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STATE

TELEPHONE NUMBER

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FROM:

Louise Floyd

NAME

TELEPHONE No.

SUBJECT:

MESSAGE:



Fact Sheet: Fetal Alcohol Syndrome

April 25, 1997
Office of Communication
Media Relations Division
(404) 639-3286

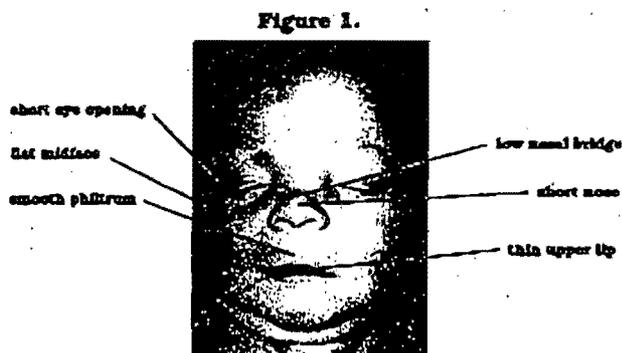
- Consuming alcohol during pregnancy is the cause of Fetal Alcohol Syndrome (FAS), a leading preventable cause of birth defects and mental retardation.
 - FAS is a serious, lifelong condition that is characterized by facial abnormalities, growth retardation, and central nervous system deficits including learning and developmental disorders. Not all children affected by prenatal alcohol use are born with the full syndrome, but may have selected abnormalities. Estimates of the prevalence of FAS vary from 0.2 to 1.0 per 1000 live births.
 - A new study released by CDC finds that rates of frequent drinking (≥ 7 drinks per week or ≥ 5 drinks on any occasion in the past month) among pregnant women have increased substantially from 0.8% in 1991 to 3.5% in 1995. The rate of 3.5% in 1995 translates to at least 140,000 pregnant women drinking at these more harmful levels each year.
 - Health advisories urging women —pregnant or planning a pregnancy— not to drink alcohol were first issued by the U.S. Surgeon General in 1981, and were reiterated by the Secretary of Health and Human Services in 1990 and 1995.
 - Prenatal alcohol consumption is a leading, preventable cause of birth defects and mental retardation.
- Health-care providers should advise pregnant women and those planning a pregnancy not to drink alcohol.
- "Alcohol and Other Birth Defects Awareness Week" is May 11-17, 1997.

National Center for Environmental Health

National Center for Environmental Health Alcohol Use During Pregnancy

Consuming alcohol during pregnancy is *the* cause of Fetal Alcohol Syndrome (FAS), a leading preventable cause of birth defects and mental retardation.

FAS is a serious, lifelong condition that is characterized by the facial features shown in Figure 1., growth retardation, and central nervous system deficits including learning and developmental disorders. Not all children affected by prenatal alcohol use are born with the full syndrome, but may have selected abnormalities. Estimates of the *prevalence* of FAS vary from 0.2 to 1.0 per 1000 live births.



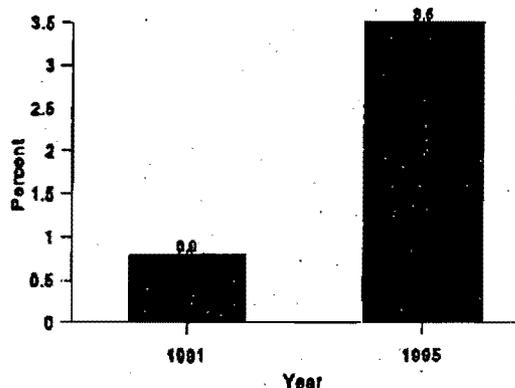
→ A new study released by CDC finds that rates of frequent drinking (≥ 7 drinks per week or ≥ 5 drinks on any occasion in the past month) among pregnant women have increased substantially from 1991 to 1995 (Figure 2). The rate of 3.5% in 1995 translates to at least 140,000 pregnant women drinking at these more harmful levels each year.

→ Health advisories urging women who are pregnant or planning a pregnancy not to drink alcohol were first issued by the U.S. Surgeon General in 1981, and were reiterated by the Secretary of Health and Human Services in 1990 and 1995.

→ Findings from the above study are a signal of the need for health care providers and others who work on behalf of healthy mothers and babies to reinforce the message of abstinence from alcohol use during pregnancy.

Figure 2.

Frequent Alcohol Use by Pregnant Women



May 11-17 is Alcohol and Other Birth Defects Awareness Week. Take part in spreading the word,
"Alcohol and pregnancy do not mix!"

Photo courtesy of Streissguth, A.P. & Little, R.E. (1994). Alcohol, Pregnancy, and FAS: 2nd Ed., Project Cork Institute Medical School Curriculum, Dartmouth Medical School.



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MMWR™

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Alcohol and Other Drug-Related Birth Defects Awareness Week — May 11-17, 1997

The National Council on Alcoholism and Drug Dependence (NCADD) has designated May 11-17, 1997, as Alcohol and Other Drug-Related Birth Defects Awareness Week. During this week, CDC, in collaboration with NCADD, will highlight the harmful effects of prenatal alcohol exposure on a fetus.

From 1991 to 1995, rates of alcohol use during pregnancy increased, especially for frequent drinking, underscoring the need for renewed attention to advising pregnant women to abstain from alcohol use. Associations between adverse pregnancy outcomes and moderate to heavy alcohol use during pregnancy continue to be reported. Health-care providers should educate women about the recommendations of the Surgeon General (1) and the Secretary of Health and Human Services (2) regarding the need for women who are pregnant or are planning a pregnancy to abstain from alcohol use.

State health departments can use state-based rates of reported frequent alcohol use by women of childbearing age to develop messages aimed at preventing alcohol use among pregnant women. In conjunction with a report in this issue of *MMWR* about alcohol use among childbearing-aged and pregnant women, the Council of State and Territorial Epidemiologists is providing state health departments and Behavioral Risk Factor Surveillance System coordinators with information focusing on fetal alcohol syndrome (FAS) and state-specific rates of self-reported alcohol use among women of childbearing age.

Additional information about Alcohol and Other Drug-Related Birth Defects Awareness Week is available from NCADD, telephone (212) 206-6770; World-Wide Web, <http://www.ncadd.org>; and from the National March of Dimes, telephone (888) 663-4637, <http://www.modimes.org>. Additional information about FAS and other alcohol-related birth defects and developmental disabilities is available from CDC, telephone (770) 488-7268, <http://www.cdc.gov/nceh/programs/programs.htm>; and from the National Institute on Alcohol Abuse and Alcoholism, telephone (301) 443-3860, <http://www.niaaa.nih.gov>.

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U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES / Public Health Service

Alcohol Consumption Among Pregnant and Childbearing-Aged Women — United States, 1991 and 1995

Moderate to heavy alcohol use by women during pregnancy has been associated with many severe adverse effects in their children, including fetal alcohol syndrome (FAS)—with facial dysmorphism, growth retardation, and central nervous system deficits—and other neurodevelopmental effects (1). Early-prenatal alcohol exposure can occur unintentionally (i.e., before a woman knows she is pregnant); in addition, women who drink at high levels before pregnancy are at increased risk for drinking during pregnancy (2). Ongoing surveillance for alcohol consumption among pregnant and childbearing-aged women is important for monitoring the impact of efforts to prevent this risk behavior. This report analyzes and compares data from the 1995 Behavioral Risk Factor Surveillance System (BRFSS) and previously reported 1991 BRFSS data for women aged 18–44 years (3), and presents the prevalence of alcohol consumption among pregnant women and overall and state-specific prevalence rates among women of childbearing age. The findings indicate a substantial increase in alcohol use among pregnant women from 1991 to 1995.

BRFSS is an ongoing, state-based, random-digit-dialed telephone survey of the U.S. civilian, noninstitutionalized population aged ≥ 18 years. In 1995, all 50 states* participated in the BRFSS.[†] A total of 33,585 women aged 18–44 years were interviewed about their amount and frequency of alcohol consumption during the month preceding the survey. Based on their responses, drinking patterns were categorized as "any drinking" (consumption of at least one drink of alcohol during the preceding month)[‡] and as "frequent drinking" (consumption of an average of seven or more drinks per week or five or more drinks on at least one occasion). Data were weighted to reflect the probability of selection and state-specific postcensus population estimates by age, sex, and race, and standard errors were calculated by using SUDAAN. The small numbers of pregnant women sampled in each state preclude accurate state-specific prevalence rates for alcohol consumption among pregnant women.

In 1995, 4.7% of women aged 18–44 years reported being pregnant at the time of the interview. Of these, 16.3% reported any drinking during the preceding month, compared with 12.4% in 1991 ($p = 0.07$) (Table 1). The rate of frequent drinking among pregnant women was approximately four times higher in 1995 than in 1991 (3.5% in 1995 and 0.8% in 1991, $p < 0.01$). This difference persisted after controlling for selected sociodemographic characteristics (i.e., age, household income, marital status, employment status, education level, smoking status, and race). Among all childbearing-aged women in 1995, 50.6% reported any drinking, and 12.6% reported frequent

*For consistency over time, national analyses were restricted to the 47 states that participated in the BRFSS in both 1991 and 1995. State-specific analyses for 1995 included all 50 states.

[†]In analyzing the BRFSS, CDC used two methods of calculating response rates. The "upper bound" response rate is the ratio of completed interviews to the sum of all completed, refused, and terminated interviews. The Council of American Survey Research Organizations (CASRO) rate is more conservative, and follows a method developed by CASRO. This method factors in unanswered attempts and thus provides a measure of both telephone sampling efficiency and willingness to participate. For 1995, the median participant "upper bound" response rate was 80%, and the median CASRO response rate was 68%.

[‡]In 1991, women were asked, "Have you had any beer, wine, wine coolers, cocktails, or liquor in the past month?" In 1995, women were asked, "During the past month, have you had at least one drink of any alcoholic beverages such as beer, wine, wine coolers, or liquor?" Other alcohol consumption questions did not change from 1991 to 1995.

TABLE 1. Prevalence of reported alcohol consumption among pregnant and childbearing-aged women (18-44 years) — United States, Behavioral Risk Factor Surveillance System, 1991 and 1995*

Reported consumption level	Pregnant women					All women				
	1991 (n=1,053)	95% CI [†]	1995 (n=1,313)	95% CI	p value	1991 (n=26,105)	95% CI	1995 (n=30,415)	95% CI	p value
Any drinking[§]	12.4	(9.5-15.2)	16.3	(13.1-19.4)	0.07	49.4	(48.4-50.3)	50.6	(49.7-51.6)	0.02
↙ Drinks per week	12.2	(9.4-15.0)	14.6	(11.5-17.6)	0.27	43.9	(43.0-44.9)	45.7	(44.8-46.5)	0.01
7-14 Drinks per week	— [‡]		0.9	(0.0- 1.8)	—	3.4	(3.1- 3.8)	3.0	(2.6- 3.3)	0.04
>14 Drinks per week	0.1	(0.0- 0.3)	0.3	(0.0- 0.7)	0.28	1.4	(1.2- 1.6)	1.1	(0.9- 1.3)	0.04
≥5 Drinks on occasion**	0.7	(0.2- 1.2)	2.9	(1.5- 4.3)	0.003	10.5	(10.0-11.1)	10.5	(9.9-11.1)	0.96
Frequent drinking^{††}	0.8	(0.3- 1.4)	3.5	(1.9- 5.1)	0.002	12.4	(11.8-13.1)	12.6	(12.0-13.3)	0.67

*Because weighted data are used in this analysis, results for 1991 may be slightly different from those reported previously. For consistency, national analyses were restricted to the 47 states that participated in the BRFSS in both 1991 and 1995.
[†] Confidence interval.
[‡] Levels of any drinking may not add to the total prevalence of any drinking because some women did not respond to questions about consumption, frequency and amount. One additional state was eliminated from the breakdown of any drinking because questions regarding consumption frequency and amount were not asked in that state in 1995.
[§] Too few observations to calculate a reliable estimate.
^{**} Five or more drinks on at least one occasion during the preceding month.
^{††} Consumption of an average of seven or more drinks per week or five or more drinks on at least one occasion during the preceding month.

