

# SIDS & Infant Death Program Manual and Trainer's Guide



# SIDS/ID Program Manual



Health Resources and Services Administration  
Maternal and Child Health Bureau, SIDS/ID Program



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## Glossary of Acronyms

<b>AAP</b>	American Academy of Pediatrics
<b>ACOG</b>	American College of Obstetricians and Gynecologists
<b>ALTE</b>	Apparent Life-Threatening Event
<b>AMCHP</b>	Association of Maternal and Child Health Programs
<b>ART</b>	Assisted Reproductive Technology
<b>ASIP</b>	Association of SIDS and Infant Mortality Programs
<b>ASTHO</b>	Association of State and Territorial Health Officials
<b>BTS</b>	Back to Sleep Campaign
<b>CDC</b>	Centers for Disease Control and Prevention
<b>CDR/CFR</b>	Child Death Review/Child Fatality Review
<b>CDF</b>	Children's Defense Fund
<b>CE</b>	Continuing Education
<b>CHCS</b>	Center for Health Care Strategies
<b>CHIP</b>	Children's Health Insurance Program
<b>CPR</b>	Cardiopulmonary Resuscitation
<b>CPSC</b>	Consumer Product Safety Commission
<b>CSAP</b>	Center for Substance Abuse Prevention
<b>DHHS/HHS</b>	Department of Health and Human Services
<b>DTaP</b>	Diphtheria, Tetanus and Pertussis vaccine
<b>EMT</b>	Emergency Medical Technician
<b>ETS</b>	Environmental Tobacco Smoke
<b>FAS</b>	Fetal Alcohol Syndrome
<b>FD</b>	Fetal Death
<b>FDA</b>	Food and Drug Administration
<b>FIMR</b>	Fetal Infant Mortality Review
<b>HRSA</b>	Health Resources and Services Administration
<b>ICD-10</b>	International Statistical Classification of Disease Code, 10th Revision
<b>ICD-9</b>	International Statistical Classification of Disease Code, 9th Revision

## **Glossary of Acronyms**

<b>IHS</b>	Indian Health Service
<b>IMR</b>	Infant Mortality Rate
<b>IOM</b>	Institute of Medicine
<b>ISA</b>	International Stillbirth Alliance
<b>LBW</b>	Low Birth Weight
<b>MCH</b>	Maternal and Child Health
<b>MCHB</b>	Maternal and Child Health Bureau
<b>ME</b>	Medical Examiner
<b>ME/C</b>	Medical Examiner/Coroner
<b>MOD</b>	March of Dimes
<b>NACCHO</b>	National Association of County and City Health Officials
<b>NAPHSIS</b>	National Association for Public Health Statistics and Information Systems
<b>NCCC</b>	National Center for Cultural Competence
<b>NCEMCH</b>	National Center for Education in Maternal and Child Health
<b>NCHS</b>	National Center for Health Statistics
<b>NIAAA</b>	National Institute on Alcohol Abuse and Alcoholism
<b>NICHD</b>	National Institute of Child Health and Human Development
<b>NICU</b>	Neonatal Intensive Care Unit
<b>NIDA</b>	National Institute of Drug Abuse
<b>NIH</b>	National Institutes of Health
<b>NMR</b>	Neonatal Mortality Rate
<b>NOFAS</b>	National Organization on Fetal Alcohol Syndrome
<b>NSIDPSC</b>	National SIDS and Infant Death Program Support Center
<b>NSIDRC</b>	National SIDS and Infant Death Resource Center
<b>OID/ID</b>	Other Infant Death/Infant Death
<b>OMH</b>	Office of Minority Health
<b>PHN</b>	Public Health Nurse
<b>PNMR</b>	Post-Neonatal Mortality Rate

## **Glossary of Acronyms**

<b>PRAMS</b>	Pregnancy Risk Assessment Monitoring System
<b>Project IMPACT</b>	Project Infant Mortality Policy and Communication Tools
<b>PSA</b>	Public Service Announcement
<b>PTSD</b>	Post-Traumatic Stress Disorder
<b>RDS</b>	Respiratory Distress Syndrome
<b>SIDS</b>	Sudden Infant Death Syndrome
<b>SIDS/ID</b>	Sudden Infant Death Syndrome/Infant Death
<b>SUDC</b>	Sudden Unexplained Death in Childhood
<b>SUI/CD</b>	Sudden Unexplained Infant/Child Death
<b>SUID/SUDI</b>	Sudden Unexplained Infant Death/Sudden Unexplained Death of an Infant
<b>SUIDIRF</b>	Sudden Unexplained Infant Death Investigation Report Form
<b>USPHS</b>	United States Public Health Service
<b>VLBW</b>	Very Low Birth Weight
<b>WHO</b>	World Health Organization
<b>WIC</b>	Special Supplemental Nutrition Program for Women, Infants and Children

# Introduction

**T**he death of a child is considered the most stressful and enduring loss for parents.<sup>1</sup> Research indicates that compared to the loss of a parent or spouse, the loss of a child is more intense.<sup>2</sup> One reason is that for many parents, the parent-child bond is integral to the parents' identity.

Currently, the deaths of children account for less than 5 percent of all deaths in the United States. Maternal and Child Health (MCH) program services have vastly improved life expectancy across the population, especially with immunization programs and improved sanitation and nutrition. While such deaths have become less common, for those parents, families, communities and health professionals who experience these deaths, it is devastating, and the impact is far-reaching.

The purpose of this manual and accompanying training guide is to support the staff of local and State programs to provide comprehensive Sudden Infant Death Syndrome and Infant Death (SIDS/ID) risk reduction and bereavement program services so that children have the best possible chance for survival and if a child does die, his family is appropriately supported.

This document was developed by the United States Department of Health and Human Services, Health Resources and Services Administration, Maternal and Child Health Bureau, under a contract with First Candle/SIDS Alliance, contract no. 02-0224P. You may copy or adapt the document as long as you properly credit the source.

This manual is designed for program staff who include [Title V program](#) staff, child-health staff, nurses, health educators, Child Death Review (CDR) teams, Fetal Infant Mortality Review (FIMR) teams, [Healthy Start](#) staff and nonprofit staff. Because this manual covers a great range of SIDS/ID program information, not all sections will be applicable for all programs. Fundraising, lobbying and media activities may be limited by nonprofit status or an oversight organization.

The manual also includes a trainer's guide, specifically adapted from the [National Cancer Institute](#), which focuses on how to conduct trainings, presentations and informational sessions to a variety of audiences. The trainer's guide includes eight PowerPoint shows for specific audiences and checklists to assist in the planning and logistics of conducting trainings.

The manual is divided into clearly-defined sections that deal with specific SIDS/ID program topics. Both the manual and trainer's guide include active hyperlinks to Web sites and Internet documents that can be accessed for greater detail. Internal hyperlinks

are also included to endnotes and glossary entries. References for useful resources and inexpensive educational materials are also included.

SIDS/ID programs should fulfill a number of public health functions. For the purposes of this manual, we have specifically adapted the *Public MCH Program Functions Framework: Essential Public Health Services To Promote Maternal and Child Health in America* to address sudden and unexplained infant death bereavement and risk reduction program services.<sup>3</sup>

- **Chapter 1: What is SIDS?**
- **Chapter 2: Risk Reduction Education.** Critical Program Function: To inform and educate the public and families about risk factors for SIDS and infant death in order to protect themselves and others.
- **Chapter 3: Bereavement Support Services.** Critical Program Function: To link parents, families and caregivers to support services and ensure access to quality bereavement care.
- **Chapter 4: Training.** Critical Program Function: To help ensure the capacity and competency of the personnel involved in SIDS risk reduction and bereavement services.
- **Chapter 5: Program Expansion.** To inform and educate the public and families about risk factors for perinatal and child death in order to protect themselves and others and to link parents, families and caregivers to support services and ensure access to quality bereavement care.
- **Chapter 6: Research and Statistics.** Critical Program Function: To provide State and local agencies with data on SIDS, sudden infant death and other conditions in order to investigate hazards, conduct needs assessments, determine risk factors and behaviors of parents, families and other caretakers and implement and monitor tracking systems for services and outcome indicators.
- **Chapter 7: Partnerships and Collaborations.** Critical Program Function: To mobilize community partnerships between policy-makers, health care providers, families, the public and others to address SIDS, infant death and perinatal death and improve support to families experiencing such losses. Partnerships can address data collection, advocacy, linkage, provider education, standard setting, policy development or system enhancement.
- **Chapter 8: Public Relations and the Media.** Critical Program Function: To disseminate qualitative public health information on risk reduction, new research initiatives and bereavement resources in a variety of media venues.
- **Chapter 9: Fundraising and Development.** Critical Program Function: To identify alternative and additional resources to expand the capacity of the health and social services systems to improve bereavement support services and risk reduction efforts.

## About this Manual

Consideration and care were employed to ensure that this manual is not simply a duplication of existing work. A comprehensive literature and information search for program manuals, training guides and relevant materials was conducted to generate ideas on the substance and format of the *SIDS/ID Program Manual and Training Guide*.

The National SIDS and Infant Death Program Support Center ([NSIDPSC](#)) worked with the National SIDS and Infant Death Resource Center ([NSIDRC](#)), the National Center for

Cultural Competence (NCCC), National Institute of Child Health and Human Development (NICHD), Project Infant Mortality Policy and Communication Tools (Project IMPACT) and several other programs and organizations to identify the materials and content contained in this guide. As much as possible, materials are referenced in the appropriate sections.

The content of this manual and training guide was guided by three key documents:

- Healthy People 2010 Initiative
- *The Public MCH Program Functions Framework: Essential Public Health Services To Promote Maternal and Child Health in America*
- *Trainer's Guide for Cancer Education*

The objectives for the [Healthy People 2010](#) initiative were developed through the collaborative efforts of the U.S. Public Health Service, health professionals and interested citizens.

The *Public MCH Program Functions Framework: Essential Public Health Services To Promote Maternal and Child Health in America*, prepared by Holly Ann Grason and Bernard Guyer, Johns Hopkins University Child and Adolescent Policy Center, for [HRSA](#), [MCHB](#), [AMCHP](#), [ASTHO](#), [CityMatCH](#) and [NACCHO](#) is a tool to assist State, local and Federal maternal and child health programs to better serve the health needs of women and children. The framework outlines the core public health functions related to maternal and child health. These functions have been specifically adapted to address sudden and unexplained infant death bereavement and risk reduction program services.

The [National Cancer Institute's Trainer's Guide for Cancer Education](#) (NIH Publication No. 02-5052, 2001) was adapted to provide trainers with the necessary skills, knowledge and materials to conduct effective trainings for multiple audiences on reducing the risk of sudden and unexplained infant death and how to cope with sudden and unexplained infant death.

The development of this manual has been guided by numerous talented and dedicated individuals who provided constructive and critical feedback at different phases of this project. Their guidance has been invaluable in producing this manual. It was also guided by a formal expert panel who committed their time and expertise:

- **Lori Ahrens**, Acting Director, [SIDS Resources, Inc.](#)
- **Deborah Boyd**, Executive Director, [First Candle/SIDS Alliance](#)
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- **Velma Harris Walker**, Program Coordinator for Family Services, [SIDS Resources, Inc.](#)

- **Laura Hillman**, MD, Neonatologist, [University of Missouri Hospital](#), Medical Director, [NSIDPSC](#)
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- **Mary McClain**, MA, Program Coordinator, [Center for SIDS, Boston Medical Center](#)
- **Susan Potts**, SIDS Coordinator, [Florida Department of Health](#)
- **Paul Rusinko**, Director, [MCHB SIDS and Infant Death Program](#)

First Candle respectfully acknowledges the leadership and vision of Paul Rusinko in the development and publication of this manual and training guide. The enormity and importance of this work has been clearly understood by Paul from the start. His guidance and perseverance throughout this process deserves public acknowledgement and our sincere expression of appreciation.

# What is SIDS?

The term Sudden Infant Death Syndrome (SIDS) was first introduced in 1969<sup>1</sup> and was further refined to a SIDS definition in 1991.<sup>2</sup> SIDS has historically been defined as the sudden and unexplained death of an apparently healthy infant up to one year of age that remains unexplained after a thorough case investigation.

SIDS is now defined as the sudden and unexplained death of an apparently healthy infant younger than one year of age that remains unexplained after a thorough case investigation including the performance of a complete autopsy, examination of the death scene and review of the clinical history. It is the leading cause of death for infants during the [postneonatal](#) period.

## History of Federal Initiatives

During the 1960s, a number of parents who experienced the sudden and unexpected deaths of their infants began to come together to find answers for why their babies died. Parents formed organizations and networks to advocate for research and bereavement services for families. Parents also organized to increase the public's awareness of these deaths. During the 1970s, a number of smaller parent organizations merged into larger national organizations—such as the National SIDS Foundation and the Center for the Prevention of Sudden Infant Death Syndrome which formed the [SIDS Alliance](#) (now First Candle/SIDS Alliance)—that continued to advocate for national legislation for bereavement support, training and education and public awareness.

With the passage of the Sudden Infant Death Syndrome Act ([Public Law 93-270](#)) of 1974, the Federal commitment to the prevention of SIDS was significantly broadened. The act:

- Assigned responsibility for conducting SIDS research to the National Institute of Child Health and Human Development ([NICHD](#)). NICHD was to report annually to Congress on SIDS research and its budget.
- Authorized the Secretary of Health, Education and Welfare [HEW, now the Department of Health and Human Services ([HHS](#))] to develop a program of public information and educational materials about SIDS.
- Authorized the Secretary of HEW to gather and provide information on the causes of SIDS and provide grants and contracts to programs to offer information and counseling to families.
- Authorized appropriation of funds to carry out these activities for fiscal years 1975 to 1977. The program continued to be authorized in one-year increments until 1978

and the passage of [Public Law 95-613](#), which extended authorization through fiscal year 1981.

State-level programs and services dramatically changed in 1981 when Congress passed the [Maternal and Child Health \(MCH\) Services Block Grant Act](#), which established a Federal-State partnership for services at the State and local levels and substantially changed the organization of program services.

SIDS became one of the eligible services to be provided under the MCH Block Grant along with other programs and services with the purpose of improving the health of mothers and children consistent with the applicable health status goals and national health objectives established under the Public Health Service Act for the Year 2000.

At this time, 59 territories, jurisdictions and States receive funds under the MCH Block Grant. State and local SIDS/ID programs usually receive funding through the block grants. There is no single program model for the State's provision of risk reduction and bereavement support services for families experiencing fetal or infant losses. Depending on the organizational model for a particular State or local area, program services vary.

## Definition

While most conditions or diseases are diagnosed by the presence of specific symptoms, SIDS is a diagnosis of exclusion. A SIDS diagnosis is assigned only after all other causes of death have been ruled out through:

1. An autopsy
2. An examination of the death scene
3. A complete review of the infant's medical history

Often, the cause of an infant's death can only be determined through the process of collecting information, conducting forensic tests and procedures and interviewing parents and physicians.

**Autopsy.** An autopsy provides anatomical evidence through microscopic examination of tissue samples and vital organs. An autopsy is important to the diagnostic process because SIDS is a diagnosis of exclusion. A definitive diagnosis cannot be made without a thorough postmortem examination that fails to point to any other cause of death.

**Death Scene Investigation.** A thorough death scene investigation involves interviewing parents, other caregivers and family members, visiting the death scene and possibly conducting reenactments and collecting items. Although potentially painful for a family, a detailed scene investigation may shed light on the cause of death, sometimes revealing a recognizable and possibly-preventable cause.

**Review of the Infant's Family Case History.** Often, a comprehensive review of the medical history of the infant and the infant's family is critical to determining a SIDS death. A careful review of documented and anecdotal information about the victim's or family's history of previous illnesses, accidents or behaviors may further corroborate information from an autopsy and a death scene investigation.

These procedures help distinguish SIDS deaths from those resulting from accidents, abuse or previously undiagnosed conditions such as cardiac or metabolic disorders.

## Research

While the cause or causes of SIDS is unknown, there is evidence that some SIDS infants are born with physiological abnormalities that make them more vulnerable to SIDS.<sup>3</sup> Studies of SIDS victims have revealed that many of these infants have abnormalities in the part of the brain involved in the control of breathing and waking during sleep.<sup>4</sup> Infants born with defects in other parts of the brain or body may also be more prone to a sudden death. Some researchers speculate that these abnormalities may stem from prenatal exposure to a toxic substance or the lack of a vital compound in the prenatal environment such as sufficient oxygen.<sup>5</sup>

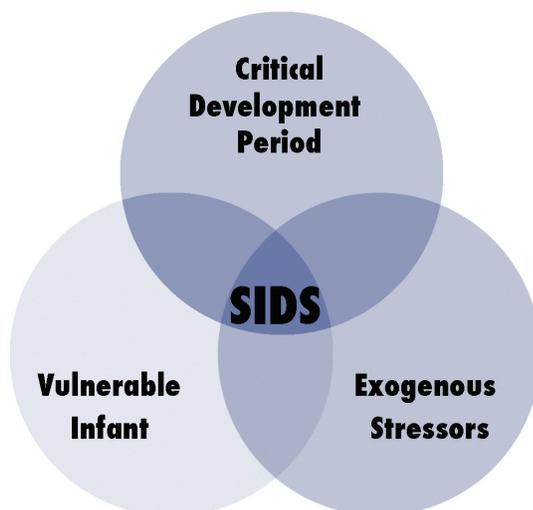
It has been more than 30 years since Congress passed the landmark legislation that gave the **NICHD** responsibility for SIDS research. Since that time, the focus of research has been in five areas:<sup>6</sup>

1. The brain and its control over breathing and body temperature
2. Infant development, especially in the areas in which development affects infants' natural protective reactions to their environment, such as turning their head and waking response
3. Infant care and sleep environment
4. Infection and the body's ability to avoid and recover from infection
5. Genetics

Early research efforts were based on single-cause theories for SIDS.<sup>7</sup> Today, as a result of that time and those efforts, many researchers believe that there is no one cause of SIDS. Instead, researchers take a multifaceted approach that addresses not only the possibility of a number of different causes but a variety of physiological and environmental interactions as well. The leading theory is the Triple Risk Model theory.<sup>8</sup>

## Triple Risk Model

According to the Triple Risk Model,<sup>9,10,11,12</sup> SIDS can occur when three elements come together: an infant's critical development period, a vulnerable infant and exogenous stressors.



The **critical development period** encompasses the rapid growth phases that occur during an infant's first 6 months of life, considered to be a time of vast physiological change and instability for an infant's system. During this developmental period, changes occur in homeostatic controls such as sleeping and waking, breathing, heart rate, blood pressure and temperature.

The **vulnerable infant** represents an infant with an underlying defect or abnormality. In this model, normal infants do not die of SIDS. Instead, there are pathophysiological reasons behind these

seemingly sudden deaths such as defects of the brain that control respiration, heart rate or cardiac function.

Finally, **exogenous stressors** are external or environmental challenges that a normal infant can overcome and survive but an already-vulnerable infant might not. These stressors include the risk factors such as prone sleep position, loose and soft bedding, secondhand tobacco smoke exposure or an upper respiratory infection.

Alone, these stressors do not cause an infant's death, but may reduce an infant's chances of survival. According to this model, all three elements must come together for SIDS to result.<sup>13</sup>

Past research has provided convincing evidence that supports the Triple Risk Model. The research has specifically shown that:<sup>14</sup>

- The underlying weakness is most likely in a part of the nervous system that regulates homeostatic control.
- The critical period likely relates to the development of the nervous system and its interactions with other physical systems such as immunologic, cardiovascular and respiratory systems.
- Exogenous risk factors most likely interact with those parts of the nervous system that protect infants from life-threatening events.

When considering which infants could be at risk for SIDS, medical researchers have concluded that no single risk factor is likely to be sufficient to cause a SIDS death. Rather, several risk factors combined may contribute to an infant's SIDS death.

Because of the complexity of SIDS, eliminating the syndrome requires a multidisciplinary approach involving pediatricians, epidemiologists, pathologists, neuroscientists, geneticists, infectious disease experts, nurses and investigators in the behavioral and social sciences, as well as other disciplines.<sup>15</sup>

At present, we do not know which infants are vulnerable or exactly when an infant is going through a period of critical development. Because of the uncertainty, we must apply risk reduction measures to all infants during their first year of life.

## Epidemiology

### National Statistics

The [Centers for Disease Control and Prevention's National Vital Statistics System](#) annually releases national [data on infant mortality](#), which includes information on the number of SIDS deaths and rates. NICHD also conducts a household survey that examines a number of different infant care practices such as sleep position, breastfeeding and child care. [Chapter 6: Research & Statistics](#) provides a detailed discussion on using statistics to support risk reduction efforts and evaluation of program efforts.

The [infant mortality rate](#) in 2002 increased to a rate of 7.0 infant deaths per 1,000 live births, compared with a rate of 6.8 in 2001.<sup>16</sup> Preliminary data for 2003 indicates an infant mortality rate of 6.9 infant deaths per 1,000 live births, which is not statistically different from the rate in 2002. Aside from the increase in 2002, which was concentrated among neonates, the U.S. infant mortality rate has decreased or remained level since 1958.<sup>17</sup>

According to preliminary data from the CDC, there were 28,422 infant deaths in the United States in 2003. Of those deaths, 1,994 were due to SIDS—a 14.7 percent decrease from 2002. The CDC points out that the magnitude of this decrease may be the result of error due to delayed reporting in the preliminary file. For 2002, the preliminary weighted count of SIDS deaths was only 89 percent of the final count.

Recent declines may also reflect a change in the way SIDS is diagnosed by the medical community. Further discussion on diagnostic shift can be found at the end of this chapter. Deaths due to SIDS have been declining since 1988 as can be observed in Table 1.1.

**Table 1.1 : SIDS Deaths and SIDS Rates per 1,000 Live Births, 1983 to 2003<sup>18</sup>**

Year	Total	Rate per 1,000 Births	
1983	5,305	1.46	
1984	5,245	1.43	
1985	5,315	1.41	
1986	5,278	1.41	
1987	5,230	1.37	
1988	5,476	1.40	
1989	5,634	1.39	
1990	5,417	1.30	
1991	5,349	1.30	
1992	4,890	1.20	
1993	4,669	1.17	
1994	4,073	1.03	
1995	3,397	0.87	
1996	3,050	0.78	
1997	2,991	0.77	
1998	2,822	0.71	
1999	2,648	0.66	<i>ICD-10 in use from 1999</i>
2000	2,523	0.62	
2001	2,234	0.55	
2002	2,295	0.57	
2003	2,162	0.52	
2004 *	2,109	0.51	

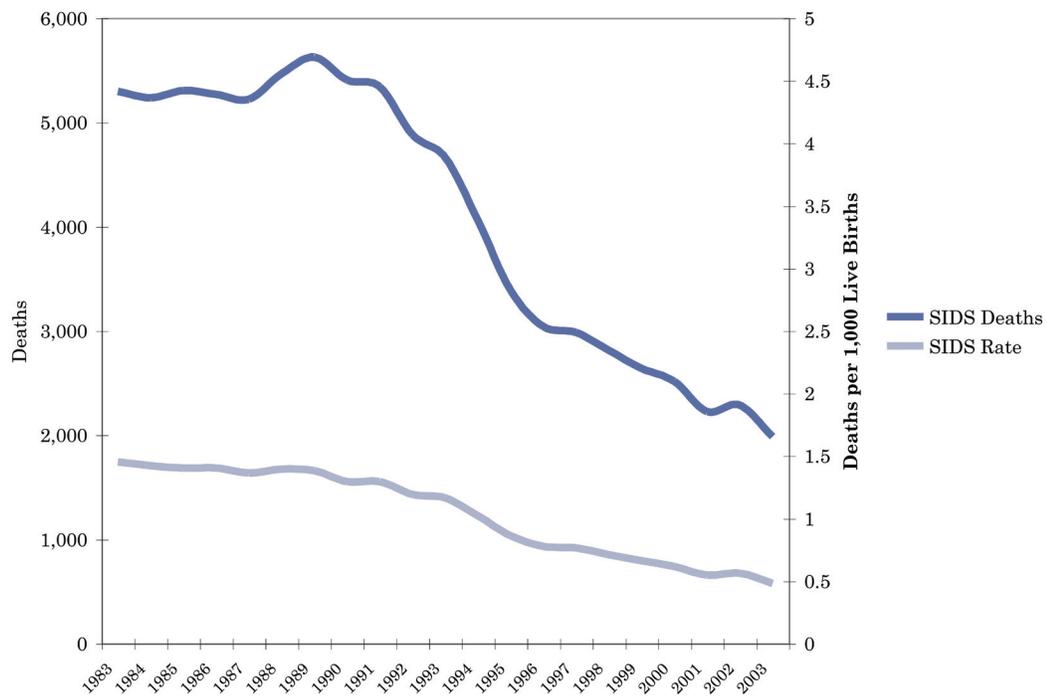
\* Data is preliminary and subject to change.

To further demonstrate the significance of the [Back to Sleep \(BTS\) campaign](#) and SIDS risk reduction efforts, Chart 1.1 is a graphical representation of SIDS rates from 1983 to 2003. The most significant declines can be observed from 1994 to 1998, which coincides with launch of the BTS campaign. For more information on the BTS campaign, see [Prone](#)

Sleep Position and the Back to Sleep Campaign on page 11.

In discussing national statistics, it is important to note that International Statistical Classification of Diseases (ICD) codes changed in 1998 from the 9th classification to the 10th classification. The ICD-10 is used to code and classify mortality data from death certificates.

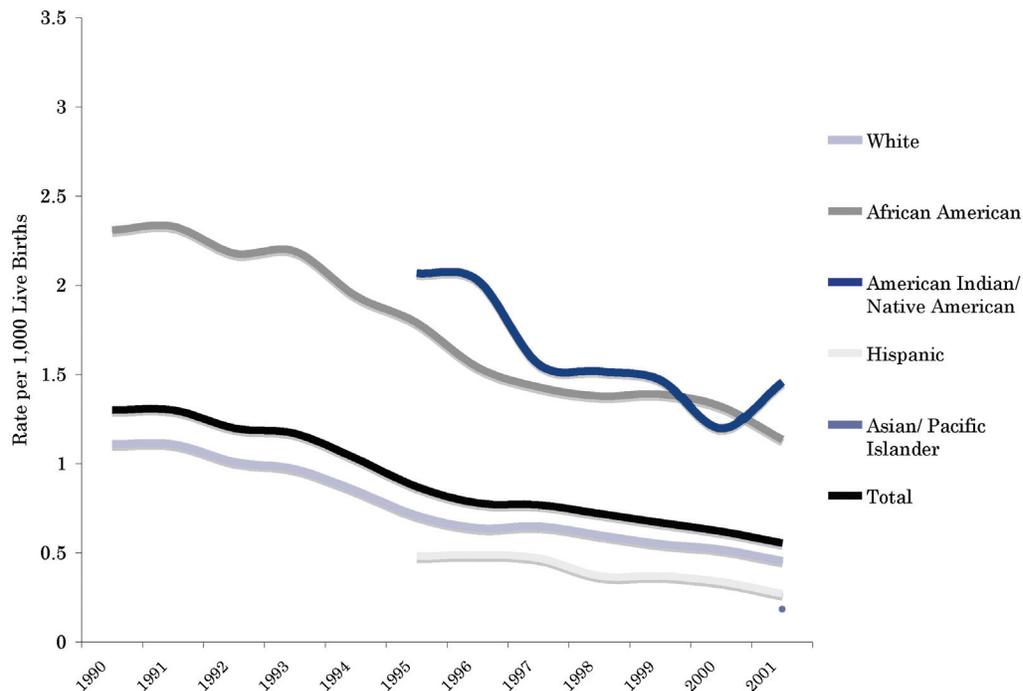
**Chart 1.1 : U.S. SIDS Rates, 1983-2003**



## SIDS Racial Disparities

Chart 1.2 displays SIDS rates for different ethnic and racial groups. In the science of epidemiology, it is important to understand how different groups compare. The decline in SIDS rates has not been equal for all racial and ethnic groups in the United States. African Americans have a SIDS rate more than twice the rate of Whites, and Native Americans have an almost three times greater rate. Factors that contribute to this disparity may include the higher incidence of prenatal/infant health problems, insufficient access to up-to-date prenatal/infant health information and certain behavioral factors such as bedsharing.<sup>19,20</sup>

However, it is important to remember that research and studies conducted are on specific populations within these groups. It would be ineffective to generalize any groups according to this information. Income, education and geography also are important contributors to any measure of health status.

**Chart 1.2 : U.S. SIDS Rates by Race, 1990-2001**

## African Americans

African Americans have a long, complicated and diverse history in the United States. They account for approximately 13 to 14 percent of the population in the United States currently. Approximately 80 percent of the African American population resides in urban settings and more than 50 percent of all African Americans live in 13 States.

Differences in health are varied but include higher disease and illness rates, higher rates of chronic conditions and a shorter life expectancy. It is important to note that African American women also have lower rates of high-risk behaviors such as smoking, alcohol use and other drug use. Poverty and racism are generally believed to have a profound impact on African American women's health.

**SIDS/ID Rates.** While infant mortality declined by 10 percent overall during the last ten years, the infant mortality rate among African Americans remains more than twice that of Whites. This substantial gap has not diminished since 1990.<sup>21</sup> In addition, African Americans have a SIDS rate of 1.4 deaths per 1,000 live births.

**Prevalence of Risk Factors.** Researchers have been able to pinpoint a number of important risk factors specific to African Americans that may contribute to a higher risk for SIDS and other infant deaths.<sup>22</sup> Nearly ten years after the American Academy of Pediatrics (AAP) recommended that infants be placed to sleep on their backs to reduce their risk of SIDS, African Americans remain twice as likely to place infants on their stomachs to sleep as other racial/ethnic groups.<sup>23</sup>

Research also shows that while only 12 percent of infants with White mothers sleep in an adult bed, 41.8 percent of infants with African American mothers sleep in adult beds.<sup>24</sup>

African American infants are also at higher risk for accidental suffocation compared to infants in the non-African American population.<sup>25</sup>

Although published research on bedsharing and co-sleeping patterns in African American households remains scarce, there is some evidence to suggest that the practice may be common.

There is research that has been conducted on a number of urban populations in the United States that indicates that African American mothers are more likely to bedshare. Studies in Chicago<sup>26</sup> and St. Louis<sup>27</sup> found that bedsharing was most common among low-income, predominantly African American mothers and that as many as half of them routinely practiced bedsharing, compared to a national average of 12.8 percent. In Washington, D.C., a recent study found that mothers who are single, move frequently and have less than 12 years of education were more likely to bedshare.<sup>28</sup>

## Native Americans

In the 2000 census reports, 2.5 million Americans identified themselves as Native American/Alaska Native, and 4 million identified themselves as part Native American/Alaska Native.

The [Bureau of Indian Affairs](#) currently provides Federal services to approximately 1.5 million Native Americans and Alaska Natives who are members of more than 562 Federally-recognized tribes and Alaska villages in 32 contiguous States and in Alaska. The bureau administers 45.6 million acres of tribally-owned land, 10 million acres of individually-owned land and 309,189 acres of Federally-owned land, which is held in trust status.

Approximately 50 percent of these tribes are located in Alaska.<sup>29</sup> The majority of Native Americans/Alaska Natives live in urban areas while only one-third live in reservations.

Native Americans/Alaska Natives are very culturally distinctive, diverse and complex and growing more than three times as rapidly as Whites. Given their distinct languages and small population groupings, it is almost impossible to generalize across all Native Americans/Alaska Natives.

When addressing Native American communities, it is important to note that some groups prefer the term “Native American” while others prefer “American Indian.” Use the term that the group your program is working with uses.

**SIDS/ID Rates.** The decline in SIDS has also not been as significant for Native Americans in certain areas of the United States. The leading cause of infant mortality among Native American infants is SIDS.<sup>30</sup> The Indian Health Service (IHS) reports that in IHS service areas, the SIDS rate averages 2.3 times the U.S. rate for all races and three times the rate for Whites. SIDS is responsible for 21.9 percent of all infant deaths reported by IHS. However, in some IHS service areas, the percentage of SIDS deaths is much higher, ranging from 24.1 percent to 35.2 percent.<sup>31</sup>

It is well-documented that overall, Native Americans have one of the highest rates of infant mortality among any racial or ethnic group in this country.

**Prevalence of Risk Factors.** Several studies have found that there was no evidence of significant interaction between risk variables and ethnicity. It appears that the high rate of SIDS deaths among Native Americans is due to the high prevalence of risk factors in

the population and not an intrinsic risk based on Native American race. These risk factors include unsafe sleep practices, smoking, late or no prenatal care, maternal alcohol use and binge drinking during pregnancy. Native American women have the highest rates of smoking compared to any other race/ethnic group.<sup>32,33</sup>

Within Native American populations, certain nationalities/tribes are also more likely to place infants to sleep on their stomachs than other nationalities/tribes.<sup>34</sup>

In December 1992, the [Aberdeen Area Infant Mortality Study](#)<sup>35</sup> was created to examine why Northern Plains Indian infants were at a greater risk for SIDS. The study was funded by NICHD, IHS and the CDC. The results of the study highlighted areas of Native American family health that could be improved.

