Approved:	3-13-01	_
	Date	

#### MINUTES OF THE SENATE PUBLIC HEALTH AND WELFARE.

The meeting was called to order by Chairperson Senator Susan Wagle at 1:30 p.m. on February 7, 2001 in Room 231-N of the Capitol.

All members were present except:

Committee staff present: Ms. Renae Jefferies, Revisor of Statutes

Ms. Lisa Montgomery, Revisor of Statutes

Ms. Margaret Cianciarulo, Committee Secretary

Conferees appearing before the committee: Ms. Laura Howard, Assistant Secretary

SRS Health Care Policy Senator Jim Barnett, District 17

Others attending:

See Attached Guest List

### Follow-up information from February 5, 2001 Committee meeting

Chairperson Wagle opened the meeting by introducing Ms. Laura Howard, Assistant Secretary, SRS Health Care Policy, who was here to provide information in response to several questions raised during the February 5, 2001 Committee meeting regarding NFMH residents and alternative services in the community. A copy of her response is (Attachment #1) attached hereto and incorporated into the Minutes by reference.

### Presentation on Fetal Alcohol Syndrome

With this business aside, the Chair recognized Dr. Jim Barnett (Senator Barnett) who gave an educational presentation on fetal alcohol syndrome. Highlights of Dr. Barnett's overview included: statistics regarding alcohol and other drug use within the last year; a comparison of the effects of drugs on prenatal development and their effects during pregnancy (additional research); facial formation of FAS compared to normal formation, and possible solutions emphasizing research by Abel. Dr. Barnett also touched on the effects of social drinking on the IQ of a population, secondary disabilities, learning problems by age, repeat offenders of the law, and how to diagnose FAS. In summary, he presented a comparison of House and Senate Budgets, showing how all departments were affected by FAS; stating that to correct a child they must be diagnosed by age six; FAS facts; and his proposal. A copy of his presentation is (Attachment #2) attached hereto and incorporated into the Minutes by reference.

Committee discussion related to comments and questions from Senators Salmans, Harrington, Steineger, Haley, Praeger, and Wagle ranging from Kansas ranking 34<sup>th</sup> in giving funds, excise tax introduced in Massachusetts, more awareness about alcohol abuse, to the media needing to become more responsible.

Senator Steineger did voice concern that if Dr. Barnett's "Network" was based out of Emporia, how will the rest of Kansas be made aware. Senator Barnett said there would be five sites available in the State. Senator Haley voiced an interest in how the sites would be located. Senator Barnett said the start up would begin in Emporia since the dollars are already in place.

### Adjournment

As it was 2:30 p.m., Chairperson thanked Dr. Barnett for his presentation noting that the Committee would continue hearing tomorrow. The meeting adjourned at 2:30 p.m.

The next meeting is scheduled for February 8, 2001

#### SENATE PUBLIC HEALTH AND WELFARE COMMITTEE

# **GUEST LIST**

DATE: Welnesday, Jebruary 7, 2001

NAME	REPRESENTING
Will Jetheri	Heuth Midwest
Marcha Atrahm	Cast of the.
Delosie Collins	Jo. Co. Developmental Supports
Mark Elmone	Lo. Co. Developmental Supports
Diano Miedomann	United Immein Janultan
Heather Corpuny	Children's Mercy Hospital
Kim m. Weaver	Wichita Nephrology Group
DAVE GORDON	Hillsing MEDICAL OFFICE
Ding Poertner, Secretary to	Sen. Gin, Barnett
Feberer Zepide	Sen. Farnett
Savan Bahan	Assurated Pres
DAVID MCCIVRE	LANSAS HEALTH INSTITUTE
Dorra dorlin	SRS/HUPISATR
Bot Hedbery	ACC
Carla Makun	PPKM
Leen Muser	KDHE
Faida Kanen	KOHE
Deanna McClerahan	KDHE
Mike Farmer	Kansas Catholic Conference

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# KANSAS DEPARTMENT OF SOCIAL AND REHABILITATION SERVICES

915 SW HARRISON STREET, TOPEKA, KANSAS 66612

JANET SCHALANSKY, SECRETARY

MEMORANDUM TO:

Senator Susan Wagle, Chair

Senate Public Health and Welfare Committee

FROM:

Laura Howard, Assistant Secretary

SRS Health Care Policy

REGARDING:

Follow-up to Committee Questions on February 5, 2001

DATE:

February 6, 2001

Thank you for the opportunity to appear before the Senate Public Health and Welfare Committee on February 5 in support of S.B. 120. During that meeting, several questions were raised regarding NFMH residents and alternative services in the communities. The following information is being provided in response to those questions.

Length of Stay: As of 9/30/00, 56% of residents (whose NFMHs reported this data) had lived there more than 3 years.

Community Services: It is predicted that nearly all consumers would receive a minimum of Case Management and Attendant Care; however, many might also choose employment, housing and psychosocial supports. An important component of Attendant Care (for some) would be medication management.