Alcohol Consumption — Continued

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Editorial Note: Official advisories warning against the use of alcohol by both pregnant women and women considering pregnancy were first released in 1981 (4) and again in 1990 (5) and 1995 (6). Although no safe level of alcohol consumption among pregnant women has been established, frequent consumption is associated with a greater risk for FAS and other neurodevelopmental effects (7,8). Despite the established health risk, substantial numbers of women continue to drink during pregnancy, and some at frequent levels. The BRFSS findings indicate that from 1991 to 1995, the prevalences of both any and frequent alcohol consumption by pregnant women increased substantially, even though the prevalences of these behaviors remained stable among all women aged 18-44 years. Alcohol consumption patterns in child-bearing-aged women varied by geographic location; reasons for this variation may include age and sociocultural differences.

The findings in this report are subject to at least four limitations. First, the percentage of women responding to BRFSS who reported they were pregnant was lower than other estimates (9) because BRFSS rates are point prevalence estimates, reflecting the status at the time of the interview rather than over an entire year. Second, BRFSS data were self-reported and may be subject to both recall and reporting biases. For example, because of the social stigmatization associated with heavy alcohol consumption, some women may underreport alcohol use. Third, because the question used to measure drinking status was modified from 1991 to 1995, the number of women with alcohol consumption categorized as any drinking possibly decreased in 1995 (women consuming less than one drink would have answered "yes" to the question in 1991 [any alcohol] but not in 1995 [at least one drink]). Finally, because the number of pregnant women in this sample who were drinkers was relatively small, the estimated prevalence rates are subject to both systematic biases and random variability. Despite these limitations, BRFSS is the largest ongoing population-based data source in the United States to include a representative sample of adult women and information on both alcohol consumption and pregnancy status.

CDC will continue to use BRFSS to track alcohol-use patterns in pregnant women to assess public health efforts to reduce this risk behavior. Additional analyses of BRFSS data will include examining data from multiple years to further characterize trends and geographic differences in the drinking patterns of pregnant women and to identify risk factors associated with frequent alcohol use. Health-care professionals who provide care to women of childbearing age should inform their patients about the advisory on alcohol consumption, which recommends abstinence for women who are pregnant or planning to become pregnant. Because approximately half of the pregnancies in the United States are unintended (10), information about the effects of alcohol on the fetus should be provided to all childbearing-aged women who report frequent drinking.

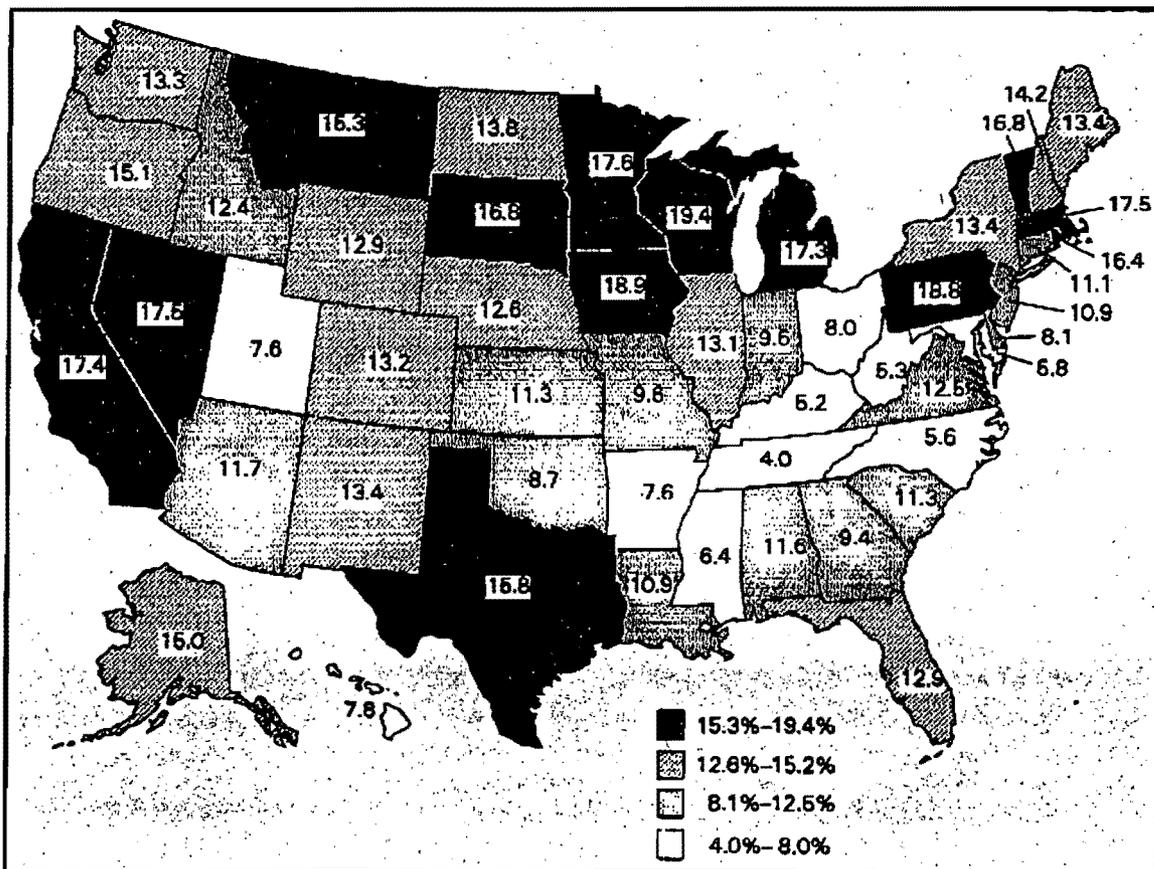
Alcohol Consumption — Continued

drinking—prevalences similar to those in 1991 (49.4% reported any drinking, and 12.4% reported frequent drinking).

The estimated state-specific prevalence of alcohol consumption among women aged 18–44 years varied substantially by state for both any drinking (from 26.1% in Utah to 68.2% in Wisconsin) and for frequent drinking (from 4.0% in Tennessee to 19.4% in Wisconsin) (Figure 1). For any drinking, rates were highest in Wisconsin, Massachusetts, Vermont, Rhode Island, and Connecticut. For frequent drinking, rates were highest in Wisconsin, Iowa, Pennsylvania, Minnesota, and Nevada. In general, in 1991 and 1995, prevalence rates of any and frequent drinking were highest in the northern regions.

Reported by the following BRFSS coordinators: J Durham, MPA, Alabama; P Owen, Alaska; B Bender, Arizona; J Senner, PhD, Arkansas; B Davis, PhD, California; M Leff, MSPH, Colorado; M Adams, MPH, Connecticut; F Breukelman, Delaware; C Mitchell, District of Columbia; D McTague, MS, Florida; E Pledger, MPA, Georgia; J Cooper, MA, Hawaii; C Johnson, MPH, Idaho; B Steiner, MS, Illinois; N Costello, MPA, Indiana; P Busick, Iowa; M Perry, Kansas; K Asher, Kentucky; R Meriwether, MD, Louisiana; D Maines, Maine; A Weinstein, MA, Maryland; D Brooks, MPH, Massachusetts; H McGee, MPH, Michigan; N Salem, PhD, Minnesota; P Arbuthnot, Mississippi; T Murayi, PhD, Missouri; P Smith, Montana; S Huffman, Nebraska; E DeJan, MPH, Nevada; K Zaso, MPH, New Hampshire; G Boeselager, MS, New Jersey; W Honey, MPH, New Mexico; T Melnik, DrPH, New York; K Passaro, PhD, North Carolina; J Kaske, MPH, North

FIGURE 1. Prevalence of reported frequent alcohol consumption* among childbearing-aged women (18–44 years) — United States, Behavioral Risk Factor Surveillance System, 1995



*Consumption of an average of seven or more drinks per week or five or more drinks on at least one occasion during the preceding month.

*Alcohol Consumption — Continued**References*

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Rubella and Congenital Rubella Syndrome — United States, 1994-1997

Indigenous rubella and congenital rubella syndrome (CRS) have been targeted for elimination in the United States by the year 2000 (1). Progress toward reaching this goal is monitored through the National Notifiable Diseases Surveillance System and the National Congenital Rubella Syndrome Registry. From 1969 through 1989, the numbers of annual reported cases decreased 99.6% for rubella and 97.4% for CRS (Figure 1). Following a slight resurgence during 1990-1991, the number of reported rubella cases reached record lows during 1992-1996 (annual average: 183 reported cases). This report summarizes the characteristics of rubella and CRS cases and outbreaks reported in the United States from 1994 through 1996* and provisional data as of April 18, 1997. The findings indicate sustained low incidence of rubella and CRS since 1992 and possible interruption of transmission of rubella virus in late 1996.

Rubella

During 1994-1996, a total of 32 states, the District of Columbia, and New York City reported 567 rubella cases; 22 sites reported one to five cases, seven reported six to 19 cases, and five reported ≥ 20 cases; these five sites accounted for 75% of all rubella cases (Figure 2). Symptom onset for reported confirmed cases peaked during February 1994, June 1995, and April 1996, reflecting large outbreaks in Massachusetts, Connecticut, and North Carolina (range: 36-128 cases). Based on provisional data as of

*Reports for 1996 are provisional.

Prevention of Fetal Alcohol Syndrome: Program Development and Evaluation

Developmental Disabilities Branch, Fetal Alcohol Syndrome Prevention Section, DBDDD, NCEH

Goal To design, implement, and evaluate prevention strategies for specific high-risk groups to prevent the occurrence of FAS and other alcohol-related birth defects.

Collaborators 16 state health departments; 3 CDC funded university projects; Indian Health Service; NIAAA funded research projects; Birth Defects and Genetics Diseases Branch, DBDDD, NCEH; Disabilities Prevention Program, NCEH.

Background Although the prevention of FAS, in theory, is simple - prevent alcohol use in pregnant women or promote contraception among alcoholic women - there are many complicated issues in designing and implementing interventions in different population subgroups. Most prevention and intervention activities have focused on mass public, education, screening for alcohol use in prenatal clinics, professional training for health care providers, and identifying high risk women and providing them with a variety of intervention services. These widespread strategies, though laudable, are resource intensive and may not make an impact on the population which is at highest risk for giving birth to children with FAS. The FAS Prevention Section is working with collaborators to develop data-driven and innovative approaches to FAS prevention. Accurate and complete case ascertainment is a critical aspect of this work because it will improve our understanding of mothers who give birth to children with FAS, enable us to better identify high risk women and to better define the spectrum of outcomes and needs of children exposed to alcohol in-utero.