The study revealed the positive impact of public health nurses' visits to Northern Plains Indian women before and after they gave birth in reducing the risk of infants' death. Infants who lived in homes where a public health nurse visited, before or after birth, were 80 percent less likely to die from SIDS than infants in homes not visited.

The study also found that:

- Binge drinking (five or more drinks at a time) during a mother's first trimester of pregnancy made it eight times more likely that her infant would die from SIDS.
- Any maternal alcohol use during the periconceptional period (three months before pregnancy or during the first trimester) was associated with a six-fold increased risk of SIDS.
- Infants wearing more than two layers of clothing had more than a six-fold increased risk of dying from SIDS.

## Hispanics

According to the 2000 census, Hispanics are the fastest-growing minority group in the United States. Those who identify themselves as Hispanic come from a variety of countries in Latin America, the Caribbean and Europe. Almost 40 percent of Hispanics are foreign-born. Ninety percent live in urban areas and the States with the largest populations include California, Texas, New York, Florida, Illinois, Arizona and New Jersey. The cities with the largest populations include New York City, Los Angeles, Chicago and Houston.

Hispanics can be of many different ethnicities and there are significant health differences between subpopulations. Such variation limits the usefulness of comparing health outcome measures for all Hispanics against White, African American and other populations. For example, Mexican Americans have better health measures than Puerto Ricans.

**SIDS/ID Rates.** The Hispanic population as a group experiences a SIDS rate that is below the national rate as well as the White population rate at 0.27 death per 1,000 live births. It is important to note that in certain Hispanic subpopulations, such as Puerto Ricans and Cubans in New York City, the SIDS rate is greater than that of the White population.

**Prevalence of Risk Factors.** Within Hispanic populations, certain groups are more likely to place infants to sleep on their stomachs.<sup>36</sup> Additionally, 25.5 percent of infants with Hispanic mothers sleep in an adult bed.<sup>37</sup> Hispanic populations might also have a greater tendency to overdress infants, possibly leading to overheating.

## Asian Americans, Native Hawaiians and Pacific Islanders

In the United States, those who identify themselves as Asian Americans and Pacific Islanders come from a variety of islands, territories and countries. Approximately 10.4 million Asian Americans/Pacific Islanders live in the United States and U.S. Pacific Island jurisdictions—4 percent of the total U.S. population.<sup>38</sup>

**Pacific Islanders.** Pacific Islanders include Native Hawaiian, Polynesian, Micronesian and Melanesian peoples who live on 22 islands. There are more than 1,000 different languages spoken and 40 percent of the population does not fluently speak English.<sup>39</sup> In 1990, nearly 50 percent of Pacific Islanders lived in Hawaii, 30 percent in California, 4 percent in Washington and 2 percent in Texas and Utah. Infant mortality rates are two times higher in the Pacific Island jurisdictions.

**Asian Americans.** Asian Americans include Vietnamese, Korean, Japanese, Filipino, Chinese and Asian Indian populations. More than 90 percent of Asian Americans live in urban areas such as Los Angeles, New York City, San Francisco, Honolulu and Washington, D.C. The States with the highest populations are California, New York, Hawaii, Texas, Illinois, New Jersey and Washington. Many Asian Americans have come to the United States since 1965. While Asian Americans and Pacific Islanders are commonly perceived as having few health problems, they do experience disparities in health care access.

**SIDS/ID Rates.** This particular group experiences the lowest SIDS/ID rates at 0.185 per 1,000. It is important to note that the traditional infant sleep position is supine for many of these groups and sleep surfaces tend to be firm.

## Risk Factors

To be able to effectively educate the public about reducing the risk of SIDS, program staff must understand the risk factors for not only SIDS but risks to overall infant safety and health.

It is important to stress the distinct difference between a “risk factor” for a disease and the “cause” of a disease. A “cause” refers to something that leads to something else with some degree of certainty through a recognized series of normal or abnormal events. For example, infection with known bacteria causes some cases of meningitis by invading the brain and resulting in the immune system trying to fight back. The cause or causes of SIDS remain unknown and possible chains of events are only hypotheses or theories. Therefore, the best we can do is reduce the risk of rather than prevent SIDS.

“Risk factors” are factors that are found more frequently in a group of people with a certain problem than in a group of people without that particular problem. An expected connection between the risk factor and the problem is often not obvious. Research consistently points to certain risk factors for SIDS. Some risk factors are completely non-modifiable such as gender and age distribution but others are categorized as such because after the infant is born, there is little that can be done to change the circumstances of the birth. Modifiable factors deal with circumstances that relate to the infant health and well-being that can be changed after birth.

Modifiable risk factors for SIDS include:

- Prone sleep position
- Soft or loose bedding
- Inappropriate sleep environments
- Bedsharing
- Overheating
- Environmental tobacco smoke
- Maternal alcohol and illegal drug use

Non-modifiable risk factors include:

- Male gender
- Age Distribution: 2 to 6 months
- Low birth weight
- Prematurity
- Maternal smoking during pregnancy
- Young maternal age especially mothers less than 18 years old
- Late or no prenatal care
- Fall/winter season
- Higher parity

Risk factors have traditionally been used to help establish the cause of a disease and to then treat that cause. However, if risk factors are known but the cause(s) is not, as in SIDS, the question becomes whether or not it is reasonable to try to change or modify known risk factors in the hope that it may decrease the chances of the problem happening.

It is helpful to consider the risk/benefit ratio when deciding whether modifiable risk factors should be changed. In the case of SIDS risk factors, it is reasonable to change these factors as they not only affect the risk for SIDS but other areas of infant and child health as well and they do no harm to the infant.

## Modifiable Risk Factors

### Prone Sleep Position and the Back to Sleep Campaign

In the United States during the 1980s, researchers initially did not believe that stomach (prone) sleep was a risk factor for SIDS because most infants slept on their stomachs. However, in countries where fewer infants normally slept on their stomachs, the higher rates of SIDS among infants who slept prone made the prone-sleep position a very strong risk factor. The finding of this strong risk factor in other countries led researchers to try to figure out how prone sleep was associated with infant death.

In April 1992, the [AAP's Task Force on Infant Sleep Position](#) issued a statement recommending that infants be placed on their back or side to sleep to reduce the risk of SIDS. The recommendation came after the AAP reviewed extensive international research that indicated that sleep position was a factor for SIDS risk.

In 1994, the national BTS campaign was initiated as a joint effort of the U.S. Public Health

Service's (USPHS's) [NICHD](#) and [MCHB](#), the [AAP](#), the SIDS Alliance (now [First Candle/SIDS Alliance](#)) and the Association of SIDS and Infant Mortality Programs (ASIP).

In 1996 at the fourth SIDS International Conference, it was reported that infants who sleep on their sides have a greater risk of dying from SIDS than infants who sleep on their backs. As a result of the ongoing research on sleep position and SIDS, the AAP changed its message to pediatricians and parents to recommend the supine (back) sleep position as the preferred sleep position.

According to the 2005 AAP policy statement on SIDS, [The Changing Concept of Sudden Infant Death Syndrome: Diagnostic Coding Shifts, Controversies Regarding the Sleeping Environment, and New Variables to Consider in Reducing Risk](#), the AAP no longer recognizes side sleeping as a reasonable alternative to fully supine sleeping.

Although the side position is safer than the prone sleep position, the side position still carries a greater risk for SIDS than the back position.<sup>40</sup> While it is unclear how sleep position affects the risk of SIDS, the issue of side sleeping is more complicated than infants who sleep on their sides simply rolling over onto their stomachs.

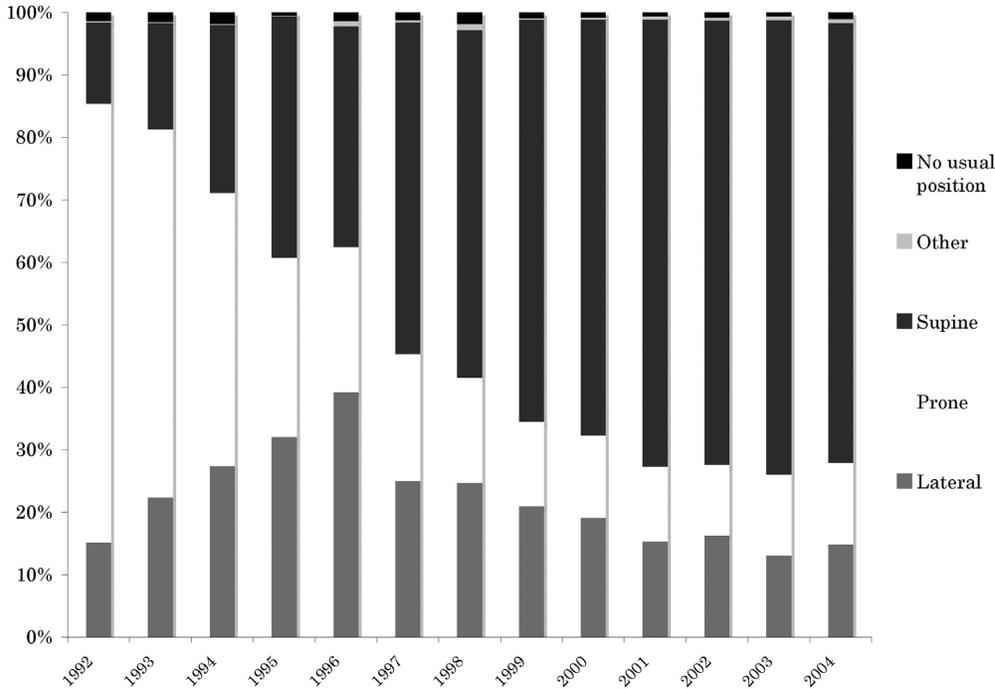
To continue the national decline in SIDS rates, it is important to sustain the BTS public health messages. When caregivers were surveyed in a 1994 to 1998 study,<sup>41</sup> 79 percent recalled recommendations for the back sleeping position from at least one of four sources: physicians, nurses, reading materials and television/radio.

Although respondents said that physicians had the greatest influence in their choice of infant sleep position, only 41 percent recalled that their physician had recommended back sleeping. The majority of caregivers who switched infants to the stomach sleep position recalled that the back sleeping position was recommended by only one of the four sources.

Caregivers who received recommendations from all four sources were six times more likely to place infants on their backs to sleep than those who had received only a single recommendation.<sup>42</sup> These results show that sustained exposure from television and print media as well as consistent endorsement from health care professionals are both needed to prevent regression on the positive maternal and child health behaviors that have been achieved.

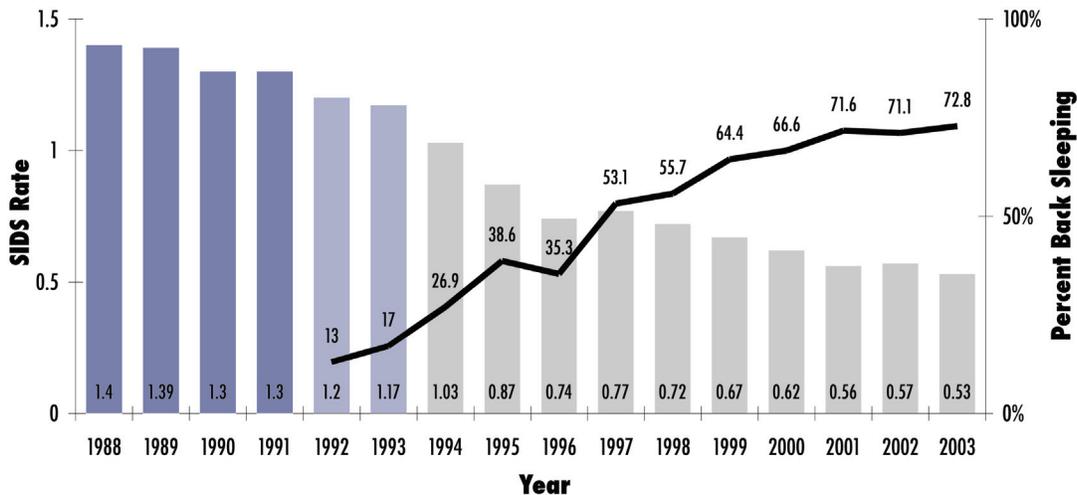
**Chart 1.2 : U.S. Infant Sleep Position, 1992-2004**

Linking infant sleep position to the reduction in the number of SIDS deaths is important for the continuation of SIDS risk reduction messaging and research. This graph clearly demonstrates the change in position from prone to supine during the last 12 years.



**Chart 1.3 : U.S. SIDS Rate and Sleep Position, 1985-2003**

If we further explore the SIDS rate and sleep position we can demonstrate the impact of sleep position on the SIDS rate in the United States. The dark blue bars (1988-1991) are prior to the first AAP recommendation. The light blue bars (1992-1993) are immediately after the AAP recommendation. The gray bars (1994-present) are during the Back to Sleep campaign.



## Loose Bedding and Inappropriate Sleep Environments

Epidemiologic studies identified sleeping with pillows, quilts, comforters, sheepskins, loose bedding and soft mattresses as risk factors for SIDS when placed under the infant or over an infant's head. While the number of infants put to sleep on their backs has increased, so has the number of infants placed to sleep in unsafe sleep environments such as an adult bed, couch or sofa. Adult beds are likely to have pillows, blankets, comforters and other loose bedding which increase an infant's risk of SIDS.

NICHHD reports that despite the large-scale efforts spearheaded by the CPSC to promote safe infant sleep environments, the use of soft bedding has not decreased appreciably since 1992.<sup>43</sup> Other recent studies have indicated that infants who sleep in adult beds are at higher risk for death, especially when soft bedding is used or when they share a bed with adults and other children.<sup>44</sup>

## Bedsharing

Research demonstrates that bedsharing under certain conditions, such as extreme maternal fatigue or smoking and alcohol use, is associated with an increased risk of SIDS and other accidental infant deaths. Studies have also shown that infants who share a bed with smokers are at higher risk for SIDS.

According to the 2005 AAP policy statement on SIDS, [The Changing Concept of Sudden Infant Death Syndrome: Diagnostic Coding Shifts, Controversies Regarding the Sleeping Environment, and New Variables to Consider in Reducing Risk](#), the AAP does not recommend bedsharing during sleep. Infants may be brought into bed for nursing or comforting, but should be returned to their own crib or bassinet when the parent is ready to return to sleep. However, there is growing evidence that roomsharing is associated with a reduced risk of SIDS. The AAP recommends a separate but proximate sleeping environment.

Since 1987, NICHHD has funded a [National Survey of Families and Households](#) which gathers information from families with infants about their infant sleep practices. Since 1993, the number of infants who bedshare has more than doubled from 5.5 percent to 12.8 percent. Currently, 44 percent of infants spend some time sleeping in an adult bed.<sup>45</sup>

Often, parents and caregivers are not aware of the increased risk of SIDS and accidental infant deaths that bedsharing poses. Some new mothers find it easier to breastfeed and bond with their infant if the infant is in their bed. Other parents and caregivers may bedshare because they cannot afford or do not have enough room for a crib. Still others may be misinformed, believing that bedsharing may reduce the risk for SIDS when the opposite is true.

Of special concern is the increase of bedsharing in groups not traditionally associated with the practice including mothers older than 18 years of age, White mothers and mothers living in the Mid-Atlantic, Midwest and South. It has been postulated that the BTS campaign raised parents' concerns about sleep safety and inadvertently resulted in parents bedsharing out of a desire to keep their infant safe while asleep.

It is important to note that the terms "bedsharing" and "co-sleeping" are not the same. Co-sleeping is when an infant sleeps in the same room as an adult while bedsharing is when an infant sleeps in an adult bed or other sleep surface with other people.

A recent study found that the risk of suffocation is approximately 20 times greater

for infants who sleep in adult beds compared to those who sleep in cribs.<sup>46</sup> The study, conducted by researchers from the CPSC and St. Louis University, compared the characteristics of suffocation deaths reported to the CPSC in the 1980s and the 1990s to describe how deaths occurred on specific sleep surfaces such as adult beds, cribs and sofas or chairs.<sup>47</sup>

For some time SIDS/ID, FIMR and CDR program staff have been voicing concerns about the growing numbers of infants who died in adult beds and other unsafe sleep areas. Some programs began developing educational messages and responding to bedsharing concerns and unsafe sleep environments by developing targeted educational campaigns and crib distribution programs. This is a complex and sensitive issue for SIDS parents, breastfeeding advocates and others.

## Overheating

Overheating, sometimes referred to as thermal stress, has been identified as a modifiable risk though it is still unclear why thermal stress may trigger a SIDS death. A number of hypotheses and theories continue to be investigated and new information and research are published periodically. Research indicates that SIDS deaths are more common in the winter and fall seasons. One theory links seasonality with overheating and a tendency to overdress during colder seasons.<sup>48</sup>

Parents should maintain a comfortable room temperature for the infant while avoiding overheating. Risk reduction campaigns should place greater emphasis on the hazards of overheating and thermal stress and should continue to reinforce the importance of placing infants on their backs to sleep with no head covering.<sup>49</sup>

## Environmental Tobacco Smoke

Environmental or secondhand smoke is a risk factor for SIDS.<sup>50</sup> Research shows that exposure to cigarette smoke in the environment after birth doubles an infant's risk of SIDS. Secondhand or passive smoke contains a number of hazardous chemicals including nicotine, ammonia, arsenic, methane and carbon monoxide.<sup>51</sup>

With regard to tobacco exposure and possibly secondhand exposure in utero, it is postulated that smoke exposure may disrupt the sleep arousal mechanism in infants and contribute to death by compromising an infant's ability to respond to adverse conditions.

## Non-Modifiable Risk Factors

There are certain risk factors such as age range and gender that are non-modifiable. However, there are other non-modifiable risk factors such as maternal smoking, low birth weight, prematurity and maternal alcohol and drug use that are important to public health prevention and awareness activities that aim to decrease teen pregnancy and increase access to quality prenatal care and information because healthy mothers and pregnancies have a greater likelihood of producing good birth outcomes and infants who survive.<sup>52</sup>

To prevent many non-modifiable risk factors, risk behaviors need to be addressed before and during women's pregnancies.

## SIDS Age Range

The distribution of age at death has been a consistent epidemiologic feature of SIDS cases. The risk of SIDS peaks at 2 to 4 months of age. SIDS is rare during the first month of life and after the age of 6 months. About 90 percent of SIDS cases occur in infants less than 6 months old.<sup>53</sup>

Research has focused on pathophysiological features specific to infants in the 1- to 6-month age distribution in understanding the interaction between age distribution and SIDS. As discussed in the Triple Risk theory, the 2- to 4-month period is a critical development period for infants. Due to the vast amount of growth and changes infants encounter in this time frame, physiologically they are considered unstable and less able to react to environmental stressors.

A current and emerging issue related to age distribution is **bedsharing**. Studies of parent-infant bedsharing have been found to be strongly associated with a younger age at death, independent of any other factors.<sup>54,55</sup> Other studies have found bedsharing to be a risk factor for infants less than six months of age, but the prone position as a risk factor for all age groups.<sup>56</sup>

## Gender

Studies have consistently reported a higher ratio of male to female infants who die of SIDS (60 males : 40 females) independent of any other risk factor. Currently, there is further research to gain a greater understanding of exactly why this is the case by examining differences in X and Y chromosomes and hormonal levels between the genders.

## Maternal Smoking

Cigarette smoking and environmental smoke exposure collectively represent one of the most lethal health hazards for women and infants. Smoking has been shown to dramatically increase a woman's risk of complications during pregnancy and birth and to decrease an infant's chances of survival and good health.

Approximately 20 percent of all women in the United States smoke, according to the 2002 [National Health Interview Survey](#) and the 2002 [Behavioral Risk Factor Surveillance System](#).<sup>57</sup> Studies reveal that nationally, 11.4 percent of pregnant women smoke and in some States, as many as 27 percent of pregnant women smoke. Also, many non-smoking pregnant women are frequently exposed to secondhand smoke from their partners, spouses or co-workers.<sup>58,59</sup>

A number of epidemiological studies have supported a relationship between smoking and the risk of SIDS.<sup>60,61</sup> It is important to recognize and address the impact of smoking as a risk factor for not only SIDS but also other maternal complications and an infant's risk of serious health problems.

Case-control, population-based studies from several countries indicate that cigarette smoking during pregnancy triples an infant's risk for SIDS. While it is unknown exactly how smoking affects a baby in utero, abnormalities in the developing nervous system have been observed in animals exposed to cigarette smoke in utero.

Based on these epidemiological investigations, it is believed that sustained cigarette-smoke exposure further compromises already vulnerable infants. It may disrupt the arousal mechanism in infants and contribute to neonatal death by compromising an infant's ability

to respond to life-threatening situations.<sup>62</sup>

It is important for SIDS/ID programs to address smoking because after sleep position, exposure to smoke during pregnancy is the most important modifiable risk factor for SIDS. In addition, low birth weight births, preterm deliveries and perinatal deaths are linked to smoking during pregnancy. Smoking is the most important modifiable cause of poor pregnancy outcome.

Expanded efforts to educate and promote smoking cessation are critical for pregnant women. Due to the recent litigation with the tobacco industry and the resulting financial settlements, there are expanded national resources to assist State and local program staff addressing smoking during pregnancy.

Programs such as [Campaign for Tobacco-Free Kids](#), [Smoke-Free Families](#) and other public health campaigns have been able to implement successful smoking cessation programs and educational-awareness efforts on the harmful effects of smoking resulting in a decrease in the number of women who smoke during pregnancy.

To be most effective, collaborate with a coalition in your area. Contact the local branch of health organizations such as the [American Heart Association](#), [American Cancer Society](#) or [American Lung Association](#). They can let you know about groups you can join in your area, and they may already have begun efforts to tackle the problem of secondhand smoke in your community. For more information on collaborating, see [Chapter 6: Partnerships and Collaborations](#).

## Low Birth Weight and Prematurity

A low birth weight (LBW) infant is an infant who weighs less than 2,500 grams (5.5 pounds) at birth. LBW infants may be premature (born before the completion of the 37th week of pregnancy) or full-term. LBW affects about 7.6 percent of infants born each year in the United States. About half of all cases of LBW are related to teenage pregnancy, cigarette smoking during pregnancy, poor nutrition before and during pregnancy and poor health of the mother.

The incidence of LBW continues to grow and has become a major public health issue in the United States. LBW and prematurity are major risk factors for overall infant mortality, including a three to six times greater risk of SIDS in comparison to normal birth weight and gestational period infants.<sup>63,64</sup> The latest infant mortality statistics reveal that in contrast to infant mortality, the last decade saw no significant drop in the rate of LBW and, in fact, LBW now appears to be on the rise.

There are unique challenges to working with LBW and premature infants because neonatal intensive care units (NICU) often place these infants in the prone position. Very low birth weight (VLBW) infants suffer from a higher prevalence of certain medical conditions, such as gastrointestinal reflux and upper airway problems, that lead some medical professionals to recommend the prone sleep position. It is also possible that physicians, NICU nurses and other medical professionals remain uncomfortable recommending non-prone sleeping for VLBW infants, despite the AAP's recommendations and the physiologic data that support it.<sup>65</sup>

Research shows that parents of VLBW infants are more influenced by both the recommendations of a physician, and the practices of the nursery more than parents of normal birth weight infants. Prior to discharge, VLBW, LBW and preterm infants should be transitioned to the supine position and infant sleep position should be discussed with

the parents.<sup>66</sup>

## Maternal Alcohol and Drug Use

Substance abuse is a particularly challenging issue for public health professionals. Researchers find it nearly impossible to separate maternal substance abuse from other confounding factors that impact the overall health and safety of infants.<sup>67</sup>

Prenatal illicit drug use has become an increasingly important public health problem during the past two decades. Epidemiologic studies designed to assess the association between substance abuse and adverse pregnancy outcomes have consistently documented higher rates of placental abruption.<sup>68</sup>

There are studies that have found a higher incidence of SIDS among infants exposed to substance abuse<sup>69,70</sup> and other studies that have not seen an increase.<sup>71</sup>

There is no doubt that substance and alcohol use negatively impacts infant health and safety. The extent of the impact and the short- and long-term consequences continue to be under investigation. While substance and alcohol abuse have been grouped in this brief section, the two issues are very different with respect to medical consequences for infants.

The negative impact of alcohol abuse in utero is indisputable.<sup>72,73,74</sup> The AAP, CDC, USPHS and numerous other organizations and nonprofits follow the risk reduction recommendation that women should not drink alcoholic beverages if they intend to become pregnant or are pregnant or nursing.

However, for three decades a relationship between alcohol use and SIDS had not been found. Only very recent research suggests that a link may even exist in certain populations as seen in the Aberdeen study of Native Americans which found that binge drinking was a risk factor for SIDS.

## Protective Measures

Prone sleep position, environmental and prenatal tobacco exposure, overheating and illegal drug exposure are considered risk factors for infants because research indicates infants are more likely to experience negative outcomes when their environment includes one or all of these variants. Some factors, such as pacifiers, swaddling and breastfeeding are speculated to protect infants against SIDS. For example, it is clear that breastfeeding clearly results in improved infant health. What is unclear is how these practices are protective against SIDS specifically.

### Pacifiers

Research indicates that there may be an association between pacifier use and a decrease in SIDS, but the mechanism by which the pacifier is helping in reducing the risk is unclear. Key points of the research are:<sup>75</sup>

- More control infants used a pacifier for their last—or reference—sleep, giving an apparent protective effect against SIDS. The significance of this association increased when controlled for other factors.
- Studies completed in New Zealand, Netherlands, Norway and the United States did report an association between pacifier use and SIDS that was protective.<sup>76,77,78,79</sup>

There are many theories on how pacifiers might be protective in the sleep environment. One recent study suggests that pacifiers lower the auditory arousal threshold.<sup>80</sup> There appears to be an association between the use of a pacifier and a reduced risk of SIDS. However, the pathophysiology of SIDS upon which pacifiers may exert a positive effect remains unclear because pacifiers do not stay in an infant's mouth for a very long period of time—approximately 20 minutes—during sleep. Theories that require pacifiers to be in the mouth are difficult to support for this reason.

Concern with possible negative outcomes related to pacifier use such as associated reduced breastfeeding, dental issues, ear infections and product safety have delayed making a recommendation to use a pacifier to reduce the risk of SIDS.

The 2005 AAP policy statement on SIDS, [The Changing Concept of Sudden Infant Death Syndrome: Diagnostic Coding Shifts, Controversies Regarding the Sleeping Environment, and New Variables to Consider in Reducing Risk](#), recommends the use of pacifiers at nap time and bedtime throughout the first year of life. The evidence that pacifier use inhibits breastfeeding or causes later dental complications is not compelling enough to discredit the recommendation.

However, it is recommended that pacifier introduction for breastfed infants be delayed until 1 month of age to ensure that breastfeeding is firmly established. In addition, if the infant refuses the pacifier, it should not be forced. There is a slight increased risk of ear infections associated with pacifier use, but the incidence of ear infection is generally lower in the first year of life, especially the first 6 months, when the risk of SIDS is the highest.

## Swaddling

Swaddling, a method of wrapping an infant securely in a blanket or cloth, is a common infant care practice in many cultures.<sup>81</sup> Some researchers suggest that swaddling reduces the risk of SIDS because it helps infants sleep more comfortably on their back. If an infant startles while asleep, his own body movements can cause him to wake up. Swaddling can limit those movements and help an infant feel secure.<sup>82</sup>

However, SIDS researchers caution that swaddling can contribute to overheating. It is critical to teach parents and health care professionals how to properly swaddle infants if an infant is to be swaddled. Usually swaddling is effective only during the first 4 to 6 weeks of life. It should then be discontinued as the infant grows and becomes more mobile.

## Breastfeeding

Campaigns to increase breastfeeding in the United States have had good success in increasing the number of women who initially elect to breastfeed. In 2001, breastfeeding rates in the hospital were 72.2 percent among Whites, 73.0 percent among Hispanics and 52.9 percent among African Americans. These rates were the highest recorded since national breastfeeding data has been collected. However, disparities remain between African American women and women of other racial and ethnic groups. However, efforts to convince mothers to maintain breastfeeding have been less successful.

The percentage of women who report that they are still breastfeeding at 6 months postpartum reached a high of 32.5 percent in 2001. At 6 months postpartum, 38.5 percent of White, 38.2 percent of Hispanic, 32 percent of Native American and 21.9 percent of African American women were still breastfeeding.<sup>83</sup> There is a long list of reasons why breastfeeding is good for infants. Whether reducing the risk of SIDS should be added to

that list remains unclear. Breastfeeding is a weak protective factor for SIDS compared to sleep position, which is why studies vary in whether an effect was even found. Data presented at the [Society for Pediatric Research](#) is probably the strongest data for an association yet seen.

The 2005 AAP policy statement on SIDS, [The Changing Concept of Sudden Infant Death Syndrome: Diagnostic Coding Shifts, Controversies Regarding the Sleeping Environment, and New Variables to Consider in Reducing Risk](#), states that although breastfeeding is beneficial and should be promoted for many reasons, the AAP Task Force on Sudden Infant Death Syndrome believes that the evidence is insufficient to recommend breastfeeding as a strategy to reduce the risk of SIDS.

Regardless of whether it is protective against SIDS, breastfeeding is clearly beneficial for the overall health of an infant. It would be remiss, however, if breastfeeding was not addressed in the context of how it relates to bedsharing.

Bedsharing, as previously discussed, is a risk factor for SIDS that has also been promoted by some breastfeeding groups and lactation consultants to increase the number of breastfeeding mothers. This is currently a very controversial debate as to how to address the risks of bedsharing while encouraging breastfeeding.

## What SIDS is Not

One of the most important advances in SIDS research is answering the question of what SIDS is not. SIDS is not due to an adverse reaction to immunizations or vaccines, apnea or an apparent life-threatening event or caused by child abuse or cribs.

### Immunizations and Vaccines

One common misconception is that [DTaP vaccines](#) are associated with SIDS deaths. Some people think there is a causal connection because a moderate proportion of children who die from SIDS have recently been vaccinated with DTaP. Because infants receive many immunization shots during the critical development period of one to six months of age and 90 percent of SIDS deaths occur within this time frame, it is only logical that many SIDS victims have recently received vaccines.<sup>84</sup>

This does not mean that the immunization had anything to do with the infant's subsequent sudden and unexpected death. Specifically, considering that most SIDS deaths occur during an age range when three DTaP shots are given, DTaP shots preceding a number of SIDS deaths simply by chance would be expected.

Because SIDS is the leading cause of death during the postneonatal period, it is important to respond to concerns that vaccination might play a role in SIDS. The cause and effect of immunizations and SIDS has been comprehensively studied for more than two decades. In 2003, the Institute of Medicine ([IOM](#)) released a report reviewing the epidemiologic evidence, focusing on three outcomes: SIDS, all Sudden Unexpected Infant Death (SUID) and neonatal death which is an infant death, whether sudden or not, during the first four weeks of life.

In fact, when a number of well-controlled studies were conducted during the 1980s, the investigators found nearly unanimously that the number of SIDS deaths temporally associated with DTaP vaccination was within the range expected to occur by chance proving that the SIDS deaths would have occurred even if no vaccinations had been given.

In several of the studies, infants who had recently received a DTaP shot were found to be less likely to die from SIDS.

IOM reported that all controlled studies that have compared immunized versus non-immunized children have found either no association or a decreased risk of SIDS among immunized children and concluded that the evidence does not indicate a causal relation between the DTaP vaccine and SIDS.<sup>85</sup>

Currently, both the [CDC](#) and [AAP](#) recommend that infants receive multiple doses of vaccines during their first year of life. If there were no vaccines, there would be many more cases of disease and along with them, more deaths.

## Apnea and Apparent Life-Threatening Events

Apnea of infancy is defined as an unexplained episode of cessation of breathing for 20 seconds or longer or a shorter respiratory pause associated with [bradycardia](#), [cyanosis](#), [pallor](#) and/or marked [hypotonia](#).

An apparent life-threatening event, or ALTE, is defined as an episode that is frightening to the observer and is characterized by some combination of [apnea](#) (central or occasionally obstructive), color change (usually [cyanotic](#) or [pallid](#) but occasionally [erythematous](#) or [plethoric](#)), marked change in muscle tone (usually marked limpness) and choking or gagging. An infant will require significant intervention, such as vigorous shaking, mouth-to-mouth breathing or full CPR, to be revived from an ALTE.<sup>86</sup>

During the 1970s, a suggestion was made for continuous cardiorespiratory monitoring at home to reduce the risk of SIDS.<sup>87</sup> The hypothesis that apnea is a precursor to SIDS was first proposed in 1972, but it has never been proven.

