

FASD Legislative Action

Legislative Priorities

The National Organization on Fetal Alcohol Syndrome (NOFAS) Advocacy Goals for the 109th Congress

The National Organization on Fetal Alcohol Syndrome (NOFAS) has a number of ambitious goals concerning legislative initiatives, administration activities, and current practices in the medical fields relevant to FASD. It is our sincere hope that by focusing on the following activities, NOFAS is serving not only its own mission, but the mission of all those who care about FASD prevention and support.

- Passage of “The Advancing FASD Research, Prevention and Services Act”, in both the Senate and House of Representatives.
- Inclusion of FASD language in the following legislation:
 - Start Healthy, Stay Healthy Act of 2005 (S.740)
 - Prevent Prematurity and Improve Child Health Act of 2005 (S. 710)
 - Health Professionals Substance Abuse Act (S.538) (HR 1789)
 - Prematurity Research Expansion and Education for Mothers who deliver Infants Early Act (PREEMIE Act) (S. 707) (HR 2861)
- Conduct a comprehensive FASD briefing for members and staff of the Senate and House of Representatives.
- Increase the level of funding received from the federal agencies, i.e. SAMHSA, CDC, NIH.
- Increase the level of involvement by state and federal education and justice departments on issues concerning FASD.
- Build coalitions with other advocacy groups to help achieve our mission and allow our voice become stronger.
- Expand the membership of the Congressional Caucus on Fetal Alcohol Spectrum Disorders.
- Increase the level of local and national media attention.

NOFAS Advocacy Priorities

NOFAS advocates for the prevention of Fetal Alcohol Spectrum Disorders (FASD) and increased quality of life for those currently living with the disorder. Our priorities fall under the two main categories listed below, with references to specific issues relevant to all those who support the vision of a world free from the effects of prenatal alcohol exposure.

I. Prevention and Treatment Programs to Combat FASD

- FASD research and surveillance to create an epidemiological basis for tracking and identifying the disease.
- Initiatives to encourage the cessation of drinking while pregnant.
- Education reform to include new curricula or literature in primary and secondary schools highlighting the harm of drinking while pregnant.
- Inclusion of FASD in medical school textbooks and board exams.
- Training for substance abuse counselors and prevention experts on the harms of prenatal alcohol exposure and the skills necessary to identify and address FASD.
- Clinical research and development of medical strategies to further understand and prevent FASD.

II. Increased Access to Support Services for those Living with FASD

- Screening of newborns and children in order to better identify those with FASD.
- Development of the necessary screening, analysis, and treatment procedures for those with FASD who enter the foster care, juvenile justice, or adult criminal justice system, coupled with follow-up services for those leaving such systems.
- Intervention training for professionals who work in the high risk settings of mental health clinics, treatment centers, psychiatric units, and foster programs.
- Creation and dissemination avenues through which individuals with FASD will have access to quality health care.
- Ensuring teacher training and access to special education in and out of school for those with the myriad learning disabilities that are associated with FASD.
- Creation and implementation of vocational and living support services, including psychological and physical care, when needed.

Tell your House Representatives to Join the Congressional Caucus on FASD

Act now to help educate our policymakers on FASD- the leading cause of mental retardation

The Congressional Caucus on Fetal Alcohol Spectrum Disorders currently has over 40 members of the House of Representatives. This caucus is co-chaired by Rep. Ramstad (R-MN) and Rep. Pallone Jr. (D-NJ). The purpose of the caucus is to increase awareness of FASD among policymakers. The caucus raises awareness by means of “Dear Colleague” letters, in support of FASD related legislation, Congressional briefings, and lending a voice on FASD terminology among the scientific community. Email your Congress Representative and encourage him/her to join the FASD caucus. We need more Congressional awareness on FASD. If your representative is already a member, email and thank him/her for joining the caucus, and encourage your Representative to bring his/her colleagues on board as well.

Congress:

- [S.3705](#) 'A bill to amend title XIX of the Social Security Act to improve requirements under the Medicaid program for items and services furnished in or through an educational program or setting to children, including children with developmental, physical, or mental health needs, and for other purposes.'
- [S.1722](#) Advancing FASD Research, Prevention, and Services Act
- [S.1619](#) Improving Education for Homeless and Foster Children with Disabilities Act of 2003
- [S.1580](#) Healthcare Equality and Accountability Act - Family Care Act of 2005
- [S.1321](#) A bill promoting alternative learning environments
- [S.1226](#) 2003 Act to Prevent Developmental Disabilities in Education
- [S.1194](#) Mentally Ill Offender Treatment and Crime Reduction Act of 2003
- [S.1057](#) Indian Healthcare Improvement Act Amendments of 2005
- [S.740](#) Start Healthy, Stay Healthy Act of 2005
- [S.710](#) Prevent Prematurity and Improve Child Health Act of 2005
- [S.707](#) PREEMIE Act
- [S.538](#) Health Professionals Substance Abuse Act
- [S.486](#) Senator Paul Wellstone Mental Health Equitable Treatment Act of 2003