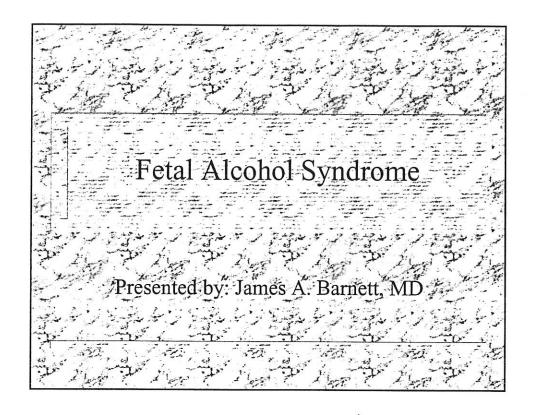
Housing: While most consumers do not have existing housing (other than to return to living with a relative), CMHC Case Managers' expertise in linking consumers to affordable housing and to subsidies which increase its affordability ensures that this will not be a significant barrier. In addition, as residents in NFMHs are from many different counties of residence, no one community should receive too great an influx of low income housing customers. And, CMHCs are able to utilize flex funds and Alternate Care Funds in assisting consumers with start-up and emergency housing costs, as well as accessing community resources to obtain various needs such as furniture and housewares.

Medication Management: This service, as all others, is individually tailored to each consumer. Some may need a weekly visit from a nurse to assist in filling a pillbox. Some may need daily telephone call reminders. Some may need visits from Attendant Care workers or nurses to assist them in taking their medications properly. And, some may have periods in which they require 24-

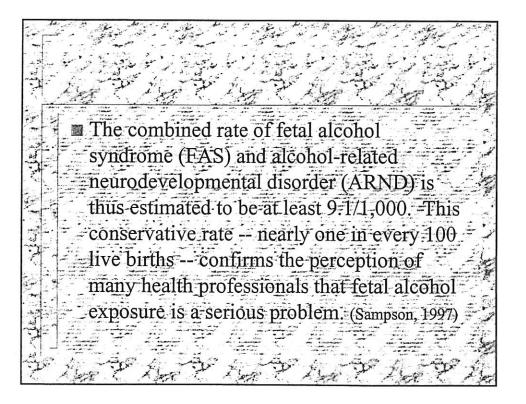
Senate Public Health & Welfare Committee Meeting Wate 2-7-01 Otto Ament 1-1 Senator Susan Wagle Follow-up on S.B. 120 Page 2

hour Attendant Care to assist them in compliance and safety. The ability to assist the consumer in ascertaining their service needs, and in identifying when those change, is an attribute in which the CMHCs excel.

If you or other members of the Committee have other questions as you consider S.B. 120, please let me know.



7.



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Teratology 1997 Nov;56(5):317-26

# Incidence of fetal alcohol syndrome and prevalence of alcohol-related neurodevelopmental disorder.

Sampson PD, Streissguth AP, Bookstein FL, Little RE, Clarren SK, Dehaene P, Hanson JW, Graham JM Jr

Department of Statistics, University of Washington, Seattle 98195, USA.

We critique published incidences for fetal alcohol syndrome (FAS) and present new estimates of the incidence of FAS and the prevalence of alcohol-related neurodevelopmental disorder (ARND). We first review criteria necessary for valid estimation of FAS incidence. Estimates for three population-based studies that best meet these criteria are reported with adjustment for underascertainment of highly exposed cases. As a result, in 1975 in Seattle, the incidence of FAS can be estimated as at least 2.8/1000 live births, and for 1979-81 in Cleveland, approximately 4.6/1,000. In Roubaix, France (for data covering periods from 1977-1990), the rate is between 1.3 and 4.8/1,000, depending on the severity of effects used as diagnostic criteria. Utilizing the longitudinal neurobehavioral database of the Seattle study, we propose an operationalization of the Institute of Medicine's recent definition of ARND and estimate its prevalence in Seattle for the period 1975-1981. The combined rate of FAS and ARND is thus estimated to be at least 9.1/1,000. This conservative rate--nearly one in every 100 live births--confirms the perception of many health professionals that fetal alcohol exposure is a serious problem.

# Publication Types:

- Review
- · Review, tutorial

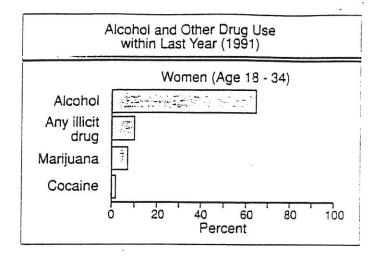
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# 4. Alcohol and Other Drug Use within Last Year

Drinking is culturally acceptable, and about two-thirds of Americans report drinking alcoholic beverages <sup>11</sup>. More than 86.2 billion dollars was spent on alcoholic beverages in 1990 <sup>12</sup>. Using the profits from these sales, the alcoholic beverage industry has developed attractive and persuasive advertising to encourage use of its product.