In fact, evidence indicates that there is no clear relationship between apnea and SIDS. Despite the lack of a scientific foundation or evidence of efficacy, home cardiorespiratory monitoring continues to be a common practice in the United States.<sup>88</sup>

## Suffocation and Positional Asphyxia

Much confusion and concern has also arisen in recent years about the potential relationship between SIDS and suffocation. Some parents whose infant has died sometimes struggle with the question of whether their infant actually suffocated. The answer is not always easy to determine and often depends on circumstantial evidence found at the time of death.<sup>89</sup>

Suffocation causes death from a restriction of oxygen flow to the blood vessels. When this happens, the cells of the body can no longer function properly and vital organs fail. Suffocation is generally divided into four categories: smothering, choking, mechanical suffocation and environmental suffocation. Smothering is defined as physical obstruction of the nose and mouth while choking is characterized by an obstruction within the airway. Mechanical suffocation occurs when external pressure is applied to the body, preventing chest movement and respiration. Environmental suffocation occurs when oxygen is displaced from the atmosphere an individual is breathing.

In some instances, these types of suffocation leave subtle signs after death, but a SIDS death may be difficult to distinguish from death by accidental or intentional suffocation.<sup>90</sup> Many SIDS infants will have had a resuscitation attempt which will often leave clinical markings similar to suffocation. Experienced forensic pathologists can usually discern the

signs of resuscitation from those of suffocation.

Asphyxia refers to a breathing insufficiency that leads to an inadequate intake of oxygen and exhalation of carbon dioxide. It can be caused by a variety of factors, some of which may be related to sleep position or bedding materials.

“Positional asphyxia” is a term that was created by some pathologists and used when a SIDS infant was found in the prone sleep position. Its use has been strongly discouraged. If a pathologist cannot distinguish SIDS from suffocation, accidental or non-accidental, the case should be diagnosed as “undetermined.”

A scientific study reported that similar unsafe sleeping practices were occurring in a majority of cases diagnosed as SIDS, accidental suffocation and cause undetermined. This is the first study to scrutinize these diagnoses together in terms of sleep practices common to all three postmortem diagnoses. Most notably, these practices included bedsharing and placing infants to sleep on surfaces other than cribs.<sup>91</sup>

## Maltreatment, Child Abuse and Infanticide

It has only been during the past few decades, around the same time that SIDS was being defined, that child abuse and the maltreatment of children has gained the attention of the government and medical community.

It is extremely important to understand that SIDS is not child abuse and SIDS families should always be approached in a non-accusatory manner. Retrospective studies that looked at infanticide and child abuse clearly and conclusively found that child abuse is not a cause of SIDS. Several cases of infanticide, sensationalized by the media, have had severely detrimental effects on the public’s perceptions of what is SIDS.<sup>92</sup> Research indicates that approximately 5 percent of SIDS deaths are the result of homicide.<sup>93</sup> Statistically it is possible for a subsequent SIDS death to occur in a family, but it is improbable.

The AAP statement, [Distinguishing Sudden Infant Death Syndrome From Child Abuse Fatalities](#), provides professionals with information and guidelines to avoid distressing or stigmatizing families of SIDS victims while allowing for the accumulation of appropriate evidence in potential cases of death by infanticide. The differentiation between SIDS and fatal child abuse can be a critical diagnostic decision.

The following chart lists the expected appearance of a SIDS infant at time of death and the appearance of a child abuse infant at time of death.

<b>SIDS Infant</b>	<b>Child Abuse, Maltreatment</b>
Seem well developed, but may be small for their age.	The infant may be obviously wasted away (malnutrition).
Have signs of normal hydration and nutrition.	
Have no external signs of injury.	Visible signs of injury, including broken bones, bruises, burns, cuts, head trauma, black eyes, scars and welts/wounds.
Have other siblings who seem normal and healthy.	Other siblings may look abused or neglected.

**SIDS Infant****Child Abuse, Maltreatment**

Parents indicate infant was well and healthy when put to sleep.

Parents' story does not sound right or cannot account for all the injuries on the infant.

Lividity, or the appearance of dark, pooled blood on the side the infant was lying. May have the appearance of bruising. The pattern of lividity helps determine the position of the body at the time of and following death.

Blood-tinged or frothy fluid draining from nose/mouth.

Cold skin and rigor mortis, or stiffening, which takes place quickly in infants. Parents may fear the infant "froze."

Vomit, which should not be misinterpreted as the infant dying of aspiration. Diaper wet and full of stool.

Small marks, such as a diaper rash appearing more severe.

## Diagnosis

Sudden, unexplained infant deaths or sudden unexplained death in infancy (SUID/SUDI) are deaths for which no cause of death was obvious when the infant died. SIDS is the most frequently determined cause of SUID.

### Diagnostic Shift

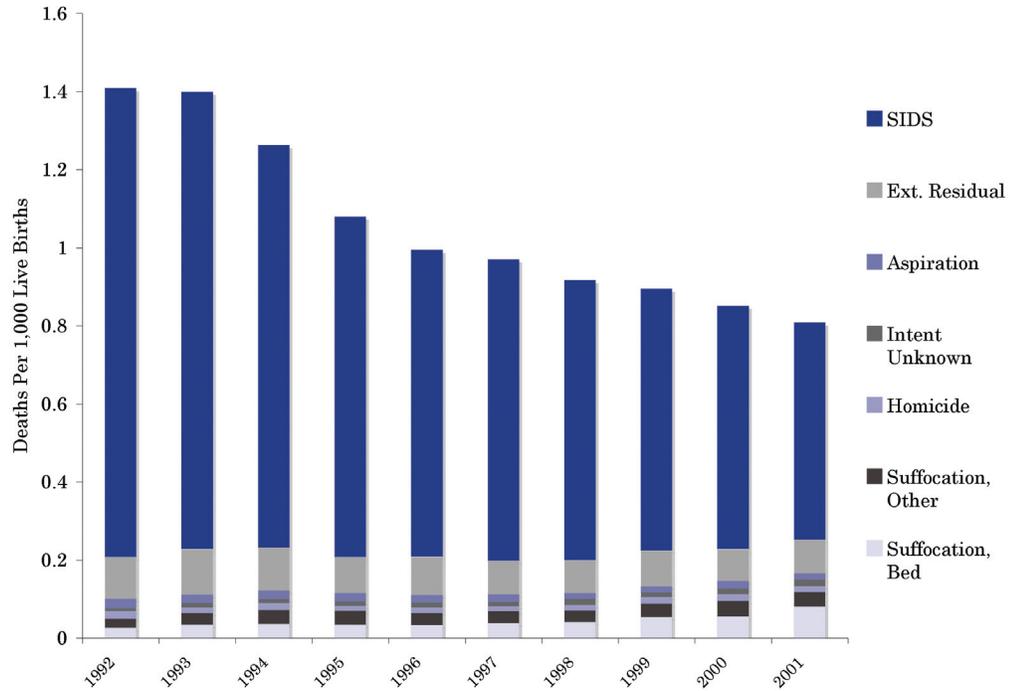
SIDS programs and researchers have suggested that the recent modest decline in SIDS rates may not only be due to successful public health campaigns, but also changes in classification—or a diagnostic shift. This decline may reflect medical examiners and coroners not assigning a SIDS diagnosis when bedsharing or other risk factors are present. In the past, these same deaths would have been labeled SIDS. Today, they are likely to be diagnosed as undetermined or accidental asphyxia.

Researchers have reviewed international and national data to examine and compare trends. The data appears to support a genuine decline in SIDS deaths although there does appear to be some level of diagnostic shift. Researchers have found while there has been no increase of infant deaths due to aspiration, there has been an increase of suffocation deaths and potentially a very small number of SIDS deaths reclassified as suffocation.<sup>94</sup>

During the past few years (1999-2001), the decline has not been as significant as the previous years. One explanation for this might be a diagnostic shift. Along with the decrease in SIDS diagnosis, there has been an increase in the "undetermined" diagnosis. The failure of the total postneonatal death rate to fall from 1999 to 2001 also suggests that

some deaths are being reclassified to other causes.<sup>95</sup>

**Chart 1.4 : SIDS and Undetermined Diagnosis**



# Risk Reduction Education

## 2

**Critical Program Function:** To inform and educate the public and families about risk factors for SIDS and infant death in order to protect themselves and others.

To reduce SIDS/ID rates further, program staff must sustain and expand the BTS campaign, address racial disparities, address soft bedding and bedsharing, aggressively address educational messaging about SIDS and smoking and provide guidance to parents on pacifiers and breastfeeding.

## AAP SIDS Risk Reduction Recommendations

Despite major decreases in the incidence of SIDS during the past decade, SIDS is still responsible for more infant deaths during the postneonatal period than any other cause of death during infancy in the United States. In the 2005 policy statement, [The Changing Concept of Sudden Infant Death Syndrome: Diagnostic Coding Shifts, Controversies Regarding the Sleeping Environment, and New Variables to Consider in Reducing Risk](#), the American Academy of Pediatrics (AAP) addresses several issues that have become relevant since they last published a statement in 2000.

The AAP no longer recognizes side sleeping as a reasonable alternative to fully supine (lying on back) sleeping. The AAP also does not recommend bedsharing during sleep. Infants may be brought into bed for nursing or comforting, but should be returned to their own crib or bassinet when the parent is ready to return to sleep. However, there is growing evidence that roomsharing (infant sleeping in a crib in the parent's bedroom) is associated with a reduced risk of SIDS. The AAP recommends a separate but proximate sleeping environment.

Research now indicates an association between pacifier use and a reduced risk of SIDS, which is why the revised statement recommends the use of pacifiers at nap time and bedtime throughout the first year of life. The evidence that pacifier use inhibits breastfeeding or causes later dental complications is not compelling enough to discredit the recommendation. However, it is recommended that pacifier introduction for breastfed infants be delayed until 1 month of age to ensure that breastfeeding is firmly established. In addition, if the infant refuses the pacifier, it should not be forced. There is a slight increased risk of ear infections associated with pacifier use, but the incidence of ear infection is generally lower in the first year of life, especially the first 6 months, when the risk of SIDS is the highest.

The policy recommendations include:

- **Back to sleep:** Infants should be placed for sleep in a supine position (wholly on back) for every sleep.
- **Use a firm sleep surface:** A firm crib mattress, covered by a sheet, is the recommended sleeping surface.
- **Keep soft objects and loose bedding out of the crib:** Pillows, quilts, comforters, sheepskins, stuffed toys and other soft objects should be kept out of an infant's sleeping environment.
- **Do not smoke during pregnancy:** Also avoiding an infant's exposure to second-hand smoke is advisable for numerous reasons in addition to SIDS risk.
- **A separate but proximate sleeping environment is recommended** such as a separate crib in the parent's bedroom. Bedsharing during sleep is not recommended.
- **Consider offering a pacifier at nap time and bedtime:** The pacifier should be used when placing infant down for sleep and not be reinserted once the infant falls asleep.
- **Avoid overheating:** The infant should be lightly clothed for sleep, and the bedroom temperature should be kept comfortable for a lightly clothed adult.
- **Avoid commercial devices marketed to reduce the risk of SIDS:** Although various devices have been developed to maintain sleep position or reduce the risk of rebreathing, none have been tested sufficiently to show efficacy or safety.
- **Do not use home monitors as a strategy to reduce the risk of SIDS:** There is no evidence that use of such home monitors decreases the risk of SIDS.
- **Avoid development of positional plagiocephaly (flat back of head):** Encourage "tummy time." Avoid having the infant spend excessive time in car-seat carriers and "bouncers." Place the infant to sleep with the head to one side for a week and then changing to the other.
- **Ensure that others caring for the infant (child care provider, relative, friend, babysitter) are aware of these recommendations.**

## Back to Sleep Campaign Messages

Based on the AAP's recommendations, NICHD has modified its BTS risk reduction messages.

1. **Always place your baby on his or her back to sleep, for naps and at night.** The back sleep position is the safest, and every sleep time counts.
2. **Place your baby on a firm sleep surface, such as on a safety-approved crib mattress, covered by a fitted sheet.** Never place your baby to sleep on pillows, quilts, sheepskins, and other soft surfaces.
3. **Keep soft objects, toys and loose bedding out of your baby's sleep area.** Don't use pillows, blankets, quilts, sheepskins, and pillow-like crib bumpers in your baby's sleep area, and keep all items away from your baby's face.
4. **Do not allow smoking around your baby.** Don't smoke before or after the birth of your baby, and don't let others smoke around your baby.
5. **Keep your baby's sleep area close to, but separate from, where you and**

**others sleep.** Your baby should not sleep in a bed or on a couch or armchair with adults or other children, but he or she can sleep in the same room as you. If you bring your baby in bed with you to breastfeed, put him or her back in a separate sleep area, such as a bassinet, crib, cradle, or a bedside cosleeper (infant bed that attaches to an adult bed) when finished.

6. **Think about using a clean, dry pacifier when placing the infant down to sleep, but don't force the baby to take it.** If you are breastfeeding your baby, wait until your child is one month old or is used to breastfeeding before using a pacifier.
7. **Do not let your baby overheat during sleep.** Dress your baby in light sleep clothing, and keep the room at a temperature that is comfortable for an adult.
8. **Avoid products that claim to reduce the risk of SIDS because most have not been tested for effectiveness or safety.**
9. **Do not use home monitors to reduce the risk of SIDS.** If you have questions about using monitors for other conditions talk to your health care provider.
10. **Reduce the chance that flat spots will develop on your baby's head:** Provide "Tummy Time" when your baby is awake and someone is watching; change the direction that your baby lies in the crib from one week to the next; and avoid too much time in car seats, carriers and bouncers.

## Healthy People 2010 Goals

Back sleeping and safe sleep environments are important contributors to reducing deaths from SIDS and suffocation as well as reducing overall infant mortality. The [Healthy People 2010](#) goals provide the following targets for SIDS/ID programs to strive for:

- Reduce deaths from SIDS from 0.72 death per 1,000 live births in 1998 to 0.25 death per 1,000 live births in 2010.
- Increase the percentage of healthy full-term infants who are put down to sleep on their backs from 35 percent in 1996 to 70 percent in 2010.
- Reduce accidental deaths caused by suffocation from 4.1 deaths per 100,000 population in 1998 to 3.0 deaths per 100,000 population in 2010.
- Reduce cigarette smoking among pregnant women from 11.4 percent in 2002 to no more than 2 percent in 2010.<sup>1</sup>

## Developing SIDS Risk Reduction Campaigns

The success of the BTS campaign illustrates that health communication strategies can effectively reduce the risk of SIDS or SUID. Specifically, health communication efforts by SIDS/ID staff can:

- Increase parent and caretaker awareness of SIDS as a problem.
- Increase parent and caretaker knowledge of risk reduction methods.
- Motivate parents and caretaker to follow safe sleep recommendations.
- Influence parent and caretaker attitudes toward bedsharing.
- Reinforce the importance of institutionalizing BTS messages within the community.

It is important to realize that health communication messages can not overcome availability or accessibility barriers. For example, messages addressing bedsharing can not overcome barriers such as the inability to purchase a safe crib.

There are many excellent free or low-cost resources and tools to assist health professionals in planning, developing, implementing and evaluating health communication efforts. One that many public health professionals are familiar with is [CDCynergy](#).

Originally created for use within the [CDC](#), CDCynergy has been adapted for use by public health professionals on a national, State and local level. CDCynergy is a multimedia CD-ROM used for planning, managing and evaluating public health communication programs. This innovative tool is used to guide and assist users in designing health communication interventions within a public health framework.

The planning model is designed to guide the user through systematically conceptualizing, planning, developing, testing, implementing and evaluating health communication activities while promoting accountability and the importance of evaluation. The user is presented with a step-by-step detailed tutorial, case examples and a wealth of resources including a diverse media library and cumulative evaluation plan. The program also provides the user with a link to a word processing template to aid in writing a detailed intervention campaign.

CDCynergy does not assume that communication is the only solution to a public health problem, but guides users through a process in which users:

- Use research to help describe and determine the causes of the health problem and detail the audience segments affected by the problem.
- Explore a wide range of possible strategies for the problem.
- Systematically select the strategies that may show the most promise.
- Understand the role communication can play in planning, implementing and evaluating selected strategies.
- Develop a comprehensive communication plan that includes audience research, pre-testing, production, launch and evaluation.

[Tailored editions](#) have been developed including CDCynergy XE which support systematic conceptualization, planning, execution and evaluation of comprehensive public health programs. For more information, contact the [Public Health Foundation](#) at <http://bookstore.phf.org>.

## Campaign Components

SIDS/ID programs often provide expertise, staff and funding to support SIDS risk reduction and safe sleep educational efforts. These efforts can take many forms including individual counseling and education, group training sessions, media campaigns and dissemination of printed materials. No matter what type of campaign you choose to undertake, there are materials and resources available to support your efforts.

### Distribute Resources

A key function of SIDS/ID programs is to distribute educational materials including pamphlets, brochures, posters and door hangers to community-based organizations,

pregnant women, grandparents and child care providers as well as publicizing the availability of free or low-cost resources to consumers and providers.<sup>2</sup>

Program staff can distribute written materials to:

- Mothers at their prenatal classes, midwives/OB offices, beauty shops and supply stores, faith settings, baby showers, health fairs, PTA meetings, WIC clinics, MOMS groups, sororities, child care provider centers and drug and grocery stores, for example.
- Grandparents at faith settings, bingo, AARP meetings, beauty shops and senior housing, for example.
- Fathers at barbershops, sporting events, faith settings, prenatal classes and fraternities, for example.

Educational resources can either be produced by your organization or obtained through other organizations. There are many sources of excellent SIDS risk reduction materials available for free or low-cost. At the end of the chapter, some of the best sources for materials including brochures, door hangers, fact sheets and videos are listed.

If you decide to develop new materials or adapt existing materials, there are many resources available to assist in the implementation and evaluation of your health educational efforts. It may be necessary and helpful to collaborate with community-based organizations to conduct SIDS risk reduction and safe sleep education. For more information, see [Chapter 7: Partnerships and Collaborations](#).

## **Launch Public Relations Campaigns**

To educate the public about SIDS/ID risk factors, you may want to launch a public relations campaign which may include the use of paid broadcast time or print space (advertisements), donated time and space (public service announcements) or a combination of paid and donated time and space. For more information, see [Chapter 8: Public Relations & the Media](#).

## **Conduct Trainings**

As part of a risk reduction campaign, it is necessary to train community members such as health care professionals, members of civic and health associations, members of faith associations, members of professional associations, child care providers and others in risk reduction. Trainings will need to be repeated periodically to ensure that trainees receive up-to-date information, resources and referrals. For more information and resources on training, see [Chapter 4: Training](#) and the [accompanying trainer's guide](#).

## **Launch Community-Specific Campaigns**

Depending on your area's demographics, it may be necessary to launch risk reduction campaigns that target specific communities. To effect change within minority communities and, thus, begin to eliminate health disparities, it is necessary for programs to use materials that are culturally- and linguistically-appropriate. It is also important to work with community-level health care providers, alternative media and other resources traditionally accessed by racial/ethnic groups such as faith-based groups, civic organizations and tribal councils.

Given the disparities in health outcomes, one of the most important and often-challenging

roles public health programs and nonprofit health organizations face is the development and dissemination of resources that are both culturally- and linguistically-competent.

Local and State programs may support the development of new culturally-appropriate SIDS and safe sleep materials for internal and external use that are linguistically- and age-appropriate<sup>3</sup> by:

- Conducting periodic surveys on the knowledge, attitudes and practices of parents, grandparents, child care providers and foster parents on safe sleeping. Surveys, focus groups and community meetings can also identify barriers to safe sleeping such as not having a crib and language and cultural differences. These can also assist in understanding of public perceptions of back sleeping.
- Providing technical assistance to community-based organizations and community health providers to address the needs of non-English speakers.
- Involving minority families in constructing targeted health messages that answer their specific concerns.

## **Resources for Working With Minority Communities**

### **The Office of Minority Health Resource Center**

In 1985, the Department of Health and Human Services (HHS) established the Office of Minority Health (OMH). OMH advises the Secretary of HHS and the [Office of Public Health and Science](#) on public health program activities affecting American Indians and Alaska Natives, Asian Americans, African Americans, Hispanics/Latinos, Native Hawaiians and other Pacific Islanders.

OMH operates the OMH Resource Center (OMHRC), which serves as an information and referral service on minority health issues for professionals, community groups, consumers and students. It assists the Office of Public Health Services and OMH in distributing scientifically-valid and culturally-competent health information, encourages public participation in HHS programs and assists in conducting health campaigns.

### **The National Center for Cultural Competence**

The [National Center for Cultural Competence \(NCCC\) SIDS/ID Project](#) is designed to increase the capacity of SIDS/ID programs to plan, implement and evaluate culturally- and linguistically-competent service delivery systems as a multifaceted approach to addressing the disparities in infant mortality outcomes. The project works to support the infusion of cultural and linguistic competency into approaches to eliminating these disparities. The SIDS/ID Project has three goals that guide its work:

1. Promote networking and information exchange among programs concerned with SIDS/ID at the national, regional, State and local levels.
2. Foster linkages among SIDS/ID programs at all levels to enhance the development of cultural and linguistic competence.
3. Provide training, technical assistance and consultation to advance the state-of-the-art in delivery of SIDS/ID related services and the development of policies and practices that support cultural and linguistic competence.

### **Linguistic Competence and Health Literacy**

Linguistic competence is the ability of health care stakeholders to effectively address

the language and cultural needs of the public. Communication barriers and cultural differences between providers and families may lead to poorer treatment adherence and disease management.

Health literacy is the ability to read, understand and act on health care information. Often, health education materials are written at reading levels that are too high for those who speak English as a second language.

When providers speak a different language than their patients, it is likely that diagnostic and treatment barriers will occur.<sup>4</sup> Parents may also conceal their inability to understand a physician. In 2001, a survey of adults found that minority populations are more likely to have difficulties communicating with health care providers compared to the White population.<sup>5</sup> This may be because 14 percent of the nation's population speaks a language other than English at home. In New York, Los Angeles, Miami, Honolulu, Newark and El Paso, more than 40 percent speak a language other than English. Although only 31 percent of Hispanics were born outside the United States, 77 percent report Spanish as the main spoken language at home.<sup>6</sup>

The [National Adult Literacy Survey](#) has found that non-Whites, immigrants, the elderly and those with low incomes are more likely to have difficulty understanding health education information.<sup>7</sup>

## **Reducing the Risk in African American Communities**

To address the disparity in African American SIDS rates, the [BTS campaign](#) sponsors, the [National Black Child Development Institute](#), [First Candle/SIDS Alliance](#) and several other organizations worked together to develop materials for a new initiative to reduce SIDS in African American communities.

NICHD also joined forces with three national African American women's organizations in a program to reduce the risk of SIDS among African American infants. The leadership and members of the [National Coalition of 100 Black Women](#), the Women in the NAACP and [Alpha Kappa Alpha Sorority](#) held three summits with NICHD to learn how to conduct SIDS risk reduction trainings and outreach activities in communities around the country.

In addition, HRSA has also provided funding for four States (Illinois, Michigan, Mississippi and South Carolina) to create evidence-based interventions and strategies to lower infant mortality caused by preterm birth, LBW and SIDS among African Americans.

## **Reducing the Risk in Native American Communities**

In response to the Aberdeen findings, NICHD has been working with members from the Native American community to discuss infant mortality and SIDS in the Northwest and the Northern Plains. They brought together individuals representing Native American and Alaska Native communities from the five IHS service areas that have the highest rates of SIDS—Aberdeen, Alaska, Bemidji, Billings and Portland—to identify and develop community-driven strategies for increasing SIDS awareness and reducing the number of infant deaths in Native American and Alaska Native communities. NICHD also formed a small work group of representatives of the participants from the regions, to guide the direction of the follow-up meeting and future of the outreach initiative.

NICHD is proceeding to the next phase in developing adaptable materials and support material for diverse Native American and Alaska Native communities. The work group

and partners will be involved throughout the development of the plan and will continue to provide guidance and feedback at various stages.<sup>8</sup>

In 2003, HHS and the [CJ Foundation for SIDS](#) collaborated to support the reduction of racial and ethnic disparities in SIDS among American Indians. Efforts supported activities to reduce alcohol use by pregnant women, reduce maternal and secondhand smoke, increase the knowledge of SIDS among pregnant and teenage mothers and enhance local BTS campaigns. SIDS risk reduction activities were expanded to the [Great Lakes Inter-Tribal Council](#) in Lac Du Flambeau, WI; the University of North Dakota in Grand Forks, ND and the Aberdeen Area Tribal Chairmen’s Health Board in Aberdeen, SD.

Most recently, OMH, as part of the [Closing the Health Gap Initiative](#), has funded a demonstration effort to promote and reduce disparities in infant mortality during the next three years. The Aberdeen Area Indian Health Service Tribal Organization will oversee this project.

## Reducing the Risk in Hispanic Communities

After English, Spanish is the most common language spoken in the United States. There is a range of practical ways to accommodate the growing numbers of non-English speakers. Program staff may find the following methods useful in addressing linguistic barriers:<sup>9</sup>

- Recruit and retain bilingual/bicultural staff.
- Support the use of interpreters.
- Support the development of language skills training in staff.
- Use telephone interpreter services.

## Risk Reduction Resources

<b>African American Outreach</b>	Alpha Kappa Alpha Sorority	<a href="http://www.aka1908.com">www.aka1908.com</a>
	National Coalition of 100 Black Women	<a href="http://www.ncbw.org">www.ncbw.org</a>
	NICHD’s Back to Sleep Resource Kit for African American Outreach	<a href="http://www.nichd.nih.gov/sids/Resource_kit.htm">www.nichd.nih.gov/sids/Resource_kit.htm</a>
<b>Alcohol: Fetal Alcohol Syndrome</b>	CDC’s educational materials including those targeted to African American women	<a href="http://www.cdc.gov/ncbddd/fas/default.htm">www.cdc.gov/ncbddd/fas/default.htm</a>
	NIAAA’s English/Spanish educational materials, database	<a href="http://www.niaaa.nih.gov">www.niaaa.nih.gov</a>
	NOFAS’s educational materials, State resource directory, further reading	<a href="http://www.nofas.org">www.nofas.org</a>
<b>Bibliographies</b>	NSIDRC’s topical bibliographies	<a href="http://www.sidscenter.org">www.sidscenter.org</a>

## Risk Reduction Resources

<b>Child Care</b>	Caring for Our Children: National Health and Safety Performance Standards: Guidelines for Out-of-Home Child Care Programs, Second Edition	<a href="http://nrc.uchsc.edu/CFOC/index.html">http://nrc.uchsc.edu/CFOC/index.html</a>
	Stepping Stones to Using Caring for Our Children, Second Edition	<a href="http://nrc.uchsc.edu/STEPPING">http://nrc.uchsc.edu/STEPPING</a>
<b>Cultural and Linguistic Competence</b>	Office of Minority Health's National Standards for Culturally and Linguistically Appropriate Services in Health Care	<a href="http://www.omhrc.gov/templates/browse.aspx?lvl=2&amp;lvlID=15">www.omhrc.gov/templates/browse.aspx?lvl=2&amp;lvlID=15</a>
<b>Cultural Competence</b>	Further reading from NCCC SIDS/ID Project	<a href="http://www3.georgetown.edu/research/gucchd/nccc/nccc5.html">www3.georgetown.edu/research/gucchd/nccc/nccc5.html</a>
	NCCC SIDS/ID Project provides topical conference calls on topics related to cultural and linguistic competence for SIDS/ID programs.	<a href="http://www3.georgetown.edu/research/gucchd/nccc/topicalcallseries.html">www3.georgetown.edu/research/gucchd/nccc/topicalcallseries.html</a>
	NCCC SIDS/ID Project's pool of consultants on cultural and linguistic competence and brokering consultant pool services for SIDS/ID programs	<a href="http://www3.georgetown.edu/research/gucchd/nccc/consultant.html">www3.georgetown.edu/research/gucchd/nccc/consultant.html</a>
<b>Cultural Competence: Products</b>	NCCC SIDS/ID Project's products on cultural and linguistic competence and SIDS/ID	<a href="http://www3.georgetown.edu/research/gucchd/nccc/pubs_sids.html">www3.georgetown.edu/research/gucchd/nccc/pubs_sids.html</a>
<b>Drug Use</b>	The Center for Substance Abuse Prevention's educational materials, planning and implementation tools, online courses	<a href="http://prevention.samhsa.gov">http://prevention.samhsa.gov</a>
	U.S. Department of HHS Substance Abuse and Mental Health Services Administration	
	National Institute on Drug Abuse's educational materials, further reading, opportunities for research, fellowships and research information	<a href="http://www.nida.nih.gov">www.nida.nih.gov</a>
<b>General</b>	CJ Foundation for SIDS's educational materials and further reading	<a href="http://www.cjsids.com">www.cjsids.com</a>

## Risk Reduction Resources

<b>General</b>	First Candle's educational materials and further reading	<a href="http://www.firstcandle.org">www.firstcandle.org</a>
	NICHD's Back to Sleep campaign educational materials and further reading	<a href="http://www.nichd.nih.gov/publications/pubskey.cfm?from=sids">www.nichd.nih.gov/publications/pubskey.cfm?from=sids</a>
	NSIDRC's educational materials, publications, bibliographies and further reading including <i>What is SIDS?</i> (also in Spanish)	<a href="http://www.sidscenter.org">www.sidscenter.org</a>
<b>Health Literacy</b>	Further reading from the Center for Health Care Strategies	<a href="http://www.chcs.org">www.chcs.org</a>
<b>Linguistic Competence</b>	Access Project and the National Health Law Program's Language Services Action Kit for working to assist people with limited English proficiency	<a href="http://www.accessproject.org/adobe/language_services_action_kit.pdf">www.accessproject.org/adobe/language_services_action_kit.pdf</a>
	Further reading from NCCC SIDS/ID Project	<a href="http://www3.georgetown.edu/research/guchd/nccc/nccc5.html">www3.georgetown.edu/research/guchd/nccc/nccc5.html</a>
	NCCC SIDS/ID Project provides topical conference calls on topics related to cultural and linguistic competence for SIDS/ID programs	<a href="http://www3.georgetown.edu/research/guchd/nccc/topicalcallseries.html">www3.georgetown.edu/research/guchd/nccc/topicalcallseries.html</a>
<b>Linguistic Competence</b>	NCCC SIDS/ID Project's pool of consultants on cultural and linguistic competence and brokering consultant pool services for SIDS/ID programs	<a href="http://www3.georgetown.edu/research/guchd/nccc/consultant.html">www3.georgetown.edu/research/guchd/nccc/consultant.html</a>
<b>Linguistic Competence: Products</b>	NCCC SIDS/ID Project's products on cultural and linguistic competence and SIDS/ID	<a href="http://www3.georgetown.edu/research/guchd/nccc/pubs_sids.html">www3.georgetown.edu/research/guchd/nccc/pubs_sids.html</a>
<b>Linguistic Competence: Reading Level</b>	SMOG test to determine the reading level of publications	<a href="http://www.sph.emory.edu/WELLNESS/reading.html">www.sph.emory.edu/WELLNESS/reading.html</a>
<b>Maternal and Child Health</b>	Virtual library of maternal and child health information from Maternal and Child Health Library at Georgetown University	<a href="http://mchlibrary.info">http://mchlibrary.info</a>
	MOD's educational materials and resources	<a href="http://www.marchofdimes.com/professionals/2222.asp">www.marchofdimes.com/professionals/2222.asp</a>

## Risk Reduction Resources

<b>Minority Outreach</b>	Closing the Gap newsletter. Each issue is devoted to a specific health topic of concern to minority communities	<a href="http://www.omhrc.gov/omh/sidebar/omh-publications.htm">www.omhrc.gov/omh/sidebar/omh-publications.htm</a>  To be placed on the mailing list for upcoming issues, call the resource center at 800-444-6472.
	HHS's Initiative to Eliminate Racial and Ethnic Disparities in Health	<a href="http://www.raceandhealth.hhs.gov">www.raceandhealth.hhs.gov</a>
<b>Minority Outreach: Technical Assistance</b>	NCCC SIDS/ID Project provides capacity building targeted technical assistance to regional and State SIDS/ID programs and responds to requests for information and technical assistance via a toll-free number (800-788-2066) or e-mail	<a href="http://www3.georgetown.edu/research/gucchd/nccc/targetedassistance.html">www3.georgetown.edu/research/gucchd/nccc/targetedassistance.html</a>  <a href="mailto:cultural@georgetown.edu">cultural@georgetown.edu</a>
	OMHRC provides capacity-building and specialized technical assistance services a toll-free telephone service (800-444-6472) accessible throughout the United States, Puerto Rico and the Virgin Islands, and provides a TDD telephone (301-589-0951) for the hearing-impaired. Bilingual information specialists answer English and Spanish-language inquiries	<a href="http://www.omhrc.gov/templates/browse.aspx?lvl=2&amp;lvlID=66">www.omhrc.gov/templates/browse.aspx?lvl=2&amp;lvlID=66</a>
<b>Native American Infant Mortality Study</b>	Aberdeen Area Tribal Chairmen's Health Board and the Aberdeen Area Infant Mortality Study	<a href="http://www.aatchb.org">www.aatchb.org</a>  <a href="http://www.uic.edu/sph/cade/mchepi/meetings/may2003/slides/may2003.ppt">www.uic.edu/sph/cade/mchepi/meetings/may2003/slides/may2003.ppt</a>
<b>Native American Outreach</b>	Indian Health Service	<a href="http://www.ihs.gov">www.ihs.gov</a>
<b>Native American-Targeted Materials</b>	CJ Foundation for SIDS's resource kit including a manual, two videos and a resource CD that contains posters, brochures, PSAs, radio spots and other educational materials	<a href="http://www.cjsids.com">www.cjsids.com</a>
<b>Prenatal Care</b>	March of Dimes' educational materials and resources	<a href="http://www.marchofdimes.com/professionals/2222.asp">www.marchofdimes.com/professionals/2222.asp</a>

