of the 118 children in the Hild study, only three mothers appeared "reasonably" stable.

Hild cites as an example of "ping-ponging" custody, the case of one Alaska FAS child who had lived in seven foster homes by the time she was three.[3]

D. Costs not included in this estimate.

Medical researchers have not yet determined a reliable rate of incidence for the majority of physical defects common to FAS victims and these costs have not been included in this estimate. These physical anomalies include visual problems, kidney and genital tract problems, and dental and skeletal defects (more frequently found in adolescents and adults), including club foot and scoliosis and neurotube defects such as spina bifida. Also not included are on-going lifelong medical costs associated with the ill health of patients with these problems. (Despite their illnesses, however, FAS patients are expected to live a normal life span.) Transportation, anesthesiology and some physician costs for first-year hospitalization and costs of FAE babies with physical damage are also not included.

Many social costs are also not included in this estimate. FAS children and adults are at high risk for physical and sexual abuse. They may exhibit signs of depression; some may be suicidal; a few may become violent. As they grow into adulthood, some may exhibit increasingly inappropriate sexual behavior.

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[3] Streissguth believes stability is important to the well-being of FAS patients. "We usually find great improvement in emotional development and social functioning when children with both full and partial FAS have stable and supportive living arrangements. Improved behavior which often occurs, even in the absence of changes in IQ, should not be ignored simply because it is more difficult to measure and quantify." "Psychological and Behavioral Effects in Children Prenatally Exposed to Alcohol", Alcohol Health and Research World, Fall 1988, p. 10.

Many of the costs of welfare, child abuse, sexual abuse, psychiatric care, incarceration, stress on the care-giver and loss of a useful member of society are not included in this report. Hild has stated that "without early intervention, all FAS and most FAE patients will be on welfare." In addition, this report does not consider what may be the enormous, but still unrecognized, costs of learning disabilities suffered by children afflicted with FAE.

TABLE I

LIFETIME COST ESTIMATES OF SPECIFIC BIRTH DEFECTS IN FAS BIRTHS -- ALASKA

	Birth Defect	Annual Cost per Patient	Number of Times or Years	Lifetime Cost per Patient	Prevalence	Number Per Yr (% x 26)	Lifetime Cost: All Born 1988
	ANNUAL FAS BIRTHS (29 BIRTHS; 26 SURVIVORS)						
1	Neonatal Unit/Providence	99,740	1	99,740		11	1,097,140
2	Neonatal Physician	11,065	1	11,065		11	121,715
3	First Year Rehospitalization	13,470	1	13,470		3	40,410
4	Initial Audio Screening	100	1	100	52%	15	1,500
5	Audio Check-up	100	4	400	100%	26	10,400
6	Otitis Media Surgery	1,224	1	1,224	56%	15	18,360
7	Hearing Aid	1,260	14	17,640	33%	9	158,760
8	Hearing Aid Mold	50	65	3,250	33%	9	29,250
9	Heart Surgery	75,000	1	75,000	5%	1	75,000
10	Cleft Palate Surgery	65,000	1	65,000	12%	3	195,000
11	Infant Learning Program (HSS)	2,513	3	7,539	100%	26	196,014
12	H/C Child: phys defect (HSS)	8,700	18	156,600		7	1,096,200
	H/C Child: devel delay (HSS)	8,700	3	26,100	58%	15	391,500
13	Minimal Special Eductn (DOE)	4,000	15	60,000	42%	11	660,000
14	Child Mental Retardation (DOE)	20,000	15	300,000	58%	15	4,500,000
15	DD Child (HSS)	25,000	18	450,000	58%	15	6,750,000
16	Alaska Youth Initiative (HSS)	90,000	12	1,080,000		1/2	540,000
17	DD Adult Initial Training(HSS)	45,000	3	135,000	58%	15	2,025,000
18	DD Adult Supervised Work (HSS)	22,500	44	990,000	58%	15	14,850,000
19	Institution	109,000	65	7,085,000	3%	1	7,085,000
	Lifetime Costs for FAS Births: 1988						39,841,249
	Lifetime Costs per FAS Birth			1,373,836			
20	ANNUAL FAE BIRTHS AT TWICE FAS RATE (58)						
21	Infant Learning Program (HSS)	2,513	3	7,539	58%	34	256,326
22	DD Child (HSS)	25,000	18	450,000	58%	34	15,300,000
23	Child Mental Retardation (DOE)	20,000	15	300,000	58%	34	10,200,000
24	DD Adult Initial Training(HSS)	45,000	3	135,000	58%	34	4,590,000
25	DD Adult Supervised Work (HSS)	22,500	44	990,000	58%	34	33,660,000
	Lifetime Costs for FAE Births: 1988						64,006,326
	Total FAS/FAE Births						103,847,575

NOTES TO FAS COST TABLE

Numbers refer to line numbers on the table.

1. Neonatal Unit. Charges per FAS patient in the Providence Hospital Neonatal Intensive Care Unit were $68,910 in 1987 and $130,570 in 1988, for an average of $99,740. Average length of stay of FAS infants in the Neonatal Intensive Care Unit more than doubled between 1987 and 1988. It was 27 days in 1987 and 65 days in 1988 (v. 19.7 and 23.7 days for all low birthweight babies in the unit). Statistics provided by Lisa Wolf of Providence Hospital.

2. Neonatal Physician. Physician costs per FAS child were $6,130 in 1987 and $16,000 in 1988, for an average of $11,065. Estimates by Sharon Lee of Alaska Neonatal-Perinatal Associates.