However, the cost of excessive alcohol use is high: nearly 120 billion dollars in 1983, with about one in every ten adult Americans reporting alcohol abuse or alcoholism. In a household survey of women's drinking, young women ages 21 through 34 were more likely to report intoxication and episodic heavy consumption than women in older age groups; they were also more likely to develop signs of problem drinking over a five-year period. Nineteen percent of all women drinkers in this survey reported at least two alcohol-related problems. There is some evidence that the rate of drinking problems among youngerwomen is increasing over time.

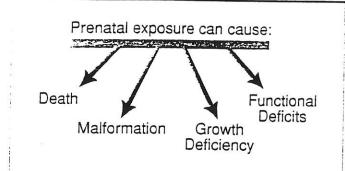
The number of childbearing-age women who use alcohol is notably greater than the number who use cocaine, marijuana, and other illicit drugs. This reflects the legal status of alcohol contrasted to the prohibition of illegal substances and the "War on Drugs" (5).

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# PART III: ALCOHOL AS A TERATOGEN: AN OVERVIEW

This section describes the scientific basis for understanding the impact of alcohol on the developing embryo and fetus. The concept of a continuum of alcohol effects, influenced by dose and timing of exposure as well as the genetic vulnerability of the mother and child, is introduced.

# Alcohol is a Teratogenic Drug



# 10. Alcohol is a Teratogenic Drug

Teratogenic drugs are those that cause undesirable modifications in the embryo or fetus when consumed during pregnancy. The main types of teratogenic outcomes are: death, malformations, growth dericiency, and functional deficits (1). Alcohol can cause all of these, and this has been demonstrated in both humans and animals Fetal effects of prenatal alcohol exposure reflect the dose and pattern of alcohol consumption by the mother, the time during pregnancy that the alcohol was consumed. the genetic susceptibility of the fetus itself, and certain physiologic characteristics of the mother herself such as the rate at which she metabolizes alcohol 151. As is true of all teratogens, not all offspring who are exposed are affected, but this does not mean that fetal alcohol effects do not occur in others. The variability in severity of alcohol effects among exposed offspring can be high. even in response to the same dose and timing of exposure

Alcohol is also a neurobehavioral teratogen, which is the name for that class of teratogenic drugs that cause prenatal damage to the Central Nervous System (CNS) <sup>16. See Section VI.</sup>

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- 3. Schenker S, Becker HC, Randall CL. Phillips DK, Baskin GS. Henderson GI. Fetal alcohol syndrome: Current status of pathogenesis. Alcohol Clin Exp Res. 1990; 14:635-647.
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### Comparison of the effects of drugs on prenatal development

Prenatal alcohol exposure seems to have a more devastating long-lasting effect on the child than other street drugs (that have been studied—ed.). It is often difficult to identify the harm caused by illicit drugs because they are frequently taken in combination with alcohol. (Alcohol the drug is often seen as benign, not as "bad as" other drugs since it is legal. This chart provides a clear visual that this is not true.—ed.)

EFFECT	ALCOHOL	MARLIUANA	COCAINE	HEROIN	TOBACCO
Low Birth Weight	х		×	х	х
Impaired Growth	х				
Facial Malformation	х				
Small Head Size	×				
Intellectual & Developmental Delays	x	×			
Hyperactivity, Inattention	x	x		х	x
Sleeping Problems	x	х	х	x	×
Poor Feeding	x		х		
Excessive Crying	х	x	х	х	
Higher Risk for Sudden Infant Death Syndrome				x	x
Organ Damage, Birth Defects	X				
Respiratory Problems	x			x	x

Alcohol destroys cells in the fetus, causing malformations. (These physical changes contribute to learning and behavioral differences that continue into adolescence and adulthood—ed.) Some effects of cocaine tend to diminish over time, and long-term damage may not be as severe as was originally predicted. Test scores of children exposed to heroin show their physical and psychological development are usually within normal range.

Sources: US Department of Health and Human Services, 1994; Day et al., 1994

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# Effects of alcohol and other drug use during pregnancy: Additional research

	Alcohol	Amphetamine/ Methamphetamine	Cocaine	Marijuana	Tobacco
Spontaneous Abortion	x		×		
Increased rate of SIDS			х	х	х
Increased rate of stillbirth	X	x	x		
Low birth weight	х	х		х	х
Behavioral problems	X	х		G.	
Learning problems	x	X			

# PART II: FETAL AND MATERNAL EXPOSURE

This section addresses special issues with respect to alcohol use during pregnancy and measuring alcohol dose to the fetus.