## Risk Reduction Resources

<b>Safe Sleep</b>	Alabama Child Death Review System's educational materials	<a href="http://www.adph.org/cdr/default.asp?templatename=0&amp;deptid=118&amp;templateid=2305">www.adph.org/cdr/default.asp?templatename=0&amp;deptid=118&amp;templateid=2305</a>
	First Candle's educational materials	<a href="http://www.firstcandle.org">www.firstcandle.org</a>
	Florida Department of Health's educational materials	<a href="http://www.doh.state.fl.us/family/mch/docs/pdf/safebabebro.pdf">www.doh.state.fl.us/family/mch/docs/pdf/safebabebro.pdf</a>
	Humboldt County Public Health Branch's educational materials	<a href="http://www.co.humboldt.ca.us/health/Safe%20Infant%20Sleeping%20ROCH.pdf">www.co.humboldt.ca.us/health/Safe%20Infant%20Sleeping%20ROCH.pdf</a>
	Indiana Perinatal Network's educational materials	<a href="http://www.indianaperinatal.org/education-materials-consumer.aspx">www.indianaperinatal.org/education-materials-consumer.aspx</a>
<b>Safe Sleep: Bedsharing</b>	ASIP's further reading	<a href="http://www.asip1.org/pdf/bed_sharing_1.pdf">www.asip1.org/pdf/bed_sharing_1.pdf</a>
	Workshop Proceedings: Sleeping Arrangements, Context, Biology and Culture: Beyond the "Bedsharing Debate"	8th International SIDS Conference, Edmonton, Alberta, 2004
<b>Safe Sleep: Breastfeeding</b>	ASIP's further reading	<a href="http://www.asip1.org/pdf/breastfeeding_1.pdf">www.asip1.org/pdf/breastfeeding_1.pdf</a>
<b>Sleep Position</b>	AAP's educational materials	<a href="http://www.aap.org/bst/showdetl.cfm?&amp;DID=15&amp;Product_ID=1854">www.aap.org/bst/showdetl.cfm?&amp;DID=15&amp;Product_ID=1854</a>
<b>Smoking</b>	CDC's advertising campaigns for stopping tobacco use	<a href="http://www.cdc.gov/tobacco">www.cdc.gov/tobacco</a> <a href="http://www.cdc.gov/tobacco/mcrc">www.cdc.gov/tobacco/mcrc</a> <a href="http://www.cdc.gov/tobacco/mcrc/resource.htm">www.cdc.gov/tobacco/mcrc/resource.htm</a>
	Educational materials, further reading, toolkits from National Partnership to Help Pregnant Smokers Quit	<a href="http://www.helppregnantmokersquit.org">www.helppregnantmokersquit.org</a>
	Office on Smoking and Health's resources for advertising on a tight budget	<a href="http://www.cdc.gov/tobacco/mcrc/tbudget.htm">www.cdc.gov/tobacco/mcrc/tbudget.htm</a>
	Smoke-Free Families' educational materials, further reading	<a href="http://www.smokefreefamilies.org">www.smokefreefamilies.org</a>
<b>Smoking: Cessation</b>	ACOG Resource Center	<a href="http://sales.acog.com/acb/stores/1/product1.cfm?SID=1&amp;Product_ID=166">sales.acog.com/acb/stores/1/product1.cfm?SID=1&amp;Product_ID=166</a>

## Risk Reduction Resources

<b>Smoking: Cessation</b>	Arizona Smokers Helpline/ASH	<a href="http://www.ashline.org">www.ashline.org</a> 800-556-6222
	California Smoker's Helpline	<a href="http://www.californiasmokershelpline.org">www.californiasmokershelpline.org</a> 800-NO-BUTTS
	Colorado Quitline	<a href="http://co.quitnet.com">co.quitnet.com</a> 800-639-QUIT
	Connecticut QuitLine	<a href="http://www.ctquitline.org">www.ctquitline.org</a> 866-END-HABIT
	Florida Quit-for-Life Line	877-U-CAN-NOW
	Massachusetts Try To Stop Smoker's Quitline	<a href="http://www.trytostop.org/support/quitline.asp">www.trytostop.org/support/ quitline.asp</a> 800-879-8678
	Minnesota Group Health Quit Line	English 877-270-7867 Spanish 877-266-3863 TTY 877-777-6534
	Nebraska Toll-Free Quit Line	<a href="http://www.hhs.state.ne.us/tfn/ces/cesindex.htm">www.hhs.state.ne.us/tfn/ces/ cesindex.htm</a> 866-NEBQUIT
	New York State Smokers Quitline	<a href="http://www.nysmokefree.com">www.nysmokefree.com</a> 888-609-6292
	Oklahoma Tobacco Helpline	<a href="http://www.health.state.ok.us/program/tobac/">www.health.state.ok.us/program/ tobac/</a> 866-PITCH 'EM
	Oregon QUIT Smoking Hotline	<a href="http://www.Oregonquitline.org">www.Oregonquitline.org</a> 877-270-7867
	Pennsylvania Free Quitline	877-724-1090
	South Dakota Quitline	866-SD-QUITS
	Tennessee S.M.A.R.T. Moms	800-884-9301

## Risk Reduction Resources

<b>Smoking: Cessation</b>	The Great Start Quitline sponsored by American Legacy Foundation and American Cancer Society	<a href="http://www.americanlegacy.org">www.americanlegacy.org</a> <a href="http://www.cancer.org">www.cancer.org</a> 866-66-START
	The National Partnership to Help Pregnant Smokers Quit and Center for Tobacco Cessation's tool kit for State government officials and advocates to help educate decision makers about the importance of comprehensive tobacco treatment under Medicaid for pregnant women	<a href="http://partnership.mediastudio.tv/policy/medicaid.asp">partnership.mediastudio.tv/policy/medicaid.asp</a>
	The Partnership for Smoke-Free Families Program's technical assistance manual	<a href="http://www.smokefreefamilies.org/documents/PSFManual.pdf">www.smokefreefamilies.org/documents/PSFManual.pdf</a>  Hard copies are available at 919-843-7663 or <a href="mailto:smokefreefamilies@unc.edu">smokefreefamilies@unc.edu</a> .
	U.S. Public Health Service and Smoke-Free Families' educational materials	English: <a href="http://www.helppregnantmokersquit.org/documents/tearsheet.pdf">www.helppregnantmokersquit.org/documents/tearsheet.pdf</a>  Spanish: <a href="http://www.helppregnantmokersquit.org/documents/tearsheetspan.pdf">www.helppregnantmokersquit.org/documents/tearsheetspan.pdf</a>
	Utah Quit Line	888-567-TRUTH (8788) (English) 877-2NO-FUME (Spanish)
	Washington State Quitline	<a href="http://www.quitline.com">www.quitline.com</a> 877-270-STOP
	Wisconsin Tobacco Quit Line	877-270-STOP (7867) 877-2NO-FUME (266-3863) (Spanish) 877-777-6534 (TTY)
<b>Smoking: Secondhand Smoke</b>	CDC's toolkit	<a href="http://www.cdc.gov/tobacco/ETS_Toolkit/index.htm">www.cdc.gov/tobacco/ETS_Toolkit/index.htm</a>

## Risk Reduction Resources

<b>Spanish Hotline</b>	First Candle’s English/Spanish information hotline (800-221-7437)	<a href="http://www.firstcandle.org">www.firstcandle.org</a>
<b>Spanish Materials</b>	First Candle’s educational materials	<a href="http://www.firstcandle.org/enespanol/index.htm">www.firstcandle.org/enespanol/index.htm</a>
	NCCC SIDS/ID Project’s educational materials	<a href="http://www3.georgetown.edu/research/gucchd/nccc/espanol.html">www3.georgetown.edu/research/gucchd/nccc/espanol.html</a>
	NICHD’s Back to Sleep campaign educational materials	<a href="http://www.nichd.nih.gov/publications/pubskey.cfm?from=sids">www.nichd.nih.gov/publications/pubskey.cfm?from=sids</a>
	NSIDRC’s educational materials, publications and bibliographies	<a href="http://www.sidscenter.org">www.sidscenter.org</a>
<b>Spanish Web site</b>	First Candle’s English/Spanish Web site	<a href="http://www.firstcandle.org/enespanol/index.htm">www.firstcandle.org/enespanol/index.htm</a>
	NCCC SIDS/ID Project’s English/Spanish Web site	<a href="http://www3.georgetown.edu/research/gucchd/nccc/espanol.html">www3.georgetown.edu/research/gucchd/nccc/espanol.html</a>

# 2

# Bereavement Support Services

**Critical Program Function:** To link parents, families and caregivers to support services and ensure access to quality bereavement care.

Program staff may:

- Develop and disseminate information on bereavement service availability and facilitate utilization.
- Provide bereavement support services to families affected by the death of an infant or young child including SIDS, miscarriage, ectopic pregnancy, termination, stillbirth and neonatal death.
- Provide or foster culturally- and linguistically-appropriate staff, resources, materials and communication for bereavement support.
- Improve the provision of bereavement services to minority and underserved families by supporting the development of new organizational relationships, materials and program models.
- Ensure the quality and expand the availability of in-service training in bereavement support for professionals and paraprofessionals who may interact with families who experience infant death.
- Monitor and evaluate bereavement support services. Services should be provided regardless of gender, race, religion, culture, language, age or sexual orientation.

Today, the deaths of children account for less than 5 percent (approximately 55,000) of all deaths in the United States. While sudden deaths have become less common, for those parents, families, communities and health professionals who experience these deaths, the experience is devastating, and the impact is far-reaching.

Historically, families and professionals observed that because of the nature of SIDS, the impact on families and communities was intense and long-lasting.<sup>1</sup> SIDS deaths were seen as being unique because:

- The child's death was sudden. The family had no reason to expect that the child was ill or would die.
- The cause of the child's death is unknown, which left the family with more questions than answers.
- The criminal justice system was often involved, and families often faced suspicion and accusations of child abuse.

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The variety of bereavement support services that have been developed to address these unique needs include information and referrals, counseling and case management, peer support services, ongoing communication and public awareness. While bereavement support has improved greatly since the 1960s, much more remains to be done.

In 2003, the Institute of Medicine (IOM) published [When Children Die: Improving Palliative and End-of-Life Care for Children and Their Families](#), which detailed the state of services to families experiencing the death of a child from any cause. IOM found that bereaved families often failed to receive competent, compassionate and considerate care for their physical, emotional and spiritual needs. However, the report notes that better bereavement support is possible.

State and local SIDS/ID program staff play a critical role in improving and maintaining services to families, professionals and the community. In order to improve bereavement services, it is important for staff to understand the grief and bereavement process, the unique aspects of a sudden unexplained death such as SIDS, the role of community bereavement providers, the role of training and education and existing bereavement resources.

## Grief and Bereavement Definitions

In this manual, the term “family” refers to parents, legal guardians, siblings, grandparents and other close relatives. “Parent” refers to biological parents, formal and informal adoptive parents and legal guardians.

**“Bereavement” is a term that covers the experience of parents and family in the anticipation of a death, the death itself and the subsequent adjustment to living following the death of a loved one.**

Bereavement includes the adaptation of parents and family members and their expressions and experience of grief and the changes in relationships and circumstances.<sup>2</sup>

**“Grief” is a term that refers to the specific cognitive, emotional and social difficulties following the death of a loved one.<sup>3</sup>**

It describes an individual’s feelings and behavior in response to a death or loss. Grief is a natural response to a felt loss and a way of repairing emotional damage. Parents and family members vary in their experience of grief: its duration, expression and intensity.

**“Mourning” refers to the social rituals and expressions of grief that are defined by family, culture or society.**

Mourning can also be understood as the process of attempting to cope or learn to live with loss and grief.<sup>4</sup> The term “grief process” is often used to describe “mourning.”

### Symptoms of the Newly-Bereaved

Some of the symptoms are physical and some are psychological. Typical symptoms include:

- Aching arms
- General fatigue

- Intrusive thoughts
- Nausea & vomiting
- Drug/alcohol use
- Compulsive or obsessive behavior
- Vulnerability
- Lack of control
- Interpersonal problems
- Self-blame
- Sleep disturbances
- Blaming others

## Phases and Stages of Grieving

During the late 1960s when Dr. Elisabeth Kubler-Ross began to formally evaluate grief in terminal cancer patients, she divided it into consecutive phases including shock and disbelief, depression, anger and acceptance. She believed that understanding the phases of grieving may help staff interact with patients and caregivers. Since then many different theories have been developed to assist the dying, their families and caregivers in understanding the grief process.

It is important to understand that these stages, phases and theories are only guides and that grief is very individual. While some people will experience these phases distinctly, for others their grief responses will overlap and flow back and forth. The period of grieving will vary by the relationship and circumstances of death.<sup>5</sup>

### 1. Shock and Numbness

- Stunned, disbelief
- Denial
- Short attention span
- Difficulty concentrating
- Impaired decision-making
- Resistance to stimuli
- Time confusion
- Failure to accept reality
- Impeded functioning

### 2. Searching and Yearning

- Sensitivity to stimuli
- Anger/guilt
- Impatience
- Irritability
- Sleeping difficulties

- Aching arms
- Preoccupation with deceased

### 3. Disorientation

- Parents or caregivers may think they are going crazy
- Social withdrawal
- Disorganization
- Forgetfulness
- Depression
- Guilt
- Sense of failure
- Exhaustion
- Sadness
- Insomnia
- Weight loss/gain

### 4. Reorganization

- Renewed energy
- Easier decision-making
- Ability to laugh and smile again
- Reestablishment of eating and sleeping habits
- Planning for the future

Another more current understanding of bereavement, first developed by Dr. J.W. Worden in the early 1980s, identifies grief not as a succession of phases through which a person passes with little or no control, but as a series of four tasks to adapt to one's loss and changed life.<sup>6</sup> These include:

#### **Task 1: "To Accept The Reality Of The Death"**

The bereaved parent understands that the death has occurred and that it is irreversible.

#### **Task 2: "To Work Through The Pain Of Grief"**

Grief brings with it many strong and mixed feelings such as pain, anger, guilt and sadness, and parents may try to avoid these intense feelings.

#### **Task 3: "To Adjust To Everyday Life Without The Deceased"**

Caring for a child is a very time-consuming process and after a loss, parents and caregivers are suddenly forced into inactivity and must restructure their schedules and responsibilities.

#### **Task 4: "Moving On In Life While Staying Connected With The Deceased"**

Parents adapt to their loss and find a new “normal” which includes creating a changed relationship with the deceased. Families report that “resolution” and “acceptance” are inaccurate expectations and that integration of the loss is more appropriate. Parents may never accept the loss but will integrate the loss into their life. Parents report developing an ongoing relationship with their child through their memories and mental life.

## **Special Considerations of Sudden Unexplained and Unexpected Infant Deaths**

The death of a child is considered the most stressful and enduring loss for parents. Research indicates that compared to the loss of a parent or spouse the loss of child is more intense. One reason is that for many individuals, the parent-child bond is integral to the parent’s identity.

Understanding the differences and similarities between losses that are sudden and unexpected such as SIDS and accidents and those losses that are expected such as cancer is critical to improving bereavement support to families.

While all bereaved families need information, privacy, support and involvement in decision-making, there are some differences when the death is sudden and unexpected. The differences include:

- Intense shock and distress for the family that also may include fear and anxiety.
- A family member is usually in a hospital setting and must quickly contact and summon other family members and friends. Families may feel both overwhelmed and isolated. While most SIDS deaths take place in the home or child care setting, most will be transported to a hospital or health care setting.
- Family members must make decisions quickly that require them to change their framework from their child’s life to his or her death. Decisions such as organ donation and funeral arrangements will be discussed.
- Dealing with many different types of personnel from transport to the emergency room. Families are faced with interacting with numerous prehospital providers, law enforcement, emergency room staff and other families and children in the emergency room.
- Experiencing grief in a situation in which the family does not have a relationship with the health personnel or completely understand the medical information.
- The child’s death from SIDS or unintentional accident is sudden. The family had no reason to expect that the child was ill or would die.
- The cause of the child’s death is unknown, which left the family with more questions than answers.
- The criminal justice system is often involved and families face suspicion and accusations of child abuse when the death is from SIDS or is unexplained.

## **Impact of Death on Parents**

The way that a individual parent grieves depends on a variety of factors. There are five variables that influence the way people grieve.<sup>7</sup> These five variables are:

- The relationship of the parent to the child.
- The circumstances surrounding the death.
- The personality of the bereaved. This may include the parent's maturity.
- The developmental situation of the bereaved person, that is, how one's being a child, adolescent, adult or elderly person influences one's grief and mourning.
- The support system that the bereaved person has and how effective the support system is.

Parents will experience the death of their child in a unique fashion. No two people will grieve exactly the same way. Support services, therefore, need to help family members and others understand and accept that their loved ones may not necessarily experience any of the common reactions to grief and may not demonstrate any of the same behaviors or manifestations that they will.

Parents of an only child report magnification of feelings regarding loss of identity (Are they still a parent?), greater intensity regarding guilt and anger at the death and greater difficulty in letting go. Holidays and anniversaries are much more difficult and there is a greater idealization of how perfect life was when the baby was still alive. It is also important to recognize that non-traditional families such as single parents, same-sex partners, foster parents and others may have different experiences.

## Guilt and Grief

One of the most common parent and caregiver reactions to a SIDS death is guilt and self-blame. Guilt for a SIDS parent is enormous, regardless of what that parent did or did not do. Types of guilt include:<sup>8</sup>

- **Death causation guilt:** resulting from parent's perceived contribution to or failure to protect the child from death.
- **Illness-related guilt:** resulting from perceived deficiencies in the parental role during the child's illness or at the time of death.
- **Parental role guilt:** the belief that the parent failed to live up to self- or societal expectations in the overall parental role.
- **Moral guilt:** resulting from the belief that the child's death was punishment or retribution for something the parent did or failed to do.
- **Survival guilt:** the belief that children should outlive their parents.
- **Grief guilt:** resulting from the parent's behavioral or emotional reactions of grief at the time of or following the child's death.

## Anger and Grief

After the death of a child, parents may blame each other for the death leading to anger or conflict. Parents may also blame other family members, Emergency Medical Technicians (EMTs), child care workers or physicians causing friction in relationships and unresolved anger.

## Gender and Grief

Gender differences may also lead to conflict and misunderstanding between parents.

There is a wealth of research exploring gender differences regarding grieving and bereavement. Men are reported as more likely to contain their emotions, grieve alone and use physical activities as an expression of grief. Women are more likely to openly-express their feelings and want to talk about the death.

It is important to note that current literature acknowledges that some women do not grieve like most women and some men do not grieve like most men. The following information points out some of the differences between not just male/female grief but mother/father grief.

Feminine grief may include:

- Tears, crying, uncontrollable weeping
- Deep depression, listlessness
- Extreme irritability, physical complaints
- Abandonment, loneliness
- Loss of identity (motherhood)
- Social isolation, altered relationships
- Guilt, blame and search for what went wrong
- Problems with decision-making

Masculine grief may include:

- Loss of hopes and dreams, loss of control
- Loss of role as protector and one who fixes
- Expected to show strong exterior, take action, move on quickly
- May tend to work more, reluctance to talk
- More permission to be angry and cover depression with outbursts
- “How is your wife doing?”

Couples will have different styles, timetables and meaning in dealing with the death and loss. Giving permission to each other (partners, family members) to grieve individually, as is appropriate and most useful for them, is key to not only the survival of the relationship but the health of it. Current research findings do not demonstrate that there are higher divorce or separation rates in couples that experience the death of a child. Relationships with family and spouses may strengthen or weaken over time.<sup>9</sup>

## Children’s Grief

Children are impacted by the death of infants in their role as siblings, family members or peers. As bereaved children have special needs, families need to be provided information on how children react to grief and bereavement. Children’s understanding of death is influenced by both their developmental stage and by their past experiences.

- Children younger than age 2 do not understand death. They may be clingy, cranky or display regressed behavior. They need routines to be maintained and physical reassurance.
- Preschool children may view death as temporary or reversible. Children’s reactions may include showing no reaction, aggression, separation anxiety and

talking or acting out death. They need facts presented briefly and simply. Children may ask insensitive questions that are disturbing to parents or adults but are normal. Children need reassurance that they will always be cared for and not separated from their parents.

- School-age children between ages 5 and 9 may understand that death is permanent and that all people and animals will die, but may still not believe that they may die. They may react by not showing any reaction or they may experience sadness, anger, confusion or guilt for causing the death. They may also worry about parents or others dying. They need death explained in concrete terms, reassurance of their own safety and all questions answered.
- From ages 9 to 12, children will understand that death is final and they and others will die. They may still see death as a punishment for their thoughts and feelings.
- Teenagers understand that death is final, and that they will also die. They think like adults and may feel sadness, pain, guilt and anger like adults do. Some teenagers may want to be able to talk about the death while others do not. They may feel self-conscious about expressing grief in public.

Normal childhood responses to death include intense grieving altering with normal childhood play. Children experience what they can handle and then move on until later. Sad feelings may persist for long periods of time.

Children may also feel that something they thought or did contributed to the death. It is not uncommon for children to fear others dying. While some children may want to participate in memorial services, others may be fearful of the funeral services. If children do not participate in the funeral services, they can say goodbye in other ways. Creation of mementos of the sibling can be a helpful memorial for children.

Information provided to children and adolescents should be provided in many formats including written materials, audiovisual materials, group meetings and one-on-one counseling. The broader community of teachers, parents, peers and coaches needs information about children and grief and trauma. It is useful for siblings to be able to talk or meet with other children who have experienced a similar loss.

Research shows that surviving siblings report feelings of isolation, anxiety, depression and neglect. Services to children should:

- Validate the normalcy of their feeling and reactions. Neighbors, teachers, peers and community may not validate a child's grief.
- Acknowledge the circumstances of the death. Waking up to a parent finding a sibling dead, witnessing first responders arriving and the involvement of law enforcement may all increase a child's stress or trauma.
- Take into account their developmental age and understanding of death.

Staff should facilitate communication between parents and child. Parents may be so preoccupied with the death that they are unavailable to the child. How parents process the loss has an impact on how the child processes the loss.

Parents and caregivers need to be alert for danger signs from a child including sleep difficulties, persistent anxiety, frequent emotional outburst, changes in school performance, poor grades, social withdrawal, depression, not eating and obsessive thoughts about the infant or child.

In recognition of the special bereavement needs of children and teenagers, a number of programs have developed to support bereaved children across the nation. These programs may provide counseling and peer support groups for children and resources to the broader community. The losses children and teens may experience include death and divorce. There have also been online bereavement support programs developed for children. These programs provide excellent resources for children as well as parents and caretakers.

## Child Care Providers' Grief

Child care providers may have many unique and powerful feelings after experiencing the death of an infant in their care, including:

- Guilt
- Distrust of their ability to care for children
- Crying spells or depression
- Loss of sleep or appetite
- Over-protectiveness or impatience with children
- Anger, even with the infant who died
- Fear that it will happen again

## Grandparents' Grief

Grandparents of infants who have died have a special role when an infant death occurs. While they provide critical bereavement support to parents, they are also grieving themselves. Grandparents may neglect their own grieving to focus on their bereaved child's needs. Grandparents may feel pain over the loss of the grandchild but also helplessness and frustration in the face of their child's pain and anguish. Grandparents may need information about what to expect during their child's bereavement process in order to support their child. It is important to also note that grandparents may also be the primary caretakers of the infant.

## Complicated Grief

Before grieving can be labeled normal, disturbed or distorted, there must be an understanding of what the loss means to the bereaved and how their thoughts, feelings and actions attempt to cope with or avoid that loss.<sup>10</sup>

The distinction between the normal range of grief reactions and extreme reactions should always be made by a health care professional. Sometimes, family members may experience extreme reactions to their grief, called complicated grief. Screening and treatment for Post-Traumatic Stress Disorder (PTSD) may be needed for parents and children who have experienced a sudden death because they are at higher risk of traumatic stress and complicated grief.<sup>11</sup>

Referrals for mental health services might be necessary if a family member:

- Indicates that he/she wants to kill himself/herself. Although many family members feel this way at times, someone who describes how, when or where

he/she would commit suicide should be referred to a suicide prevention hotline or crisis intervention service immediately.

- Fears that he/she will hurt, or confesses that she has hurt, their spouse or a surviving child. This situation also calls for immediate attention.
- Seems continually anxious or depressed, especially if he/she tells or hints that he/she is unable to care for her home or family.
- Continually uses alcohol or drugs—prescription, over-the-counter or illegal—to alter his/her mood, induce sleep or numb pain.
- Says that he/she has, or appears to have, gained or lost over 25 pounds.
- Frequently expresses relief or indifference over the infant’s death.
- Continually blames him/herself or another person for the child’s death. Persistent relationship difficulties with spouses, surviving children or extended family members may also indicate the need for referral to professional assistance.

A single or occasional occurrence of most of these situations is usually not a cause for great concern. However, if repeated over a period of weeks or months, these reactions may indicate that a family member is experiencing complicated grief and might best be served by a medical or counseling professional.

### **Guidelines for Working With Suicidal Family Members**

Be aware that many family members will occasionally express thoughts that may initially sound alarming, such as “I just want to be with my child “ or “Life’s not worth living anymore now that my child is gone.” The vast majority of the time, however, the family member has absolutely no intention of acting on these thoughts.

Crisis intervention professionals often employ steps which follow the acronym S-L-A-P:

- **S - Specificity:** How specific is the plan? Does the family member say, “I don’t know. I’ll take some pills or something” or do they say “I’m going to use a gun and I will do it after the kids are at school. I’ll send the kids to my mother’s after school so they won’t find me.” The more specifics they can give you about her plan, the higher the risk.
- **L - Lethality:** How lethal is the method they have chosen? Some methods have a higher failure rate or allow more time for rescue than others.
- **A - Availability:** How readily available to her is the method? “I’m going to use a gun. It’s in my husband’s third drawer under his socks. The bullets are in the closet” or “I have an open bottle of sleeping pills here in my hand” are much more dangerous than “I was thinking of going out to buy a gun this afternoon.”
- **P - Proximity:** What is the family member’s proximity to help? Is help nearby or will someone be returning home soon? Or have they gone (or plan to go) somewhere isolated or selected a time when they know they will be alone for some time.

### **Culturally-Competent Support Services**

Across all cultures, the parent-child relationship is, and has been, the most enduring and significant.<sup>12</sup> Parents’ cultural and religious background influences their views on death,

perinatal death, burial and cremation and the grief and mourning process. Even when parents and families are assimilated into life in the United States, they may rely on their cultural backgrounds and traditions when a death occurs.

Culturally-appropriate bereavement care requires open and respectful communication. Such communication is difficult when there are cultural differences between the family and health care providers. The difficulty may be increased when language, religious and class differences also exist. Some areas where differences may occur include:

- Meaning and understanding of the cause of death
- Value of the infant or child
- Meaning of pain and suffering
- Role of the family in the decision-making process
- Appropriate role of the health care professional
- Care of the body after death
- Appropriate expressions of grief

There are other considerations that impact provision of bereavement services to families. The existence of health disparities means that some groups experience deaths from different causes than others. African Americans and Native Americans have a higher proportion of deaths from causes such as SIDS, prematurity and asthma than Whites. Disparities also exist in access and use of support services.

It is important to respect that racial/ethnic groups tend to rely on well-established community resources, such as religious congregations, extended family and ethnic community centers, for bereavement support instead of participating in the SIDS-specific bereavement programs offered by State health departments and nonprofit organizations.

The lack of linguistically-competent services in Spanish and other languages is also a barrier to supporting families. Pediatric service providers must be prepared to meet the diverse cultural and linguistic needs of families.

Service providers are also impacted by changes in the overall U.S. population. There are an increasing number of nurses, social workers and other health care providers who are immigrants or members of minority groups. The varied backgrounds of care providers influence their expectations of appropriate bereavement care for families.<sup>13</sup>

To assure that minority families receive appropriate bereavement support, community service providers who traditionally work with bereaved families need to be identified and provided with the appropriate information specific to SIDS/SUID. As with the delivery of risk reduction messages, encouraging greater involvement by community leaders and families is the best chance for impacting the lives of families within any racial/ethnic group.

## **Provision of Culturally- and Linguistically-Appropriate Bereavement Support**

Program staff must be able to address the bereavement needs of a diverse population. To meet the needs of underserved populations in receiving culturally-appropriate bereavement support, programs should:

- Work with representative community organizations to prepare and disseminate

materials.

- Provide leadership and resources for recruitment and retention of persons of color.
- Provide training on cultural competency and health problems associated with particular ethnic groups.
- Ensure translation of materials and services into other languages.
- Support local ethnic group support providers such as funeral homes and faith institutions.

Funeral homes are a major provider of bereavement support in many underserved communities. Funeral directors have an important role in providing an early positive outlet for grief, knowledge of existing local resources to assist a family in making arrangements, planning the funeral services and assistance to the parents in their return to work.<sup>14</sup>

## Religious, Faith and Spiritual Support

Spiritual and religious beliefs can also play an important role in the grief process. Parents' beliefs can provide comfort and hope during such a difficult experience for parents. Families may also question their religious beliefs at this critical time in their lives and blame God for the loss of their infant. Members of the clergy and faith-based organizations can play an important role in helping families maintain their faith and accept the death.

Many parents, grandparents and caregivers will seek leadership and guidance as preparations are made for the funeral of their infant, after-care for the family and other ministerial support. Families may look to their faith leader to serve as a consoling counselor, biblical reference and anger manager. Because family members may question their religious and spiritual beliefs, the clergy play an important role in helping families maintain their faith.

Hospitals often have chaplains who provide spiritual comfort to families after the death of a child. Because many SIDS deaths are pronounced at the hospital, a chaplain may be available to the family. The role of spiritual care in patient care is recognized in hospital accreditation standards.

Ongoing support is often provided to families through bereavement support groups sponsored by faith-based organizations. The groups usually meet at the organization's facilities and vary in format. These may be facilitated by trained volunteers. They aim to provide a safe haven where the bereaved can share their feelings.

Clergy and volunteers report that training on support after an infant death is rare. Clergy and volunteers may also lack training in identifying complicated grief or major depression. To improve services to families or to expand bereavement support within the community, program staff can conduct education and training to members of faith-based organizations about infant death, signs and symptoms of major depression or complicated grief and providing mental health referrals. There are many national faith organizations and resources available to assist professional, clergy and laity and bereaved families.

## Community-Based Bereavement Services

Today, the level and type of support provided to SIDS families varies greatly nationwide depending on a State's SIDS service history, existing legislation, State funding, advocacy efforts, partnerships and health care facilities. While all States receive Title V funding,

which can be used to support SIDS/ID services, there is enormous variation between State program models in providing bereavement support. There are three general models:

1. Program staff directly provide services using public health nursing or social workers at the local or State level. (For example, Tennessee and Mississippi)
2. States use sub-contracts to one or more community-based organizations, health centers or academic institutions to provide bereavement support. The State programs' role then becomes to administer and oversee the grant or contracts. Programs also provide leadership for the development of resources to maintain or expand service provision. (For example, Georgia and California)
3. Programs collaborate with other health organizations such as Healthy Start or FIMR that incorporate bereavement support into their existing services. (For example, Florida and Kansas)

Typical family support services provided or funded include:

- Hotlines
- Information and referrals
- Bereavement packets
- Home visits
- Peer support
- Web sites
- Bereavement support for professionals

## Information and Referrals

Funding for a community-based system of supportive services to bereaved families after a SIDS death included information and referral systems to inform families of services available to them. To develop and facilitate such referrals, a SIDS education and awareness effort for death investigators and first responders was initiated.