- [S.RES.499](#) 'A resolution designating September 9, 2006, as "National Fetal Alcohol Spectrum Disorders Awareness Day".
- [H.R.5803](#) 'To amend the Public Health Service Act to establish a State family support grant program to end the practice of parents giving legal custody of their seriously emotionally disturbed children to State agencies for the purpose of obtaining mental health services for those children.'
- [H.R.4212](#) Advancing FASD Research, Prevention, and Services Act
- [H.R.4167](#) 'To amend the Federal Food, Drug, and Cosmetic Act to provide for uniform food safety warning notification requirements, and for other purposes.'
- [H.R.3561](#) Healthcare Equality and Accountability Act - Family Care Act of 2005
- [H.R.3293](#) Prevent Prematurity and Improve Child Health Act of 2003
- [H.R.2861](#) PREEMIE Act
- [H.R.2268](#) Start Healthy, Stay Healthy Act of 2003
- [H.R.2256](#) Help Expand Access to Recovery and Treatment (HEART) Act of 2003
- [H.R.1811](#) Family Opportunity Act of 2003
- [H.R.1789](#) Health Professionals Substance Abuse Act
- [H.R.1359](#) Child Healthcare Crisis Relief Act
- [H.R.1350](#) Individuals with Disabilities Education Improvement Act of 2004

Alabama:

- [SB67](#) Sudden Infant Death Syndrome

Alaska:

- [HB213](#) ALCOHOL SERVER EDUCATION

California:

- [SB899](#) Substance Abuse and Crime Prevention Act of 2000 (Proposition 36)
- [SB899](#) Substance abuse treatment funding
- [SB653](#) Alcohol and drug programs
- [SB653](#) Alcohol and drug programs
- [AB1141](#) Alcohol and drug treatment
- [AB926](#) Substance abuse: adult recovery maintenance facilities

Colorado:

- [HB1183](#) CONCERNING ALCOHOL CONSUMPTION

Connecticut:

- [HB6901](#) AN ACT CONCERNING UNDERAGE DRINKING.
- [HB5951](#) AN ACT CONCERNING THE DRINKING OF ALCOHOL BY MINORS ON PRIVATE PROPERTY.

Hawaii:

- [HB1286](#) Community Correctional Centers; Alcohol and Drug Support

Idaho:

- [H698](#) Scholarship/drug/alcohol free stdnt
- [H274](#) Scholarship, drug/alchol free student

Iowa:

- [SF48](#) SF48

- [HF89](#) HF89

- [HF89](#) HF89

Montana:

- [SB249](#) SB249 - substance abuse prevention and treatment

- [HB715](#) HB715 - Services for Fetal Alcohol Syndrome

- [HB252](#) HB252

- [HB252](#) HB252 - An Act Increasing Certain Taxes on Alcoholic Beverages

Nevada:

- [SB307](#) Requires posting signs warning of risk of drinking while pregnant

New Jersey:

- [S485](#) Alcohol Education, Rehabilitation. & Enforcement Fund

- [AJR88](#) Fetal Alcohol Syndrome Awareness Day-Sept 9

- [A333](#) Health care coverage for addiction treatment

New Mexico:

- [SB1022](#) Establishing drug addiction and FAS as child abuse

New York:

- [S1944](#) Fair Insurance Treatment Act

- [A7325](#) Testing of newborns for presence of alcohol

- [A6925](#) health education course

- [A3940](#) A3940 - Professional's loan forgiveness program

- [A2511](#) Maltreated/Neglected child includes children of alcohol/drug abusers

Pennsylvania:

- [SB727](#) Drug and Alcohol Treatment and Prevention Fund

- [SB315](#) Loan Forgiveness Program

- [HB1649](#) Drug and Alcohol Treatment and Prevention Fund

South Carolina:

- [S49](#) Health coverage

Washington:

- [HB2095](#) Authorizing the use of pharmaceutical birth control or tubal ligation in cases of children born alcohol or drug-affected.

- [HB2093](#) Protecting an unborn quick child from harm by the use of alcohol or any illicit drug.

1996 Regular Session

Details for Bill 4111

([Bill Definitions](#))

Bill History

SUMMARY:

Mandatory signs to be posted warning of the possible dangers of the consumption of alcohol during pregnancy and establishing a special fund for educational purposes concerning fetal alcohol syndrome

SPONSOR(S):

Mr. Speaker (Mr. Chambers), Leach, Petersen, Pulliam,

SUBJECT:

Alcohol

CODE AFFECTED:

60 - 6 - 25,

DATE	ACTION	JOURNAL PAGE
03/07/96	On second reading to Finance	1
03/07/96	Read 1st time	1
03/07/96	On 1st reading	
03/07/96	Immediate consideration	1
03/07/96	Reported do pass with amends and title amend; but first t Finance	1
02/29/96	To Health and Human Resources	
02/29/96	To Health and Human Resources then Finance	
02/29/96	Introduced in Senate	3
02/28/96	Communicated to Senate	7
02/28/96	Passed House (Voice vote)	7
02/28/96	Read 3rd time, Special Calendar	7
02/27/96	On 3rd reading, Special Calendar	
02/27/96	Read 2nd time, Special Calendar	6
02/26/96	On 2nd reading, Special Calendar	
02/26/96	Read 1st time, Special Calendar	6
02/23/96	On 1st reading, Special Calendar	
02/23/96	By substitute, do pass	5
02/14/96	To House Finance	4
02/14/96	Do pass, but first to Finance	4
01/18/96	To House Judiciary	
01/18/96	Introduced in House	
01/17/96	To Judiciary then Finance	
01/17/96	Filed for introduction	

Senate Bill No. 252

(By Senators Plymale and White)

[Introduced March 6, 1997; referred to the Committee
on the Judiciary.]