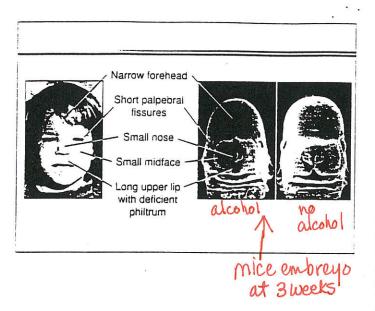
Ethanol Crosses the Placenta Freely



# 6. Ethanol Crosses the Placenta Freely

When a pregnant woman drinks, so does her fetus, for alcohol freely crosses the placenta and levels in the fetal and maternal blood are approximately equivalent. Shortly after the mother consumes an alcoholic beverage, fetal effects are apparent. In humans, fetal breathing movements were drastically suppressed by the amount of ethanol in one or two drinks (2.3). In monkeys, a boius dose of ethanol was followed by collapse of the umbilical vessels within minutes (4). Other animal studies indicate that there is a direct deleterious action of alcohol on the developing fetus, even in early gestation (5).

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### 13. Formation of FAS Face in the Mouse from 2 Doses of Alcohol

A characteristic face is an important differentiating reature of fetal alcohol syndrome. This mouse study of Suilla and colleagues demonstrates how brief prenatal aiconcexposure, at a critical moment in development, can produce major defects in the developing brain that are manifest in the face (1.2). (See slide 20 for a description of the characteristic FAS face and references 4 and 5 tomore additional studies.) Two doses of ethanoi were administered on day 7, the embryos developed cranicfacial malformations closely resembling those seen in the human fetal alcohol syndrome. "Striking histologica: changes occurred in the developing brain within 24 hours of exposure," 11. Not all exposed fetuses were affected, and some were much more severely affected than others from the same dose and timing of ethanci. Two of the 72 fetuses were exencephalic or anencephalic while 30 of 72 had eye malformations, including coloboma of the iris, microphthalmia, and apparent anophthalmia. The primary growth deficiency of the eve was reflected in shortened palpebral fissures. Short palpebral fissures are a primary facial feature of FAS. This range of eye defects in children with FAS/FAE has also been described clinically 16.7). This study demonstrates that chronic or regular alcohol use was not necessary to produce changes in brain development. in humans, this exposure would be equivalent to heavy or binge drinking during the third week of pregnancy.

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alcohol

no alcohol

# 11. Animal Models of FAS: Ethanol Exposed Pup Compared to Normal

When fetal alcohol syndrome was first identified, many scientists believed that it was caused not by maternal alcohol use, but by poor diet, other drugs of abuse, or by some other unidentified factor. Animal studies have since shown that even in the absence of these other factors, alcohol exposure is correlated with decreased growth, and increased morphologic abnormalities, central nervous system involvement, and embryo/fetal death. Poor diet and other health hazards may alter the risk of fetal alcohol effects, but they are not the primary cause.

For example, consider the pups shown on this slice. Ethanol (2.1 g/kg) was given orally twice daily, throughout pregnancy, to the mother of the smaller animal; this is roughly equivalent to 10.5 oz 100-proof vodka twice daily for a 60 kg human. (Mean peak blood ethanci concentrations of 205 mg/dl were obtained in the groups of animals given this dose.) Mothers of the control pups received isocaloric amounts of sucrose in place of the ethanol. Amounts of food and water ingested were the same for both experimental and control animals. At this dose of ethanol, rates of stillbirth and early mortality were sharply increased and the number of offspring per litter decreased. The weight, crown to rump length, and head circumference of surviving ethanol-exposed pups were significantly lower than controls, as is clearly evident from the slide. Fetal alcohol effects have been demonstrated in many other types of experimental animals, including mice, rats, hamsters, monkeys and chickens (see slide 12).

1. Ellis FW, Pick JR. An animal model of the fetal alcohol syndrome in beagles. Alcohol Clin Exp Res. 1980; 4:123-134.

# Major Effects of Ethanol by Trimester of Pregnancy

Increased risk of spontaneous abortion

Decreased fetal growth

Major morphological abnormalities

1st

2nd

3rd

**CNS Effects** 

# FACT SHEET Fetal Alcohol Syndrome

Booze News

ILIZYIUU II:33 AM

Emailthe Alcohol Policies Project

The consumption of alcohol during pregnancy is one of the leading preventable causes of birth defects and childhood disabilities in the United States. The adverse effects associated with fetal alcohol syndrome (FAS) range from growth deficiency, brain structure and function anomalies, and abnormalities of the head and face. It is estimated that in 1992 the cost of treating FAS-affected infants, children, and adults was over \$1.9 billion. The lifetime cost per child affected with FAS is estimated to be \$1.4 million.

# FAS and Public Awareness

- In 1981 the Surgeon General first advised that women should not drink alcoholic beverages during pregnancy because of the risk of birth defects.
- Public law 100-690 was implemented in 1989, requiring warning labels on all alcoholic beverages sold in the United States.
- Since 1990 the Dietary Guidelines for Americans have stated that women who are pregnant or planning to become pregnant should not drink alcohol.
- As of 1998, 19 states require the posting of <u>alcoholhealth warning signs</u> where alcoholic beverages are sold.