Generally, it is financially prohibitive for programs to operate a dedicated toll-free crisis or information hotline. Local or State programs may fund nonprofit hotlines to provide information and referrals to facilitate access to bereavement services. These hotlines often connect callers to a national hotline after hours or to local peer support contacts.

If you do not have your own toll-free number, you can publicize national ones such as First Candle's (800-221-SIDS) or the American SIDS Institute's (800-232-SIDS) which operate 24 hours a day. A cost-effective alternative is for State or local programs to ensure that updated service information is provided to all existing community services resource directories and hotlines.

It is important to make referrals to counseling and bereavement services in the area where the family lives. You may want to develop a bereavement resource directory identifying counselors, funeral home aftercare programs, hospital- or community-based bereavement programs, mental health professionals or clergy who are willing to assist grieving families in your service area, whether it be local, regional or Statewide.

In some States, the medical examiner/coroner either makes a referral to a SIDS program or provides information to the family from a local SIDS program. In such systems, only those families who consent to contact will be referred to a SIDS program. However, a

few systems provide the local SIDS program with the names of all SIDS families while simultaneously informing the families that their names have been forwarded.

Many States and counties do not have an organized referral system in place. In these areas, local SIDS programs generally receive referrals to newly-bereaved SIDS families from the medical examiner/coroner, hospital personnel, police department, social workers, service agencies, funeral directors, clergy or families themselves.

If program staff are concerned about the type or number of referrals made to their program, staff should examine how current referrals are made and consider conducting a survey of local hospitals, funeral directors, emergency personnel or other key responders to see how and to whom they are presently referring grieving families.

A common barrier to providing referrals to families is confidentiality. Although all deaths are a matter of public record, public agencies may try to protect newly-bereaved families by sharing limited information on families. For information on the impact of the Health Insurance Portability and Accountability Act (HIPAA) see [The FIMR Process and HIPAA](#) and [www.hhs.gov/ocr/hipaa](http://www.hhs.gov/ocr/hipaa). Program staff need to develop partnerships and relationships with those responding professionals and agencies that have this information to identify newly-bereaved families.

Typical contacts may include:

- Coroners, their investigators, pathologists and secretarial staff
- Hospital personnel
- Community physicians
- First responders and prehospital professionals (police, EMTs/paramedics, fire personnel)
- Funeral directors and aftercare bereavement coordinators
- Clergy
- Community mental health professionals
- [Healthy Start](#) programs
- Bereavement organizations
- Hospital genetics program personnel
- Fertility program personnel

These local professionals can be contacted with a letter of introduction or brochures that describe your program's supportive services. These letters should be followed up with a personal meeting or telephone call to ask for their assistance in referring newly-bereaved families to your organization.

While notification within the 24- to 48-hour period following a sudden and unexpected infant death is ideal, often it may take longer before notification is made. Due to changes in the diagnostic process, families may not know the infant's final cause of death for several weeks or months, and program staff should be prepared to offer services and support while the family waits for the diagnosis.

## Family Contact

After a referral is made, staff may provide initial contact by a letter of condolence or

telephone call and offer information and referrals to peer- and professional-support systems. Families may be provided with a brochure or fact sheet detailing services and appropriate contact information. Often this type of outreach includes follow-up contacts and community education.

Program staff should also be prepared to send contact information to the infant's extended family and the family's friends and co-workers. Child care providers, grandparents and siblings are often ignored grievers, but counseling and information should be made just as available to them.

It is not always possible to locate all identified grieving families. Some families choose not to return to the site of the death and move to a new location very quickly following the death. It is also important to be aware that some grieving families may refuse your offers of support. Be respectful but prepared to assist them at a later time if they choose.

Families often have a strong support network of family, neighbors, co-workers, friends, community and religious affiliations immediately after an infant death. This system may experience a breakdown within a few of months. It is important for programs to continue to remind families that the program's services are available throughout the first year and beyond. These reminders may be in the form of letters, cards or telephone calls.

Families may display various reactions to an offer of support. Some will seek you out and want immediate attention and answers to their questions. More commonly, families display some apprehension and, on occasion, become defensive and avoid contact altogether. These reactions are often based on a variety of emotional, environmental and cultural factors surrounding the issue of death and professional intervention.

## Home Visits

Visiting the family at home may be useful to:

- Supply the family with information about SIDS.
- Answer, or provide resources for, any medical questions the family may have.
- Discuss the death with family members and assess how they appear to be handling the loss.
- Determine whether the family needs assistance from social service or health care professionals or agencies.

The best person to follow up on a sudden infant death is a compassionate person who makes the effort to go to where the family is, both physically and emotionally. To provide effective support for families, staff should thoroughly understand the issues facing bereaved parents as they work through the grief of losing their infant.

Staff training for home visits should include:

- The psychological and emotional reactions of grief and the impact that the death has on the family system.
- How to respond to the emergency and support parents through the crisis.
- Practical techniques to help themselves and others cope with SIDS.
- A discussion about taking care of themselves as a health professional and available resources.
- Understanding normal grief reactions.

- Understanding their own feelings and reactions about death.
- Knowledge of signs and symptoms of abnormal reactions.
- Knowledge of any special circumstances related to the sudden and unexpected death of an infant.
- Knowledgeable of national, State and local bereavement programs and resources.

The accompanying trainer's guide includes the following bereavement training curriculums:

- Public health nurses
- First responders and emergency service personnel
- Child care trainers and providers
- Community groups

## Counseling

While there are SIDS-dedicated bereavement counseling programs, they are the exception and most families do not receive bereavement counseling through such programs. There are a wide variety of community bereavement providers such as grief assistance programs, hospitals, hospices, funeral grief programs and spiritual/religious organizations that are available for families. Counseling can be short- or long-term depending on the family's needs.

The provision of counseling with a family may have an important impact on families' grieving process, recovery and coping. Counseling may reduce the development of Post-Traumatic Stress Disorder (PTSD) by addressing the circumstances of the infant's death leading to a lessening of fear and anxiety.<sup>15</sup> Counseling is also effective when a parent is experiencing complicated grief.

A good resource for program staff is [ASIP's Bereavement Counseling for SIDS and Infant Mortality: Core Competencies for the Health Care Professional](#).

## Peer Contact Programs

SIDS families often find the services of a peer contact comforting. A peer contact is a parent, foster parent, grandparent, other relative or child care provider who has experienced the death of an infant due to a sudden unexplained death. Peer contacts are volunteers who give their time to contact grieving family members and offer support.

A peer contact has good active listening and coping skills, empathy and compassion and a non-judgmental attitude. Peer contacts provide support through telephone calls, written notes and e-mails. The purpose of peer contact programs is to provide insight, hope, information and objectivity to grieving families through someone who has had a similar loss.

## Peer Support Groups

There are many models of peer support or self-help groups that provide bereavement support to families. Support groups can be sponsored by SIDS/ID programs, faith organizations and nonprofit organizations. In general, they offer bereaved parents and others encouragement, sympathy, practical help and support from others who have also

had similar losses. It can be very helpful for the grieving to see others who have survived similar losses.

Dr. C. Everett Koop, the former U.S. Surgeon General, participated in a [Compassionate Friends](#) support group after the death of his son. He actively supports the use of self-help groups for parents to assist them with their stress, hardship and pain. Faith institutions may offer bereavement support groups that are facilitated by pastoral counselors or trained volunteers.

Support groups can be led by trained professionals or by parents. There are many resources and training opportunities available to assist staff to start up or improve support groups.

## Internet Support Programs

There are increasing numbers of Internet-based bereavement programs that provide bereavement support for families. The Internet can be an asset for families who may be unable to access services due to geographic or time constraints. In addition, the Internet is very helpful for parents seeking parent-to-parent support and support for siblings of infants or children who have died.

There are many well-established national bereavement programs that provide Internet bereavement support as part of their service continuum for families. They provide excellent educational materials, resources and supports to families. There are also a growing number of Internet bereavement programs that only provide Internet support. Web sites often have numerous loss-specific groups that parents can join. Typical services include:

- **Chat Groups/Rooms**, which allow real-time exchange
- **Message Boards**, which allow parents to read and write messages to others
- **Listservs**, which is a private e-mail group for parents to read and write messages

SIDS/ID programs may wish to start their own Internet-based support community or publicize national or local organizations. Although the Internet is used for bereavement support, there are no standards of care for such programs. Reviews of Web sites have found that most online resources do not address the needs of the poor, low-literacy readers or non-English-speaking populations. However, Internet usage is quickly growing among these populations and the families with incomes of less than \$25,000.<sup>17</sup>

## Professional Support

Recognition of stress is a key part of successfully coping with the stress and maintaining a healthy mental attitude. Stress is an inescapable part of the job of a SIDS/ID professional. The death of a child may be the most stressful situation in a program staff member's career. Professionals may appear anxious and fearful of having to experience this again. Feelings of denial, helplessness and burnout are all very common. Some professionals may even reevaluate their profession.

What can help prevent these symptoms is debriefing with peers and being able to freely share the experience with others and work through any blocks that may interfere with responsibilities. Private counseling may be useful, especially in the absence of consistent and available support.

## Bereavement Support Resources

<b>Bereaved Children</b>	American Academy of Child and Adolescent Psychiatry's <a href="#">Facts for Families</a> including <a href="#">Children and Grief</a>	<a href="http://www.aacap.org">www.aacap.org</a>
	Don Imus Ranch	<a href="http://www.msnbc.msn.com/id/3359675">www.msnbc.msn.com/id/3359675</a>
	Fernside's <a href="#">Resources for Educators and Literature</a>	<a href="http://www.fernside.org">www.fernside.org</a>
	Hospice Net's <a href="#">articles on children and death</a> including <a href="#">Talking to Children About Death</a> , <a href="#">Helping Young Surviving Children, Children and Grief</a> , <a href="#">Helping Teenagers Cope with Grief</a> , <a href="#">Children's Understanding of Death</a>	<a href="http://www.hospicenet.org">www.hospicenet.org</a>
	National Funeral Directors Association's <a href="#">information on explaining death to children</a>	<a href="http://www.nfda.org">www.nfda.org</a>
	The Dougy Center for Grieving Children and Families provides <a href="#">grief support and training</a> nationally to individuals and organizations that assist children grieving the death of a loved one. Information on <a href="#">resources</a> , training opportunities and <a href="#">locations of centers</a> can be found on their Web site.	<a href="http://www.dougy.org">www.dougy.org</a>
<b>Bereavement Guidelines for Professionals</b>	National SIDS and Infant Death Program Support Center's <a href="#">Bereavement Guidelines for Health Professionals, Funeral Directors and Clergy</a>	<a href="http://www.firstcandle.org/health/health_human.html">www.firstcandle.org/health/health_human.html</a>
<b>Bibliographies</b>	NSIDRC's <a href="#">bibliographies</a>	<a href="http://www.sidscenter.org">www.sidscenter.org</a>

## Bereavement Support Resources

<b>Child Care Provider's Grief</b>	Caregivers Hurt, Too—a video about a SIDS death that occurs with a child care provider. This video reenacts a SIDS death in a child care setting, describes the emotional trauma providers experience and includes information on support and resources. Emergency procedures, the investigative process and strategies to reduce the risk of SIDS are also presented. This video was produced by Gina Clement and the Maryland SIDS Information and Counseling Program.	<a href="http://www.infantandchildloss.org">www.infantandchildloss.org</a>
<b>Counseling</b>	Association of SIDS and Infant Mortality Programs' Bereavement Counseling for Sudden Infant Death Syndrome (SIDS)	<a href="http://www.asipl.org">www.asipl.org</a>
	MISS Foundation's "Power of Compassion: A Phenomenological Approach to Child Death"	<a href="http://www.missfoundation.org">www.missfoundation.org</a>
<b>Culturally-Competent Bereavement Support</b>	National Fetal Infant Mortality Review Program's <i>When an Infant Dies: Cross-Cultural Expressions of Grief and Loss</i>	<a href="http://www.acog.org/departments/dept_web.cfm?recno=10">www.acog.org/departments/dept_web.cfm?recno=10</a>
<b>Faith-Based Support</b>	Bereavement Ministry Program: A Comprehensive Guide For Churches	By Jan Nelson and David Aaker
<b>Faith-Based Support: Catholic</b>	National Catholic Ministry to the Bereaved, a <a href="#">membership</a> organization, that provides <a href="#">resources</a> and <a href="#">training</a> to support the bereavement ministry	<a href="http://www.griefwork.org">www.griefwork.org</a>
<b>Faith-Based Support: Christian</b>	Mourner's Path provides training for laity and clergy in Christian bereavement support.	<a href="http://www.mournerspath.com">www.mournerspath.com</a>
<b>Faith-Based Support: Jewish</b>	Jewish Women's Network provides a <a href="#">bereavement booklet</a> for women and aims to make Jewish tradition accessible.	<a href="http://www.jwn.org.uk">www.jwn.org.uk</a>

## Bereavement Support Resources

<b>Faith-Based Support: Jewish</b>	Judaism 101 provides information on <a href="#">death and mourning</a> from an Orthodox Jewish perspective.	<a href="http://www.jewfaq.org">www.jewfaq.org</a>
	The Jewish Bereavement Project provides books, links and resources on infertility, <a href="#">pregnancy and infant losses</a> , laws, customs and bereaved children.	<a href="http://www.jewishbereavement.com">www.jewishbereavement.com</a>
<b>General</b>	American Academy of Bereavement/CMI Education Institute	<a href="http://www.bereavementacademy.org">www.bereavementacademy.org</a>
	Association of SIDS and Infant Mortality Programs' Infant Mortality: Core Competencies for the Health Care Professional	<a href="http://www.asip1.org">www.asip1.org</a>
	Compassion Books has more than 400 resources to help children and adults with grief and bereavement.	<a href="http://www.compassionbooks.com">www.compassionbooks.com</a>
	Institute of Medicine's <a href="#">When Children Die: Improving Palliative and End-of-Life Care for Children and Their Families</a>	<a href="http://www.iom.edu">www.iom.edu</a>
	MISS Foundation has various resources including a <a href="#">downloadable funeral planner</a> .	<a href="http://www.missfoundation.org">www.missfoundation.org</a>
	National SIDS and Infant Death Resource Center's educational materials	<a href="http://www.sidscenter.org">www.sidscenter.org</a>
<b>Grandparent's Grief</b>	Alliance of Grandparents, A Support in Tragedy (AGAST), is an all-volunteer organization dedicated to helping grandparents through the trauma, stress and grief after the loss of a grandchild. Their Web site provides resources to help grandparents including packets of information on dealing with grief and helping their children, a newsletter and peer support for grandparents.	<a href="http://www.agast.org">www.agast.org</a>

## Bereavement Support Resources

<b>Home Visits</b>	Grief Counseling and Grief Therapy: A Handbook for the Mental Health Professional	by J. William Worden
	National Fetal Infant Mortality Review Program's <a href="#">A Guide for Home Interviewers</a>	<a href="http://www.acog.org/departments/dept_web.cfm?recno=10">www.acog.org/departments/dept_web.cfm?recno=10</a>
	Sudden Infant Death Network of Ohio's <a href="#">A Guide for the Sudden Infant Death Home Visit</a>	<a href="http://www.sidsohio.org">www.sidsohio.org</a>
<b>Internet-Based Support</b>	Bereaved Families Online	<a href="http://www.bereavedfamilies.net">www.bereavedfamilies.net</a>
	Bereaved Parents of the USA	<a href="http://www.bereavedparentsusa.org">www.bereavedparentsusa.org</a>
	Grief Net	<a href="http://www.grief.net">www.grief.net</a>
	Growth House	<a href="http://www.growthhouse.org">www.growthhouse.org</a>
	KidsAid	<a href="http://www.kidsaid.com">www.kidsaid.com</a>
	MISS Foundation	<a href="http://www.missfoundation.org">www.missfoundation.org</a>
	The Sudden Infant Death Syndrome Network	<a href="http://www.sids-network.org">www.sids-network.org</a>
	Compassionate Friends	<a href="http://www.compassionatefriends.org">www.compassionatefriends.org</a>
	The Sudden Unexplained Death in Childhood (SUDC) <a href="#">Peer Contact Program</a>	<a href="http://www.sudc.org">www.sudc.org</a>
<b>Internet-Based Support: English/Spanish</b>	Grief Recovery Online	<a href="http://www.groww.org">www.groww.org</a>
<b>Internet-Based Support: Quality of Services</b>	Innovations in End-of-Life Care, Yvette Colon, MSW, ACSW, BCD	<a href="http://www.edc.org/lastacts">www.edc.org/lastacts</a>
<b>Peer Contact</b>	First Candle/SIDS Alliance Peer Contact Manual and National Peer Contact Program	<a href="http://www.firstcandle.org">www.firstcandle.org</a>

## Bereavement Support Resources

<b>Peer Support</b>	Center for Loss and Life Transition	<a href="http://www.centerforloss.com">www.centerforloss.com</a>
	The American Self-Help Clearinghouse, Northwest Covenant Medical Center	<a href="http://www.mentalhelp.net/selfhelp">www.mentalhelp.net/selfhelp</a>
<b>Pregnancy and Neonatal Loss</b>	Hygeia provides reference and links for pregnancy and neonatal loss	<a href="http://www.hygeia.org">www.hygeia.org</a>
<b>Support Groups</b>	Bereavement Support Group Guide: Guidebook for Individual or Professionals Who Wish to Start a Bereavement, Mutual, Self-Help Group	by Margaret Pike, RN, MSN, EdD, and Sara Rich Wheeler, RN, BS, MSN 800-252-3775
<b>Support Materials</b>	RTS Bereavement Services	<a href="http://www.bereavementprograms.com">www.bereavementprograms.com</a>
	First Candle/SIDS Alliance's materials including <a href="#">State grief resources</a>	<a href="http://www.firstcandle.org/whenababy/whenababy.html">www.firstcandle.org/whenababy/whenababy.html</a>
	March of Dimes	<a href="http://www.marchofdimes.com/pnhec/572_3997.asp">www.marchofdimes.com/pnhec/572_3997.asp</a>
	NSIDRC	<a href="http://www.sidscenter.org">www.sidscenter.org</a>
	SIDS Survival Guide	by Joani Nelson Horchler and Robin Rice Morris

# Training

**Critical Program Function:** To help ensure the capacity and competency of the personnel involved in SIDS risk reduction and bereavement services.

Training for professionals and the community is a key component of educational outreach efforts for SIDS/ID programs to undertake within their communities. Programs often provide information and training to health and human service professionals—such as first responders, child care providers, nurses and physicians—to raise the level of awareness of SUIDs in the community and to improve overall services to families.

HRSA/MCHB recognized this need and provided funding for a comprehensive SIDS/ID training guide which includes specific PowerPoint presentations by subject matter for targeted professionals, including child care providers, public health nurses, newborn nursery nurses, EMS providers and first responders focusing on skill-enhancements trainings. NSIDPSC will be working closely with HRSA/MCHB to review and update the information as needed.

## Risk Reduction Training

Risk reduction education needs to be far more comprehensive than simply stating that “back is best.” Presentations, depending on the audience, must include appropriate evidence-based information which discusses sleep safety for infants as well as information to promote protective factors for overall infant health and safety such as breastfeeding. Risk reduction efforts need to be cross-culturally-competent and relevant.

Program staff activities may include:

- Ensuring access for staff to continuing education.
- Acting as an advocate for the training needs of local health care providers.
- Providing, funding or co-sponsoring training for local community-based programs, health departments, managed care organizations, hospitals and others.
- Collaborating with ethnic organizations, civic organizations and private providers to address training needs with respect to cultural competency.
- Collaborating with State professional organizations to support continuing education courses, especially those on underserved and minority populations.
- Developing trainings that take a multi-disciplinary approach and work with families

and professionals from a wide range of backgrounds.

- Providing discipline-specific training such as trainings for child care providers and public health nurses.

## Bereavement Support Training

Professional education is needed to support bereavement care that is competent, continuous and coordinated. Because most infant and child deaths are sudden and unexpected, specialized training is essential for a number of health care professionals including first responders, emergency department nurses, labor and delivery nurses, newborn nursery nurses, NICU nurses, palliative care nurses, child care providers, physicians, social workers, program managers, fetal infant mortality review staff and genetics counselors.

State program staff activities may include:

- Ensuring access for staff to continuing education in bereavement counseling and information.
- Acting as an advocate for the training needs of local health care providers.
- Providing, funding or co-sponsoring training for local community-based programs, health departments, managed care organizations, hospitals and others.
- Collaborating with ethnic organizations, civic organizations and private providers to address training needs with respect to cultural competency.
- Collaborating with State professional organizations to support continuing education courses, especially on underserved and minority populations.
- Developing trainings that take a multi-disciplinary approach and work with families and professionals from a wide range of backgrounds.
- Providing discipline-specific training such as trainings for child care providers, public health nurses, first responders and EMTs.
- Coordinating peer contact support and providing training and education to individuals willing to become peer contacts.

The majority of children who die are transported to hospitals or clinics. As such, hospitals need to develop protocols for informing and counseling parents whose children have died. The [National Association of Social Workers](#) has developed [bereavement guidelines for social workers in emergency room settings](#) to assist staff in addressing sensitive issues such as medical examiner referrals, organ and tissue donation, funeral home identification, notification of family, completion of death records and release of the body.

## SIDS/ID Trainer's Guide

The trainer's guide that accompanies this manual includes comprehensive information on SIDS trainings for both risk reduction and bereavement. The guide was designed to provide trainers with the necessary skills, knowledge and materials to conduct effective trainings for multiple audiences on reducing the risk of sudden and unexplained infant death and how to cope with sudden and unexplained infant death.

PowerPoint presentations addressing specific audiences and learning objectives are included as part of the guide. The slides and handouts include the latest national data

available on infant mortality and SIDS. Sample State data slides have been provided with suggestions on how to obtain similar data for your State. Custom presentations have been developed for specific audiences:

- Child care providers (both center- and home-based)
- Child care trainers
- Newborn nursery personnel
- Public health nurses
- First responders and EMS personnel
- Community groups

## **Child Care Trainers and Providers**

### **Risk Reduction Training for Child Care Providers**

It is estimated that 48 percent of infants are in child care for some part of their day. Child care encompasses babysitters, grandparents and other relatives in addition to licensed centers, family-based centers, informal centers and other related organizations. In 1997, researchers found that more than 20 percent of SIDS deaths were occurring in child care settings, more than double what is expected given the number of infants in child care at any given time.

In addition, one-third of these deaths occurred within the infant's first week and one-half of these deaths occurred on the infant's first day in child care. It was also discovered that of the infants who died, 59.5 percent of these infants were found on their stomachs but were usually placed to sleep on their backs. This is called unaccustomed prone sleeping, which is a contributing factor to the high rate of SIDS in child care settings.<sup>1</sup>

Research indicates that many child care providers would benefit from health and safety information which includes an increased awareness of the BTS messages. Child care providers often have misconceptions about aspiration and place infants to sleep based on prior experience, ideas related to infant comfort and parental preference. It is clear that child care provider trainers need to supply child care providers with the tools and skills they need to practice infant sleep safety measures within their settings.

Prior to 1998, most States did not legislate/regulate sleep position for infants in child care settings.<sup>2,3</sup> In 2002, [Healthy Child Care America](#) and NSIDPSC partnered in the development and release of a free SIDS risk reduction curriculum for child care providers, which has since been translated into Spanish, based on the [National Caring for Our Children National Health Safety Guidelines](#). Since publication of research and programming began, 30 States have implemented SIDS risk reduction regulations and legislation for child care settings. However, training and enforcement of the regulations remains undocumented.

The Web site of the [National Resource Center for Health and Safety in Child Care](#) (NRC) provides each State's [licensing requirements](#). The resource center's Web site also offers a publication of national standards on reducing the risk of SIDS, based on [National Caring for Our Children National Health Safety Guidelines](#), second edition. The information is geared toward assisting States in drafting licensing requirements to reduce SIDS rates.

To have the most impact and most effectively use time, energy and resources, staff should ideally target trainings to child care trainers. Many child care centers have designated

trainers who train center staff on a variety of topics. Home-based center providers, kin care providers and more informal child care providers might be members of local or regional associations which have trainers that provide continuing education and contact hours at specific meetings and dates. Training the trainers will increase the capacity of the message and curtail the SIDS/ID programs' workload. The other option is to directly train child care providers.

### **Bereavement Sensitivity Training for Child Care Providers**

As previously discussed, the number of infants who die in child care settings has grown with the increase in the use of child care providers, child care centers and informal child care providers (grandparents, extended family, unlicensed child care providers). Therefore, it is important to provide skill development training in the area of bereavement information to these providers.

## **Newborn Nursery Personnel**

### **Risk Reduction Training for Newborn Nursery Personnel**

Newborn nursery staff and nurses perform an essential service in our society. New parents often look to this staff to guide them in infant health care and practices that will provide the best start in life for their new baby. The newborn nursery staff skills update PowerPoint presentation addresses not only risk reduction messages but the importance and opportunities for patient education and modeling best practices to patients and clients.

Research shows that while most nurses are aware of the AAP's back sleep recommendation, they may not actually follow these recommendations. A 1999 study showed that while 97 percent of the MCH nurses surveyed reported awareness of the recommendation, only 67 percent agreed. The majority of the nurses who disagreed cited "experience" or "the potential adverse consequences of the supine position" as their reasons for disregarding the recommendations.<sup>4</sup> Studies have also found that newborn nursery staff do not uniformly recommend the supine position to families.<sup>5,6</sup>

A California study conducted at eight perinatal hospitals found that only 34 percent of the nursery staff reported consistently encouraging mothers to practice supine infant sleep positioning.<sup>7</sup> Another study found that nurses with fewer years of experience are more likely to encourage parents to use the back-only position. Nurses with more years of experience do not use or recommend this position primarily because they believe infants do not sleep well in that position.<sup>8</sup>

Physicians, neonatal intensive care nurses and other medical professionals remain uncomfortable recommending non-prone sleeping for VLBW infants despite the AAP's recommendation and the physiological data to support it.<sup>9</sup> Nurses in both well-baby units and NICUs report skepticism of the BTS message because of fear of aspiration. However, it is clear that there has been no increase in the number of infants who die of aspiration from being placed in the supine position.<sup>10</sup>

In addition, nurses do not always realize their impact on parents' decision regarding sleep position. Modeling suggested behaviors, such as back sleeping, can be a powerful educational tool in conjunction with written educational materials.

Many hospitals offer in-service continuing education and human resources departments will often have staff dedicated to in-service seminars. A large barrier and limitation is staff time. Hospitals and nurses continue to experience a shortage of staff and time. Therefore,

it will be important to look for ways to work with hospital's administration to make training a priority for staff and within the constraints of various schedules.

### **Bereavement Sensitivity Training for Newborn Nursery Personnel**

How professionals interact with families has a direct impact on bereaved parents' feelings of support and comfort.<sup>11</sup> Today, nurses are one of the key health professionals to play an important role with families when an infant dies.

In hospitals and clinic settings, nurses provide bereavement support to families when a SIDS death or fetal loss occurs. Hospital nurses provide crisis support to families often within moments of an infant's death because most SIDS infants are transported directly to emergency rooms. Obstetrical nurses support families when a stillbirth or neonatal death occurs.

This presentation is useful for the emergency department, labor and delivery, newborn nursery nurses and NICU staff. It will provide hospital staff with greater understanding when dealing with families who have experienced the death of an infant. Often, pastoral care or a social worker will be called in to assist the family, but it will be nurses that will be caring for the families initially. Therefore, they need to be prepared appropriately.

### **Public Health Nurses**

#### **Bereavement Sensitivity and Support Training for Nurses**

After a family leaves the hospital or clinic, it is often nurses who provide home visits and other services to bereaved families. This may include helping families to understand the grieving process, identifying the differences between grief and depression, connecting with medical care and local resources and providing guidance on medical care, returning to work and planning for future children.

However, nursing training and education do not always prepare nurses to support families after a loss. During trainings conducted by NSIDPSC staff in Tennessee and Mississippi, nurses expressed feelings of limited preparation for meeting the challenge of supporting families in the initial and continuing grief process. If they are uncomfortable, nurses may avoid parents in the hospital and community nurses may avoid making home visits to bereaved families. To better support families and staff, training on appropriate bereavement support is needed for nurses.

### **First Responders and Emergency Medical Services Personnel**

#### **Risk Reduction Education for First Responders and Emergency Medical Services Personnel**

SIDS education and awareness continue to be a crucial component for first responders and EMTs. In many rural areas, first responders provide many preventive health services and information such as injury safety and immunizations. With the current health care system and the fact that some uninsured populations access emergency service personnel for health care services, it is apparent that emergency medical personnel have a greater opportunity to provide information to their communities regarding risk reduction and infant sleep safety.

## Bereavement Sensitivity Training

First responders and EMTs will require greater focus on information related to bereavement because they will be dealing with the deaths of these infants immediately. The PowerPoint presentation provides greater detail on how to deal with families in a compassionate and thoughtful manner during the crisis as well as enhancing the skills of first responders when dealing with families such as:

- **Comfort, never blame.** The role of the prehospital professional in the setting of unexpected infant or child death is difficult. After death has been determined, prehospital professionals should comfort the parents and never blame. Offering sensitive support to the family and gathering accurate information in a non-threatening manner helps to alleviate the future emotional burden of the surviving family members. This may be challenging, because the professional may be struggling with overwhelming personal emotional responses to loss of a patient.
- **Long-lasting impact on parents.** Everything that a prehospital professional says and does has a long-lasting impact on parents. Parents will carry what are called “flashbulb memories” for many years. Every detail of the SIDS event will be remembered, including what emergency personnel say and do. Prehospital professionals should take care that you do not appear judgmental or blaming. Phrasing of history questions which suggest responsibility must be avoided. Misguided statements such as “looks like the baby might have suffocated” are very harmful and are inappropriate. Prehospital professionals should not diagnose or declare death.
- **Assist parents with transportation.** Prehospital professionals should allow one parent to remain with the baby during transportation to the hospital and, if possible, arrange for the other parent to be driven to the hospital, help the parents secure the home and arrange for someone to care for any siblings.
- **Notify the hospital so that bereavement support is alerted.** The hospital can have a nurse or social worker ready to meet the parents.
- **Show compassion.** Showing compassion and having a sympathetic attitude is very important. There are no rules for dealing with parents’ reactions. Parents can react in many ways—sometimes violent and angry, sometimes shocked and numb. Prehospital professionals should not take things personally and be prepared for expressions of anger and blame.
- **Respect cultural differences.** Sometimes, there is a cultural difference between the prehospital professional and the parent or caregiver and this conflict may appear in unrecognizable rituals and behaviors. This scenario represents another important challenge to the professional. Cultural diversity, if not respected, can deeply endanger the communication with the caregiver.

The presentation also includes information on the pros and cons of transporting suspected SIDS infants, the prehospital professional’s immediate response to an infant death and critical incident stress debriefing.

## Community Groups

### Risk Reduction Education

To reduce SIDS/ID rates further, health professionals must sustain and expand the BTS campaign, address racial disparities, address soft bedding and bedsharing, aggressively

address educational messaging about SIDS and smoking, provide guidance to parents on possibly-protective factors such as pacifiers and breastfeeding and address diagnostic shift and issues surrounding coding causes of death.

There are numerous community groups that would benefit from a SIDS/ID risk reduction presentation. Please refer to [Chapter 7: Partnerships and Collaborations](#) for a listing of some community and civic organizations.

### **Bereavement Sensitivity Training for the Community**

Bereavement, grief and loss are difficult topics for communities to cope with, and even more so if infants and children are involved. This presentation can be appropriately presented for faith-based organizations, funeral directors, racial/ethnic groups, community centers and nonprofit organizations to raise awareness of the unique impact a SUDI poses for the entire community as well as the family. It can serve as a powerful motivator to the risk reduction message.