A BILL to amend article six, chapter sixty of the code of West Virginia, one thousand nine hundred thirty-one, as amended, by adding thereto a new section, designated section twenty-five, relating to requiring display of signs warning of the possible danger of birth defects which may be caused by the consumption of alcohol during pregnancy; imposing a fine upon persons who violate this section; and setting up a special fund derived from the fines collected to be used for the purpose of educating the public about fetal alcohol syndrome.

Be it enacted by the Legislature of West Virginia:

That article six, chapter sixty of the code of West Virginia, one thousand nine hundred thirty-one, as amended, be amended by adding thereto a new section, designated section twenty-five, to read as follows:

ARTICLE 6. MISCELLANEOUS PROVISIONS.

§60-6-25. Mandatory signs to be posted warning of the possible dangers of consumption of alcohol during pregnancy.

(a) On or before the fifth day of October, one thousand nine hundred ninety-seven, all retail liquor licensees shall display signs provided by the alcohol beverage control commissioner warning of the possible danger of birth defects as a result of the consumption of alcohol during pregnancy. These signs shall be displayed upon the licensed premises in the following manner:

(1) If a licensee holds a license providing for on-premises consumption, the sign shall be posted in plain view at the main entrance to the liquor licensed portion of the establishment and in the men's and women's public rest rooms closest to the licensed area: *Provided*, That self-service "mini-bars" in hotel guest rooms are exempt: *Provided, however*, That airports, convention centers, sports facilities and other licensed premises with more than one authorized location of sales, service and consumption shall post signs in plain view to the majority of patrons entering or approaching the liquor licensed portion of the premises.

(2) If the licensee holds a license providing for the sale of alcohol for off-premises consumption, the sign shall be posted in plain view at each cash register where alcohol is sold and at the main entrance to the licensed premises.

(3) If the licensee is a liquor manufacturer, the notices shall be posted in plain view at the main entrance to areas where alcohol is sold for off-premises consumption. If a manufacturer's tasting rooms have separate buildings or separate entrances, the sign shall be posted in plain view at the main entrance to the tasting area.

(b) The alcohol beverage control commissioner shall make signs and replacements available.

(c) Failure to comply with the provisions of this section is a violation of the rules of the commissioner and shall result in the imposition of a fine of not less than one hundred dollars nor more than one thousand dollars for each violation.

(d) The proceeds from the fines collected for violation of this article shall be deposited in a fund created and maintained by the commissioner. The commissioner shall use the moneys deposited in the fund to educate further the public concerning the dangers of fetal

alcohol syndrome.

NOTE: The purpose of this bill is to require establishments which sell, serve or manufacture alcohol to post signs warning of the danger of alcohol consumption during pregnancy. The bill imposes a fine for failure to comply, and dedicates moneys collected to education about the dangers of fetal alcohol syndrome.

This section is new; therefore, strike-throughs and underscoring have been omitted.

COMMITTEE SUBSTITUTE

FOR

H. B. 2394

(By Delegates Leach, Staton, Beane, Hubbard,

Pulliam, Facemyer and Compton

)

(Originating in the Committee on Finance)

[March 28, 1997]

A BILL to amend article six, chapter sixty of the code of West Virginia, one thousand nine hundred thirty-one, as amended, by adding thereto a new section, designated section twenty-five, relating to requiring all persons licensed to sell alcoholic liquor, wine or nonintoxicating beer at retail, either for consumption on-premises or off-premises, or both, to display signs warning of the possible danger of birth defects that may be caused by the consumption of alcohol during pregnancy; placement of signs; duties of commissioner to make signs available; imposition of civil administrative penalty for violation; legislative rules; creation of "fetal alcohol syndrome fund"; and disposition of moneys.

Be it enacted by the Legislature of West Virginia:

That article six, chapter sixty of the code of West Virginia, one thousand nine hundred thirty-one, as amended, be amended by adding thereto a new section, designated section

twenty-five, to read as follows:

ARTICLE 6. MISCELLANEOUS PROVISIONS.

§60-6-25. Mandatory signs to be posted warning of the possible dangers of consumption of alcohol during pregnancy.