# FAS Statistics

- In 1995, four times as many pregnant women frequently consumed alcohol as in 1991. Researchers speculate that the increase in alcohol consumption by pregnant women may be attributed to widespread reports on the health benefits of moderate drinking.
- 51% of women of child-bearing age between 18-25 and 53% between 26-34, report the use of alcohol within the past month.
- 17% of women of child-bearing age between 18-25 and 13% between 26-34, report binge drinking (five or more drinks on one occasion) within the past month.8
- . A national survey found that more than half of women age 15-44 drank while pregnant.9
- Of the women who reported drinking during their pregnancy, 66% reported drinking in their first trimester; 54% reported drinking in their third trimester. 10
- FAS is estimated to occur in 1 to 2 live births per every 1,000 in the United States each year.11
- Fetal Alcohol Effects (a less severe set of alcohol-related abnormalities) is estimated to occur in 3-5 live

Per la

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oirths per every 1,000 in the United States each year.2, 11

" ad Alcohol Syndrome

 According to the birth defects monitoring program, FAS rates among American Indians are 3.0 per 1000 live births compared to a rate of 0.6 per 1000 live births among Blacks and 0.1 per 1000 live births among Whites. 12

- FAS is not just a childhood disorder, 13 exposure to alcohol as a fetus can cause a wide range of lifelong physical and mental disabilities.14
- · Fetal alcohol exposure may increase the risk for later alcohol, tobacco, and drug dependence in adults. 15

# Possible Solutions: Treatment, Education, & Higher Taxes

- . Studies have shown that FAS is completely preventable and that the consumption of alcohol can result in lifelong physical and mental impairments on the fetus. Research suggests that all pregnant women should be screened for alcohol use during prenatal visits. Women who test positive, or prove to be atrisk, should be identified early by physicians and referred for counseling and treatment.16
- A recent survey illustrated the need for physician education on "how much" alcohol consumption is "too much" during pregnancy. 41% of physicians placed the threshold for FAS at one to three drinks per day while 38% placed the threshold at one or fewer drinks per day. 17 Both opinions directly contradict the Surgeon General's advice that women not consume any alcoholic beverages during pregnancy because of the risk of birth defects.
- Research by Abel suggests that the most effective public health strategy for reducing FAS is a combination of public health messages that target alcohol abuse, coupled with higher taxes on alcoholic beverages. Abel states that recent studies have shown that heavy drinking and binge drinking are sensitive to price changes, and that price elasticities are relatively high for heavy drinkers who are aware of the consequences of their drinking. 18
- Studies have shown that alcohol beverage warning labels have increased awareness of the risks involved with alcohol consumption during pregnancy. 19 However, over time the alcohol warning labels have become commonplace, with the message often being overlooked. Changing the appearance (i.e., size, color, etc.) and rotating different warning labels on alcoholic beverage containers may help prolong awareness while eventually decreasing the number of women who expose their fetuses to alcohol.

References

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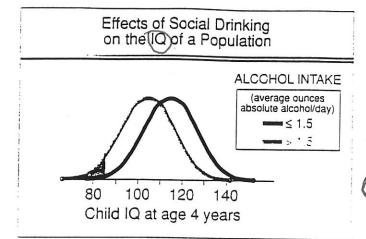
For more information on Fetal Alcohol Syndrome contact:

The National Organization on Fetal Alcohol Syndrome (NOFAS) http://www.nofas.org

The ARC of the United States (A National Organization on Mental Retardation) http://www.thearc.org

The Fetal Alcohol and Drug Unit (University of Washington) http://depts.washington.edu/fadu

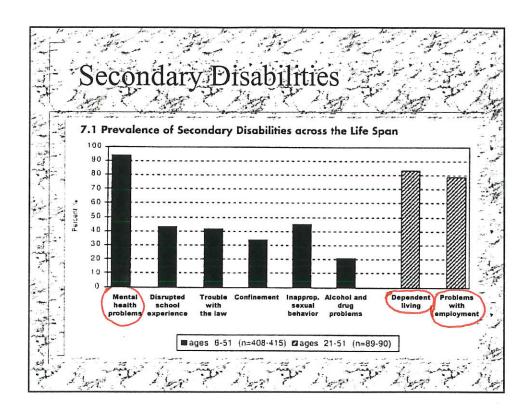
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# 61. Effects of Social Drinking on the IQ of a Population