### **Training Resources**

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<b>African American Communities</b>	NICHD's African American Back to Sleep Training Guide	<a href="http://www.nichd.nih.gov/sids/Resource_kit.htm">www.nichd.nih.gov/sids/Resource_kit.htm</a>
<b>Child Care</b>	Back to Sleep/Healthy Child Care America's Child Care Providers Speaker's Kit in English and Spanish	<a href="http://www.healthychildcare.org/section_SIDS.cfm">www.healthychildcare.org/section_SIDS.cfm</a>
<b>Death Scene Investigation</b>	SIDS Foundation of Washington's Death Scene Investigation Training CD	<a href="http://www.sidsfwa.org">www.sidsfwa.org</a>

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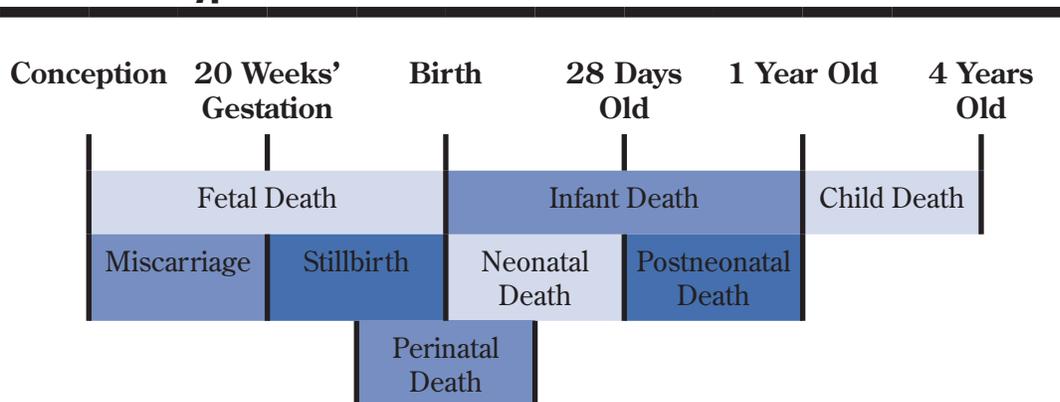
# 4

# Program Expansion

Many State and local SIDS programs have begun expanding the range of services they provide while preserving specific emphasis on SIDS services. Depending on local resources and community needs, organizations may include fetal deaths as well as deaths of children up to the age of 4.

These SIDS programs continue to support and develop educational programs specifically-oriented toward SIDS risk reduction while expanding to include sleep safety and supporting maternal, prenatal and child health where appropriate in their communities. The decision to expand services often depends on an area's needs and resources. Expansion may include partnerships with other organizations, as appropriate, to provide bereavement support.

**Chart 5.1 : Types of Death**



## Fetal Death

The rate of fetal mortality is nearly equal to the rate of infant mortality in the United States. In 2002, the infant mortality rate was 7.0 per 1,000 live births and the fetal mortality rate was 6.4 per 1,000 live births plus fetal deaths. Although interventions for problems like gestational diabetes and pre-eclampsia are credited with the significant reduction of fetal deaths during the past 40 years from a rate of 15.8 in 1960, the fetal death rate has since leveled off, falling from only 7.5 in 1990 to 6.4 in 2002.<sup>1</sup>

At present, as many as 50 percent of fetal deaths are attributed to unknown causes. The high rate of undetermined deaths is due partially to the lack of a national mandate for the

collection of fetal death data. Only 40 States code for the age and cause in fetal deaths and, because there is no standard protocol for this data collection, varying quality of fetal death data presents difficulties in developing comparative analyses. It is generally acknowledged that the number of fetal deaths in the United States may be underreported by as much as 15 percent.<sup>2</sup>

Fetal mortality rates vary by race, ethnic origin, marital status and age of the mother, with the youngest and oldest mothers experiencing the greatest risk of fetal mortality. In 2002, the fetal mortality rate was more than two-fold higher for African American mothers, at 11.9, than for White mothers, at 5.5.<sup>3</sup>

## Miscarriage

Miscarriage, also known as spontaneous abortion, is the term health care providers use to describe the loss of a pregnancy from natural causes before the 20th week of pregnancy. Most miscarriages occur very early in pregnancy, in some cases before a woman even knows she is pregnant. Researchers estimate that among women who already know they are pregnant, nearly 15 percent will have a miscarriage.

There are many different causes for miscarriage, some of them known and others unknown. In most cases, there is nothing a woman can do to prevent a miscarriage. Having a miscarriage does not mean that a woman will not become pregnant again or that she will not have normal pregnancies in the future. For most women, miscarriage is not a sign of another health problem.

## Stillbirth

Stillbirth in United States is defined as the death of a baby in utero at 20 weeks' gestation or later, in many cases at full term. The definition varies in other countries. In Sweden the defining mark is 28 weeks and in Norway it is 16 weeks. According to national statistics, stillbirths occur in nearly one in 200 pregnancies, or 26,000 cases, in the United States every year. Worldwide, there are 4 million stillbirths each year according to the [World Health Organization](#).

In the United States in 2002, stillbirth occurred at a rate of 3.2 per 1,000 births.<sup>4</sup> In 2000, there were 13,497 early fetal deaths (20-27 weeks' gestation) and 13,506 late fetal deaths (at or later than 28 weeks' gestation).<sup>5</sup>

Stillbirth is a term that describes when a baby dies. Stillbirth is not a cause of death. Many institutions report up to two-thirds of stillbirths as unexplained.<sup>6</sup>

It has been speculated by some researchers that some stillbirths that are at or close to full term may be gestational SIDS. Epidemiologists have found a two-fold risk for SIDS in infants whose mothers delivered a stillborn. Research is underway investigating if late fetal mortality may have shared etiology with SIDS as some of the risk factors for SIDS are also risk factors for stillbirths and other perinatal deaths.<sup>7</sup>

Stillbirth occurs in mothers of all ages, races and backgrounds and in mothers who have received excellent prenatal medical care. Stillbirth can occur before delivery or as a result of complications during labor and delivery. Some stillbirths are caused by complications during pregnancy.

Some common complications that can lead to stillbirth are:

- Pre-eclampsia
- Preterm labor
- Diabetes
- Placental abruption
- Birth defects
- Intrauterine growth restriction

Other complications can be caused by bacterial infections, unexplained asphyxia, isoimmunization, fetal bleeding, severe chorioamnionitis<sup>8</sup> and sexually transmitted infections during pregnancy, common infections, illness, injuries and accidents. A greater risk of stillbirth has been found in:

- Women more than 35 years of age
- Women who have given birth to five or more children
- Women who did not receive prenatal care
- Hispanic and African American women

In many cases, a pregnancy that ends in stillbirth is medically uneventful and no signal of trouble manifests itself until delivery day when it is discovered on monitors that the baby no longer has a heartbeat.

Despite how often stillbirth occurs and how painful it can be for families, little research has been done on this type of pregnancy loss. Research on stillbirth is difficult to conduct for a variety of reasons including a family may decline an autopsy, the issuance of fetal birth certificates is not always required and the criteria for reporting stillbirths differ from State to State.

To encourage more stillbirth research, NICHD is supporting a new research initiative, [Research on the Scope and Causes of Stillbirth in the United States](#). NICHD awarded \$3 million to fund the Stillbirth Research Collaborative Network—five research centers across the country and one independent data center to collect and analyze statistics on stillbirths. Through this effort, NICHD will create a network of research sites whose sole focus will be on understanding stillbirth: its features, its causes and its effects on a woman’s uterus. Patients in this network will include women from a variety of ethnic and socioeconomic backgrounds.

Another stillbirth study is the Maternal Observations and Memories of Stillbirth ([MOMS Study](#)) study, a world-wide effort that has attracted mothers of stillborn babies and live babies from more than 27 countries. These volunteers are asked to fill out a 35-minute questionnaire about their birth experiences in an effort to provide international researchers with a database that helps them figure out what characterizes stillbirth pregnancies. To date, 4,000 women have enrolled in the study. Seventy-five percent are from the United States and 25 percent are from 27 other countries.

## Legislation and Fetal Death Documentation

Although no standard protocol exists to assess fetal death, there are several models such as the Wisconsin Stillbirth Service Project (WiSSP). In 1983, medical geneticist and stillbirth father Richard M. Pauli began the WiSSP Program, one of the first efforts to establish a hospital protocol to uniformly assess what happens to stillborn babies on a case-by-case basis. Today, WiSSP is affiliated with more than 70 hospitals in Wisconsin.

Legislation has been directed at treating fetal deaths the same as live births or infant deaths in terms of data collection and documentation. Although States issue a report of fetal death or certificate of fetal death, few require a certificate of birth for a stillborn infant.

Advocacy groups such as the [National Stillbirth Society](#) have worked actively to mobilize parents in all States to push for the legislation. Arizona became the first State to issue a certificate of birth for a stillborn infant. Certificates for a stillbirth are issued in Arizona, Indiana, Louisiana, Maryland, Massachusetts, Michigan, New Jersey, Utah and Virginia. As of 2004, 15 States have passed legislation that gives stillbirth parents the option of obtaining a stillbirth certificate in addition to a fetal death certificate. To many stillbirth parents, receiving this certificate makes a positive psychological difference because it acknowledges their baby's life, not just his or her death.

## Infant Death

Advances in medical technologies are generally credited for the dramatic declines in overall infant mortality in the United States since the 1960s. During this period, medical interventions capable of allowing the survival of premature infants and babies born weighing as little as 500 grams have become almost commonplace. Similarly, rapid advances in technologies used to monitor pregnancies have improved outcomes for at-risk pregnancies and emergency deliveries.

However, progress toward improving the infant mortality rate began to slow significantly in the 1980s. Between 1980 and 1990, U.S. infant mortality rates dropped 3.4 points, which was less than half the rate of decline of the previous ten years. Between 1990 and 2000 the rate fell only 2.3 points.<sup>9</sup> During the past five years, the infant mortality rate has nearly stagnated, declining from 7.3 deaths per 1,000 live births in 1996 to 6.8 in 2001.<sup>10</sup> Preliminary data for 2002 indicates that the infant mortality rate has increased to a 7.0 rate.<sup>11</sup> Of the more than 4 million births in 2001, the [National Center for Health Statistics](#) reported 18,777 neonatal deaths, or deaths that occurred before the 28th day of life.

Despite progress in reducing infant deaths, the United States' infant mortality rate still ranks poorly among the world's industrialized nations at 27th.<sup>12</sup> The United States may have reached the point in which the ability to ensure the survival of the next generation depends less on medical technology and more on our ability to educate women of childbearing age, expectant mothers and families.

### Leading Causes of Infant Mortality

In the United States, about 27,600 infants died in 2002. The three leading causes of infant death were congenital anomalies (birth defects), preterm/LBW and SIDS. Together, these three causes were to blame for almost half of the infant deaths in 2002. Other causes of death included maternal complications, complications during the pregnancy, birth complications, infant respiratory problems, infection and other illnesses. The 10 leading causes of infant death in 2002 accounted for 68.4 percent of all infant deaths in the United States.

#### Table 5.1 : Ten Leading Causes of Infant Death

1. Congenital malformations, deformations and chromosomal abnormalities

2. Disorders related to short gestation and LBW, not elsewhere classified
3. SIDS
4. Newborn affected by maternal complications of pregnancy
5. Newborn affected by complications of placenta, cord and membranes
6. Accidents
7. Respiratory distress of newborn
8. Bacterial sepsis of newborn
9. Diseases of the circulatory system
10. Intrauterine hypoxia and birth asphyxia

Based on the Tenth Revision International Classification of Diseases, 1992

## **Congenital Anomalies**

The more familiar term for congenital anomalies is birth defects. For more than 20 years, birth defects have been the leading cause of infant mortality in the United States. In 2000, birth defects accounted for 5,743 deaths of infants younger than 1 year old, reflecting a rate of infant mortality due to birth defects of 139.2 per 100,000 live births. The cause of about 70 percent of all birth defects is unknown. Common concerns for birth defects are exposure to environment pollution, various occupational hazards, dietary factors and medications.<sup>13</sup>

In early 1998, Congress passed the Birth Defects Prevention Act of 1998, which became [Public Law 105-168](#). This bill authorized the [CDC](#) to:

- Collect, analyze and make available data on birth defects.
- Operate regional centers for applied epidemiologic research on the prevention of birth defects.
- Inform and educate the public about the prevention of birth defects.

The CDC also monitors birth defects through State birth defects prevention activities. The CDC continues to fund and conduct research into birth defects.

## **Low Birth Weight**

An important component of decreasing infant mortality is to prevent LBW. The rate of infant death increases significantly with decreasing birth weight for infants weighing less than 2,500 grams. As previously explained, LBW is a risk factor for SIDS. It is also a leading cause of infant mortality on its own in the United States. LBW is often caused by prematurity. In 2001, 11.6 percent of live births were born too early, or prior to the 37th week of pregnancy, and 7.6 percent were born too small, weighing less than 2,500 grams or 5.5 pounds.

## **Respiratory Distress Syndrome**

Respiratory Distress Syndrome (RDS) occurs primarily in infants born too early and is a result of lungs that are not fully developed. The lungs of a full-term baby contain a foamy fluid known as surfactant. Surfactant helps the air sacs, or alveoli, in the lungs expand in order to let in air. Because of their early birth, premature babies' lungs have not yet developed surfactant. Without surfactant, a baby's lungs cannot inflate properly and the

baby will have difficulty breathing.

## Sudden Unexplained Death in Childhood

While a cause is found for most sudden unexpected child deaths, in some rare cases no cause is ever identified.

Sudden Unexplained Death in Childhood (SUDC) is the sudden death of a child older than one year of age which remains unexplained after a thorough case investigation, including a review of the clinical history and circumstances of death, and performance of a complete autopsy with appropriate ancillary testing. In 2002, SUDC occurred at a rate of 1.3 deaths per 100,000 live births. SUDC is similar to a typical SIDS case except for the age of the child.<sup>14</sup>

## Steps to Program Expansion

If program staff are considering expanding their scope of services it may be helpful to talk to program staff that have expanded their scope of services already, review relevant resources and think through possible steps involved in an expansion effort.

Step 1: Review your existing core set of services to determine whether you are meeting basic services to SIDS families.

Step 2: Review possible expansion criteria. Criteria may include:

- **Sudden, unexpected infant/child deaths**, including those from accidents, previously undiagnosed illnesses or defects.
- **Fetal deaths**, or those associated with miscarriages and stillbirths, which may be explained or unexplained.
- **Infant/child deaths occurring in hospitals**, including those due to birth defects or illness, which were previously-diagnosed and anticipated.
- **Infant or child deaths due to homicide.**

Step 3: Review possible expansion criteria and considerations. Considerations may include:

- Training and education needs of volunteers and staff
- Resource needs for expansion
- Impact on existing bereavement services
- Impact on existing risk reduction services
- Impact on existing referral process
- Partnerships
- Financial requirements for expansion

Step 4: Obtain stakeholders support for a possible expansion.

- Review and revise mission.
- Communicate the reason(s) for considering expansion.
- Conduct a survey of families, both those whose child died of SIDS and those from other causes, to solicit their ideas about expansion.
- Inform all existing families about possible program expansion.

Step 5: Conduct community needs assessment. Programs need to estimate the number of additional deaths that would be included with various program expansions:

- Obtain statistics and information on type and number of deaths in local or State area.
- Decide how in-depth your organization can go with available staff.
- Conduct a survey of existing service providers such as funeral homes, hospitals and emergency rooms to determine where families are currently being referred.
- Conduct a survey of existing professional and community training programs including those that currently train first responders in responding to child deaths, hospice programs, health care providers in grief and risk reduction and child care providers in general grief and risk reduction.
- Hold a community meeting to discuss the unmet needs in the community and to locate other available bereavement support. Typical partners would include:
  - Health departments
  - [Hospitals](#)
  - Health promotion organizations and agencies
  - [Local March of Dimes chapter](#)
  - [Local FIMR](#)
  - [Local CFR](#)
  - Funeral homes (NFDA's Web site includes a [member list](#).)
  - [Local SHARE chapter](#)
  - [Local MISS Foundation chapter](#)
  - [Local Compassionate Friends chapter](#)
  - [Local Parents of Murdered Children chapter](#)
  - [Local MADD chapter](#)

Step 6: Internally review organizational and community assets and resources:

- What additional services or resources can your organization offer with little or no additional staff?
- What additional services or resources can other organizations offer with little or no additional staff?
- Determine whether there are enough additional resources available for expansion.

Step 7: Determine organizational priorities:

- Rank identified expansion criteria based on organizational priorities and community input.
- Identify barriers and develop a plan to address them.
- Set target implementation date.

Step 8: Examine finances. New service areas provide both financial opportunities and challenges.

Opportunities:

- New funding opportunities may open from health departments and others. The [March of Dimes](#) may be a new funding source for some programs.
- New families can mean more volunteers and a broader financial base.
- Possible joint ventures may be possible with new partners as well as new possibilities for special events.

Challenges:

- There may be competition for local funds.
- Families may financially support other charities while receiving services from your organization.
- Stakeholders may not buy into the expansion and may reduce their financial support.

# 5

## **Risk Reduction Expansion Considerations for Sudden, Unexpected Infant/Child Deaths**

SUI/CD can be from accidents and previously undiagnosed illnesses or defects. The educational messages that may be considered due to accidents and unintentional injuries include car seat safety, safe sleep environment (including bedsharing, bedding and safe cribs), child safety (including at home, at the grandparents' and in child care settings), water safety, gun safety and fire and poisoning prevention.

The educational messages that may be considered for deaths due to unexpected infections/illnesses, such as pneumonia, influenza, asthma and measles, include how to recognize when an illness requires emergency care, when families should use emergency rooms and the importance of immunizations.

Programs have various options for the level of involvement in any child safety and illness prevention education campaigns. If there are existing coalitions operating in your area, you can join an existing coalition. It is important to determine your level of commitment. For example, consider whether your staff will agree to distribute the coalition's literature at activities, be trained as presenters, help sponsor a campaign or work information into existing SIDS presentations.

If no coalition exists, you can consider serving as a local member to a national or regional effort, inviting others to join in coordinating a campaign, distributing literature or including education in other presentations. Programs may also decide to initiate a comprehensive campaign alone for one or more of the educational messages above. This requires the most significant commitment of resources.

The target audiences for unintentional injuries and sudden illnesses are both the family and the community. Audiences include:

- New parents, grandparents
- Teens, both parents and babysitters
- Men
- Women of childbearing age
- Minority or underserved communities
- Public health system
- Professionals including parent educators, infant CPR instructors, babysitter instructors, home economics teachers, child care providers, physicians, clinic nurses and child care licensing staff

## **Necessary Resources**

To appropriately address the prevention of childhood illness and unintentional injury, program staff needs to develop expertise to review materials already available. New materials will cost money to purchase. If culturally-appropriate materials are not available, the program may need to create new brochures, PSAs and curricula, which will cost time and money.

Training will also be needed for staff and volunteers responsible for conducting education. Additional research may be needed to better understand underlying causes of accidental deaths or sudden deaths. For example, your staff should try to find out whether smoke alarms were present in deaths due to fire or whether suffocation deaths were due to overlying, wedging or the obstruction of mouth or nose. Once these underlying causes are understood, appropriate messages can be developed.

## **Potential National Partners and Supporters**

Each of the following organizations provides educational materials and information on most unintentional childhood injuries:

- [National SAFE KIDS Campaign](#)
- [National CDR](#)
- [SAFE USA](#), sponsored by CDC's Center for Injury Prevention and Control
- [National Resource Center for Health and Safety in Child Care](#), funded by MCHB

- U.S. Consumer Products Safety Commission
- National Safety Council
- American Red Cross
- U.S. Fire Administration
- National Fire Protection Association

Other national organizations that more narrowly address unintentional injuries:

- American Trauma Society
- American Association of Poison Control Centers
- Emergency Medical Services for Children

Some national organizations that address sudden illnesses:

- American Academy of Pediatrics
- Asthma and Allergy Foundation of America
- National Partnership for Immunization
- KidsHealth, a project of the Nemours Foundation

## Risk Reduction Considerations for Infant/Child Deaths Occurring in Hospitals

As most of these types of deaths cannot be directly prevented, prevention education messages must be broader health messages. There are four major areas of health education prevention messages.

- 1. General preconceptual care messages** would be to plan for a healthy baby prior to a pregnancy. Preconceptual care messages can be targeted to at-risk mothers and mothers who had poor outcomes from previous pregnancy, because they are at higher risk for subsequent poor outcomes.
- 2. General prenatal care messages** would include information on:
  - Why to seek prenatal care early
  - How to find free or affordable care
  - How to eat a nutritious diet
  - Why not to smoke or use alcohol or drugs
- 3. Testing and screening information**
  - Prenatal testing such as Amniocentesis, Chorionic Villus Sampling (CVS) and other types of tests
  - Newborn screening tests
- 4. Specific risk reduction measures**
  - BTS campaign
  - Stop smoking campaigns
  - Folic acid campaigns
  - Multiple birth education risks

Programs have many participation options in prenatal and preconception education including joining existing coalitions such as the [Healthy Start](#) programs, [March of Dimes](#) programs or [Healthy Mothers, Healthy Babies](#).

Again, it is important to consider whether your staff will agree to distribute the coalition's literature at activities, be trained as presenters, help sponsor a campaign or include information into existing SIDS presentations. Target audiences are likely to include all women of childbearing age, pregnant women, teenage parents, fathers, grandparents and underserved populations. Professional audiences may include health professionals, parent educators, life-skill teachers in schools, childbirth educators and paraprofessionals.

## **Necessary Resources**

Your organization will need:

1. Staff and expertise to review materials already available. While some materials will cost money, a number of free materials are available. Healthy Start has developed a number of culturally-appropriate materials.
2. Local and State health departments are likely to have existing campaigns and materials.
3. Training for staff and volunteers responsible for conducting education.
4. Relevant information from focus groups or other research.

## **Potential National Partners**

There are a number of national organizations that provide educational materials and information related to infant/child deaths occurring in hospitals. Key organizations include:

- [American Academy of Pediatrics](#)
- [American College of Obstetricians and Gynecologists](#)
- [American Cancer Society](#)
- [American Lung Association](#)
- [Bright Futures](#)
- [Cardiac Risk in the Young](#)
- [Centers for Disease Control and Prevention](#)
- [Center for Child Death Review](#)
- [Genetic hereditary disorder organizations](#)
- [Healthy Mothers, Healthy Babies](#)
- [International Birth Defects Information Systems](#)
- [International Stillbirth Alliance](#)
- [La Leche International](#)
- [March of Dimes](#)
- [MISS Foundation](#)
- [National Black Child Development Institute](#)
- [National Healthy Start Association](#)
- [National Maternal and Child Health Clearinghouse](#)

- National Organization on Fetal Alcohol Syndrome
- National Perinatal Information Center
- National Stillbirth Society
- National Women’s Health Network
- National Fetal and Infant Mortality Review
- Office on Smoking and Health
- RTS Bereavement Services
- SHARE
- State-funded tobacco settlement organizations

## Bereavement Expansion Considerations

The [Institute of Medicine](#) notes that an important factor in bereavement is the difference between sudden unexpected deaths and those that are expected. Sudden, unanticipated deaths in children are the norm. Forty-three percent of deaths from ages 1 to 4 are due to unintentional causes: brief, unanticipated illnesses and homicide. The majority of deaths are due to acute process or trauma-related.<sup>15</sup>

Bereavement issues to consider before expanding include:

- Not all deaths will have autopsies and the referral sources for support will broaden to include hospitals and other health care professionals. Programs must market their available support services to area health departments, hospitals and emergency rooms. A referral form and system would need to be developed. There would be a need for presentations to potential referral sources regarding the organization’s expansion of services to SUI/CD.
- New clinical skills may be necessary for service providers. Staff will need knowledge of major causes of sudden infant/child death, such as leukemia and meningitis, and increased knowledge of overall infant/child mortality and statistics. Staff will also need increased medical training on hospital care and family experiences. The medical issues and concerns regarding subsequent children will vary.
- Service providers must have an increased knowledge of grief issues that pertain to deaths from accidents and sudden illnesses. Support group facilitators will need training to be aware of the special features and problems inherent in varying causes of death and what impact they may have on bereaved families. For example, some discussion during support groups will not be applicable to all attendees. A facilitator must possess the clinical skills to discern the contrasted needs of an entire group, such as a baby who did not suffer versus a baby who did, preventable death versus unpreventable death and known cause of death versus unknown cause of death.
- Existing peer contact systems have to be modified to meet the needs of not only families receiving a SIDS diagnosis but also accidental suffocations, undetermined cause of death, stillbirths, etc. Existing peer contact systems can expand their expertise as new peer contact volunteers are recruited, which may increase the capability of matching families based on the type of loss they experienced.

Programs should not duplicate or compete with already-existing services within their

communities. Organizations need to work collaboratively and to partner with other agencies and effectively utilize existing resources. Already-established bereavement organizations include the Compassionate Friends, March of Dimes and RTS Bereavement Services.

## Fetal Bereavement Considerations

While there are many similarities in fetal death grief issues with those surrounding SIDS, there are also some differences. While miscarriages are the most frequent perinatal loss, it is also the most unacknowledged loss. It is estimated that one-third of all pregnancies result in a miscarriage. Some mothers may experience feelings of responsibility, guilt or personal failure, especially if they have experienced multiple miscarriages.

For some stillbirths, mothers may not be aware that their child has died until the actual birth, while other mothers may have known the child had died. In these cases, the mother may have carried the child to term knowing the outcome. Mothers may have post-partum physical reactions including breast fullness and normal hormonal blues.

In the United States, 50 percent of stillbirths have no known cause. Unlike a SIDS death or a child death, parents who have a stillborn baby may not have anyone investigate the death. As a result, they may have feelings that no one cared and their infant was unimportant.

After a stillbirth or miscarriage, families rarely have many memories or mementos. [RTS Bereavement Services](#) conducted a study of families who experienced a miscarriage and found that 75 percent of the participants were grieving. The most critical question in the survey in determining the feelings families had toward the loss was whether the participants thought of the pregnancy as a baby. Often, families experiencing a miscarriage or stillbirth have to fight to have their loss viewed as the loss of a baby, not a fetus.

A number of hospitals have begun using written protocols to better support grieving mothers. There has been some research on the use of such protocols including whether holding a newborn resulted in less depression and PTSD. However, more research is needed.<sup>16,17</sup>

Miscarriages after infertility treatments, medical terminations and after multiple birth losses may be especially traumatic for parents. Assisted reproductive technology (ART) procedures have increased since 1981 with the birth of the first infant through ART. Mothers who undergo ART treatments are more likely to deliver multiple-birth infants than women who conceive naturally. Multiple births are associated with increased pregnancy complications, premature delivery, LBW and higher mortality and morbidity. In 2001, a total of 29,344 live births and 40,687 infants resulted from 107,587 ART procedures in 384 medical centers. The States with the highest rates of procedures were California, New York, Massachusetts, Illinois and New Jersey.<sup>18</sup>

Fifteen percent of women of reproductive age reported a past infertility health-care visit.<sup>19</sup> Increasing numbers of women are seeking ART services and success rates vary greatly.

# Bereavement Considerations for Infant/Child Deaths Occurring in Hospitals

Bereavement services for infant/child deaths occurring in hospitals may be a more difficult expansion for an organization to undertake because the deaths take place in the hospital, the deaths are often expected and the bereavement issues are, therefore, different. It may make sense to pilot the expansion in this area to a limited geographical area, such as a county, initially.

## Training and Education Considerations

- Medical issues related to common birth defects, LBW, etc.
- How bereavement issues are different for families with an expected death and issues related to subsequent children
- How to accept changes in programs and philosophy

## Bereavement Service Considerations

- It may be possible to match new families for peer counseling based on type of death.
- New families could also join existing support groups with appropriate notice to existing members if the numbers are so small that only one support group exists. When possible, add a second support group for the new families.
- Expected deaths (after long-term illness) require palliative care as well as bereavement support for the family after the death.

## Referral Considerations

- Start with reviewing how current referrals are made to organization. If some are from hospitals, it may not be too difficult to add hospital deaths.
- Determine if new referral mechanisms are needed. These may include reviewing the obituaries, establishing contacts and providing literature to funeral homes, emergency rooms and hospitals.
- Conduct a survey of hospitals to determine where these referrals or services are currently being provided. It is possible that for some types of deaths, services exist in the hospital or community.

Infants born with problems that are incompatible with life may live for extended periods of time. This may include extreme prematurity, severe congenital anomalies or other conditions. With the wide spread usage in sonograms and diagnostic testing, increasing numbers of parents are informed ahead of the infant's birth about lethal congenital anomalies. These families face different issues and their need for support begins at diagnosis.

# Research & Statistics

**Critical Program Function:** To provide State and local agencies with data on SIDS, sudden unexpected infant death and other conditions in order to investigate hazards, conduct needs assessments, determine risk factors and behaviors of parents, families and other caretakers and implement and monitor tracking systems for services and outcome indicators.

For SIDS/ID program staff to develop and evaluate risk reduction efforts, establish the need for bereavement support services or provide accurate training and education, program staff requires up-to-date data on fetal, perinatal and infant death and morbidity at the local and State levels. State and local providers need to understand the strengths and limitations of the data collection systems and data analysis methodology that exist in United States.

Each State is responsible for the collection of vital statistics, which includes the recording of vital events such as births and deaths. The recording of such events occurs in the jurisdiction in which the event occurs: all 50 States, 5 U.S. territories, New York City and the District of Columbia.

Vital statistics collected by the State or jurisdiction are provided to the National Center for Health Statistics (NCHS), the Social Security Administration (SSA), the CPSC and the National Institute of Occupational Safety and Health. These vital statistics provide a critical source of public health data which is mostly complete and generally consistent among jurisdictions.

The data quality is limited, however, by the lack of timeliness, accuracy and poor reporting of some events such as fetal deaths. Data quality is also limited by the lack of a national standard data set for births and deaths. For example, whether or not an autopsy was completed is listed on the death certificate by most States, but this information is not collected nationally.

There are efforts underway to address these limitations and to develop a national model vital statistics system by [NCHS](#), [SSA](#) and the National Association for Public Health Statistics and Information Systems ([NAPHSIS](#)).

Programs should:

- Create, maintain and improve surveillance systems of SIDS/ID deaths that can be disseminated to policy makers and advocates.

- Gather data that includes demographic information such as race, ethnicity and geographic location which will help identify populations or locations that need particular attention.
- Prepare or participate in Statewide or local needs assessments for SIDS. Publish and disseminate needs assessments.
- Prepare SIDS data fact sheets.
- Identify hazards, develop or address appropriate interventions and prepare reports to inform policy makers.
- Analyze data from FIMRs and CFRs. Report and provide guidance for system improvements.
- Collaborate with vital record agencies to ensure that relevant data is available, timely and accurate.
- Evaluate and monitor program outcomes.

## Obtaining Data

To plan appropriately and to track progress it is critical to have accurate, up-to-date statistical information on city, county, State, regional and national levels. Obtaining current and reliable data is often a challenge for program staff. State public health departments often have limited data on their Web sites, but usually publish reports on vital statistics annually.

Infant mortality issues are often separate reports, which may or may not include perinatal health. If you are unable to locate the necessary information, contact your State or local health department directly.

The PowerPoint slides included in the trainer's guide were created using data from a number of these different States and national resources. The slides are an example of the type of local data you may wish to monitor. The following resources will guide you in obtaining similar data for your State or local jurisdictions.

### **Health Resources and Services Administration (HRSA) Maternal and Child Health Bureau (MCHB)**

There are many useful resources on the [HRSA](#) and [MCHB](#) Web sites including national and State data, performance measurements and a State contact directory listing. The Maternal and Child Health Information Resource Center ([MCHIRC](#)) is dedicated to the goal of helping MCH practitioners on the Federal, State and local levels to improve their capacity to gather, analyze and use data for planning and policymaking. The MCHIRC is funded by MCHB's Office of Data and Information Management. The MCHIRC's projects include:

- [Title V Information System data](#) from annual Title V Block Grant applications and reports submitted by the 59 U.S. States, territories and jurisdictions. Information on key measures of maternal and child health in the United States.
- [MCH Program Data Abstracts](#) continue to be made available online as collected from discretionary grant recipients.
- [Child Health USA](#) includes population characteristics, health status of infants, children and adolescents, health services utilization, State- and city-level data and

MCH measures and goals.

- [Women's Health USA](#) contains current and historical data on some of the most pressing health challenges facing women and their families. Data on health and health-related indicators is presented in three categories: population characteristics, health status and health services utilization.
- [Technical Assistance](#) for State and local MCH Agencies
- [Additional Resources](#), including helpful links and publications
- Archives of [DataSpeak](#) periodic telephone conference calls and Internet audioconferences on MCH topics.
- Information on [Graduate Student Internships](#) with city and State health departments in MCH data evaluation and monitoring, program evaluation and needs assessment.

## Healthy People 2010

Healthy People 2010 is a set of national health objectives to achieve during the first decade of the new century. It can be used by States, communities, professional organizations and others to help them develop programs to improve health.

Healthy People 2010 builds on initiatives pursued during the past two decades. The 1979 Surgeon General's Report, Healthy People and Healthy People 2000: National Health Promotion and Disease Prevention Objectives both established national health objectives and served as the basis for the development of State and community plans. Like its predecessors, Healthy People 2010 was developed through a broad consultation process, built on the best scientific knowledge and designed to measure programs over time.

[www.healthypeople.gov](http://www.healthypeople.gov)

## The Centers for Disease Control and Prevention's National Center for Health Statistics (NCHS)

The CDC's National Center for Health Statistics (NCHS) collects and compiles national infant mortality data, including regular provisional and final data on SIDS. Two databases of particular interest for studying the epidemiology of SIDS are the [linked birth and infant death data](#) and the National Maternal and Child Health Survey.