(a) Beginning the fifth day of October, one thousand nine hundred ninety-seven, all persons licensed to sell alcoholic liquor, wine or nonintoxicating beer at retail, either for consumption on-premises or off-premises, or both, shall display signs provided by the alcohol beverage control commissioner warning of the possible danger of birth defects which may result from the consumption of alcohol during pregnancy. These signs shall be displayed upon the licensed premises in the following manner:

(1) If a licensee holds a license providing for the retail sale of alcoholic liquor, wine or nonintoxicating beer for on- premises consumption, the sign shall be posted in plain view at the main entrance to the licensed portion of the establishment and in the men's and women's public rest rooms closest to the licensed area: *Provided*, That self-service "mini-bars" in hotel guest rooms are exempt: *Provided, however*, That airports, convention centers, sports facilities and other licensed premises with more than one authorized location of sales, service and consumption shall post signs in plain view to the majority of patrons entering or approaching the licensed portion of the premises.

(2) If the licensee holds a license providing for the retail sale of alcoholic liquor, wine or nonintoxicating beer for off-premises consumption, the sign shall be posted in plain view at the main entrance to the licensed premises.

(3) If the licensee is a liquor manufacturer, the notices shall be posted in plain view at the main entrance to areas where alcohol is sold for off-premises consumption. If a manufacturer's tasting rooms have separate buildings or separate entrances, the sign shall be posted in plain view at the main entrance to the tasting area.

(b) The alcohol beverage control commissioner shall make signs and replacements warning of the possible danger of birth defects which may result from the consumption of alcohol during pregnancy available to each licensee governed by the provisions of this section.

(c)(1) Upon a determination by the commissioner that a licensee has failed to comply with the provisions of this section, the commissioner may impose a civil administrative penalty of not less than one hundred dollars nor more than one thousand dollars for each violation. The provisions of section fifteen of this article shall not apply to a violation of this section.

(2) The commissioner shall propose legislative rules for promulgation pursuant to the provisions of chapter twenty-nine-a of this code setting forth:

(A) objective criteria against which the exercise of the commissioner's discretion in the determination of whether to impose a civil administrative penalty is to be measured; and
(B) procedures meeting the requirements of due process through which an alleged violation of this section may be contested.

(3) The proceeds of civil administrative penalties collected for violations of this section shall be deposited in a fund hereby established in the state treasury to be known as the "fetal alcohol syndrome fund". The commissioner shall expend the moneys deposited in the fund to educate the public concerning the dangers of fetal alcohol syndrome without appropriation except as provided in this subsection. After the sum of five thousand

dollars has been deposited into the fund during a fiscal year, any additional deposits shall be made to the state fund, general revenue. fund. Any moneys remaining in the fund on the thirtieth day of June of each year shall be subject to reappropriation for expenditure during the following fiscal year.



Chuck Lupton

SAMHSA FASD Center for Excellence, 2003

Introduction

Every year, about 40,000 babies are born with symptoms of prenatal alcohol exposure. These symptoms vary in severity and may include physical defects, cognitive deficits, and behavior problems. Many children with prenatal alcohol exposure need special education services, and few are able to live independently as adults. Some become involved in criminal activity and are incarcerated.

These myriad difficulties make prenatal alcohol exposure extremely expensive to treat and address. Diagnosis can be difficult, and finding effective medications and therapies is a challenge. In the three decades since fetal alcohol syndrome (FAS) was first identified, billions of dollars have been spent caring for those affected.

Even before FAS was identified, billions were spent treating birth defects and other symptoms that were probably related to prenatal alcohol exposure but were not directly attributed to it. Today, services are provided to individuals with disabilities related to prenatal alcohol exposure even though they might not have a formal diagnosis.

In addition to full FAS, prenatal alcohol exposure can cause differing degrees or patterns of problems, known as fetal alcohol effects (FAE), alcohol-related birth defects (ARBD), and alcohol-

related neurodevelopmental disorders (ARND). Although not as severe as full FAS, these conditions are also expensive to treat. The entire group of disorders related to prenatal alcohol exposure is known as fetal alcohol spectrum disorders (FASD), because they fall into a spectrum of disability ranging from mild or moderate to severe.

About the Cost of FAS

Very little data are available on the cost of FAS, and none were found for FAE, ARBD, or ARND. Many sources discuss the cost of substance abuse, but few specifically address FASD. The information found to date was developed from the 1980s to the mid-1990s. A search for more recent data primarily yields references or updates to earlier work.

Over 30 reports, articles, and other publications include references to the cost of FAS. More than 80 Internet sites also discuss the issue. Most cost information falls into two categories:

1. Total annual cost of FAS to the Nation
2. Lifetime cost of each child born with FAS

Some of the estimates use well-documented approaches that clearly describe the cost components and formulas used. Others provide no documentation at all. A limited amount of other national, State, and local cost information is available.

The Issues in Estimating the Cost of FAS?

When doing cost estimates of an illness or condition, a number of issues can arise. Some examples pertinent to the estimation of the cost of FAS are:

- Incidence or prevalence rate to use. Retrospective estimates can produce higher estimates than prospective ones.
- Health impacts and associated care/services to include. For instance, what medical conditions are to be treated and what percentage of affected persons have each particular condition? Is lost productivity to be estimated? Are indirect costs such as administrative, policy, and research costs to be included? Are nonworkforce morbidity costs to be included?
- Adjustments for the difference in the value of current dollars versus dollars that will be needed years in the future. Most economists agree on when it should or should not be done.