Major Accomplishments

- Funded the University of Cincinnati and State of Oklahoma to implement interventions in different settings for women who drink during pregnancy
- Developed screening instruments and manuals for enhancing casefinding
- Developed inventory of public and professional training materials on FAS
- Collaborated in the development of a national FAS prevention program directory
- Funded the development of a teachers manual for educating students with FAS
- Coordinated national FAS prevention conferences in 1991 and 1993

Future Plans/Issues

- Develop data base on FAS prevention activities
- Develop intervention models based on the results of descriptive epidemiology of characteristics of mothers with children with FAS, using Native American data
- Assist states and universities in identifying their target populations for intervention by helping them identify screening instruments and providing epidemiological data
- Continue to fund and provide scientific consultation to state and university programs to develop methods for locating, interviewing, and tracking high risk mothers to evaluate their utilization of health care and substance use treatment services
- Collaborate with states to develop interagency FAS coalitions/task forces
- Assist with development of FAS prevention research and dissemination of results
- Foster the development of better case definitions and data on exposure and outcome

Surveillance of Fetal Alcohol Syndrome (FAS)

Developmental Disabilities Branch, Fetal Alcohol Syndrome Prevention Section, DBDDD, NCEH

Goals

1) To investigate methodologies for improving FAS case detection and for using existing data collection systems for estimating the incidence of FAS and performing descriptive epidemiology; 2) To improve surveillance by promoting uniform case definition and data acquisition among researchers and health care professionals as a precondition for establishing more representative national data sets.

Collaborators

Indian Health Service; CDC funded state and university FAS Projects; NIAAA funded FAS research projects; FAS Study Group of the Research Society on Alcoholism; DPP, NCEH; Birth Defects and Genetics Diseases Branch, DBDDD, NCEH;

Background

Established surveillance systems provide data to help: 1) evaluate the extent of a particular disease in human populations; 2) set priorities for public health agencies; 3) develop policies and implement programs designed to reduce the burden of that disease; 4) monitor and evaluate prevention strategies. However, surveillance for FAS is in its infancy. There is currently no state or national surveillance system that is appropriately tailored to the unique problems presented by FAS. FAS is a difficult and subjective diagnosis; many professionals do not feel adequately prepared to make the diagnosis. Moreover, there is controversy about how a related condition, Fetal Alcohol Effects, fits into FAS surveillance. CDC conducts FAS surveillance through BDMP and MACDR, which ascertain cases in the first year of life. However, it appears difficult to diagnose FAS accurately in the newborn period. In short, there is no currently available comprehensive model of FAS surveillance. The FAS Prevention Section is taking steps to help establish FAS surveillance models by assisting states to develop innovative surveillance strategies at the state level and by facilitating discussion, research and consensus building among experts at the national level.

Major Accomplishments

- Prepared a descriptive analysis of the characteristics of Native American children diagnosed with FAS; presented at the annual meeting of the Research Society on Alcoholism
- Cross-linked data from multiple programs serving children with FAS in Alaska and estimated prevalence and published results for Alaska in an MMWR article (4/30/93)
- Funded a statewide community based program to find FAS cases in NM
- Developed and implemented a three-tiered method for screening all first graders for FAS in two counties in Washington State
- Published an MMWR article (5/7/93) on FAS surveillance using data from BDMP
- Enlisted the cooperation of FAS Study Group of the Research Society on Alcoholism and NIAAA in collaborative efforts to refine the FAS case definition

Future Plans

- Organizing a collaborative meeting between CDC/RSA/NIAAA for January 18 or 19.
- Developing recommendations for uniform data collection in FAS surveillance and research
- Designing an alcohol exposure study using the 1988 NMIHS and the 1991 Follow-Up Study
- Preparing articles which address a variety of issues in FAS surveillance, KABB in selected populations, identifying and assisting high risk drinkers, and clinical features of FAS.

**Centers for Disease Control and Prevention
FAS Cooperative Agreements
4/18/96**

Colorado

Colorado is building upon the currently existing Colorado Registry for Children with Special Needs to provide improved FAS surveillance among children from birth to age seven. Another major program effort involves increasing ascertainment of problem drinking and providing counseling services to women of childbearing age, in both educational settings (high schools) and public health programs (prenatal, WIC, family planning). Other activities include FAS educational campaigns directed at both service providers and the public, following and interviewing mothers of children diagnosed with FAS, and working with high risk teen in the Department of Children and Youth Services.

Georgia

A major program goal in Georgia is to increase collaboration and networking among institutions, agencies and community-based programs which address alcohol use and abuse by women of childbearing age. This activity will help identify available resources as well as involve many institutions in the design of an approach to FAS prevention. Other priority activities are conducting a training program for health care professionals, developing a statewide resource guide for professionals, and exploring the use of existing data collection systems to conduct surveillance of FAS. Responsibility for the program is shared between the Women's Health Unit and the Office of Perinatal Epidemiology of the Division of Public Health.

Oklahoma

Oklahoma is implementing a comprehensive FAS Prevention Program. It includes: 1) identifying pregnant women who are problem drinkers and referring them for care; 2) coordinating the efforts of various agencies to ensure for their care; 3) targeting women of childbearing age with problem drinking for treatment and reproductive health services; and 4) improving FAS surveillance. The interagency efforts incorporate a variety of strategies: incorporating pregnancy testing and prenatal referral into alcohol treatment center protocols; implementing a preconceptual project in a university setting; investigating a passive surveillance system for monitoring FAS in newborns; and developing a resource directory for prenatal care providers of services to women with alcohol abuse problems.

Missouri

Missouri has established an interagency FAS coalition which coordinates FAS activities in the state. Over time, this project has evolved into one that is educational in nature, and focuses on training WIC providers to increase their ability to ascertain women who are heavy alcohol users, (or if pregnant using alcohol at all), and institute proper follow-up.

Washington

Washington is developing FAS prevention projects in King County and among two Native American tribes. In addition, it is involved in a descriptive study of the mothers of children diagnosed with FAS at the University of Washington School of Medicine's FAS Clinic. In King County, an assessment of resources needed for the treatment of children with FAS is being conducted. Using information from both projects, a model program for early identification, referral, tracking and prevention will be developed and piloted. The state project also plans to conduct a needs assessment of activities in the rest of the state and to encourage the development of local FAS Prevention Task Forces. Prevention approaches which work in the pilot projects will be disseminated to the rest of the state.

University of Cincinnati

The University of Cincinnati has been funded to design and test an antenatal intervention program aimed at identifying women who are using alcohol prenatally and providing a broad array of informational and support services. Elements of the intervention include educational sessions, in-depth case management, parenting classes, support during labor and the immediate postpartum period, and gift incentives for participation. The ultimate goal of the study is to bring about abstinence during the pregnancy. The study design is a randomized controlled trial testing the intervention against usual care. Participants will be drawn from a variety of clinical facilities in the greater Cincinnati area. Another major objective of the study is to train health care providers in the participating clinics to better ascertain alcohol use among clients and understand the impact of prenatal alcohol use on fetal development and infant outcomes.

University of New Mexico

The University of New Mexico proposes to make the state of New Mexico a model state in applied research, awareness, surveillance and prevention of Fetal Alcohol Syndrome through close coordination of the research project activities with other on-going programs, including the Disabilities Prevention Program. Research activities focus on three areas: 1) evaluation of techniques for population-based epidemiology and ascertainment of affected individuals; 2) definition of key indicators in high-risk women, stratified by ethnic group; and

3) determination of the efficacy of population-wide prevention efforts.

University of Washington

The University of Washington, Department of Pediatrics conducts an FAS Clinic which serves as a statewide resource for the diagnosis of children suspected of having alcohol-related birth defects. Using this clinic as the point of contact, this project will locate and interview the mothers of children diagnosed with FAS in order to identify factors that have enhanced or hindered sobriety and contraceptive use. The project will provide the mothers with referrals to alcohol treatment and family planning services. Ultimately, the project will be able to assess, from the mothers' point of view, the availability of alcohol treatment and health care/family planning resources as well as barriers to access. Information from this investigation will be used to design a primary prevention program for FAS.

CDC/IHS Memorandum of Agreement (MOA) Projects

South Dakota

The current CDC/IHS Agreement specifies research projects in South Dakota only.

SAQ Validation Study

A validation study of a self-administered questionnaire (SAQ) aimed at ascertaining substance abuse among prenatal clients was funded by IHS and IRB approval granted to the PI, Loretta Badheart Bull during the time of the last MOA. CDC was asked to assist in designing the validation study. Epidemiologic assistance only was provided. CDC did pay for contractors to assist in data collection, data entry, and creation of the data base.

Under the current agreement, CDC is to continue to provide contract support for data gathering, data entry, and some analyses. A CDC epidemiologist is to provide oversight in assuring data quality, methodologic soundness, and completion of analyses necessary to the study.

Case-control Study of Children with FAS

A case-control study of children determined to have FAS through ICD-9 Codes and verification of case definition by medical records is being conducted in the Aberdeen IHS Area. IRB approval from IHS is attached. CDC's role in this is similar that for the SAQ Validation Study.

Alaska

The current CDC/IHS MOA includes no projects in Alaska. The Division has plans to fund a cooperative agreement for continued surveillance and prevention activities. One remaining activity from last year is the review of charts of children identified in a case series compiled by Dr. Grace Egeland.

C O V E R**S H E E T****FAX**

To: Sara Herwitz, Intern
Domestic Policy Council
The White House

Fax: 202-456-5557

Subject: Back to Sleep campaign

Date: August 21, 1997

Pages: 19, including this cover sheet

Here is some material on the Back to Sleep campaign. I hope it is helpful. There are active Back to Sleep or SIDS risk reduction campaigns in approximately 20 states.

I will be out of the office on Friday. If you have any questions please call my co-worker Daisy Whittemore at 301-435-3459.

From the desk of...

Ruth Dubois
Coordinator, Back to Sleep Campaign
National Institute of Child Health and Human
Development
31 Center Drive, Room 2A32
Bethesda, MD 20892-2425

301-435-2457
Fax: 301-496-7101

HHS NEWS

U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES

EMBARGOED FOR RELEASE AT 11:00 a.m.
Thursday, March 20, 1997

Contact: NICHD Press Office
(301) 496-5133 or
(301) 435-3457

CLINTON ADMINISTRATION ANNOUNCES EXPANDED BACK TO SLEEP CAMPAIGN TIPPER GORE TO LEAD NEW EFFORT

The Clinton Administration announced today that Tipper Gore will lead an expanded public education effort designed to help prevent Sudden Infant Death Syndrome (SIDS). The national *Back to Sleep* campaign, which has already reached many parents and health professionals with the message that placing babies on their backs to sleep can reduce the risk of SIDS, will now be expanded to target grandparents, babysitters, and day care workers as well.

HHS Secretary Donna E. Shalala also announced that the Gerber Products Company will help to spread the word that babies should be placed on their backs to sleep by placing the *Back to Sleep* message on its cereal boxes, in mailings to new parents, and on its toll-free information number.

Largely as a result of a 1992 American Academy of Pediatrics (AAP) recommendation and the increase in awareness produced by the *Back to Sleep* campaign, SIDS deaths in the United States declined by about 30 percent between 1992 and 1995. However, many caregivers still place babies on their stomachs to sleep. In announcing her new role, Mrs. Gore emphasized the need to reach Americans who may not have heard about this new recommendation in order to ensure that the message reaching parents and other caregivers on infant sleep position is clear and consistent.