CDC WONDER is an integrated information and communication system for public health. Wide-ranging OnLine Data for Epidemiologic Research (WONDER) is an easy-to-use Internet system that makes the information resources of the CDC available to public health professionals and the public at large. It provides access to a wide array of public health information. The CDC WONDER database can be accessed at [wonder.cdc.gov](http://wonder.cdc.gov).

[www.cdc.gov/nchs](http://www.cdc.gov/nchs)

## U.S. Census

The U.S. Census bureau gathers demographic data and limited social indicators. There is information regarding births and deaths further separated by ethnicity, race and socioeconomic status. The bureau also collects information on the number of households that have grandparents providing care to grandchildren.

[www.census.gov](http://www.census.gov)

## **State Maternal and Child Health Directors**

This Web site includes contact information for all [Federal State MCHB directors and Children with Special Health Care Needs \(CSHCN\) directors](#). Many SIDS and infant death- and health-related programs are managed through MCHB block grants.

[https://performance.hrsa.gov/mchb/mchreports/link/state\\_links.asp](https://performance.hrsa.gov/mchb/mchreports/link/state_links.asp)

## **Pregnancy Risk Assessment Monitoring System (PRAMS)**

**PRAMS**, the Pregnancy Risk Assessment Monitoring System, is a surveillance and research program managed by the [CDC](#) and State health departments. PRAMS collects State-specific, population-based data on maternal attitudes and experiences before, during and shortly after pregnancy.

The goal of the PRAMS project is to improve the health of mothers and infants by reducing adverse outcomes such as LBW, infant mortality and morbidity and maternal morbidity. PRAMS provides State-specific data for planning and assessing health programs and for describing maternal experiences that may contribute to maternal and infant health.

Not all States participate in PRAMS. Currently, 31 States and New York City participate in PRAMS. Four other States previously participated in PRAMS. Even States that are no longer participating in PRAMS are still releasing reports from previously-collected data.

[www.cdc.gov/prams](http://www.cdc.gov/prams)

## **State and Community Fetal Infant Death Review Programs**

Established in 1990, NFIMR is a collaborative effort of MCHB and ACOG. NFIMR is a resource center that provides information and advice about implementing the fetal and infant mortality review method. Topics include confidentiality, liability, data collection, home interview techniques, coalition building, implementing recommendations, coordinating with other local mortality reviews and using local FIMR information for regional/State assessment and planning. Referrals to expert consultants are also available.

[www.acog.org/from\\_home/departments/dept\\_web.cfm?recno=10](http://www.acog.org/from_home/departments/dept_web.cfm?recno=10)

## **Children's Defense Fund**

The mission of the Children's Defense Fund (CDF) is to leave no child behind and to ensure every child a healthy start, a head start, a fair start, a safe start and a moral start in life and successful passage to adulthood with the help of caring families and communities.

CDF provides a strong, effective voice for all the children of America who cannot vote, lobby or speak for themselves and pays particular attention to the needs of poor and minority children and those with disabilities. CDF educates the nation about the needs of children and encourages preventive investment before they get sick or into trouble, drop out of school or suffer family breakdown. CDF began in 1973 and is a private, nonprofit organization supported by foundation and corporate grants and individual donations. Their Web site includes national and State data on a variety of topics.

[www.childrensdefense.org](http://www.childrensdefense.org)

## March of Dimes

The [March of Dimes](#) has developed [PeriStats](#), an online source for perinatal statistics. The PeriStats Web site is an interactive perinatal data resource providing maternal, infant and child health-related data at the State level and, for many indicators, at the county level. Data is also available for the District of Columbia and Puerto Rico. PeriStats extracts data from NCHS and presents the data in graphs and charts. The Web site also provides comparative data and rankings.

[www.marchofdimes.com/peristats](http://www.marchofdimes.com/peristats)

## Kaiser Family Foundation

The [foundation's Web site](#) contains the latest State-level data on demographics, health and health policy including health coverage, access, financing and State legislation. You may compare data for all the States by choosing a topic in the category listing. Information will be displayed as bar graphs, tables or color-coded maps.

[www.statehealthfacts.kff.org/cgi-bin/healthfacts.cgi](http://www.statehealthfacts.kff.org/cgi-bin/healthfacts.cgi)

## KIDS COUNT

KIDS COUNT, a project of the Annie E. Casey Foundation, is a national and State-by-State effort to track the status of children in the United States. By providing policy makers and citizens with benchmarks of child well-being, KIDS COUNT seeks to enrich local, State and national discussions concerning ways to secure better futures for all children. Each year, a data book is released which includes information on infant mortality rates, health disparities and socioeconomic status indicators in charts and graphs as well as State and national rankings.

[www.aecf.org/kidscount](http://www.aecf.org/kidscount)

## Child Trends

Child Trends is a 26-year-old nonprofit, nonpartisan research organization dedicated to improving the lives of children by conducting research and providing science-based information to improve the decisions, programs and policies that affect children and their families. Their Web site includes reports and publications on health insurance access, poverty, issues related to socioeconomic status and more.

[www.childtrends.org](http://www.childtrends.org)

## State Health Agencies

The [Food and Drug Administration](#), [American Public Health Association](#), the [CDC](#) and the [Association of State and Territorial Health Officials \(ASTHO\)](#) maintain a link to each State's public health department.

<b>State</b>	<b>Health Agency</b>	<b>Contact</b>
<b>Alabama</b>	Alabama Department of Public Health	<a href="http://www.adph.org">www.adph.org</a>

<b>State</b>	<b>Health Agency</b>	<b>Contact</b>
<b>Alaska</b>	Alaska Department of Health and Social Services	<a href="http://health.hss.state.ak.us">health.hss.state.ak.us</a>
<b>Arizona</b>	Arizona Department of Health Services	<a href="http://www.hs.state.az.us">www.hs.state.az.us</a>
<b>Arkansas</b>	Arkansas Department of Health	<a href="http://www.healtharkansas.com">www.healtharkansas.com</a>
<b>California</b>	California Department of Health Services	<a href="http://www.dhs.cahwnet.gov">www.dhs.cahwnet.gov</a>
<b>Colorado</b>	Colorado Department of Public Health and Environment	<a href="http://www.cdphe.state.co.us/cdphehome.asp">www.cdphe.state.co.us/cdphehome.asp</a>
<b>Connecticut</b>	Connecticut Department of Public Health	<a href="http://www.state.ct.us/dph">www.state.ct.us/dph</a>
<b>Delaware</b>	Delaware Health and Social Services	<a href="http://www.state.de.us/dhss">www.state.de.us/dhss</a>
<b>Florida</b>	Florida Department of Health	<a href="http://www.doh.state.fl.us">www.doh.state.fl.us</a>
<b>Georgia</b>	Georgia Division of Public Health	<a href="http://www.health.state.ga.us">www.health.state.ga.us</a>
<b>Hawaii</b>	Hawaii State Department of Health	<a href="http://www.hawaii.gov/health">www.hawaii.gov/health</a>
<b>Idaho</b>	Idaho Department of Health and Welfare	<a href="http://www.healthandwelfare.idaho.gov">www.healthandwelfare.idaho.gov</a>
<b>Illinois</b>	Illinois Department of Public Health	<a href="http://www.idph.state.il.us/home.htm">www.idph.state.il.us/home.htm</a>
<b>Indiana</b>	Indiana State Department of Health	<a href="http://www.in.gov/isdh">www.in.gov/isdh</a>
<b>Iowa</b>	Iowa Department of Public Health	<a href="http://www.idph.state.ia.us">www.idph.state.ia.us</a>
<b>Kansas</b>	Kansas Department of Health and Environment	<a href="http://www.kdhe.state.ks.us">www.kdhe.state.ks.us</a>
<b>Kentucky</b>	Kentucky Cabinet for Health and Family Services	<a href="http://www.chfs.ky.gov">www.chfs.ky.gov</a>
<b>Louisiana</b>	Louisiana Department of Health and Hospitals	<a href="http://www.dhh.state.la.us">www.dhh.state.la.us</a>
<b>Maine</b>	Maine Bureau of Health	<a href="http://www.state.me.us/dhs/boh/index.htm">www.state.me.us/dhs/boh/index.htm</a>
<b>Maryland</b>	Maryland Department of Health and Mental Hygiene	<a href="http://www.dhmh.state.md.us">www.dhmh.state.md.us</a>

<b>State</b>	<b>Health Agency</b>	<b>Contact</b>
<b>Massachusetts</b>	Massachusetts Department of Public Health	<a href="http://www.state.ma.us/dph/dphhome.htm">www.state.ma.us/dph/dphhome.htm</a>
<b>Michigan</b>	Michigan Department of Community Health	<a href="http://www.michigan.gov/mdch">www.michigan.gov/mdch</a>
<b>Minnesota</b>	Minnesota Department of Health	<a href="http://www.health.state.mn.us">www.health.state.mn.us</a>
<b>Mississippi</b>	Mississippi Public Health	<a href="http://www.msdh.state.ms.us">www.msdh.state.ms.us</a>
<b>Missouri</b>	Missouri Department of Health	<a href="http://www.dhss.mo.gov">www.dhss.mo.gov</a>
<b>Montana</b>	Montana Department of Public Health and Human Services	<a href="http://www.dphhs.state.mt.us">www.dphhs.state.mt.us</a>
<b>Nebraska</b>	Nebraska Department of Health and Human Services	<a href="http://www.hhs.state.ne.us">www.hhs.state.ne.us</a>
<b>Nevada</b>	Nevada Department of Human Resources	<a href="http://www.hr.state.nv.us">www.hr.state.nv.us</a>
<b>New Hampshire</b>	New Hampshire Department of Health and Human Services	<a href="http://www.dhhs.nh.gov">www.dhhs.nh.gov</a>
<b>New Jersey</b>	New Jersey Department of Health and Senior Services	<a href="http://www.state.nj.us/health">www.state.nj.us/health</a>
<b>New Mexico</b>	New Mexico Department of Health	<a href="http://www.health.state.nm.us">www.health.state.nm.us</a>
<b>New York</b>	New York State Department of Health	<a href="http://www.health.state.ny.us">www.health.state.ny.us</a>
<b>North Carolina</b>	North Carolina Department of Health and Human Services	<a href="http://www.dhhs.state.nc.us">www.dhhs.state.nc.us</a>
<b>North Dakota</b>	North Dakota Department of Health	<a href="http://www.health.state.nd.us">www.health.state.nd.us</a>
<b>Ohio</b>	Ohio Department of Health	<a href="http://www.odh.state.oh.us">www.odh.state.oh.us</a>
<b>Oklahoma</b>	Oklahoma State Department of Health	<a href="http://www.health.state.ok.us">www.health.state.ok.us</a>
<b>Oregon</b>	Oregon Department of Human Services	<a href="http://www.ohd.hr.state.or.us">www.ohd.hr.state.or.us</a>
<b>Pennsylvania</b>	Pennsylvania Department of Health	<a href="http://www.dsf.health.state.pa.us/health/site">www.dsf.health.state.pa.us/health/site</a>
<b>Rhode Island</b>	Rhode Island Department of Health	<a href="http://www.health.state.ri.us">www.health.state.ri.us</a>

<b>State</b>	<b>Health Agency</b>	<b>Contact</b>
<b>South Carolina</b>	South Carolina Department of Health and Human Services	<a href="http://www.dhhs.state.sc.us">www.dhhs.state.sc.us</a>
<b>South Dakota</b>	South Dakota Department of Health	<a href="http://www.state.sd.us/doh">www.state.sd.us/doh</a>
<b>Tennessee</b>	Tennessee Department of Health	<a href="http://www.state.tn.us/health">www.state.tn.us/health</a>
<b>Texas</b>	Texas Department of State Health Services	<a href="http://www.tdh.state.tx.us">www.tdh.state.tx.us</a>
<b>Utah</b>	Utah Department of Health	<a href="http://hlunix.hl.state.ut.us">hlunix.hl.state.ut.us</a>
<b>Vermont</b>	Vermont Department of Health	<a href="http://healthvermont.gov">http://healthvermont.gov</a>
<b>Virginia</b>	Virginia Department of Health	<a href="http://www.vdh.state.va.us">www.vdh.state.va.us</a>
<b>Washington</b>	Washington State Department of Health	<a href="http://www.doh.wa.gov">www.doh.wa.gov</a>
<b>West Virginia</b>	West Virginia Department of Health and Human Resources	<a href="http://www.wvdhhr.org">www.wvdhhr.org</a>
<b>Wisconsin</b>	Wisconsin Department of Health and Family Services	<a href="http://www.dhfs.state.wi.us">www.dhfs.state.wi.us</a>
<b>Wyoming</b>	Wyoming Department of Health	<a href="http://wdh.state.wy.us">http://wdh.state.wy.us</a>
<b>American Samoa</b>	American Samoa Government Department of Health	<a href="http://www.asg-gov.net/HEALTH.htm">www.asg-gov.net/HEALTH.htm</a>
<b>District of Columbia</b>	District of Columbia Department of Health	<a href="http://www.dchealth.dc.gov/index.asp">www.dchealth.dc.gov/index.asp</a>
<b>Federated States of Micronesia</b>	Government of the Federated States of Micronesia	<a href="http://www.fsmgov.org/ngovt.html">www.fsmgov.org/ngovt.html</a>
<b>Guam</b>	Guam Department of Public Health and Social Services	<a href="http://www.cehn.org/cehn/resourceguide/gdphss.html">www.cehn.org/cehn/resourceguide/gdphss.html</a>
<b>Commonwealth of Northern Marianas</b>	Government of the Commonwealth of Northern Marianas	<a href="http://www.gov.mp">www.gov.mp</a>
<b>Commonwealth of Puerto Rico</b>	Estado Libre Asociado de Puerto Rico Departamento de Salud	<a href="http://www.salud.gov.pr">www.salud.gov.pr</a>
<b>Virgin Islands</b>	Virgin Islands Department of Health	<a href="http://www.usvi.org/health">www.usvi.org/health</a>

# Partnerships & Collaborations

**Critical Program Function:** To mobilize government, Federal, State and local partnerships between policy makers, health care providers, families, the public and others to address SIDS, infant death and perinatal death and improve support to families experiencing such losses.

SIDS/ID program staff may:

- Initiate partnerships and collaborate with grassroots organizations, community-based coalitions and others to organize health promotion activities, data collection, advocacy, linkage, provider education, standard setting, policy development or system enhancement.
- Form partnerships with Statewide professional organizations to set policies, provider education and standards of care.
- Collaborate with partners to share information and prepare needs assessments as the basis for developing educational and bereavement support plans.
- Support partners with in-kind staff, printing and postage, meeting space, equipment and other resources to support collaborative efforts.

No program has enough funding, expertise or resources to meet all the bereavement support or health education needs in their community. It is essential for program staff to develop strategic partnerships at the national, State and local levels to expand the reach of program activities, increase program credibility, foster information exchange and build trust between the program and the community served. Given the large number of potential nonprofit, State and local partners involved in maternal and child health, it is important to evaluate and select partnerships that best support your goals, further your efforts and are mutually-beneficial.

Some of the Federal governmental, national nonprofit, existing collaborative efforts and civic organizations partners actively involved with SIDS, infant death and maternal and child health are reviewed below.

## The Four Federally-Funded SIDS Programs

The SIDS/ID Program of the Infant and Child Health Branch of the Maternal and Child Health Bureau (MCHB), Health Resources and Services Administration (HRSA), U.S.

Department of Health and Human Services, funds four national resource centers that address SIDS/ID issues.

## **The National SIDS and Infant Death Program Support Center (NSIDPSC)**

NSIDPSC is administered by [First Candle/SIDS Alliance](#) and has been in operation since 1998. The NSIDPSC supports SIDS/ID programs at the local, State, regional and national levels to develop community-based services for bereavement support and risk reduction. The center also assists in improving services to underserved populations including certain racial and ethnic minorities, rural populations and migrant groups.

### **Services:**

- A toll-free hotline, 800-221-7437, which provides risk reduction education and bereavement support and referrals during normal work hours.
- A 24-hour crisis hotline for both English and Spanish speakers.
- Participates in First Candle's English/[Spanish](#) Web site, international conferences and newsletter.
- Staff attends conferences to provide outreach to professionals and the public.
- Provides train-the-trainer style training to medical staff, child care providers, first responders, police, funeral directors and others.
- Provides technical assistance to callers about bereavement and SIDS risk reduction.

**Data:** Staff provide technical assistance in interpreting SIDS and perinatal death research and statistics.

**Membership:** See [First Candle membership information](#).

**Publications:** Produces and provides health care professional and family educational [materials](#) on SIDS risk reduction, current research and trends and grief and bereavement. All publications are free and available on the center's Web site or in hard copy form. As all publications are in the public domain, materials can be tailored to local organizations with proper attribution. All publications are available in Spanish as well.

National SIDS and Infant Death Program Support Center

1314 Bedford Avenue, Suite 210

Baltimore, MD 21208

800-221-7437 (SIDS)

410-415-6628

410-653-8709 (fax)

[www.firstcandle.org/health/health\\_support.html](http://www.firstcandle.org/health/health_support.html)

## **The National SIDS and Infant Death Resource Center (NSIDRC)**

NSIDRC is administered by [Circle Solutions](#). The center provides information, services and technical assistance on SIDS and related topics. Its goal is to promote understanding of SIDS and provide comfort to those affected by SIDS through information-sharing. The NSIDRC collaborates with NSIDPSC, NCCC and the National SIDS & Infant Death Project IMPACT. All of the programs work together to provide educational materials, resources,

technical assistance, publications and services for bereavement support and risk reduction as well as to help to improve services to underserved populations.

### **Services:**

- A toll-free hotline, 800-638-2772, provides resources, technical assistance and referrals to public health and other professionals, SIDS families and the general public.
- Publishes a quarterly newsletter, *Information Exchange*.
- Staff attends national conferences to provide outreach to professionals and the public.
- Maintains the list of [State SIDS/ID contacts](#).

**Data:** Maintains a comprehensive [bibliographic database](#) that provides abstracts and citations obtained from a myriad of professional health journals.

**Publications:** Produces and provides professional and consumer educational [materials](#) on such topic areas as SIDS risk reduction, current research and trends, grief and bereavement, ethnic disparities and infant mortality statistics. Publications are limited to five free copies unless otherwise noted. All publications are free of copyright. Many publications are available for download. Some publications are available in Spanish.

#### **National SIDS and Infant Death Resource Center**

8280 Greensboro Drive

Suite 300

McLean, VA 22102

866-866-7437

703-821-8955

703-821-2098 (fax)

[www.sidscenter.org](http://www.sidscenter.org)

### **The National Center for Cultural Competence (NCCC) SIDS/ID Project**

The National Center for Cultural Competence (NCCC) [SIDS/ID Project](#) is administered by [Georgetown University](#). The NCCC SIDS/ID Project is designed to increase the capacity of SIDS/ID programs to plan, implement and evaluate culturally- and linguistically-competent service delivery systems as a multifaceted approach to addressing the disparities in infant mortality outcomes. The project provides training, technical assistance and consultation and promotes networking and information exchange.

### **Services:**

- Responds to requests for information and [technical assistance](#) via a toll-free number (800-788-2066) and e-mail ([cultural@georgetown.edu](mailto:cultural@georgetown.edu)).
- Contributes information about cultural and linguistic competence to existing newsletters, publications or Web sites broadly disseminated to or accessed by SIDS/ID programs.
- Hosts a series of [topical conference calls](#) on topics related to cultural and linguistic competence for SIDS/ID programs.

- Web site has a [Spanish language portal](#) specifically for families. The portal provides information, resources and links in Spanish. Translated NCCC products are also available on the Spanish language portal.
- Maintains a [pool of consultants](#) who are skilled providers of training, technical assistance or consultation related to cultural and linguistic competence in a broad range of health, mental health, education and human service arenas. The NCCC acts as a broker attempting to match consultation needs with appropriate consultants. Specific details related to the consultation (e.g., fees and logistics) are negotiated directly with the consultant. The NCCC does not incur costs for these consultations.
- Participates in planning and presenting at national conferences for constituencies concerned with SIDS/ID.
- Provides capacity-building targeted [technical assistance](#) to regional and State SIDS/ID programs.

**Data:** Maintains a database of a wide range of resources on cultural and linguistic competence (e.g., demographic information, policies, practices, articles, books, research initiatives and findings, curricula, multimedia materials and Web sites, etc.). A selected searchable bibliography of these resources is made available online. Each database entry includes information on the type of resource, category, population(s) addressed, title, author and description. Descriptions are written by NCCC faculty and staff. When available, source and contact information are provided. Most of the resources are copyrighted. It is the responsibility of each user to acknowledge and gain permission for use.

**Publications:** Produces and disseminates [publications](#) and other materials to support organizations in providing culturally- and linguistically-competent services to families affected by SIDS/ID. Ordering information is provided on the Web site. Some publications are available to download on the Web site and are available in hard copy. All publications are free. Permission is granted to reproduce these documents for distribution for non-commercial purposes. The requirements are that the documents may not be altered and that proper credit is given to the authors and the NCCC.

#### NCCC-SIDS/ID Project

Georgetown University Center for Child and Human Development

Box 571485

Washington, DC 20057

800-788-2066

202-687-5387

202-687-5503 (TTY)

202-687-8899 (fax)

[www3.georgetown.edu/research/gucchd/nccc/nccc5.html](http://www3.georgetown.edu/research/gucchd/nccc/nccc5.html)

### **The National SIDS & Infant Death Project Infant Mortality Policy and Communication Tools (Project IMPACT)**

The National SIDS & Infant Death Project IMPACT is administered by ASIP. Project IMPACT supports State and local infant death programs through sharing information, promoting policy and legislative changes, building upon resources and fostering partnerships and communication. Project IMPACT is a cooperative agreement between

MCHB and ASIP designed to enhance communication among State and local programs and between these programs and Federal and State policy-makers.

Project IMPACT disseminates SIDS/ID-related information to State, local and program officials, communicates policies and positions of the government and professional associations to service providers, researchers and others and creates opportunities for collaboration among Federal, State and local organizations to facilitate responses to existing and emerging SIDS/ID issues with a strong commitment to the development, improvement and maintenance of State and local SIDS/ID programs.

**Services:**

- Oversees a [listserv](#) with a special focus on SIDS and other infant death. The listserv features updates on research, program development, policy and legislative issues, conferences and funding opportunities and provides a forum for sharing successful outreach and education strategies.
- Staff attend national conferences to provide outreach to professionals and the public.

**Data:** Conducts survey of State SIDS/ID programs to assess needs and service capacities.

**Membership:** See [ASIP membership information](#).

National SIDS/ID Project IMPACT  
8280 Greensboro Drive  
McLean, VA 22102  
800-930-SIDS  
703-902-1260  
[www.sidsprojectimpact.com](http://www.sidsprojectimpact.com)

## State SIDS Programs

A directory of State SIDS programs can be found at <http://www.sidscenter.org/StatePrograms.aspx?fromparent=parent&id=5&heading=StatePrograms>.

## The Department of Health and Human Services' National Institute of Child Health and Human Development (NICHD)

The mission of [NICHD](#) is to ensure that every person is born healthy and wanted, that women suffer no harmful effects from reproductive processes and that all children have the chance to achieve their full potential for healthy and productive lives, free from disease or disability and to ensure the health, productivity, independence and well-being of all people through optimal rehabilitation. NICHD has been extensively involved with SIDS in several critical capacities including:

- **Strategic Research Plans.** NICHD developed five-year strategic plans for SIDS research in 1989, 1995 and 2001 in conjunction with scientists and health care professionals and with advocacy groups, nonprofits and the public input. The

last strategic plan, [From Cells to Selves](#), which includes [Targeting Sudden Infant Death Syndrome](#), is available on their Web site.

- **Research Support.** Web site includes information on [research funding](#) by NICHD; [intramural research](#); [epidemiology, statistics and prevention](#) and [research resources](#).
- **Back to Sleep Campaign.** Sponsors the ongoing [BTS campaign](#) which educates about the importance of putting babies on their backs to sleep to help reduce the risk of SIDS. It provides health information, outreach activities and publications available for order or viewing online for parents, family members, child care providers, health professionals and all other caregivers of infants. This campaign is also sponsored by MCHB, the AAP, First Candle/SIDS Alliance and ASIP.

**Communication Vehicles:** Produces and provides professional and consumer educational [materials](#) on SIDS risk reduction. Materials include brochures, door hangers, fact sheets, the transcripts for the BTS radio Public Service Announcements (PSAs), transit public service announcements, Spanish language materials and [African American-targeted materials](#). NICHD is currently working on materials for Native Americans. All publications are available on the Web site and are available for order in hard copy. All publications are free and in the public domain. You may not change the materials and must give proper attribution. Some publications are in Spanish. Staff attends national conferences to provide outreach to professionals and the public.

#### NICHD

31 Center Drive, Building 31

Room 2A32

Bethesda, MD 20892

800-505-CRIB (2742)

888-320-6942 (TTY)

301-984-1473 (fax)

[www.nichd.nih.gov](http://www.nichd.nih.gov)

[NICHDInformationResourceCenter@mail.nih.gov](mailto:NICHDInformationResourceCenter@mail.nih.gov) (Use subject line: BACK TO SLEEP ORDER.)

## The Department of Health and Human Services' Office of Minority Health

The mission of the Office of Minority Health (OMH) is to improve and protect the health of racial and ethnic minority populations through the development of health policies and programs that will eliminate health disparities.

OMH was established in 1985 by the Department of Health and Human Services (HHS). It advises the Secretary and the Office of Public Health and Science on health policy issues affecting health status and access to care among minority populations. It coordinates programs to help HHS implement minority initiatives, including the [HHS Disparities Initiative](#), the [White House Initiative on Historically Black Colleges and Universities](#), the [White House Initiative on Educational Excellence for Hispanic Americans](#), the [HHS Hispanic Agenda for Action](#), the [White House Initiative on Tribal Colleges and Universities](#), the [Executive Order on Increasing Participation of Asian Americans and Pacific Islanders in Federal Programs](#) and the [HHS Minority HIV/AIDS Initiative](#).

### Services:

- **Know What to Do for Life Campaign.** This national education campaign is designed to help reduce the infant mortality rate among African Americans by increasing awareness about the disparate rates of infant mortality, SIDS, premature birth and low birth weight within the African American community. The campaign will also highlight many of the risk factors associated with these conditions and promote risk reduction among parents and caregivers.

This initiative represents a collaborative effort among OMH, CDC, HRSA, IHS, NIH and the Office on Women's Health. National, State and local partners will help promote infant mortality prevention.

The Know What to Do for Life campaign is part of HHS's [Closing the Health Gap: Infant Mortality Initiative](#)'s three-part approach to reduce racial and ethnic disparities in infant deaths, including research coordination among HHS agencies, risk reduction efforts in communities and communications activities to improve awareness of factors that contribute to infant mortality.

- **Grants and Cooperative Agreements.** OMH organizes demonstration projects through joint agreements with operating divisions of the department, funds grants for health projects conducted by minority community organizations and coalitions and funds cooperative agreements with major national minority organizations.
- **Staff Consultants.** Regional minority health staff consultants serve in each of the [ten HHS Regional Offices](#), and help build a network of consumers and professionals working on minority health issues. OMH works with established State offices of minority health and provides technical assistance, as requested, to minority community groups.
- **OMH Resource Center (OMHRC)** serves as an information and referral service on minority health issues for professionals, community groups, consumers and students; encourages public participation in HHS programs, and assists in conducting health campaigns; distributes publications; manages exhibits; publishes funding opportunities; maintains a list of volunteer resource experts available to the public and conducts literature searches.

OMHRC operates a toll-free telephone service (800-444-6472), accessible throughout the United States, Puerto Rico and the Virgin Islands, and provides a TDD telephone (301-589-0951) for the hearing-impaired. Bilingual information specialists answer English- and Spanish-language inquiries.

**Data:** Maintains a minority health knowledge center and database and works with Federal departments to improve collection and analysis of data on the health of racial and ethnic minority populations. It monitors efforts to achieve [Healthy People 2010](#) goals for minority health.

**Publications:** During the first phase of the Know What to Do for Life campaign, HHS is releasing new radio and print public service advertisements (PSAs) that encourage audiences to learn more about SIDS and the risk factors for LBW and premature delivery. A toolkit for community and faith-based organizations will be distributed during the summer of 2005 to help disseminate the message at the local level. OMH also publishes OMH Newsletters, and assists in distributing scientifically valid and culturally competent health information including Federal and non-Federal publications. Many documents are available on the Web site.

OMH Resource Center  
 P.O. Box 37337  
 Washington, DC 20013-7337  
 800-444-6472.  
 301-251-2160 (fax)  
[info@omhrc.gov](mailto:info@omhrc.gov)  
[www.omhrc.gov/omhrc](http://www.omhrc.gov/omhrc)

## The Department of Health and Human Services' Centers for Disease Control and Prevention (CDC)

The CDC is one of the 13 major operating components of HHS. The CDC is at the forefront of public health efforts to prevent and control infectious and chronic diseases, injuries, workplace hazards, disabilities and environmental health threats. Today, the CDC is globally-recognized for conducting research and investigations and for its action-oriented approach. The CDC applies research and findings to improve people's daily lives and responds to health emergencies.

### SIDS-Related Activities:

The CDC is addressing one of the continuing challenges for SIDS researchers, as well as program managers of SIDS services: the lack of uniformity in medical examiners and coroners assigning manner and cause of death to infants. In 2002, the CDC began redesigning the 1996 guidelines for the death scene investigation of SUIDs—the Sudden Unexplained Infant Death Investigation Report Form (SUIDIRF)—in order to improve and standardize the reporting and classification of SUIDs in the United States.

The main intent of the redesign is to improve public health practice. The SUIDIRF is a national SUID investigation form used by medical examiners, coroners, death investigators and police officers in various States, counties and local jurisdictions on a voluntary basis to gather information surrounding SUIDs. The CDC is also working to improve the dissemination of diagnostic information to medical examiners, coroners and others in the SIDS/ID field.

The revised form will be available in 2005 along with appropriate training for those who will use the form to investigate SUIDs. The CDC is looking for State and local SIDS organizations to review, disseminate and publicize the revised SUIDIRF when it is published.

### Services:

- **National Infant Immunization Week.** The National Immunization Program (NIP) is a part of the CDC. As a disease-prevention program, NIP provides leadership for the planning, coordination and conduct of immunization activities nationwide. Partnering with State-level immunization programs can be a way to expand program reach. Many State programs have begun to link immunization programs to many other social and health service related programs such as Head Start and Women, Infants and Children (WIC) nutritional programs. The annual observance week emphasizes immunizing infants against 12 vaccine-preventable diseases by

the age of two. More than 500 communities across the country are expected to participate in this important week by planning community awareness and media events to promote infant immunizations to parents, caregivers, providers and their communities.

Centers for Disease Control and Prevention  
 Medical Examiner and Coroner Information Sharing Program  
 4770 Buford Highway, N.E.  
 Mail Stop F 35  
 Atlanta, GA 30341-3724  
 770-488-7060  
 770-488-7044 (fax)  
[www.cdc.gov](http://www.cdc.gov)  
[MECISPI@cehdeh1.em.cdc.gov](mailto:MECISPI@cehdeh1.em.cdc.gov)

## Department of Health and Human Services' Indian Health Service (IHS)

The Indian Health Service (IHS), an agency within HHS, is responsible for providing Federal health services to American Indians and Alaska Natives. The provision of health services to members of Federally-recognized tribes grew out of the special government-to-government relationship between the Federal government and Indian tribes.

This relationship, established in 1787, is based on Article I, Section 8 of the [Constitution](#), and has been given form and substance by numerous treaties, laws, Supreme Court decisions and Executive Orders. IHS is the principal Federal health care provider and health advocate for Indian people, and its goal is to raise their health status to the highest possible level.

The IHS currently provides health services to approximately 1.5 million American Indians and Alaska Natives who belong to more than 557 Federally-recognized tribes in 35 States.

In order to carry out its mission, uphold its foundation and attain its goal, the IHS:

1. Assists Indian tribes in developing their health programs through activities such as health management training, technical assistance and human resource development.
2. Facilitates and assists Indian tribes in coordinating health planning, in obtaining and using health resources available through Federal, State and local programs and in operating comprehensive health care services and health programs.
3. Provides comprehensive health care services, including hospital and ambulatory medical care, preventive and rehabilitative services and development of community sanitation facilities.
4. Serves as the principal Federal advocate in the health field for Indians to ensure comprehensive health services for American Indian and Alaska Native people.

Most IHS funds are appropriated for American Indians who live on or near reservations. Congress also has authorized programs that provide some access to care for Indians who live in urban areas.

IHS services are provided directly and through tribally-contracted and operated health programs. Health services also include health care purchased from more than 9,000 private providers annually. The Federal system consists of 36 hospitals, 61 health centers, 49 health stations and five residential treatment centers. In addition, 34 urban Indian health projects provide a variety of health and referral services. American Indian tribes and Alaska Native corporations administer 13 hospitals, 158 health centers, 28 residential treatment centers, 76 health stations and 170 Alaska village clinics.