In addition, when examining the cost of an illness or condition, it is important to understand the limitations of the estimates. These estimates do not:

- Estimate the amount of money or years of life that can be saved

by effective social policies and programs, since estimates include both avoidable and unavoidable costs.

- Show the budgetary impact of the illness or condition on governments, but rather on all of society.
- Seek to consider the economic benefits of prevention, and thus should not be confused with cost-benefit or cost-effectiveness studies.

In addition, when doing cost estimates, several theoretical issues arise. Based on guidelines for estimating the cost of substance abuse, [Appendix A¹](#) identifies some theoretical issues relevant to estimating FAS costs. It also describes how well-documented cost studies have addressed these issues.

How Much Does FAS Cost Each Year?

Well-Documented National Estimates

Over the past eighteen years, four sets of investigators have done well-documented studies to estimate the annual cost of FAS in the United States. These studies have detailed and rigorous approaches to cost estimation. They identify costs by category, such as health care costs, residential and support services, and productivity losses. Estimated annual costs vary greatly because varying prevalence rates and cost components were used, the knowledge base for developing estimates rapidly increased over time, and a major amount of inflation has occurred.

All three of the lower cost estimates were done by Abel and Sokol. The lowest estimate by Abel and Sokol² was \$75 million for 1984. This was based on the lowest prevalence rate of all the studies, 0.33 babies per 1,000 live births. This estimate included medical treatment for children with FAS up to age 21 and residential care due to mental retardation up to age 21. Residential care accounted for 77 percent of the total cost.

Two other studies by Abel and Sokol^{3,4} used a prevalence rate of 1.9 per 1,000 live births. In the first study, they estimated the total cost to the Nation to be \$321 million in 1984 for medical treatment and residential care. In the second study, they estimated the total 1987 annual cost at \$250 million.

Abel and Sokol's second study included "corrections" for background rates of low birthweight and costs normally incurred for housing and food, regardless of whether an individual required institutionalization. The study included additional anomalies along with hospital costs noted in diagnosis-related groups. These estimates do not include lost productivity costs, semi-independent support services (e.g., persons living in community settings with ambulatory care and special education services), or residential services due to mental retardation after age 21.

The higher set of cost estimates came from studies by Rice et al.,⁵ Rice,⁶ Harwood et al.,⁷ Harwood,⁸

and Harwood and Napolitano.⁹ Rice et al. estimated 1985 annual costs to be \$1.6 billion, using a prevalence rate of 1.9 per 1,000 live births. This cost included neonatal intensive care services and other treatment and care services up to age 21. The estimate was based on the Abel and Sokol approach used for their \$321 million estimate.

The 1985 estimate by Rice et al. also included residential care for mental retardation for persons over age 21, which accounted for 80 percent of the total annual costs. Later, Rice estimated that the total 1990 cost had risen to \$2.1 billion, based on the same prevalence rate and cost components. However, costs were adjusted based on socioeconomic indexes.

Another estimate comes from a National Institute on Drug Abuse/National Institute on Alcohol Abuse and Alcoholism (NIAAA) study by Harwood et al. They estimated the 1992 annual cost to be \$2.9 billion based on the approach used by Harwood and Napolitano. This was based on a prevalence rate of 2.0 per 1,000 live births. This cost estimate included several components:

- Treatment and care services to age 21
- Home and residential care services for moderate and severe cases of mental retardation to age 65
- Special education services
- Lost productivity

An extrapolation by Harwood of the 1992 NIAAA study estimated that costs had risen to \$4.022 billion by 1998. This updated estimate adjusted for the change in national health care expenditures and in the consumer price index for medical services. It also adjusted for changes in the adult population in the United States and in the hourly compensation index for lost productivity. No adjustment was made for FAS-specific trends.

In 1985, Harwood and Napolitano estimated 1980 annual costs at \$3.2 billion, using a prevalence rate of 1.67 per 1,000 live births. Their estimate included the cost of medical treatment, home and residential care, special education services, and lost productivity for all ages. They also estimated costs for lower and higher prevalence rates, since there was a great deal of uncertainty about prevalence at the time.

Table 1 summarizes the estimates of annual costs for the well-documented studies. The variation in estimated costs is huge. They range from \$75 million at the low end to \$4.022 billion at the high end. These results reflect the effect of very different assumptions about prevalence rates of FAS and appropriate cost components. **Table 2** provides adjusted 2002 estimates of the annual cost based on changes in population growth and inflation. Even with these adjustments, great variation in estimates persists, ranging from \$0.2 to \$11.7 billion.

Reasons Annual Cost Estimates Vary

Five major factors account for the differences in annual cost estimates:

1. Prevalence rates significantly affect overall costs. Cost estimates based on low prevalence rates, such as Abel and Sokol's 0.33 per 1,000, will be about 6 times lower than estimates based on prevalence rates of 1.9 to 2 per 1,000.
2. Differences in medical care and residential services included, the rate of use of such services by individuals with FAS, and the cost of such services all greatly affect estimated costs.
3. Residential and support services for affected individuals with mental retardation to age 65 add a great deal more costs than studies that estimate such costs only to age 21.
4. Inflation accounts for differences between estimates for various years.
5. The knowledge base for developing cost estimates has rapidly increased over time. Thus, more weight should be given to the more recent estimates, since they have learned from and built on prior estimates.
6. Estimates that include the cost of lost productivity typically will exceed estimates that exclude it.