"Placing babies on their backs to sleep is one of the most important steps that caregivers can take to reduce the risk of Sudden Infant Death Syndrome, but too many people still don't know this important, simple message," said Mrs. Gore. "Together, we need to continue to spread the word that placing infants on their backs to sleep can save infant lives."

"Gerber's help will allow the *Back to Sleep* campaign to reach more families who haven't yet heard that babies should be placed on their backs to sleep," said Secretary Shalala. "We must be vigilant in continuing to spread this important message, and Gerber's involvement will allow us to do just that."

Mrs. Gore also called on public and private groups to redouble their efforts to reach populations with the highest incidence of SIDS. Mrs. Gore noted that African-American babies are 2.4 times more likely than Caucasian babies to die of SIDS, and Native American babies are 2.8 times more susceptible.

- 2 -

Beginning in June 1997, the *Back to Sleep* message will appear on the backs of 3 million Gerber cereal boxes. The Gerber Products Company will also include the message in mailings to 2.7 million mothers of newborns. In addition, a message recorded by Mrs. Gore will play on the Gerber toll-free information number, urging parents to place their babies on their backs to sleep and to talk to their doctors for more information on infant sleep position. The message, which will play on the Gerber toll-free information number 7 days a week, 24 hours a day, is expected to be heard by about 650,000 callers.

"All told, Gerber's efforts will send the *Back to Sleep* message into the homes of about 80 percent of all parents with infants in the United States," said Dr. Daniel Vasella, President and Head of the Executive Committee for the Novartis Corporation, Gerber Products Company's parent corporation. "We are pleased to be able to help spread this critical message."

SIDS is the sudden and unexplained death of an infant under one year of age. SIDS, sometimes known as crib death, strikes nearly 4,000 babies in the United States every year. The causes of SIDS are still unclear, and it is currently impossible to predict which infants might fall victim to SIDS. Recent studies have identified almost undetectable defects in SIDS infants in a region of the brain that may control sensing of carbon dioxide, breathing, and arousal during sleep.

"Gradually, scientists are identifying the underlying problems that can signal a risk of SIDS," said Secretary Shalala. "But until SIDS is better understood and can be treated, research shows that the simple strategy of placing babies on their backs to sleep can help to reduce the risk of SIDS."

In 1992, after reviewing the available evidence, the American Academy of Pediatrics (AAP) recommended that, to reduce the chance of dying from SIDS, healthy babies should be placed on their backs or sides to sleep. In 1996, the AAP revised its recommendation clarifying that placing babies to sleep on their backs has the lowest risk and is preferred.

The National Institute of Child Health and Human Development (NICHD), part of the National Institutes of Health, launched the *Back to Sleep* campaign in 1994 to amplify the message that back sleeping can reduce the risk of SIDS and save lives. Major partners in the campaign, besides the NICHD, include HHS's Health Resources and Services Administration and the Centers for Disease Control and Prevention, the AAP, the SIDS Alliance, and the Association of SIDS and Infant Mortality Programs.

The recent decline in SIDS deaths reflects a 12 percent drop in the rate between 1993 and 1994, and an 18.5 percent drop between 1994 and 1995, the largest annual declines and the largest

- More -

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consecutive declines ever observed in the U.S. Further, SIDS dropped in 1994 from the 2nd to the 3rd leading cause of infant mortality, behind congenital anomalies and low birth weight/prematurity.

"The *Back to Sleep* campaign has made a real inroads into reducing infant deaths from SIDS and in reducing the infant mortality rate overall, but we must continue to spread the message," said Dr. Duane Alexander, Director of the NICHD.

Since its inception, the *Back to Sleep* campaign has worked to heighten awareness among parents and health care providers by producing and distributing brochures, posters, print public service announcements, and informational videos urging that babies be placed on their backs to sleep. The campaign has also spurred the development of state SIDS campaigns, developed a *Back to Sleep* internet web site (<http://www.nih.gov/nichd>), and established a toll-free phone number -- 1-800-505-CRIB -- that people can call to order *Back to Sleep* campaign materials.

Besides spreading the word that placing infants to sleep on their backs can save lives, the *Back to Sleep* campaign emphasizes several other steps that parents can take to help reduce the risk of SIDS. These include: making sure expectant mothers receive early and regular prenatal care; that they not smoke, drink alcohol, or use drugs (unless prescribed by a doctor) during pregnancy; making sure babies sleep on firm surfaces free of fluffy bedding and soft toys or pillows; keeping babies' surroundings smoke-free; ensuring that babies don't get too warm when sleeping; contacting a baby's doctor or clinic right away when a baby seems sick; ensuring that babies receive their shots on schedule; and breastfeeding.

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*****NOTE:** Radio public service announcements and actualities from Mrs. Gore on SIDS and the *Back to Sleep* campaign will be available on the HHS Radio News Hotline from March 20 through April 4, 1997. Radio feeds can be reached by calling (202) 690-8317 or (800) 621-2984.

Note: HHS press releases are available on the World Wide Web at: <http://www.dhhs.gov>.



March 1997

The Back to Sleep Campaign

National Institute
of Child Health
and Human
Development

National
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Health

The "Back to Sleep" campaign is aptly named as its main recommendation is to place healthy infants on their backs. Following this recommendation has been shown to reduce the risk of Sudden Infant Death Syndrome (SIDS). Although it is difficult to change a national pattern of tummy sleeping, this campaign has been successful in reaching many parents of new babies and back sleeping is being increasingly adopted. The success of this recommendation is borne out in the recent reduction in infant mortality rates. This trend has continued with a 6 percent drop in infant mortality this year. This reduction is largely due to the 30% reduction in SIDS deaths rate between 1992 and 1995 (U.S. Vital Statistics). The saving of approximately 1,600 infants a year is largely attributed to the Back to Sleep campaign..

Sudden Infant Death Syndrome

Prior to the campaign there were nearly 5,000 unexplained SIDS deaths a year in the United States. A SIDS death is heartbreaking as an apparently healthy baby dies suddenly and without warning. Studies in other countries showed that placing babies on their backs helped to reduce such deaths. Recent NICHD-supported research has identified almost undetectable defects in SIDS infants in a region of the brain that controls sensing of carbon dioxide, breathing, and arousal during sleep. Gradually, scientists are identifying the underlying problems that signal a risk of SIDS. But until this physiology is well understood and can be treated, this simple strategy of back sleeping saves many lives.

Surveys show that Back to Sleep is successful, but that much more needs to be done. The goal is to have all healthy babies sleeping on their backs. All caretakers need to be reached, including fathers, grandparents and babysitters. Minority groups need to hear the message in culturally sensitive ways. The message needs to be repeated and reinforced in newborn nurseries. This effective message is a low-tech, low-cost way to save lives and prevent tragedies.

History of the Back to Sleep Campaign

The Back to Sleep campaign is a public/private initiative. NICHD leads the campaign, along with the Maternal and Child Health Bureau, and other Federal agencies such as the Centers for Disease Control and the Census Bureau. The American Academy of Pediatrics (AAP) is the major private partner, along with the SIDS Alliance, a group of parents, and the Association of SIDS and Infant Mortality Programs. After weighing the evidence for the safety, the AAP made its recommendation in 1992. In 1994, NICHD began the campaign with an effort to reach every newborn nursery in the country. A toll-free telephone number was established for ordering Back to Sleep pamphlets, posters, and videos. Over 8 million pamphlets have been distributed.



"BACK TO SLEEP" CHRONOLOGY

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- 1988: Medical societies in the Netherlands adopt non-prone sleeping to protect against "cot death."
- 1991: Publication of population-based, case-control studies conducted in Tasmania, New Zealand, and Avon, England demonstrating a large association between being placed to sleep prone and SIDS.
- Despite the U.S. having a much higher prevalence of prone sleeping than these countries, the U.S. SIDS rate is much lower and contributes less to infant mortality rates.
- 1991: Public education campaigns begin in Australia, New Zealand, and the United Kingdoms advocating that infants be placed on their sides or back to reduce the risk for SIDS.
- Dec. 1991: The American Academy of Pediatrics (AAP) Task Force on Infant Sleep Position and SIDS is formed and begins to evaluate the studies on the role of prone sleep position as a risk factor.
- Feb. 1992: NICHD staff meet with scientists and health professionals from Australia, Britain, the Netherlands, and New Zealand for advice on research and public education issues.
- Mar. 1992: Meeting at NICHD of AAP Task Force and national and international experts to plan a research agenda to provide the basis for, and evaluation of a campaign. Experts divided on whether a recommendation should be made at this time.
- Apr. 1992: The AAP Task Force announces the recommendation that "healthy newborns be placed to sleep on their side or back to reduce the risk of SIDS."
- Apr./May 1992: U.S. national household survey of infant sleep position and related sleep practices initiated under NICHD sponsorship. These surveys are repeated annually.
- June 1992: The AAP Task Force position statement is published in "Pediatrics." This was followed by the publication of editorials expressing concerns regarding the recommendation.

- June/July 1992: Surveys of the membership of AAP, AAFP, and NACHC initiated under NICHD sponsorship to track practice of health professionals. Surveys of newborn nursery nurses added in 1993. These surveys have been repeated in 1994 and 1995.
- Apr. 1993: NICHD funds the prospective Tasmanian SIDS cohort study to obtain health outcome data on the safety of side sleeping position for newborns, a concern of U.S. practitioners. This study also provides the data to show a direct link between the success of the Australian campaign to increase side sleep position, and a 50% decline in the SIDS rate.
- Oct. 1993: NICHD funds analyses of the Avon Longitudinal Study of Pregnancy and Childhood, a prospective study of 14,000 that spans pre- and post-campaign periods in Avon, England, to obtain health outcome data on the safety of side or back sleeping for newborns.
- Jan. 1994: CPSC issues a safety alert warning parents not to place soft bedding under the baby and re-enforcing the AAP recommendation.
- Jan. 1994: NICHD with co-sponsorship from NIDCD and NCHS convenes international meeting of medical and scientific experts to review research data and outcomes from public health campaigns. The overwhelming opinion was that the evidence justified an increased effort to reach a larger audience with the AAP recommendation.
- Mar. 1994: The ad-hoc DHHS Interagency Panel on SIDS recommended to the Assistant Secretary of Health that DHHS adopt and promote the AAP recommendation.
- Mar. 1994: A "Back to Sleep" coalition was formed between the U.S. PHS, the AAP, the Association of SIDS Program Professionals, and the SIDS Alliance for the planning, development, and implementation of the "Back to Sleep" national public education campaign.
- May 1994: Publication in "Pediatrics" of the proceedings of the Jan. meeting and of the joint commentary from the AAP and selected federal agencies endorsing the AAP recommendation and the CPSC alert.
- May 1994: A meeting of maternal and child health organizations is convened by the U.S. PHS to enlist their active participation in the "Back to Sleep" coalition.

- June 1994: The Surgeon General issues a policy statement that "healthy infants be placed in their back or side to sleep to reduce the risk of SIDS."
- June 1994: The national public health education campaign is launched.
- Oct. 1996: AAP makes change in its recommendation regarding sleep position, to the back position being the best or preferred position and the side position as an alternative.
- Mar. 1997: Gerber Baby Products joins NICHD as a partner and includes Back to Sleep message on rice cereal boxes and 1-800 information line.
- Tipper Gore becomes spokesperson for the "Back to Sleep" campaign.