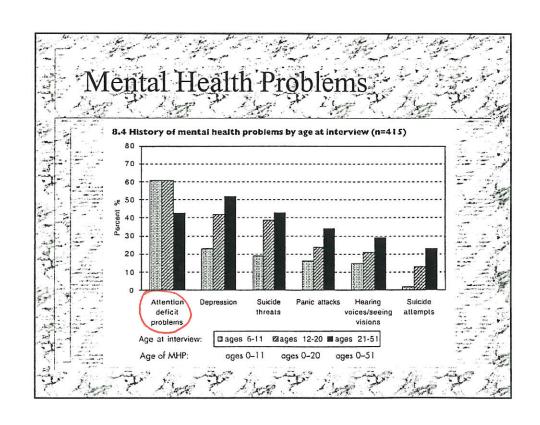
Seemingly subtle individual effects of prenatal alcondi exposure can have a significant collective impact on society. One longitudinal prospective study of a large group of pregnant women from a well-educated, middleclass community was begun before it was general knowle edge that women should not drink during pregnance. Women whose self-reported alcohol-use scores averaged over 1.5 ounces of absolute alcohol per day 3 drinks per day, on average, of beer, wine and/or liquor had children whose IQ scores averaged 5 points lower than the children of the rest of the mothers, even after statistically adjusting for maternal and paternal education, race, prenatal nutrition, aspirin and antibiotics exposure, child's sex and birth order, mother-child interactions and preschool attendance. The accompanying slide shows normal distributions picturing the effect of a 5-point mean IQ decrement on the overail average profile of the community. This level of prenatal alcohol exposure would be expected to significantly increase the proportion of children with low IQ scores (below 85) and to significantly decrease the proportion with IQ scores in the superior range.

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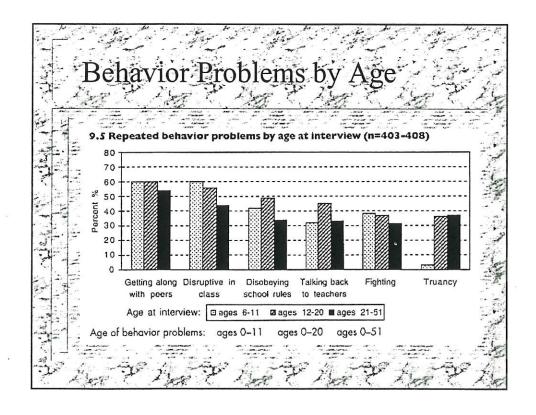


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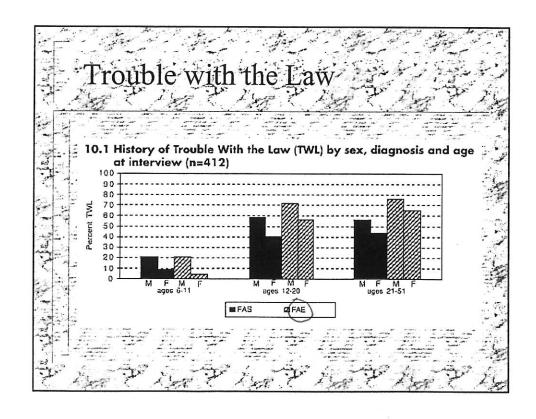
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# FETAL ALCOHOL SYNDROME IS PERMANENT

How to diagnose

The irreversible damage caused by prenatal alcohol use is, in my opinion, the most significant factor in the cycle of poverty in the inner city.

DR. LYDIA CAROS
PEDIATRICIAN,
MINNEAPOLIS

SUFFER THE

CHILDREN:

THE

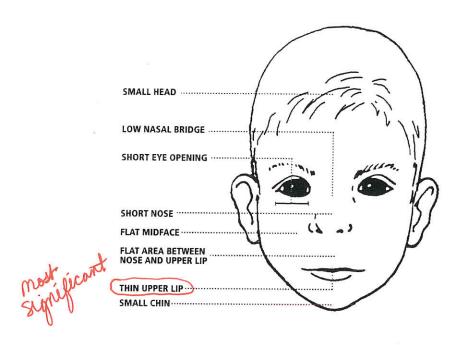
PREVENTABLE

TRAGEDY OF

FETAL ALCOHOL

SYNDROME

Children with fetal alcohol syndrome have three characteristics: abnormal facial features, stunted growth and brain injury. Fetal alcohol effects has been used to describe individuals who have a history of prenatal alcohol exposure but not all the physical or behavioral symptoms of fetal alcohol syndrome. Although not all fetal alcohol syndrome symptoms occur in children with fetal alcohol effects, both disabilities are devastating.