Table 3 shows the differences in treatment and care costs if all studies used a prevalence rate of 2 cases of full FAS per 1,000 and if residential costs for persons with mental retardation over age 21 represented 80 percent of total treatment and care costs. The updated studies by Rice and Harwood also have been excluded so that the original estimates would all be adjusted in a consistent manner.

Table 3 shows a much smaller range of treatment and care estimates, from \$2.3 billion for Abel and Sokol (1987) to \$11.1 billion for Harwood and Napolitano (1980). Other than the Harwood and Napolitano estimate, the range is \$2.3 billion to \$4.7 billion, with a median value of \$3.6 billion. This analysis supports the finding that the fundamental cost estimation approaches being used by all these authors are fairly similar (e.g., types of health conditions included utilization and service rates). The major difference is that Harwood and Napolitano had much higher estimates of treatment costs and included additional components such as home care and special education. Their estimate was the first study and used a different knowledge base than subsequent studies.

Other National Estimates

Five other estimates of the annual cost of FAS in the United States were found. However, none document how they were developed. These estimates range from \$0.5 billion to \$6 billion, as shown

below:

- [Alcoholics Victorious Web site](#) (undated): \$0.5 billion for FAS and FAE
- [Center for Science in the Public Interest Web site](#) (1990): More than \$2 billion
- [Fetal Alcohol Syndrome and Fetal Alcohol Effect Prevention and Services Act text](#), [University of Washington Fetal Alcohol and Drug Unit Web site](#) (1995): \$2.5 billion
- [Health Professions Education Partnership Act of 1998 \(U.S. Senate Bill 1754\)](#): \$2.5 billion
- [Crime Times Web site](#) (1995): \$6 billion

Cost Estimates for Other Countries

The professional literature did not include annual cost estimates for other countries. However, FAS cost estimates for other countries would probably yield very different results because of differences in health care system structures, reimbursement approaches, and public policy priorities.

What Is the Total Lifetime Cost of FAS?

Well-Documented Estimates of Lifetime Cost

The literature contains two well-documented estimates of the total lifetime cost for a person with FAS (see [Table 4](#)). Harwood and Napolitano⁹ estimated lifetime cost at \$596,000 in 1980. If this estimate is adjusted for the change in the cost of medical care services, lost productivity, and inflation, the adjusted 2002 cost becomes \$2.0 million for each individual with FAS. This figure is made up of \$1.6 million for medical treatment, special education, and residential care for persons with mental retardation, and \$0.4 million for productivity losses.

In February 1989, the Senate Advisory Council of the Alaska State Legislature¹⁰ estimated the 1988 lifetime cost of each baby born with FAS at \$1.4 million. This estimate, which adapted the approach used by Harwood and Napolitano is considered conservative because of excluded costs. The estimate included costs for:

- Medical treatment for pre- and postnatal growth retardation, heart defects requiring surgery, cleft palate, and surgery and treatment for audiologic deficits. The prevalence of these conditions was based on studies by Abel and Sokol, and Harwood and Napolitano.
- Services for infant learning, handicapped children, youth

- initiative, and developmentally disabled children.
- Special education services.
 - Social service costs, such as training and supervised work services.
 - Institutional care for mental retardation to age 65.

This estimate did not include costs for:

- Medical services for physical anomalies, such as visual problems, kidney and genital tract problems, dental and skeletal defects, anesthesiology services, and some physician costs during the first year of hospitalization.
- Welfare payments to the family.
- Mental health services.
- Criminal justice (e.g., trial and incarceration, which can cost about \$20,000 per year).
- Services for mild physical problems and learning disabilities.
- Lost productivity of caregivers and persons with FASD.

This study also notes that some costs in Alaska (specifically, intensive care services and institutionalization) are much greater than costs used by Harwood and Napolitano, even when inflation is considered. Therefore, the Alaska estimate may not be the most appropriate one to use as a national figure.

When the Alaska estimate is adjusted for changes in the medical services price index, the adjusted 2002 total cost per individual is \$2.95 million. This figure is higher than the 2002 inflation-adjusted Harwood and Napolitano estimate. It includes additional service categories (e.g., special education and child and youth services) and higher costs for some medical care services.