IMPACT OF "BACK TO SLEEP"

National Institute
of Child Health
and Human
Development

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Timeline:

- June 1992: Publication of AAP sleep position recommendation
- May 1994: Publication of Joint Commentary endorsing recommendation
- June 1994: "Back to Sleep" Campaign launched
- Oct. 1996: AAP makes change in recommendation for sleep position.

VITAL STATISTICS:

Between 1992 and 1995, the SIDS rate declined 30%, from 1.2/1000 live births to 0.84. Most of this decline took place between 1993 and 1995; a decline of 12% between 1993 and 1994, and 18.5% between 1994 and 1995.

These are the largest annual declines observed since reliable data collection began in 1985, and the only large declines observed in two consecutive years. For the first time, SIDS ranks as the third leading cause of infant mortality instead of second.

The declines in the number of SIDS deaths accounts for one-third of the declines in infant deaths in 1994 and 1995.

95% of SIDS are post-neonatal (after one month of age). About 60% of the decline in post-neonatal deaths in 1994, and 85% in 1995 are accounted for by the decline in the number of SIDS deaths.

Between 1993 and 1994, both the white and black SIDS rates declined 12%. However between 1994 and 1995, the white rate declined 30% and the black rate declined only 14%. Although the black/white ratio for infant mortality has remained constant at 2.4, it has increased for SIDS since 1991 from 2.1 to 2.4 in 1995.

The evidence regarding the contribution of changes in sleep position to declines in SIDS rates is circumstantial but quite powerful. Prone prevalence declined from 70 to 29% during the time period that the rates declined 30%. The declines parallel those seen in other countries in the early phases of their campaigns but fall short of the 50-70% reductions in SIDS mortality when they achieved greater than 90% side or back sleeping.

The other major risk factors for SIDS are smoking during pregnancy, late or no prenatal care, low birthweight, preterm birth, teen pregnancy, and use of soft bedding. Based on Annual Natality reports from NCHS, and the Household Survey (see below), most of these characteristics changed minimally or not at all over this time period. The

rate of smoking among pregnant women declined about 15% which could not account for the declines in SIDS.

Cautionary Notes: The 1995 vital statistics are preliminary; Although a concomitant decline in post-neonatal mortality confirms the decline in SIDS deaths, the magnitude of the decline should be viewed with some caution until a closer look at deaths to related causes determines the contribution of diagnostic shift.

EVALUATION:

Annual National Household Surveys: Telephone interviews of nighttime caretakers (> 80% mothers) of infants less than 8 months of age were initiated by NICHD prior to the publication of the AAP recommendation and repeated annually.

The prevalence of infants placed to sleep prone declined at a steady rate between 1992 and 1995 from 70% to 29%. The rate of decline slowed in 1996 with 24% placed prone.

Annual Surveys of Pediatric Health Practitioners: AAP, AAFP, NACHC, hospital nurseries were initiated by NICHD in 1992, and repeated annually through 1995.

Prior to the AAP recommendation in 1992, between 80 and 90% of AAP, AAFP and NACHC membership surveyed recommended prone, about 40% side and less than 10% back.

In 1995, 10% of the AAP membership, and about 20% of the AAFP and NACHC membership surveyed recommended prone; 70-85 % of the membership recommended side and 66-81% recommended back.

In 1994, 28% of head nurses in the newborn nurseries recommended prone, 99% side, and 32% back. In 1995, 4% recommended prone, 99% side, and 62% back.

In 1992, less than half of the surveyed membership of AAP, AAFP, and NACHC usually made a recommendation about sleep position. In 1995 about 70% usually made a recommendation about sleep position.

In 1995, 50-60% of practitioners had heard about "Back to Sleep." About half of these replied that it resulted in a change in practice.

OTHER STUDIES IN PROGRESS

- Longitudinal study infant care practices (co-sponsored NICHD, NIDCD): prospective study of sleep position, other SIDS risk factors from birth through one year in Boston, MA and Toledo, OH. Analyses to date confirm data obtained from the national cross-sectional surveys described above.

- Avon Longitudinal Study of Pregnancy and Childhood (co-sponsored NICHD, NIDCD). This population-based study of 14,000 pregnancies in Avon, England, spanned the pre-and post-campaign periods in Britain. Analyses of health outcomes in this data set show that there is no increased probability of visits to the doctor or adverse respiratory events in infants placed on their side or back compared to stomach. There is an increased probability of cough and fever in the prone position.

Hospitalizations and deaths are still being monitored.

Another study of a prospective cohort in Tasmania confirms no increased risk of doctors visits or respiratory events in side sleeping infants.

- Chicago Infant Mortality Study (co-sponsored NICHD, CDC, NIDCD). This case-control study of sudden infant deaths in Chicago is in the final analysis phase.
- Aberdeen Area IHS Infant Mortality Study (co-sponsored NICHD, IHS, CDC, Aberdeen Area Tribal Chairmen). This case-control study of sudden infant deaths among Native Americans in the Aberdeen Area of the IHS is in final phases of enrollment.
- Case-control study of SIDS in California (co-sponsored NICHD, NIDCD). This study is in the process of OMB clearance and will examine a variety of risk factors and exposure to the sleep position recommendation in a large diversity of populations during this critical campaign period.
- Collaborative Home Infant Monitoring Evaluation (CHIME) Study (NICHD). This study investigates life-threatening events and the maturation of cardiorespiratory control in high risk infants on home apnea monitors. The state of the art event recording monitor developed by CHIME in collaboration with industry, records infant sleep position and critical physiologic variables. It will provide data on the role of sleep position in cardiorespiratory function in infancy.



BACK TO SLEEP CAMPAIGN ACTIVITIES

National Institute
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The campaign goal is to have all U.S. babies sleeping on their backs.

Back to Sleep Outreach Activities

GOAL: To reach all parents (mothers and fathers) and caretakers of infants (including grandparents) with a special effort to reach minority populations.

- 1-800 toll-free line for ordering publications (over 30,000 calls have been logged with over 8 million parent brochures in English and Spanish distributed)
- Back to Sleep campaigns are in progress in the following 20 states: Georgia, New Jersey, California, Massachusetts, New Hampshire, North Carolina, Louisiana, Oklahoma, Utah, New Mexico, Oregon, South Carolina, Alabama, Indiana, Michigan, Iowa, Minnesota, Montana, Washington, and Alaska.
- Back to Sleep home page on the World Wide Web
- Public Service Announcements and Print Ads
- Mailing of Back to Sleep publications to 4,000 newborn nurseries in the U.S.
- Mailing of Professional and Parent brochure to members of the American Academy of Pediatrics and the American College of Obstetricians and Gynecologists
- Mailing to Nursing Organizations
- Radio and TV public service campaigns
- Back to Sleep table top exhibit

MINORITY OUTREACH

- Poster with white baby and baby that is part American Indian and part Columbian
- Spanish parent training video
- Poster with African American babies
- Print ads based on new African American baby poster
- Table top exhibit with African American babies

PUBLIC AND PRIVATE AGENCIES

The Back to Sleep campaign is co-sponsored by:

- National Institute of Child Health and Human Development, NIH
- Maternal and Child Health Bureau, HRSA
- American Academy of Pediatrics
- SIDS Alliance
- Association of SIDS and Infant Mortality Programs

- National Heart, Lung, and Blood Institute, NIH

Other Agencies Supporting the Campaign:

- Centers for Disease Control and Prevention
- Consumer Product Safety Commission
- National Institute of Nursing Research, NIH
- National Institute of Deafness and Communications Disorders, NIH
- WIC Regional Offices
- Healthy Mothers Healthy Babies Coalition
- The Office of Minority Health Resource Center, DHHS
- SIDS International
- National Center for Health Statistics

NEW INITIATIVES

- Mailing Back to Sleep material to the 4,000 newborn nurseries (including military hospitals) contacted at the beginning of the campaign in 1994.
- New collaboration with Healthy Mothers Healthy Babies Coalition to reach minorities and special populations.
- Emphasis on fathers and grandparents as caregivers.
- National alert for high-risk cold winter months.
- Emphasis on other risk factors such as smoking and soft bedding.

WORLD WIDE WEB

- Visit the Back to Sleep Campaign on the National Institute of Child Health and Human Development Home Page -- <http://www.nih.gov/nichd/>

HHS NEWS

U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES

FOR IMMEDIATE RELEASE
April 16, 1997

Contact: NICHD Press Office
(301) 496-6133

AFRICAN AMERICAN BABIES AT HIGHER RISK FOR SUDDEN INFANT DEATH SYNDROME (SIDS), BUT SIMPLE STEPS CAN SAVE LIVES, HEALTH EXPERTS SAY

African American babies are nearly two and a-half times more likely than Caucasian babies to die from Sudden Infant Death Syndrome (SIDS), but there are some simple steps all parents and other caregivers can take to reduce the risk of SIDS.

SIDS is the sudden and unexplained death of an infant under one year of age. It strikes nearly 4,000 babies in the United States every year. The causes of SIDS are still unclear, and it is currently impossible to predict which infants might fall victim to SIDS.

The American Academy of Pediatrics says the most important way to reduce the incidence of SIDS, sometimes known as "crib death," is to place babies on their backs to sleep. While health experts are uncertain about the link between the stomach sleeping position and SIDS, there is some evidence that air can become trapped underneath a sleeping infant, causing the child to rebreathe exhaled air. The Academy has stated that sleeping on the back is preferred; however, the side position is considered an acceptable alternative.

Other steps that parents and caregivers can take to reduce the risk of SIDS include:

- Babies should sleep on firm surfaces free of fluffy bedding and soft toys or pillows.
- Expectant mothers receive early and regular prenatal care. Mothers should not smoke, drink alcohol, or use drugs (unless prescribed by a doctor) during pregnancy.

More -

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- Create a smoke-free environment around your baby.
- Keep the temperature in the baby's room so that it feels comfortable to adults. Babies should not get too warm when sleeping.
- Caregivers should ensure that babies receive immunizations on schedule; and if the baby seems sick, contact the baby's doctor or clinic right away.
- If possible, consider breast feeding your baby.

"We are very proud of the Back To Sleep campaign," said Dr. Yvonne Maddox, Deputy Director of the National Institute of Child Health and Human Development (NICHD), a part of the National Institutes of Health. "This campaign has important messages for all babies, especially for those at higher risk. Everyone who takes care of infants needs to know how to reduce the risk of SIDS for African American babies."

Dr. Maddox added that public and private groups must enhance their efforts to reach these populations. "It is essential that the simple message of putting your baby on his or her back to sleep reaches everyone."

The "Back To Sleep" campaign, with the U.S. Department of Health and Human Services and the Clinton Administration, is expanding to reach not only parents and health professionals but grandparents, baby sitters, and day care workers as well.

A convenient new source of SIDS information for parents and others is the Gerber Products Company, which plans to print helpful tips on the backs of three million Gerber rice cereal boxes beginning in June 1997. The Gerber Products Company will also include the message in mailings to 2.7 million parents of newborns. In addition, a recorded message about SIDS is currently playing on the Gerber toll-free information number (1-800-4-Gerber), urging parents to place their babies on their backs to sleep and to talk to their doctors for more information on infant sleep position. The message is playing on the Gerber toll free information number 7 days a week, 24 hours a day.

- More -

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The NICHD and its partners in the campaign launched "Back to Sleep" in 1994.