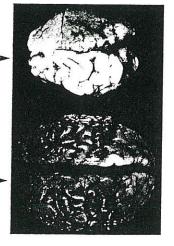
Source: Streissguth et al., 1988

#### EFFECT OF ALCOHOL ON THE BRAIN

NEWBORN BABY'S BRAIN DAMAGED BY ALCOHOL

- > DECREASED SIZE
- > NOT FULLY DIVIDED INTO LEFT AND RIGHT HEMISPHERES
- > SMOOTH SURFACE AND FEWER FOLDS INDICATE LACK OF DEVELOPMENT

NEWBORN BABY'S NORMAL BRAIN



Source: Dr. Sterling Clarren, University of Washington

PAGE 8

# Coronal Sections of Brain

FAS

Normal



# FAS is Part of FAE

(A very small part)



Fetal Alcohol Effects are all of the effects caused by prenatal alcohol exposure

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# Comparison of House; Senate Budgets (For fiscal year 2001, figures in millions)

-	AGENCY/PROGRAM HOUSE	CUNTATE	,,
	AGENCY/PROGRAM HOUSE	SENATE DIFF	
	Dept. of Education \$2,552.4	\$2,559.7 \$7.3	
	SRS, State Hospital \$1,683.4	\$1,695.9 \$12.5	
	State Universities \$1,475.6	\$1,475.8 \$0.2	-
-	Dept. of Transportation \$923.3	\$923.3 - \$0.0	
Period and	Dept. on Aging \$357.4 = =	\$359.3 _ = \$1.9 _ =	-
-	Prison System \$223.5	\$226.7 \$3.2	**
-	Dept. of Human Resources \$218.8	\$218.8	
-	Dept. of Health, Environment \$169.7-	\$173.8 \$4.1	
	Kansas Lottery \$140.0	\$140.0	
1	State Treasurer \$111.9	\$111.9 \$0.0	
	Dept. of Commerce, Housing \$86.6	\$85.7 (\$0.9)	-
-	Juvenile Justice - \$76.8	\$83.8 - \$7.0	
-	Dept. of Revenue \$77.0	\$78.4: \$1.4	
1	Court System - \$83.7	\$83.4 (\$0.3)	
	Other Agencies \$470.0	\$473.2. \$3.2.	
-	ALL AGENCIES \$8,650.1	\$8,689.7 \$39.6	
	The state of the s	the same to save	•

Instrugation!

- Living in a stable and nurturant home for over 72% of life
- Being-diagnosed before the age of 6 years
- Never having experienced violence against oneself
- Staying in each living situation for an average of more than 2.8 years
- Experiencing a good quality home from age 8-12 years
- Having applied for and been found eligible for division of developmental disabilities services
- Having a diagnosis of FAS rather than FAE/ARND

### Twelve points regarding Fetal Alcohol Syndrome/ Alcohol-Related Neurodevelopmental Disorder (FAS/ARND)

- 1 People with FAS have an invisible, underdiagnosed, and under served disability. Recognition of FAS is synonymous with recognition of brain damage
- 2. FAS/ARND is a 'hidden' population, not recognized in the DSM IV, and is often a subset within other diagnoses (e.g. ADD/ADHD, LD, ED, PDD, ODD)
- FAS/ARND includes a wide continuum of physical and behavioral effects
- 4. The most at-risk people are those with ARND. They may have none of the observable physical characteristics associated with FAS
- 5. FAS/ARND is an invisible **physical** handicapping condition whose only manifestation may be in presenting behaviors
- 6. Neurodevelopmental characteristics of people with this physical disability are incompatible with learning theory-based <u>assumptions</u> about brain function
- 7. Interventions based on principles of learning theory are incompatible with neurodevelopmental characteristics, or differences in brain function
- 8. Inappropriate and ineffective traditional interventions implemented over time have been associated with chronic frustration and the development of debilitating secondary characteristics
- An alternative explanatory theory linking neurodevelopmental characteristics with presenting behaviors expands understanding and provides a shift in perceptions, reframing interpretations of presenting behaviors: From "won't" to "can't"
- 10. This shift dictates providing environmental adaptations for those with FAS/ARND to assure adequate supports are available, prevent deterioration, and maximize realization of developmental potential. The principle of providing environmental adaptations is the same as for other physical handicapping conditions
- 11, Children, parents and professionals, all strata of communities and cultures benefit from this shared knowledge and a development of a common language to facilitate implementation of appropriate continua of care, over time
- 12. Adequate adaptations are required at home and in the community to provide appropriate levels of support over time. This suggests the need for information and support for parents and professionals to develop and implement coordinated, appropriate and effective services. Change is indicated at the level of individuals, families, institutions, policy and law.

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#### INTERNAL MEDICINE

James M. Geitz, M.D.

James A. Barnett, M.D., F.A.C.P.

W. Brock Kretsinger, D.O.

W. Timothy Duncan, M.D.

Rachel A. Duncan, M.D.

#### CARDIOLOGY

M. Usman Sheriff, M.D.

#### **EMERITUS**

Phillip W. Morgan, M.D. (1928-1966)

Edward J. Ryan, M.D. (1947-1979)

John L. Morgan, M.D. (1949-1984)

Gould C. Garcia, M.D. (1964-1999)

#### **SERVICES**

Bone Densitometry

Ultrasonography

Mammography

In-Office Laboratory

Nuclear Cardiology

Echocardiography

Cardiac Catheterization

Diagnostic

Interventional

Holter Monitor

**Exercise Testing** 

Pacemaker Clinic

proposal

# Emporia Area Fetal Alcohol Syndrome Diagnostic and Prevention Network

1. Team: Physician - (family physician, pediatrician).

Speech therapist.