Other Lifetime Cost Estimates

Ten other estimates of lifetime costs either do not document how they were developed, or represent an estimate for a specific individual:

- Streissguth (1980, unpublished data): over \$500,000
- [Center for Science in the Public Interest](#) (1990): \$750,000 to age 18

- Center on Human Development and Disability, University of Washington, which operates the FAS Diagnostic and Prevention Network (2002): \$1 million¹¹
- Fetal Alcohol Syndrome and Fetal Alcohol Effect Prevention and Services Act, [University of Washington Fetal Alcohol and Drug Unit Web site](#) (1995): \$1.4 million
- [Health Professions Education Partnership Act of 1998](#) (U.S. Senate Bill 1754): \$1.4 million
- State of Alaska: \$1.5 million (inflation-adjusted figure adapted from Federal Health Professions Education Partnership Act of 1998 to estimate the annual cost of FAS to the State)¹²
- [FASWorld](#) Web site (undated): \$2 million
- Family Ecology Center (1994): \$2.4 million
- Crime Times Web site (1995): \$ 4 million
- [FAS Community Resource Center](#): \$5 million estimated expected lifetime costs for one child with FAS, as shown below. This figure may not be representative of other children with FAS because treatment costs are higher than generally incurred, and some costs are projections that may not actually be incurred. Costs do not include the caregiver's lost wages or the costs of incarceration for the person living with FAS, if it were to occur:
 - \$1,508,000 for medical and dental care
 - \$1,376,000 for residential placement
 - \$624,000 for supported employment
 - \$530,000 for psychiatric care
 - \$360,000 for foster care and respite care
 - \$360,000 for Supplemental Security Income
 - \$240,000 for special education

How Do FAS Annual and Lifetime Cost Compare?

In discussing the costs of FAS, Harwood and Napolitano⁹ note that estimation of lifetime costs is central to the evaluation of the benefits of prevention programs to society. Bloss¹³ argues that

annual costs are helpful to describe the extent of the problem. However, lifetime costs are more useful from a public policy perspective. Further, both Harwood and Napolitano and Bloss note that it is important to calculate the present discounted value (PDV) of the stream of lifetime costs in order to have an appropriate dollar figure when making public policy decisions about whether to expand prevention services.

The present discounted value can be viewed as the amount of funds that need to be deposited today at a given interest rate (exactly equal to the discount rate) so that principal and interest will cover the expected stream of costs over time. A higher discount rate produces a lower PDV and vice versa. Thus, a PDV calculation converts estimated lifetime cost into a present dollar amount needed at the time of the child's birth.

Using the 1980 figure of \$596,000 per child with FAS and applying a discount rate of 6 percent, Harwood and Napolitano⁹ determined that the PDV lifetime cost of FAS is \$163,000. Bloss notes that if the cost to prevent a birth with FAS is less than the PDV lifetime cost for that birth, then expanding prevention services yields a net economic gain.

Bloss concludes that given the magnitude of PDV lifetime costs for each child with FAS, major prevention efforts may well be justified. However, the most widely used and recommended discount rate is now 3 percent.¹⁴ Based on a 3 percent discount rate, the PDV lifetime cost of FAS is \$269,000, meaning that even greater prevention costs are justified to prevent births of children with FAS.

Is There State or Local Cost Information?

Very little information is available at the State and local levels. The South Dakota Department of Health estimated in 1983 that the yearly cost of caring for an individual with FAS ranged from \$10,000 to \$30,000.¹⁵ Using incidence rates of 1 and 2 cases of FAS per 1,000 live births and 12,839 births per year, the annual cost was estimated to range from \$120,000 to \$360,000 (at 1 case per 1,000) to \$240,000 to \$720,000 (at 2 cases per 1,000). These costs do not include expenses for children born with fetal alcohol effects. With a 60-year life expectancy, estimated FAS costs range from \$7.2 million to \$43.2 million.

Alaska estimated the cost of FAS in 1999. The research team started with a 1995 estimate of \$1.4 million lifetime cost per child with FAS, from the Federal Health Professions Education Partnership Act of 1998. They then adjusted it for inflation and determined that the undiscounted 1999 lifetime cost was \$1.5 million.¹²

Based on the lifetime cost of \$1.5 million, the expected lifetime costs of 1999 births with FAS in Alaska are estimated to be \$21 million to \$42 million, based on prevalence rates of 1.4 to 2.8 per 1,000 live births. These cost estimates include medical costs, behavior management, and residential services. Residential services include special education, home care, speech therapy, and institutional care.

Minnesota presented information about a variety of costs associated with FAS in its 1998 report

titled *Suffer the Children: The Preventable Tragedy of Fetal Alcohol Syndrome*.¹⁶ This report identifies the types of State costs associated with FAS: special education, juvenile and criminal justice, out-of-home placement services (e.g., foster care and adoption), chemical dependency, and services for persons with mental retardation.

The cost of FAS in Minnesota was estimated by taking the State's proportion of 1985 national costs (\$1.6 billion) as estimated by Rice et al., and then adjusting it for inflation to 1991. Population data were used to prorate costs. The overall annual cost of treating persons with full FAS in Minnesota was estimated to be \$45 million in 1991.¹⁷ This cost estimate includes medical treatment and residential services for persons with mental retardation. It does not include social support and education, foster care, nonsurgical and nonintensive medical care, juvenile and criminal justice, lost productivity, or caregiver costs.