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***NOTE: HHS press releases are available on the World Wide Web at: <http://www.dhhs.gov>. A "Back To Sleep" internet web site is located at <http://www.nih.gov/nichd>, and campaign materials can be obtained by calling a toll free phone number -- 1-800-505-CRIB.

HHS NEWS

U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES

FOR IMMEDIATE RELEASE
April 16, 1997

Contact: NICHD Press Office
(301) 496-5133

AMERICAN INDIAN BABIES AT GREATEST RISK FOR SUDDEN INFANT DEATH SYNDROME (SIDS), BUT SIMPLE STEPS CAN SAVE LIVES, HEALTH EXPERTS SAY

American Indian babies are at greatest risk to die from Sudden Infant Death Syndrome (SIDS) -- almost three times more likely than Caucasian babies -- but there are some simple steps all parents and other caregivers can take to reduce the risk of SIDS.

SIDS is the sudden and unexplained death of an infant under one year of age. It strikes nearly 4,000 babies in the United States every year. The causes of SIDS are still unclear, and it is currently impossible to predict which infants might fall victim to SIDS.

The American Academy of Pediatrics says: the most important way to reduce the incidence of SIDS, sometimes known as "crib death," is to place babies on their backs to sleep. While health experts are uncertain about the link between the stomach sleeping position and SIDS, there is some evidence that air can become trapped underneath a sleeping infant, causing the child to rebreathe exhaled air. The Academy has stated that sleeping on the back is preferred; however, the side position is considered an acceptable alternative.

Other steps that parents and caregivers can take to reduce the risk of SIDS include:

- Babies should sleep on firm surfaces free of fluffy bedding and soft toys or pillows.
- Expectant mothers receive early and regular prenatal care. Mothers should not smoke, drink alcohol, or use drugs (unless prescribed by a doctor) during pregnancy.

- More -

- 2 -

- Create a smoke-free environment around your baby.
- Keep the temperature in the baby's room so that it feels comfortable to adults. Babies should not get too warm when sleeping.
- Caregivers should ensure that babies receive immunizations on schedule; and if the baby seems sick, contact the baby's doctor or clinic right away.
- If possible, consider breast feeding your baby.

"We want to make sure this advice is heard throughout the American Indian community," said Dr. Kermit Smith, Acting Chief Medical Officer of the Indian Health Service. "Everyone who takes care of infants needs to know how to reduce the risk for American Indian babies."

Dr. Smith added that public and private groups must redouble their efforts to reach populations with the highest incidence of SIDS - such as the American Indian community.

Dr. Smith's comments are part of the "Back To Sleep" campaign that the U.S. Department of Health and Human Services and the Clinton Administration are now expanding beyond parents to include grandparents, baby-sitters, and day care workers.

A convenient new source of SIDS information for parents and others is the Gerber Products Company, which plans to print helpful tips on the backs of three million Gerber rice cereal boxes beginning in June 1997. The Gerber Products Company will also include the message in mailings to 2.7 million parents of newborns. In addition, a recorded message about SIDS is currently playing on the Gerber toll-free information number (1-800-4-Gerber), urging parents to place their babies on their backs to sleep and to talk to their doctors for more information on infant sleep position. The message is playing on the Gerber toll-free information number 7 days a week, 24 hours a day.

The NICHD and its partners in the campaign launched "Back to Sleep" in 1994.

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- More -

- 3 -

***NOTE: HHS press releases are available on the World Wide Web at: <http://www.dhhs.gov>. A "Back To Sleep" internet web site is located at <http://www.nih.gov/nichd>, and campaign materials can be obtained by calling a toll-free phone number -- 1-800-505-CRIB.

Association of SIDS and Infant Mortality Programs

Confronting the tragedy of infant death through programs of support, education, and prevention

TO: Sarah Hurwitz
Domestic Policy Council
White House
FAX: 202-456-5557

FROM: Jodi Shaefer
President
Association of SIDS and Infant Mortality Programs
FAX: 410-706-0146

Number of pages including cover, 15

It was good to talk to you yesterday. Included in this fax are an overview of Project RIMI (Representation Increase for Minorities and Indigenous), an Association of SIDS and Infant Mortality Programs brochure, and the Executive Summary from the Nationwide Survey of Sudden Infant Death Syndrome Services. Please do not hesitate to call me if I can provide any additional information, 410-706-5062.

The logo for the Association of SIDS and Infant Mortality Programs (ASIP) is displayed in a large, bold, black font. The letters 'A', 'S', and 'I' are connected, and the 'P' is separate.

c/o
Center for
Infant and
Child Loss
630 West
Fayette
Street
Room 5-684
Baltimore,
Maryland
21201
(410) 706-5062

Project RIMI Information Sheet

- Representation Increase for Minorities and Indigenous -

(a project of the Education Working Group (EWG) of the SIDS Global Strategy Task Force)

Rationale:

High SIDS rates for babies in Minority and Indigenous groups are a priority concern for the international SIDS community. This inequity needs to be addressed at all levels - in research, in prevention and bereavement services and in organisational representation. Increased representation of Indigenous and Minority groups in SIDS organisations is likely to lead to increased understanding, more effective ways to work and a reducing SIDS rate for Indigenous and Minority groups, too.

Aim:

To increase representation of Indigenous and Minority groups in SIDS organisations at international, national, state and local levels.

Objectives:

- To assess current levels of representation in national, state and local SIDS organisations.
- To recommend an increase in representation where there is under representation.
- To support this with responses to survey feedback about successes and difficulties experienced.
- To reassess the impact on representation levels after two years
- To report progress and results of this project to the International SIDS Conferences in Rouen, France in 1998 and in Auckland, New Zealand in the year 2000

Method:

Stage 1.

- A letter was sent in August 1996 to the Chairperson of SIDS International, to outline the project and ask for the support of the executive and its recommendation to member countries.
- A survey was designed to assess existing levels of Indigenous and Minorities representation. It has been refined and trialed in the United States, Western Australia and New Zealand. The survey will be sent to member countries in early June 1997.
- A recommendation that representation be increased will be included in a covering letter.
- National responses will be called for by 15 August 1997 and State and local level responses called for by 15 October. Reminders will be sent to non-responding countries in October 1997.
- Analysis of stage one will be completed by December 1997.
- A response to feedback about successes and difficulties will be prepared in consultation with the Indigenous and Minorities SIDS Coalition and others, and sent out in March 1998.

Stage 2.

- A follow-up survey will be sent to member countries in early July 1999 and responses called for by 1st August 1999.
- Reminders to non-responders will be sent out during August 1999
- Analysis of Stage 2 will be completed by the end of November 1999.
- A report on the project will be completed by January 2000 and a paper presented at the Sixth International SIDS Conference in New Zealand in February 2000. Participating countries will receive a report.

Project Workers:

Kerry Hunt, Ann Callaghan, (Australia) Rosanne English, Kathy Dirks, Helen Lerner, (USA) Alison Stewart, Stephanie Cowan, (NZ) advice from the Indigenous and Minorities SIDS Coalition, advice from colleagues and local experts of project workers. other Education Working Group members

Project RIMI

Representation Increase for Minorities and Indigenous

E tipu e rea

Grow up, oh tender shoot

(Start of a famous Maori proverb, New Zealand)



**"When our trees die before they are tall,
mother earth feels the pain."**

(from a SIDS leaflet of the people of the Northern Plains, USA)

While SIDS happens amongst all peoples of the world it happens more amongst Indigenous people and people in Minority groups. Their increased involvement in SIDS organisations is likely to bring more understanding and more success in supporting families and reducing SIDS amongst all peoples of the world.

case of SIDS caused by many v. a minority

ASSOCIATION OF SIDS AND INFANT MORTALITY PROGRAMS

Confronting the tragedy of infant death through counseling, education, advocacy, and research

ASIP ACTIVITIES

- ◆ Formulate professional and program standards and collaborate with other organizations to improve the quality of bereavement counseling and support services to those affected by infant and child death
- ◆ Provide training for health care providers, emergency responders, and community groups to assure a supportive response following infant or child death
- ◆ Monitor legislation and government activities. Advocate for federal initiatives regarding infant mortality prevention, SIDS risk reduction, and the development of comprehensive services
- ◆ Support research activities for case management, epidemiology, and program evaluation
- ◆ Provide consultation and technical assistance to organizations developing infant mortality initiatives at local, national, and international levels
- ◆ Secure grants through its members (I.e., Nationwide Assessment of SIDS Services, and a model training program on infant death) to assure quality service provision at all levels

MEMBERSHIP

Full Member

Health and human services professionals who provide information, education, counseling, and support services to help families and communities cope with infant and child death or who provide consultation to a SIDS or infant and child mortality program are eligible.

Associate Member

Individuals committed to the purposes of ASIP, demonstrated by past or present activities related to SIDS or infant and child mortality programs are eligible. Administrators, peer support providers, development directors, clergy, emergency responders, and public health professionals are encouraged to apply. Associate Members are not eligible for office holding or voting privileges.

Membership includes a subscription to the *Journal of Sudden Infant Death Syndrome and Infant Mortality*.

For more information on ASIP membership call or write:

ASIP
c/o The Center for Infant and Child Loss
630 W. Fayette Street, Rm. 5-684
Baltimore, Maryland 21201
Phone 410/706-5062 • Fax 410/706-0146

The Association of SIDS and Infant Mortality Programs (ASIP, formerly ASPP, Association of SIDS Program Professionals) is an association of health and human service providers committed to bereavement support and risk reduction activities. ASIP promotes programs of counseling, education, advocacy, and research to ensure a supportive community response for those affected by infant and child death and to reduce the risk of death for future children.

ASIP



ASIP MEMBERSHIP APPLICATION

Name _____
 Degree _____
 Agency _____
 Title _____
 Address _____
 City _____
 State/Zip _____
 Phone _____
 Fax _____
 E-mail _____

Briefly describe infant mortality work

New Full
 Renewal Associate

Annual dues: \$90 for Full / \$65 for Associate

Please mail to:

ASIP

c/o The Center for Infant and Child Loss
 630 W. Fayette Street, Rm. 5-684
 Baltimore, Maryland 21201
 Phone 410/706-5062 • Fax 410/706-0146

I hereby request membership in the Association of SIDS and Infant Mortality Programs. I agree to abide by the Articles of Association as presently or hereafter duly adopted.

Signature _____

Date _____



**Association
of
SIDS
and
Infant
Mortality
Programs**

Until the 1980s HEW, now Department of Health and Human Services, (HHS) was directly responsible for providing supervision and support to the SIDS projects. Following the federal government's consolidation of funding for MCH categorical programs in the early 1980s, funds were given to each state in a "block grant" and each state was free to decide how it would allocate these funds. The 46 federally financed programs in the mid 1970s shrank to approximately 20 by 1988. In addition to the small number of continuing programs, the federal government's support services were cut to include the part-time effort of one person available at the federal level, the SIDS Clearinghouse, and a few small grants for selected special needs. As time passed, it became increasingly apparent that without a central organizing and communication source, SIDS resources would become more fragmented and in many cases would cease entirely. Thus, in 1987 the Association of SIDS Program Professionals (ASPP) was organized to help fill this gap.

The ASPP represented individuals in the United States and Canada who provided service to nearly 4,000 families each year who experienced the death of a child due to Sudden Infant Death Syndrome. As family services expanded to offer broad based bereavement support and training, the name was changed to the Association of SIDS and Infant Mortality Programs/ASIP in 1996 to reflect member activities. In addition to information and counseling, our members provide community education, peer support programs, training programs, and consultation services which link health departments, emergency responders, medical examiners, coroners, law enforcement, health and mental health professionals across the country.