Occupational therapist.

Public health nurse.

Social worker. Family advocate. Psychologist.

2. State support \$10,000.00-15,000.00 per site. (5)

3. Community support.

4. Training venues:

a) 3 days in Seattle at \$700.00 per person plus travel.

b) Telephone contact with Seattle to discuss clients (15-20 minutes) during the first 6-12 months

c) Share dossiers.

d) On-call assistance for the Seattle team to be accessible - \$3,000.00 per year.

Partnering with adults in East Central Kansas to promote health and wellness.

1301 West 12th Avenue, Suite 202, PO Box 907 • Emporia, KS 66801-0909 • 316-342-2521 • fax 316-342-6520

# tal Alcohol Syndrome Diagnostic and Prevention Network

Susan J. Astley, Ph.D. and Sterling K. Clarron, M.D., Directors University of Washington (206) 526-2206 http://depts.washington.edu/fasdpn



#### What is FAS?

Fetal alcohol syndrome (FAS) is a permanent birth defect syndrome caused by maternal consumption of alcohol during pregnancy. FAS is characterized by growth deficiency, permanent brain damage and a unique cluster of minor facial anomalies. Not all children exposed to alcohol during gestation are born with FAS. Many are born with the same level of brain damage but do not have the facial anomalies that permit a discrete diagnosis of FAS. These children need the same social, educational and healthcare services as children with FAS and far outnumber children with FAS.

How does FAS fiscally impact Washington State?

It costs Washington State only \$200,000 per year to support the Fetal Alcohol Syndrome Diagnostic and Prevention Network (FAS DPN). It costs Washington State an estimated \$1,500,000 in lifetime social and health care services for every child born with FAS. Preventing just one FAS birth will pay for over seven years of the FAS DPN operating costs. The FAS DPN has the opportunity to prevent 10-20 FAS births per year. It costs Washington State 30 times more to raise a child with FAS than to prevent FAS in a child.

# FAS facts.

- FAS is 100% proventable.
- FAS is the leading known cause of mental retardation.
- An estimated 200 children are born with FAS in Washington State each year. An additional 400 to 1,000 children are born each year with permanent brain damage associated with prenatal alcohol exposure.
- FAS is not just a health care issue. Its primary impact is on schools, foster and adoption services, the justice system, and mental health services.
- Less than 10% of adults with FAS live independently or remain employed.

# What is the Washington State FAS Diagnostic and Prevention Network?

- The Washington State FAS DPN was established in 1995 and is the first program of its kind in the nation.
- It consists of six clinical sites (Spokane, Yakima, Whitman, King, Snohomish, and Pierce counties) and one core-training site (University of Washington) linked by a statewide database. See our website [http://depts.washington.edu/fasdpn].
- The WA State FAS DPN is currently recognized as a national model for FAS Diagnosis and Prevention demonstrating an invaluable partnership between academic research and public health through interagency collaboration. Several states and provinces have requested and received training by the FAS DPN to establish similar networks in their communities.

# What does the FAS DPN do for children, families and health care professionals in Washington State?

- Diagnostic Program
  - · We provide accurate diagnoses and comprehensive care plans for individuals with prenatal alcohol exposure statewide. To date we have evaluated over 1,500 patients statewide. 87% of families report they received help from us they could not receive elsewhere. 99% would recommend our diagnostic services to other families in similar need.
  - · We have developed a comprehensive Diagnostic Guide for FAS that is being distributed and used worldwide.
- Training Program
  - · We provide FAS training to conununity health care, educational, correctional and social service providers statewide. We have trained over 1,000 professionals to date.
  - We developed a FAS medical training CD-ROM that is distributed nationally by the March of Dimes.
- Primary Prevention Program
  - · We identify women at highest risk to give birth to children damaged by prenatal alcohol, namely the birth mothers of children diagnosed with brain damage and prenatal alcohol exposure at our FAS DPN clinics. We provide the women with referrals to appropriate community-based programs including the Parent-Child Assistance Program to help them reduce their use of alcohol and practice effective family planning.
  - · Through our research we have identified factors that significantly enhance and hinder a woman's ability to stop drinking and practice effective birth control. We conducted interviews with 80 women who gave birth to children with FAS in WA State. A key finding: women who receive mental health treatment are significantly more likely to succeed in stopping drinking.
- Screening Program
  - We developed a highly accurate, computerized, FAS photographic screening tool that is now used world-wide.
  - •We provide medical screening for FAS in high-risk populations (foster care and juvenile rehabilitation) to identify children at risk. Early accurate diagnosis reduces secondary disabilities. To date, our screening program has demonstrated that the prevalence of FAS in foster care is 10 times higher than in the general population.

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