Cost information at the local level is scarce. However, the San Diego Department of Health Services once estimated that each baby with FAS cost the county **\$405,000** in direct special services from birth to age 65. In Minnesota, one county has a family of which 6 of 12 children were diagnosed with FAS. County officials had spent \$800,000 for this family alone for such services as foster care, mental health care, social services, day treatment, and specialized care. Another \$1.3 million is expected to be needed for family members still under age 18. Medical care will add to these costs.¹⁶

An FAS Prevalence and Cost Calculator can be downloaded from the Online Clinic (<http://www.online-clinic.com/content/index/index.asp>). This clinic is hosted by Dr. Larry Burd, Director of the Fetal Alcohol Syndrome Center at the University of North Dakota. This calculator allows States and provinces to estimate their prevalence of FAS and ARBD and associated costs.

Gaps in Knowledge About the Cost of FAS?

Much of the work to estimate the cost of FAS recognizes that individuals with full FAS are simply the extreme in the continuum of conditions caused by prenatal alcohol exposure. They represent the tip of the iceberg. Other babies born with FAE, ARBD, and ARND make up a much larger group. It is estimated that while the rate of FAS is 0.5 to 2 per 1,000 live births, FAS, ARBD, and ARND combined account for as many as 10 per 1,000 live births,¹⁸ or five times as many cases as FAS.¹¹

Sokol et al.¹⁹ estimated that the number of births with FAE could be 15 times greater than the number of FAS births. However, costs for these individuals have not been included in most studies as they are extremely difficult to identify. Thus, a major need is to determine the costs associated with this larger group of alcohol-affected individuals.

A number of specific cost categories are generally not included in annual and lifetime costs. Inclusion of these costs would provide a more accurate picture. Examples include juvenile and criminal justice, special education, substance abuse, mental health, and vocational services.

For example, individuals with FAS often become involved with the juvenile and criminal justice systems. A recent study found that 60 percent of subjects with FAS or FAE had been in trouble with the authorities, charged with a crime, or convicted of a crime.²⁰ However, most cost estimates do

not include law enforcement costs.

Information on the costs of the juvenile and criminal justice system (including police, court, juvenile detention, prison, and parole/probation services) for individuals with FAS are not available. Costs cannot be assigned since there are no widely used screening and diagnostic tools to identify the numbers of affected persons within these systems. Yet the costs associated with law enforcement are significant. For instance, it can cost close to \$30,000 per year to house an inmate in Federal prison.²¹ Some State prisons spend even more.²²

Many individuals with FAS also have substance abuse problems of their own. Individuals with FAS or any alcohol-related birth defect need and use special education and vocational support services. Thus, future studies will show higher costs when these other cost categories are included.

Finally, annual and lifetime cost estimates are based on national statistics about the incidence and prevalence of FAS. Costs may be more concentrated in some racial and ethnic groups, such as Native American communities, where the prevalence of FAS is higher.

The difficulty in estimating the cost of services for individuals with FAS is further compounded by two situations. First, in many communities, these individuals that are inappropriate to their needs receive services and thus cycle through service systems and incur more costs than necessary. In other cases, they do not receive services at all, and therefore there are no associated costs of service provision. In either case, calculating true costs becomes difficult.

Conclusion

By any measure, the costs of FAS to society and for each alcohol-affected individual are very high. The most recent estimate from NIAAA is that FAS costs the Nation over \$4 billion each year (higher when adjusting for inflation to 2002). The lifetime cost for each child with FAS is \$2 million or more, depending on the costs included. These extremely high costs clearly justify major prevention efforts. When the costs associated with individuals with FAE, ARBD, and ARND are added in, the wisdom of investing in prevention efforts will be even clearer.

Future studies of the cost of FAS need to:

- Determine the number of children born with FAE, ARBD, and ARND and calculate the ratio of this group to those born with FAS, so that the magnitude of the problem can be better understood.
- Update or identify the cost of each service system element used by individuals with FAS and other alcohol-affected individuals, while ensuring that costs are representative of the country as a whole.
- Determine the incidence rate by race and ethnicity so that national estimates of children born with FAS, FAE, ARBD, and ARND can be made with higher confidence.

Title: **Drug, alcohol treatment backed for new moms: Sponsor says legislation would easily pay for itself with savings in future**

Media Type: Newspaper/Magazine

Authors: Scalon, B.

Serial Title: Denver Rocky Mountain News

Year: 2004

Month/Day of Publication: April 6

Address: 100 Gene Amole Way, Denver, CO 80204

Web Page: http://www.rockymountainnews.com/drmn/local/article/0,1299,DRMN_15_2785725,00.html

Available from: <http://www.rockymountainnews.com>

Function(s)/Category: Monograph/Report/Article

Description: This article focuses on a bill for drug and alcohol treatment for new moms. It mentions that FAS is the leading non-hereditary cause of mental retardation. 12,000 infants are born each year with FAS



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Tip

Encourage your child to take small steps daily.

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Title: **Fetal alcohol spectrum disorders legislation by state introduced in 2004-2005**

Media Type: Web-Based

Web Page: <http://www.fasdcenter.samhsa.gov/documents/FASDLegislationByState1005.pdf>

Authors: SAMHSA FASD Center for Excellence

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Function(s)/Category: Fact Sheets

Description: This publication focuses on nationwide legislation pertaining to FAS. The table contains FAS legislation that was introduced or passed with the 2004-2005 legislation session. Legislation appears verbatim.