ASIP works to build and maintain a high standard of bereavement services and promotes collaboration within the professional community. ASIP participates in legislative and government activities and infant mortality research initiatives.

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NATIONWIDE SURVEY

OF

SUDDEN INFANT DEATH SYNDROME

(SIDS) SERVICES

EXECUTIVE SUMMARY

September 30, 1994

John G. Brooks, M.D.
Sarah J.M. Shaefer, R.N., M.S.
Mary E. McClain, R.N., M.S.
Howard J. Hoffman, M.A.

Supported by:

Maternal and Child Health Bureau
Health Resources and Services Administration
Public Health Service
Department of Health and Human Services
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EXECUTIVE SUMMARY

Sudden Infant Death Syndrome (SIDS) is the leading cause of postneonatal infant mortality, and is responsible for the deaths of about 6000 infants every year in the United States. SIDS is the sudden and unexpected death of an infant which remains unexplained after a full post mortem investigation. Since 1975, the federal government has supported specific programs for SIDS research, and family counseling and support and for public and professional education about SIDS, although funding levels and mechanisms have varied significantly since that time.

There are many components to a system which successfully meets the needs of families and communities affected by SIDS. The "first responders" (eg., police, firemen, paramedics, emergency room personnel) must be knowledgeable and current in their understanding of SIDS. Standardized autopsies should be performed on all infants who die unexpectedly, and there should be uniform criteria for diagnosing and reporting SIDS cases. Case management, including bereavement support and conveying accurate information about SIDS and about the results of their infant's autopsy, should be available without delay to all affected family members, and should continue for as long as is necessary. The goal is to achieve availability and effective utilization of appropriate services and resources for all families who are affected by this tragedy. In analyzing the availability of SIDS services, it is important to note geographic coverage, type and level of service, providers of service, and dollars available for service provision. This "Nationwide Survey of SIDS Services" was carried out in 1992 in response to a Congressional mandate to determine the availability and utilization of the above components of SIDS support systems throughout the United States and to serve as a basis for future planning and resource allocation. Evaluation of the quality and efficacy of services was not possible in this study. A comprehensive list of available SIDS services, including geographic coverage, services provided, obstacles to availability and utilization of services, and SIDS incidence is contained in Appendix C of the complete report.

The specific goals of this study were:

1. To identify SIDS numbers and incidence by race and sex for the entire USA and for each state and territory;
2. To identify the case referral and case management system for SIDS deaths in each state and territory;
3. To characterize patterns of utilization of existing SIDS services in each state and territory by race;
4. To identify the training of individuals responding to SIDS deaths at the community level.

Methods

Data collection was accomplished between May, 1992 and January, 1993 by mail questionnaire with telephone follow-up. Unique questionnaires were developed, validated, pilot tested, and then distributed to state and territorial Directors of Maternal and Child Health (59), Vital Statistics Directors (56), SIDS Professional Program Directors (65), SIDS Peer Support Groups (49), and a group of state and county Medical Examiners and Coroners selected by a complex random sampling technique (325), respectively. Most of the numerical mortality data was obtained for 1989 from the National Center for Health Statistics (NCHS), and was derived from the 1989 public use tapes for Multiple Causes of Death for ICD-9.

Results

Of the 554 questionnaires distributed, 448 were completed for an overall response rate of 81%. The group specific response rates were 75% for the medical examiner/coroners, 95% for the Vital Statistics Directors, 88% for the MCH Directors, 96% for the Professional Program Directors, and 78% for the Peer Programs. There are no Peer Support Programs or Professional Programs in the 8 territories. Puerto Rico was the only territory to report any SIDS deaths in 1989.

SIDS Diagnosis and Reporting

The survey of Medical Examiners (ME) and Coroners revealed that less than 50% followed a standardized infant autopsy protocol for infant autopsies. Only 19 states have legislation which mandates child specific autopsy requirements or procedures.

The criteria for diagnosing SIDS showed similar wide variability from jurisdiction to jurisdiction. Forty-nine percent of the ME/Coroners would diagnose SIDS in the first week of life, and 63% would use the diagnosis in infants under one month of age. While most of the vital statistic directors allow the diagnosis of SIDS at any age during the first year of life, after one year of age, only 11% of vital statistics directors and 44% of the medical examiners/coroners allow the diagnosis of SIDS. There were no systematic differences in this regard between the coroner, medical examiner and mixed systems. It is of concern that 5% (13/245) of ME/Coroner responded no (3) or don't know (10) to assignment of the SIDS diagnosis in the 1-12 month age range. Only 7% of the ME/Coroner respondents would make the diagnosis of SIDS in the absence of an autopsy, and 32% allowed the diagnosis of SIDS in the absence of a death scene investigation. In 1989, about 90% of cases classified as SIDS were autopsied.

While NCHS reports the number of SIDS in a given state by residence (i.e. they are reported in the state of their official residence at the time of death even if they die in a different state), many of the Vital Statistics Directors, Maternal and Child Health Directors, and Professional Program Directors report SIDS by residence and by occurrence (the infant died in their state). These variations in counting result in discrepancies between the state and NCHS calculations of state specific SIDS incidence, with NCHS usually reporting a lower number of cases. The reported national SIDS incidence for 1989 varies with a low from NCHS of 1.39/1000 live births, to a high of 1.58 from the Directors of Maternal and Child Health. To insure comparability with international SIDS incidence data, NCHS utilizes the World Health Organization (WHO) convention. WHO nosology guidelines list as SIDS only those deaths which have SIDS identified on the death certificate as the only cause of death, and which occur in infancy. The 1989 NCHS data reveal that in addition to the 5634 cases of SIDS according to the WHO convention, there are an additional 397 cases where SIDS was mentioned on the death certificate but another diagnosis (cardiac arrest in 18%) was given priority. Including these extra cases would increase the NCHS 1989 SIDS incidence by 7% to 1.51/1000 live births.

There is wide state to state variability of SIDS incidence, infant mortality, and postneonatal mortality (death rate between 1 month and 1 year of age), some but not all of which is probably due to different criteria for the diagnosis of SIDS. The SIDS incidence ranges from a high of 3.43 in Montana to a low of 0.26 in Connecticut. While nationally, SIDS accounts for 35% of postneonatal mortality, it accounts for 60% in Montana and 11% in Connecticut, supporting the hypothesis that some of the variability in SIDS incidence between these two states may be due to more liberal use of the SIDS diagnosis in Montana and more restrictive diagnosis in Connecticut.

Availability of SIDS Services

SIDS Professional Programs and MCH Directors reported SIDS services were available in 46 states and the District of Columbia and in 86% of U.S. counties. There were no professional SIDS services in four states (Arizona, Kansas, Montana, Wyoming). Peer Program services were available to SIDS families in 30 states (29% of U.S. counties). Some level of service is reported in all states; however in Kansas, there are no professional services and less than 1% of the geographic area is serviced by a Peer Program.

Forty-six percent of Maternal and Child Health Directors (24/52) reported SIDS services were centrally administered through state MCH or CSHCN (Children With Special Health Care Needs) programs, 38.4% (20/52) reported SIDS services were administered primarily through grants and contracts to SIDS counseling programs and other organizations, and 17.3% (9/52) reported their states developed alternative mechanisms to assure a programmatic state focus for SIDS services.

Twenty-one percent (11/52) reported SIDS services were provided intramurally as well as through grants/contracts awarded to SIDS counseling and information programs and SIDS Alliance Affiliates.

Annual budgets for SIDS services varied widely for all surveyed groups - MCH Directors (zero dollars to \$786,264 for 1991 with 31/52 reporting); SIDS Professional Programs (zero dollars to \$786,264 for 1991 with 40/47 reporting) and Peer Programs (zero dollars to \$148,769 for 1991 with 41/51 reporting). For all groups, the Pearson r correlation coefficient reveals a significant relationship between program budgets and number of family referrals for counseling support. However, the amount of missing data limits the generalizability of this finding.

The majority of Medical Examiners and Coroners (82%) reported they referred families to local SIDS Programs following the autopsy and SIDS diagnosis - 42% referred within 24 hours of the death and 79% within 7 days of death. Less than 50% of MCH directors, SIDS Professional Programs and Peer Programs report that 90-100% of families they serve are notified of initial autopsy results within 3 days of death or of final autopsy results. The accuracy and timeliness of family notification of autopsy results and referral to support services is unclear from this data.

A range of services are provided to SIDS families under the auspices of MCH Directors, Professional and Peer Programs. These services include contact with family immediately after death, referral of family to health department or community health nurse, discussion of autopsy results with the family, one to one peer contact, parent support group meetings, family contact through the first year of bereavement, family contact after the first year of bereavement. There is wide variability in level of service provided among programs. Each group also identified local providers of services to SIDS families which included other infant bereavement groups, county health departments, medical examiners/coroners, infant apnea programs, university based programs, SIDS parent groups and SIDS professional programs. Of the total number of families referred, Professional and Peer SIDS programs report a range of 1-30% and 1-25% respectively are teen parents, while only 11% of Professional Programs and 12% of Peer Programs report a specialized bereavement program for teen parents. Seventy-two percent of Professional Programs report teen parents participate in their regular program services.

Data regarding racial distribution of referrals and utilization of services by race are incomplete. Race of referred family is often not identified to Professional Programs by the referral source, and adequate data collection systems may not exist. Professional Programs report a total number of 4056 referrals for counseling received in 1991. Racial distribution of families included 27% Black; 58% White; 3% Asian; 2% American Indian; and 10% Hispanic. This data distribution compares with SIDS incidence by race in 1989 as reported by NCHS: 27% Black; 56% White; 2% Asian;

2% American Indian; and 9% Hispanic. Service utilization by race was reported by Professional Programs in 1991. Services and percentage of families utilizing service when race was identified include: autopsy for 3103 infants, race known for 85%; autopsy discussed with 1728 families, race known for 59%; 2370 families contacted immediately after death, race known for 61%; 575 families contacted by a SIDS parent, race known for 69%; 2543 families attended parent support group, race known for 44%; 1777 families received home visits by a health professional, race known for 69%; contact maintained with 1728 families through first year of bereavement, race known for 56% of families. Peer Programs report 1539 families received telephone or face to face contact; race was known for 1100 families. Of the 1263 families who attended parent support group meetings, race was known for 898 families.

Utilization of services by race, as reported by Professional Programs, reflects a distribution similar to the racial distribution as reported by NCHS of all SIDS. For example, when race is known Professional Programs report that blacks account for 26% of SIDS deaths in 1989 and 34% of autopsies. Utilization patterns appear to be similar for white and black families with the exception of utilization of peer support. For white families peer contact has high rates of utilization as reported by professional programs and peer groups. Peer support for black families appears to have low utilization as reported by professional and peer programs. Low utilization of all services is evident in Asian and Hispanic families. Low utilization may be due to lack of availability of services or lack of cultural sensitivity or appropriateness in the provision of SIDS services.

There is wide variation in the number of educational programs offered by professional and peer programs. Sixty-eight percent of 47 professional programs reported they conducted SIDS educational programs with a range of 1-227 programs per year conducted per respondent. Of 51 peer programs surveyed, 37% reported they conducted 468 SIDS educational programs per year with a range of 0-92 programs conducted per year per respondent. An annual SIDS research update is offered to the community by 43% of Professional Programs and 63% of Peer Programs as part of their total services.