3. First-year rehospitalization. Cost estimate is based on 1988 Providence Hospital pediatric charges of $900/day. The number of infants and average length of stay (12.5 days for moderately low birthweight infants and 16.2 days for very low birthweight babies) are from the National Institute of Medicine and are for all low birthweight infants. Applied to FAS births, these may be underestimates. Streissguth reports it is "usual" for FAS babies to be rehospitalized in the first few months of life.

4. Initial Audio Screening. The state audiologist, Communicative Disorders Program, Anchorage, reports all FAS children need a workup. This report estimates that 11 infants receive a workup in intensive care; the 15 remaining surviving infants are counted in this entry.

5. Audio Check-up. FAS children need three to four follow up checks. The $100 charge is from the Alaska Treatment Center in Anchorage; the check-up estimate is from the state audiologist.

6. Otitis Media Surgery. Estimate is from the Geneva Woods Ear Nose and Throat Associates. Source of 56% prevalence is Harwood and Napolitano. These costs do not include less severe ear problems common to 93 percent of FAS patients (Alaska Treatment Center). Twenty-nine percent of FAS patients have permanent hearing loss.

7. Hearing Aid. A hearing aid for a baby costs $1,260; it is replaced once every five years for life at this cost. Cost estimate from Alaska Treatment Center.

8. Hearing Aid Mold. A $50 ear mold must be replaced annually. Estimate from Alaska Treatment Center.

9. Heart Surgery. Up to 70 percent of FAS patients have heart problems (Streissguth reports the portion at 30-40 percent; Hild reports 70 percent). Harwood and Napolitano report 10 percent require heart surgery, but reduce the estimate to 5 percent to reflect cases actually having surgery. Cost estimates from Vicki Hild, Alaska Native Health Board FAS coordinator.

10. Cleft Palate. Costs include an average of four surgeries, dental and orthodontics work. They do not include long term speech therapy at $96/session twice or three times a week. Estimates from Vicki Hild. The 12% estimate is average of Abel and Sokol (11.5%) and Harwood and Napolitano (12.5%).

Infant Learning Program. Mary Diven of the state division of Maternal and Child Health reports these figures are "deceptively low", under estimating the true cost of rural service. Infant Learning Program costs as much as $6,000/year in some rural areas.

12. Handicapped Children's Program. Cost estimates include averages for children with heart problems, cleft palate and developmental delay. Children with physical problems can be on the program for 21 years; children with developmental delays may be on the program for as few as three years. Cost estimates by Kathy Robinson, Maternal and Child Health, Alaska Department of Education. This report estimates that one child per year has heart problems (a low estimate in view of the 30 to 70 percent with heart problems); three have cleft palates; and three more have other physical problems such as spina bifida, progressive scoliosis, or severe visual and hearing loss.

13. Minimal Special Education. Costs cover only $4,000/year for additional special education for learning disabled children, above normal operating and capital education costs (Tom Buckner, Department of Education). Christine Hagmeier of the Department of Health and Social Services cautions that patients with IQ's above 70 and below 100 "may well be more expensive than those with lower IQ's" because they an become involved in counselling, corrections and the law. These costs are not reflected in this report. The 42 percent prevalence estimate is from Streissguth.

14. Child Mental Retardation. Cost of special education for severely retarded children is $20,000 - $23,000/year, in addition to normal operating and capital education costs. Estimates from Tom Buckner, Department of Education.

15. Developmentally Disabled Child (HSS). Cost estimate by Christine Hagmeier of the Department of Health and Social Services. Costs can include foster care, in-home care, shared care, respite care, in-home training, advocacy and family support. Hagmeier reports that severely disabled children can cost between $35,000 and $85,000 with average cost of $55,000.

16. Alaska Youth Initiative. Cost estimate from John Van Den Berg, Department of Health and Social Services. This is a program for 52 severely troubled youths. The average age is 15.8 years; the average number of failed housing placements is 16. Currently five FAS youths are in the program. This report estimates children remain on the program an average of 12 years (based on Van Den Berg's report that "absolute minimum lifetime costs per child are $1 million".) It further assumes that one FAS child would enter this program every two years. Streissguth reports that aggressive behavior may be a problem for about 40% of the boys. Those from a less structured and protected environment may be "quick to anger when crossed and quick to strike out impulsively".

17. Developmentally Disabled Adult Initial Training. Costs include $25,000 residential care (example: foster care and independent living) plus initial vocational rehabilitation costs of $20,000, for a total of $45,000. Initial vocational rehabilitation costs average between two and five years. Estimate by Christine Hagmeier.

18. Developmentally Disabled Adult Supervised Work. After initial rehabilitation costs (see #17 above), costs can "fade" to between $10,000 and $25,000 for lifetime residential care plus $5,000 lifetime vocational rehabilitation care (Hagmeier). The average of this $15,000 to $30,000 range is $22,500.

19. Institution. Estimate by Ellen Ganley, Governor's Council for the Handicapped and Gifted.

20. FAE Births. Annual FAE births are calculated in this report at twice that of FAS births. This is a conservative estimate. Hild believes the actual number of FAE births annually is ten times the FAS births (or 290 FAE births and 168 developmentally disabled FAE persons.) In this report, cost estimates for FAE births are limited to mental retardation. They do not include costs associated with mild learning disabilities, physical anomalies, child abuse, sexual abuse or the justice system.

21. See #11.
22. See #15.
23. See # 14.
24. See # 17.
25. See # 18.

SOURCES

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PERSONS CONSULTED

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