Data provided limited information regarding the training of SIDS service providers. Of the 52 Maternal Child Health Directors surveyed, 31 responded and reported that 72% of community health nurses were trained prior to making home visits to SIDS families and 16 reported that 56% of peers were trained prior to contact with the family. Of 21 Professional Program respondents, 66% reported that 80% of community health nurses were trained prior to making home visits and 18 reported that 63% of peer contacts were trained. Twenty-one Peer Program respondents reported that 82% of peer contacts were trained prior to family contact. Mandatory training for police, Emergency Medical Technicians (EMT's), community health nurses, hospital emergency departments and parents was reported by 25% or

less of each of the 3 respondent groups. Mandatory training is not required by any of the respondents for clergy, fire department, or day care workers. The majority of training for all SIDS service provider groups is optional. Training is reported as unavailable for any groups in the District of Columbia, the states of Mississippi and Wyoming, the territories of Puerto Rico and the Commonwealth of Mariana Islands. Limited training is provided in 18 states for community health nurses, ambulance personnel, SIDS parents and hospital emergency department staff, day care and child welfare workers. Training is offered for at least 50% of provider groups in 30 states.

Obstacles to Availability and Utilization of SIDS Services

Maternal Child Health Directors, Medical Examiners/Coroners, SIDS Professional Programs and Peer Programs identified obstacles to availability and utilization of SIDS services. For Maternal Child Health Directors, the major obstacles to availability of services included lack of state funding to provide long term follow up during the first year of bereavement and to train public health nurses and other professionals. Lack of available services was also linked to a low number of SIDS deaths, lack of mandatory autopsy, lack of established referral mechanisms and reporting requirements, ineffective collaboration between medical examiners and other public health officials; lack of legislation to mandate funding for SIDS programs, and lack of formal peer support programs. Obstacles to utilization of SIDS services were identified as lack of services in rural areas, transportation barriers, lack of communication between agencies and continuity of professional follow-up; lack of culturally appropriate services, ethnic bias against seeking and accepting support services and parents' mobility after the death. The lengthy time interval between the infant's death and initial counselor contact contributed to less receptiveness of the family to service.

Medical examiners identified several obstacles to the availability of SIDS services including lack of adequate funding to provide for autopsies and staffing; lack of funding for public health nurse follow up; lack of organized service delivery systems, low numbers of SIDS deaths, and lack of services in rural areas. For Medical Examiners, obstacles to utilization of SIDS services included lack of family access to services in distant areas, and lack of awareness on the part of the medical examiner of the referral system. Confidentiality laws, difficulty in establishing the SIDS diagnosis, time interval between the infant's death and final autopsy report, and the family's choice to refuse services also contribute to non-utilization.

Peer programs identified the following obstacles to availability of SIDS services: lack of adequate numbers of volunteers and their long term involvement, lack of referral mechanisms, confidentiality laws, lack of mandatory autopsy laws and universal autopsy protocols, lack of use of SIDS as a medical diagnosis, lack of legislation mandating SIDS services and lack of a public health nursing network. Obstacles to utilization of services include lack of available services, funding,

volunteers, transportation, child care, telephones, and financial resources. Other obstacles include lack of bilingual peer contacts, race, class and social class differences among families, and parents choice to refuse services.

SIDS Professional Programs identified obstacles to availability of SIDS services as lack of funding for services, education and training; lack of referral and reporting systems and SIDS program management, and vast geographic areas where limited services are available. Additional obstacles included lack of mandatory autopsy and uniform autopsy protocols, and lack of available public health nurses. Several respondents reported that the provision of SIDS services is not a funding priority for MCH and public health departments. Obstacles to utilization of SIDS services listed by Professional Program respondents included lack of mandatory autopsy, lack of organized systems of death notification and SIDS case management, geographical distance from available services, and lack of transportation and telephones. Lack of communication between SIDS service providers and inadequate referral to appropriate SIDS agencies made it difficult to provide services. Cultural and religious beliefs and practices were identified as barriers to acceptance of services. Lack of culturally appropriate services for minority families and lack of specialized services for teens and single parents were also listed.

Recommendations for National Action

Consideration of the results of this comprehensive nationwide survey has led to the following recommendations for national action:

- A. The Maternal and Child Health Bureau, in conjunction with the National Institute of Child Health and Human Development, National Center for Health Statistics, National Association of Medical Examiners, Association of SIDS Program Professionals, Association of MCH Directors and other organizations concerned with services to bereaved families, should collaborate to achieve the following goals:
 1. Standardize procedures and criteria for SIDS diagnosis
 2. Educate Medical Examiners and Coroners regarding SIDS diagnosis and referral to local resources

- B. Reporting and monitoring efforts at the federal, state and local levels should be standardized and increased for infant and child mortality, including SIDS. The number of cases, availability of services and utilization by families, and demographic characteristics should be included. State wide coordination and case management is indicated.

- C. With major reform of the health care system imminent, preservation of the infrastructure for case referral and management and SIDS data collection must be maintained. With Federal support, states are encouraged to develop model programs which encompass:
 - 1. Service provision to all families whose infant/child is within the Medical Examiner/Coroner system
 - 2. Case management
 - 3. Data collection

- D. In order to improve the quality and utilization of bereavement support resources, MCHB should:
 - 1. Support regional training programs for health professionals in case management of families experiencing an infant/child death. Regional 'train the trainer' programs may be the most cost effective strategy to achieve this recommendation.
 - 2. Develop and evaluate new models of service/support for underserved families (inner city, minority, and rural populations, teens) who have lost an infant/child (e.g. demonstration projects).

- E. SIDS support services should be closely linked with broader bereavement support programs.

- F. Future NCHS national surveys on maternal and infant health should include parental evaluations of the quality of support services rendered.

Goal Specific Recommendations

Goal 1. SIDS Diagnosis

Recommendations:

- A. National standardization of:
 - 1. Autopsy protocol for infants
 - 2. Age for SIDS diagnosis up to 2 years
 - 3. Reporting of SIDS deaths by residence, not location at time of death
 - 4. Requirement for review of medical history of infants as part of death investigation
 - 5. Requirement that death scene investigation be performed only by specified trained investigators

- B. Death scene investigation is very important, but the diagnosis of SIDS should not be withheld only because a death scene investigation was not performed.
- C. Reconsideration of the SIDS definition, distinguishing between the less rigorous criteria for a clinical diagnosis of SIDS and the more rigorous criteria to be met for a research definition of SIDS. The widely accepted 1969 SIDS definition may be the best for clinical purposes.
- D. Dissemination of information, i.e. SIDS definition and autopsy protocols, to Medical Examiner/Coroner systems, possibly through this report via their professional organization.
- E. NCHS should report "total SIDS", in addition to continuing to report the number of SIDS counted using the WHO procedure for purposes of international comparison.

Goal 2. Case Referral and Management

Recommendations:

- A. Institute case management for bereaved families whose children have died of any cause, including SIDS.
- B. Inform Medical Examiners/Coroners of availability and efficacy of services to promote appropriate referral to meet the needs of bereaved families.
- C. Optimize referral to SIDS service providers through the cooperation of medical examiners, professional programs and volunteer or peer support programs.

Goal 3. Availability and Utilization of SIDS information and Counseling Services

Recommendations:

- A. Expand services to encompass all infant/child deaths that are within the medical examiner/coroner system.
- B. Increase efforts to adapt bereavement support services and delivery modes to meet the needs of underserved families, e.g. inner city, minority, and rural populations, teens.

- C. Educate health care providers in provision of culturally appropriate services.

Goal 4. Educational Programs

- A. Mandatory training for police, pediatricians and family physicians, Emergency Medical Technicians, community health nurses, emergency room personnel and investigative personnel is recommended. We further recommend that this training not be limited to SIDS but encompasses all infant/child death that is within the medical examiner/coroner system.
- B. Education for child care providers, clergy, funeral directors, and child welfare workers is encouraged.
- C. Curricula content for all groups should include SIDS and the needs of bereaved families.
- D. Training of health care providers in the case management of bereaved families and how their needs can be most appropriately met in their community, specifically with regard to SIDS cases. Training can be accomplished via undergraduate and graduate curricula as well as via continuing education programs.

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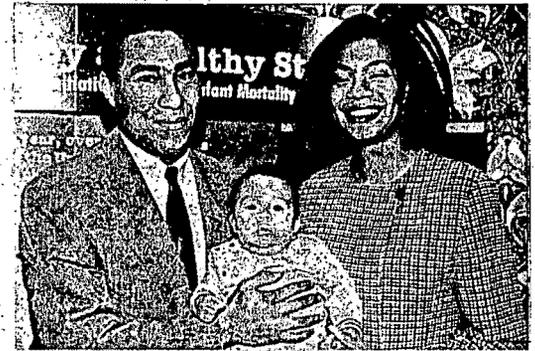
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Deputy HHS Secretary Praises Healthy Start

In a heartfelt and allegorical keynote address at the 1994 Healthy Start Grantee Meeting, Dr. Walter Broadnax, Deputy Secretary of the Department of Health and Human Services, commended Healthy Start projects for exhibiting three leadership qualities that will help them embrace the challenge of sustainability: establishing respect among project area residents, speaking the languages of the community, and identifying successful ways to overcome social and economic barriers.

Dr. Broadnax cited specific local partnerships with colleges, corporations, and churches that have been set up by Healthy Start sites around the country, and he compared Healthy Start to such milestones in children's health as the distribution of the polio vaccine in the early fifties and the establishment of the Children's Bureau in 1912. The Clinton administration recognizes, Dr. Broadnax said, even in the face of challenge, that "children and families must take their rightful places at the top of our domestic policy agenda." "It is a tragedy," he said, "that so many of our infant deaths — and so many of our children born unhealthy — could have been prevented by something as simple and effective as prenatal care." Healthy Start interventions to improve health care, medical services, on-site eligibility for Medicaid and WIC, transportation, and child care have helped many pregnant women overcome the obstacles that prevent them from receiving prenatal care.

Healthy Start does not wait for families to come in for service, Dr. Broadnax declared; in the 22 communities, program staff are out on the streets every day recruiting families, making home visits, and getting women into prenatal care and infants into pediatric care. He concluded by urging Healthy Start projects to continue the work that they have begun by tapping resources in both public and private sectors to sustain the momentum.



Richard Greenhouse

The Director's Corner

Establish state and local linkages — that was the message that went out to grantees at the 1994 Healthy Start Grantee Meeting. From November 16 to 19, over 400 participants including grantees, their consumers, and representatives from Federal, state and local governments heard presentations on topics such as networking techniques, survival linkages, and community-based systems of care. The busy agenda followed the conference theme of "Resource Development and Sustainability: Where Do We Go From Here?" and included discussions and workshops on Medicaid and managed care, collaboration and consortia development, strategic planning, leveraging public and private resources, and economic development. Infant mortality reviewers met to share concerns and successes, as did consumers and media specialists. In addition, representatives from the seven new Healthy Start Initiative-Special Projects were formally introduced to the Healthy Start network.

We are grateful to the meeting's planning committee and the Division of Healthy Start's Program Development and Coordination Branch for the scope of the meeting and the quality of its speakers. We are now convening the grantee advisory committee for the 1995 conference; any grantees interested in volunteering should contact Evelyn Barnes at (301) 443-8427.

Thurma McCann, M.D., M.P.H.
Director, Division of Healthy Start