**Services:** Clinical practice guidelines, comprehensive health care program, health finder, patient education protocols and codes, training and technical assistance

**Data:**

- **Native Health Research Database (NHRD).** The NHRD, a joint venture between IHS and the [University of New Mexico Health Sciences Center Library](#), is a database of resource documents and other materials from approximately 1970 to the present time for tribal health professionals and health care practitioners working with Native American populations.
- **Patient Education Protocols and Codes.** The [Patient Education Protocols and Codes](#) provide necessary information to assist nurses, physicians and other health care providers in documenting and tracking patient education.

**Publications:** Numerous publications are available on the Web site.

Indian Health Service  
The Reyes Building  
801 Thompson Avenue, Ste. 400  
Rockville, MD 20852-1627  
Maternal Child Health  
301-443-5070  
[www.ihs.gov](http://www.ihs.gov)

## Department of Health and Human Services's Office on Women's Health

The Office on Women's Health (OWH) in HHS is the government's champion and focal point for women's health issues and works to redress inequities in research, health care services and education that have historically placed the health of women at risk. OWH coordinates women's health efforts in HHS to eliminate disparities in health status and supports culturally-sensitive educational programs that encourage women to take personal responsibility for their own health and wellness.

**Services:** OWH supports numerous education and outreach initiatives targeted to women.

**Data:** The [National Women's Health Indicators Database](#) is an online data tool to benefit Federal, State and local health department employees as well as other health professionals, researchers, members of the press and consumers. The database can be accessed at [www.4woman.gov/statedata](http://www.4woman.gov/statedata). It contains extensive health data from the year 2000 for the entire United States and it will be updated on a yearly basis. National, regional, State and county data are available, and the data can be stratified by gender, race/ethnicity and age concurrently. The database includes statistics on reproductive health, maternal health,

mental health, prevention and other topics. Users can make their own tables and graphs out of any data in the database. The database also incorporates a mapping capability using ArcView GIS.

**Publications:** The Babies were Born to be Breastfed PSAs are available in a variety of formats, including television, radio and print advertisements. Many other [publications](#) are available on the Web site.

Office on Women's Health  
 Department of Health and Human Services  
 200 Independence Avenue, S.W., Room 712E  
 Washington, DC 20201  
 202-690-7650  
 202-205-2631 (fax)  
[www.4woman.gov](http://www.4woman.gov)

## The Environmental Protection Agency's Office of Children's Health Protection

The [EPA](#) established the Office of Children's Health Protection ([OCHP](#)) in May 1997 to make the protection of children's health a fundamental goal of public health and environmental protection in the United States. OCHP supports and facilitates agency efforts to protect children's health from environmental threats.

Public involvement is key to protecting human health and the environment. Citizens and communities need to have information and tools that enable them to take steps toward protecting their children from environmental health threats. Organizations, industry and government entities at all levels also need information to help them take child-protective actions. Providing basic information is a key focus of OCHP.

OCHP efforts to build community capacity in children's environmental health protection include:

- Providing information and tools to the public.
- Supporting community actions to protect children.
- Increasing the ability of health care providers to identify, prevent and reduce environmental health threats to children.
- Engaging youth in children's environmental health protection.
- Working with States to develop programs to address children's environmental health issues.

U.S. Environmental Protection Agency  
 Office of the Administrator  
 Office of Children's Health Protection  
 1200 Pennsylvania Avenue, N.W.  
 Mail Code 1107A  
 Room 2512 Ariel Rios North  
 Washington, DC 20004

202-564-2188  
202-564-2733 (fax)  
<http://yosemite.epa.gov/ochp/ochpweb.nsf/homepage>

## The Environmental Protection Agency's Smoke Free Homes

The EPA established [Smoke Free Homes](#) because breathing secondhand smoke can be harmful to children's health, including increasing the risk of asthma, SIDS, bronchitis and pneumonia and ear infections. Children's exposure to secondhand smoke is responsible for:

- Increases in the number of asthma attacks and severity of symptoms in 200,000 to 1 million children with asthma.
- Between 150,000 and 300,000 lower respiratory tract infections for children under 18 months of age.
- Respiratory tract infections resulting in 7,500 to 15,000 hospitalizations each year.

The developing lungs of young children are severely affected by exposure to secondhand smoke for several reasons including that children are still developing physically, have higher breathing rates than adults and have little control over their indoor environments. Children receiving high doses of secondhand smoke, such as those with smoking mothers, run the greatest risk of damaging health effects.

**Publications:** Health measures and health yearbooks, numerous brochures and fact sheets, other EPA publications on environmental health topics and background papers on children's environmental health. Many [publications](#) are free to download.

U.S. Environmental Protection Agency  
Indoor Environments Division  
1200 Pennsylvania Avenue, N.W.  
Mail Code 6609J  
Washington, DC 20460  
202-343-9370  
202-343-2392 (fax)  
202-343-2393 (fax)  
[www.epa.gov/smokefree](http://www.epa.gov/smokefree)

## Consumer Product Safety Commission (CPSC)

The [CPSC](#) is an independent, Federal regulatory agency that is charged with protecting the public from unreasonable risks of serious injury or death from more than 15,000 types of consumer products including the safety of consumer products such as toys, cribs and child furniture. The CPSC develops voluntary standards with industry, issues and enforces mandatory standards or banning consumer products if no feasible standard would adequately protect the public, obtains the recall of products or arranges for their repair, conducts research on potential product hazards and informs and educates consumers through the media, State and local governments and private organizations and by responding to consumer inquiries.

**Services:**

- A toll-free hotline (800-638-2772), available 24 hours a day, that can be used to find out whether a product has been recalled, learn how to return a recalled product or arrange for its repair, obtain information on what to look for when buying consumer products, obtain information on how to use a consumer product safely, obtain information about ordering CPSC publications, report an unsafe product and report a product-related injury.
- A wide variety of recorded messages on product recalls and consumer product safety also are available on the hotline. To report product complaints or injuries, hotline staff is available between 8:30 a.m. and 5 p.m. EST Monday through Friday, except holidays. There is staff available who speak both English and Spanish. In addition, callers can arrange to speak with CPSC staff members fluent in other languages.
- Consumers can [sign up for e-mail announcements](#) on information about recalls and safety on the [CPSC Web site](#). The Web site also includes [recalls and product safety news](#), [unsafe product reports](#), [neighborhood safety network signup](#) and [voluntary standards/research reports](#).

**Data:** [Consumer product-related statistics](#) for children’s products, child poisonings, carbon monoxide poisonings, electrocutions, fires, fireworks, sports and recreation and other products. The CPSC also has injury data on several consumer products.

**Publications:** Produces and disseminates [publications](#) and other materials on crib safety and SIDS risk reduction, child safety, children’s furniture, clothing safety, toy safety and other topics. All publications are available on their Web site organized by topic, title and category. Most are available in hard copy. All CPSC publications are free and in the public domain. The CPSC only asks that you not change the materials and give proper attribution. Several publications are available in Spanish on their Spanish Web site, [El Mundo Hispano de la CPSC](#).

U.S. Consumer Product Safety Commission  
Washington DC 20207  
800-638-2772  
[www.cpsc.gov](http://www.cpsc.gov)

## Healthy Start Programs<sup>1</sup>

[Healthy Start](#) is a component of MCHB and resides in the Division of Perinatal Systems and Women’s Health. Originally funded under the authority of Section 301 of the Public Health Service Act, Healthy Start was recently authorized by Congress as part of the [Children’s Health Act of 2000](#). Healthy Start was created to address high infant mortality rates. Healthy Start projects address multiple issues, including:

- Providing adequate prenatal care
- Promoting positive prenatal health behaviors
- Meeting basic health needs (nutrition, housing, psychosocial support)
- Reducing barriers to access
- Enabling client empowerment

Healthy Start programs are community-driven and located in the poorest neighborhoods in the United States. Since its initiation in 1991, Healthy Start has served hundreds of thousands of families. More than 90 percent of all Healthy Start families are African American, Hispanic or Native American. Healthy Start specializes in outreach and home visiting—the best way to reach the most at-risk women. Healthy Start has pioneered the use of women living in the community as outreach workers and home visitors.

Every Healthy Start project has developed a consortium, composed of neighborhood residents, clients, medical providers, social service agencies, faith representatives and the business community. This ensures that not just Healthy Start, but the whole community, is committed to reducing infant mortality and LBW.

**Communication Vehicles:** [Newsletters](#) and copies of proceedings from the past annual conferences

**Membership:** [Membership](#) in the National Healthy Start Association (NHSA) is open to all Federally-funded Healthy Start projects. Other community-based agencies and individuals are welcome to become a friend of Healthy Start by joining the association as well. The NHSA, whose members include most of the 96 Federally-funded Healthy Start projects in the United States, promotes community-based maternal and child health programs, particularly those that focus on the reduction of infant mortality, LBW and racial disparities in perinatal outcomes. The Web site provides contact information on [individual Healthy Start programs](#).

**Publications:** Individual Healthy Start's publications

**Services:** Range of member-related services

National Healthy Start Association  
P.O. Box 25227  
Baltimore, MD 21229  
410-525-1600  
410-525-1601 (fax)  
[www.healthystartassoc.org](http://www.healthystartassoc.org)  
[natlhealthystart@mindspring.com](mailto:natlhealthystart@mindspring.com)

## National Healthy Mothers, Healthy Babies Coalition

The National Healthy Mothers, Healthy Babies Coalition ([HMHB](#)) is a recognized leader and resource in maternal and child health. HMHB reaches an estimated ten million health care professionals, parents and policy makers through its membership of more than 100 local, State and national organizations. Enhanced by a network of [90 HMHB State and local coalitions](#), HMHB acts as a catalyst for change and creates partnerships among community groups, nonprofit organizations, professional associations, businesses and government agencies. By promoting optimal health for mom and baby, HMHB works to strengthen families and build healthy communities.

**Communication Vehicles:** [Members](#) can subscribe to the HMHB e-mail news alerts including the weekly Monday Morning Memo and the Coalition Connector. Members receive updates on HMHB activities, Federal initiatives, model programs and HMHB

member promotions through quarterly member mailings.

**Membership:** State and local HMHB coalitions work in their communities to promote maternal and infant health. They conduct educational initiatives, support policy and legislation, provide direct services and network to achieve their maternal and child health goals. They link health care providers, educators, policy makers, community leaders, parents and teens through a variety of activities designed to enhance the health and well-being of families. Each coalition varies in its programs to meet the unique needs of the State or community it serves. To find the HMHB coalition nearest to you, [click on the map](#) location of your choice at [www.hmhb.org/state.html#map](http://www.hmhb.org/state.html#map).

There are several levels of membership available including organizational and individual memberships. For more information on membership, contact the HMHB membership office at 703-836-6110 or [member@hmhb.org](mailto:member@hmhb.org).

**Publications:** Produces and provides professional and consumer educational materials on topic areas such as [breastfeeding](#), [immunization](#), [adolescent health](#), [maternal and child health](#) and out-of-print materials. Some publications are available on the Web site. All of them are available in hard copy. Single copies are free, but bulk orders have a fee. Member discounts on all HMHB publications. Some publications are in Spanish.

**Services:** HMHB works with a variety of partners on a number of different programs, including projects on maternal and infant health, child and adolescent health, family health and community health. Also supports conferences and awards.

National Healthy Mothers, Healthy Babies Coalition  
121 North Washington Street, Suite 300  
Alexandria, VA 22314  
703-836-6110  
703-836-3470 (fax)  
[www.hmhb.org](http://www.hmhb.org)  
[info@hmhb.org](mailto:info@hmhb.org)

## National Perinatal Association

The National Perinatal Association (NPA) promotes the health and well-being of mothers and infants enriching families, communities and our world. NPA works to engage the broadest possible coalition to improve social, cultural and economic environments for optimal health and well-being of mothers, infants and families.

NPA is committed to:

- Collaborating with all who share its mission and vision.
- Providing a multi-disciplinary forum to promote research utilization and practical applications, to improve the quality of care, caring and outcomes.
- Advocating for positive changes in conditions, policies, programs and practices to improve health.
- Developing and inspiring passionate mentors, role models and guides committed to its mission and vision.

**Communication Vehicles:** Newsletter, conferences and [Web site](#)

**Membership:** Individual and organizational

**Publications:** Transcultural Nursing

**Services:** Throughout the United States, there are a myriad of community-based, regional and national perinatal health care programs that are funded by a vast array of governmental and nongovernmental agencies. Nevertheless, there is a dearth of information available to professionals who are interested in initiating similar programs. Recognizing this, NPA offers a compendium of selected models of care that have been developed, implemented and evaluated by others.

If an organization wishes to initiate a program of a particular type (e.g., Adolescent Pregnancy: Education and Service, Neonatal Health Care Services, Reproductive Health Services, Substance Abuse Support Services for Pregnant Women), staff can refer to this quick reference and find a list of various programs around the country, a short description of each and contact information. Staff can then directly reach the contact person to discuss the specifics of a given program, innovations, outcomes, problems encountered and insights gained. Local projects can benefit from the experience of others and go forward without encountering some avoidable barriers to success.

National Perinatal Association  
2090 Linglestown Road  
Suite 107  
Harrisburg, PA 17110  
888-971-3295  
[www.nationalperinatal.org](http://www.nationalperinatal.org)  
[npa@nationalperinatal.org](mailto:npa@nationalperinatal.org)

## March of Dimes

The mission of the March of Dimes (MOD) is to improve the health of babies by preventing birth defects and infant mortality through research, community services, education and advocacy to save babies' lives. MOD researchers, volunteers, educators, outreach workers and advocates work together to give all babies a fighting chance against the threats to their health: prematurity, birth defects and LBW. MOD advocacy efforts focus on public policies and programs that relate to the foundation's mission of improving the health of babies by preventing birth defects and infant mortality and on issues that pertain to nonprofit organizations.

**Communication Vehicles:** MOD provides extensive information on pregnancy and newborn health, premature birth, genetic research and health insurance for parents, health care professionals and the public through a variety of vehicles. These include:

- The organization's [Pregnancy & Newborn Health Education Center](#) provides women with free one-on-one, confidential answers to their questions about pregnancy, preconception, newborn screening and related topics.
- The center provides a wide variety of materials including *mama*, an annual magazine full of practical and important information for parents-to-be.
- There is a monthly [e-mail newsletter](#) that contains news on the foundation, a personal spotlight and tips for a healthy pregnancy.
- The Web site hosts [online discussion opportunities](#) for parents and professionals to

share stories and meet NICU families.

**Publications:** MOD [fact sheets](#) cover a wide range of perinatal and genetic topics, with many available in both English and Spanish. Medical experts review each publication to ensure that consumers are receiving accurate and timely information. MOD also publishes a wide variety of reasonably-priced [materials](#) for health consumers and professionals including pamphlets, magazines, videos, DVDs, posters, curricula and CD-ROMs.

A limited number of [bereavement materials](#) are available at no charge for [parents or other family members](#) in the United States who have experienced the loss of a baby between conception and the first month of life. They are available in English and Spanish. Health care providers and others interested in purchasing the bereavement materials should call MOD at 800-367-6630 or e-mail [bkit@marchofdimes.com](mailto:bkit@marchofdimes.com).

**Data:** See [Chapter 5](#) for PeriStats information.

**Services:** [Continuing education information](#) including a [Nursing Education Program](#) which includes online modules that are self-directed learning opportunities and modules in print to help perinatal nurses integrate scientific and clinical advances into the care of mothers and babies. Nursing modules are written for nurses, by nurses and are a cost-effective way for nurses and certified nurse-midwives to earn continuing education credit. Nursing modules are \$20 each. Call 800-367-6630 to order.

**Membership:** Chapters are located in all States and can be found on their [Web site](#). Local chapters support community programming, sponsor fundraising events and provide small grants.

March of Dimes Birth Defects Foundation  
1275 Mamaroneck Avenue  
White Plains, NY 10605  
888-663-4637  
914-428-7100  
914-428-8203 (fax)  
[www.marchofdimes.com](http://www.marchofdimes.com)

## First Candle/SIDS Alliance

First Candle/SIDS Alliance is a national nonprofit organization which exists to promote infant health and survival during the prenatal period through two years of age through programs of advocacy, education and research. SIDS/ID bereavement services are a critical component of the mission, vision and goals. NSIDPSC, which is administered by First Candle/SIDS Alliance, provides programs and services for professionals working in the health and human service arena. The scope of their work involves providing guidance and materials for educational efforts on reducing the risk of infant death as well as providing compassionate grief support to those affected by an infant death.

### Services:

- A toll-free hotline (800-221-7437) that provides risk reduction education and bereavement support and referrals during normal work hours and a 24-hour crisis hotline for both English and Spanish speakers.
- Spanish Web site, international conferences and newsletter.

- Staff attends conferences to provide outreach to professionals and the public.
- Provides train-the-trainer style training to medical staff, child care providers, first responders, police, funeral directors and others.
- Provides information and referrals to callers about local bereavement and SIDS risk reduction.
- Provides SIDS risk reduction materials and bereavement packets to expectant families and bereaved parents.

**Data:** Staff provides technical assistance in interpreting SIDS and perinatal death research and statistics.

**Membership:** First Candle/SIDS Alliance partners with individuals and groups at the local, State and national levels interested in infant health and survival. There are several different **membership levels:** individual, professional, associate and charter members. Currently there are more than 60 members nationwide.

**Publications:** Produces and provides health care professional and family educational materials on SIDS risk reduction, current research and trends and grief and bereavement. All publications are available at low cost to organizations.

First Candle/SIDS Alliance  
1314 Bedford Avenue, Suite 210  
Baltimore, MD 21208  
800-221-7437 (SIDS)  
410-653-8226  
410-653-8709 (fax)  
[www.firstcandle.org](http://www.firstcandle.org)

## Association of SIDS and Infant Mortality Programs

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 to those affected by infant and child death and to reduce the risk of death for future children.

**Communication Vehicles:** [Web site](#), annual conference

**Publications:** Many SIDS/ID-related publications can be ordered through e-mail. Four publications are available online: [Infant Sleep Positioning and SIDS: Counseling Implications](#); [Bedsharing and the Risk of Sudden Unexpected Death in Infancy \(SUDI\): Counseling Implications](#); [Breastfeeding, Sudden Infant Death Syndrome \(SIDS\) and a Safe Sleep Environment: Counseling Implications](#) and [The Unexpected Death of an Infant or Child: Standards for Services to Families](#).

**Membership:** Full **members** are 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. Associate members are individuals committed to the purposes of ASIP, demonstrated by past or present activities related to SIDS or infant and child mortality programs. 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.

Marie Chandick  
ASIP President  
c/o New York State Center for SID  
School of Social Welfare  
Stony Brook University  
Stony Brook, NY 11794-8232  
631-444-3690  
631-444-6475 (fax)  
[www.asip1.org](http://www.asip1.org)  
[marie.chandick@stonybrook.edu](mailto:marie.chandick@stonybrook.edu)

## Fetal, Infant and Child Mortality Review Programs

### The National Fetal-Infant Mortality Review (NFIMR)

The National Fetal and Infant Mortality Review Program (NFIMR) is a collaborative effort between the American College of Obstetricians and Gynecologists (ACOG) and MCHB. It has developed a private and public partnership to provide a comprehensive approach to understanding and combating fetal and infant mortality nationwide through case reviews of fetal and infant deaths.

Established in 1990, NFIMR is a resource center providing information and advice about implementing the fetal and infant mortality review (FIMR) method. FIMR is both an ongoing community needs assessment and a mechanism to improve health status of women and infants. The resource center provides information on topics such as confidentiality, liability, data collection, home interview techniques, coalition building, taking recommendations to action, coordinating with other local mortality reviews and using local FIMR information for regional/State assessment and planning. Referrals to expert consultants are available.

In all States, the FIMR committee brings together an interdisciplinary group of individuals to review a set of infant deaths and look for common patterns. The professionals who sit on FIMR committees often include practitioners in the fields of pathology, pediatrics, perinatology and emergency medicine. FIMRs review and incorporate information from a number of different sources, including parent interviews, medical records, birth/death certificates, medical examiners/coroners, health departments, social service and physician records. Information from these reviews is then used to focus planning and policy development and to enhance efforts to develop and maintain community resources and quality programs for women and children. The FIMR process helps State and local health departments operate the core public health functions of assessment, policy development and assurance.

**Communication Vehicles:** Web site, a national conference held every three years and a

newsletter

**Publications:** NFIMR has [publications](#) addressing [cross-cultural bereavement](#), [HIPAA](#), [social marketing](#) and a [FIMR program toolkit](#). Many publications are available for downloading on the Web site, and hard copies can be ordered.

**Services:** The NFIMR program provides technical assistance to stimulate and support the development of community-based fetal and infant mortality review groups. NFIMR software supports the electronic collection, storage and processing of information used by FIMR projects. Matching the Data Abstraction Forms, NFIMR for Windows creates a case summary for review team utilization, cross-tabulations and graphs.

National Fetal-Infant Mortality Review  
American College of Obstetricians and Gynecologists  
P.O. Box 96920  
Washington, DC 20090-6920  
202-863-2587  
202-484-3917 (fax)  
[www.acog.org/departments/dept\\_web.cfm?recno=10](http://www.acog.org/departments/dept_web.cfm?recno=10)  
[nfimir@acog.org](mailto:nfimir@acog.org)

## Center for Child Death Review (CDR)

The [Center for Child Death Review](#) is a national resource center for State and local CDR programs, funded by [MCHB](#). It promotes, supports and enhances child death review methodology and activities at the State, community and national levels. It builds public and private partnerships to incorporate CDR findings into efforts that improve child health. Building on the extensive knowledge of current CDR programs, the center actively involves States in the development of center services.

CDR is mandated or enabled by law in 45 States. States implemented CDR systems to more accurately track and determine the cause of child deaths and to help prevent future deaths from occurring. The child death review process is a team of people from multiple disciplines who come together and share what they know about the circumstances of a child's death and decide what they should do to prevent other children from dying the same way. The team conducts a social autopsy of all the factors leading up to the child deaths including environmental, social, economic, health and behavioral.

While no standardized criterion for programs exists, most programs have reporting and surveillance systems in place to collect information from local reviews and publish reports. The CDR programs have resulted in [recommendations related to SIDS](#).<sup>2</sup>

**Communication Vehicles:** Newsletter and [Web site](#)

**Publications:** Numerous publications addressing [legislation](#), [investigation](#) and [team meeting](#) protocols, training curricula, reporting software, guides to effective reviews, coordinator tools, prevention resources, expert consultants and sample forms. Many of these resources are available on the Web site.

**Data:** Extensive [data on child fatality statistics](#)

**Membership:** Web site contains links to all [CDR programs](#) in the United States.

**Services:**

- The development of standardized CDR protocols and materials by Action Teams whose members include State coordinators, key community CDR contacts and national leaders.
- The development of a national Internet-based report tool and system.
- **Technical assistance, tools** and support to teams, including the establishment of a national network of experts.
- A **national meeting** of CDR coordinators.
- **Linkages** with other mortality and morbidity reviews, including fetal and infant mortality, maternal mortality and domestic violence reviews, to identify potential areas for integration and/or coordination.
- Collaboration with State Title V Programs to integrate the CDR process with State maternal and child health programs and to utilize CDR findings in Title V Assessments.
- Promotion of the CDR process to national public and private organizations, including policy makers, Federal agencies, foundations, national support resources and member organizations.

National MCH Center for Child Death Review Center  
 2438 Woodlake Circle  
 Suite 240  
 Okemos, MI 48864  
 800-656-2434  
[www.childdeathreview.org](http://www.childdeathreview.org)

## CityMatCH

**CityMatCH** is a freestanding national membership organization of city and county health departments' MCH programs and leaders representing urban communities in the United States. The mission of CityMatCH is to improve the health and well-being of urban women, children and families by strengthening the public health organizations and leaders in their communities. CityMatCH is funded in part through cooperative agreements with **MCHB** and the **CDC**. Additional support is provided by the **University of Nebraska Medical Center** and the **National MOD**.

**Communication Vehicles:** **Ask-A-Colleague Service** is a fax network which can be used by individual members to ask colleagues around the country specific questions related to MCH. **CityMatCH NewsBriefs** is a bi-weekly e-mail summary news service to members and colleagues. **CityLights** is a quarterly newsletter for membership sites and national urban MCH partners. **Emerging Issues in MCH** is a monthly teleconference that highlights research and information on different MCH topics. Guest speakers from national organizations and local public health agencies discuss their experiences and share information on programs related to the featured topic.

**Data:** City-specific data reports consist of national, comparative data regarding specific urban MCH issues such as women's health, infant mortality, LBW or late-entry prenatal care. These special data reports are periodically published in **CityLights**. The national **DaTA Institute** addresses skills development to enhance public health practices necessary in an era of change in health and human services delivery. Designed as a year-long learning experience for a cohort of selected urban MCH data-use teams, the model

integrates the institute with related capacity-building initiatives at CityMatCH, including the annual [Urban MCH Leadership Conference](#) associated workshops and new distance learning technologies.

**Membership:** [CityMatCH membership](#) is extended to city or county health departments having jurisdiction over one or more urban areas with populations of 100,000 or larger. In States where no urban area has a population greater than 100,000, one city or county health department in that State will be granted membership. In addition, any person who has an interest in urban MCH affairs, but is not a local MCH director or designee, may become an [associate member](#). Currently, there are no dues for CityMatCH members.

**Publications:** [ResourceInfo](#) is a collection of abstracts and contact information on current policy materials related to urban MCH issues. [Undoing Racism in Public Health: A Blueprint for Action in Urban MCH](#) is a report that aims to examine the scientific basis for racism as a determinant of health status and health disparities, provide an overview of existing directions, options and resources and outline a series of activities for local public health-based initiatives ranging from awareness to action.

**Services:**

- [Perinatal Periods of Risk \(PPOR\) Practice Collaborative National Initiative](#) is demonstrating the community impact of using the [PPOR approach](#), a newly-validated community tool to address infant mortality. The PPOR initiative aims to capture best practices and lessons learned, to develop and enhance supporting materials, to develop local practice expertise and to capture this experience for use by other cities. Community teams from 14 U.S. cities are developing and revising prevention strategies for their communities' feto-infant mortality problem using the PPOR approach. These strategies are part of an intense systematic learning and demonstration Practice Collaborative with CityMatCH, CDC, MOD and other national experts.
- Annual [Urban MCH Leadership Conference](#) allows major city and county MCH leaders to exchange information about current, local-level programmatic efforts aimed at preventing disease and promoting health.

CityMatCH  
 University of Nebraska Medical Center  
 982170 Nebraska Medical Center  
 Omaha, NE 68198-2170  
 402-561-7500  
 402-561-7525 (fax)  
[www.citymatch.org](http://www.citymatch.org)  
[citymch@unmc.edu](mailto:citymch@unmc.edu)

## American Legacy Foundation

The [American Legacy Foundation](#) is dedicated to building a world where young people reject tobacco and anyone can quit. The foundation was established in March 1999 as a result of the Master Settlement Agreement (MSA) between a coalition of attorneys general in 46 States and five U.S. territories and the tobacco industry and is funded primarily by payments designated by the settlement. As a national, independent public health foundation located in Washington, D.C., the foundation develops national programs that

address the health effects of tobacco use through grants, technical training and assistance, youth activism, strategic partnerships, counter-marketing and grass roots marketing campaigns, public relations and community outreach to populations disproportionately affected by the toll of tobacco.

The foundation has **two goals** that guide its work toward creating tobacco-free generations:

- To arm all young people with the knowledge and tools to reject tobacco.
- To eliminate disparities in access to tobacco prevention and cessation services.

Prevention efforts include creation of a major national tobacco youth prevention and education effort known as the truth campaign. Advertising, grassroots and promotional events and an interactive Web site, [www.thetruth.com](http://www.thetruth.com), give teens the facts about tobacco use and tobacco marketing and encourage them to get involved in the effort to inform their peers.

Cessation efforts include raising national awareness and helping reduce the toll of the epidemic of smoking-related diseases specifically among women in the United States. The foundation has developed print and television ads that feature real women struggling with tobacco-related illnesses. Free information services on how to quit smoking are available via a toll-free telephone number (800-4-A-LEGACY) and the Internet ([women.americanlegacy.org](http://women.americanlegacy.org)).

#### **Services:**

- Provides grants to support innovations in tobacco control, develops products to address priority populations efforts, funds research, created a library which includes a vast archive containing millions of declassified tobacco industry documents about the advertising, manufacturing, marketing, sales and scientific research of these products.
- The Circle of Friends: Uniting to be Smoke-Free ([www.join-the-circle.org](http://www.join-the-circle.org)) program is a national grass-roots social movement to show support for women struggling to quit smoking and to highlight the toll of tobacco-related disease on American women, their families and communities.
- The Great Start campaign ([www.americanlegacy.org/greatstart](http://www.americanlegacy.org/greatstart)), the first national media and quitline campaign to help pregnant women quit smoking, is also a part of the women and smoking initiative. Pregnant women who want to quit smoking can obtain free, confidential counseling and educational materials in English and Spanish 24 hours a day, seven days a week, by calling toll-free 866-66-START. Educational materials associated with this campaign are available on the foundation's Web site.
- Technical Assistance & Training (TAT): The foundation is committed to obtaining guidance and expertise from tobacco control experts, then sharing best practices with public and private organizations at the State and local levels to advance tobacco prevention and control. Foundation staff assists organizations, including grantees, increases the depth and breadth of their programmatic interventions and implements the strategies necessary to conduct their programs strategically and effectively. The TAT program coordinates a number of youth-oriented projects that can be tailored to accommodate a variety of participants' interests and availability.

The American Legacy Foundation has also partnered with the [American Cancer Society](#) and the [Robert Wood Johnson Foundation](#) to launch a national training

and resource center, the Tobacco Technical Assistance Consortium ([www.ttac.org](http://www.ttac.org)), to provide ongoing guidance and expertise to new and established tobacco prevention and control programs.

**Publications:** Numerous publications and fact sheets can be downloaded from its Web site.

**Data:** The foundation currently has two public-use data sets available: the National Youth Tobacco Survey (NYTS) and the Legacy Media Tracking Survey (LMTS).

American Legacy Foundation  
2030 M Street, N.W.  
Sixth Floor  
Washington, DC 20036  
202-454-5555  
202-454-5599 (fax)  
[www.americanlegacy.org](http://www.americanlegacy.org)  
[info@americanlegacy.org](mailto:info@americanlegacy.org)

## Community and Civic Partnerships

A critical partner for all educational efforts is the community-based organizations at the local and State levels.

### Working with SIDS/SUID Families

It is important to encourage family involvement in all programmatic efforts and support family participation at all levels. This could include involving family member participation on committees and advisory councils. Families may need orientation and support to help them participate. Many national or regional organizations have local chapters or members including First Candle/SIDS Alliance, CJ Foundation, ISA, NSS, SHARE, AGAST and MISS. These members are usually more than willing to assist local or State organizations in a variety of local efforts.

### Ethnic/Racial-Specific Organizations

A number of African American civic organizations have been very involved with SIDS risk reduction. In 1998, NICHD joined forces with three national African American women's organizations in a program to reduce the risk of SIDS among African American infants. The leadership and members of the [National Coalition of 100 Black Women](#), [Women in the NAACP](#) and [Alpha Kappa Alpha Sorority](#) held three summits with NICHD to learn how to conduct SIDS risk reduction trainings and outreach activities in communities around the country.

There are many national and regional Hispanic organizations that are very interested in working to address Hispanic health care needs. The [National Alliance for Hispanic Health](#) can provide excellent resources. At the local level, there are numerous Hispanic community-based organizations which have emerged that are advocates and providers of health care for Hispanics. Most of these organizations are governed by community boards and have an infrastructure and networks to facilitate educational outreach efforts.

## Collaboration Resources

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**Coalition-  
Building**

Developing Effective Coalitions: An Eight Step Guide by Larry Cohen, Nancy Baer and Pam Satterwhite

[www.childdeathreview.org/reports/Developing%20Effective%20Coalitions.pdf](http://www.childdeathreview.org/reports/Developing%20Effective%20Coalitions.pdf)

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# Public Relations & the Media

## 8

**Critical Program Function:** To disseminate qualitative public health information on risk reduction, new research initiatives and bereavement resources in a variety of media venues.

Dealing with the media is often the most difficult aspect of public relations because it can easily be intimidating. It is easy to feel like reporters are trying to put you on the spot and that everything you say can, and will, be used against you. Although this is often the case in types of investigative and crime reporting, it is not the case with public health issues. Reporters often join the profession to “give voices to the voiceless.”

Generally, reporters will be sympathetic to your cause and want to help you share your information because they do care. You just need to take the steps to let them know you are there. For this reason, it is important to understand how the media works. Then, you can use your knowledge to your organization’s advantage.

There are a variety of ways that your organization may interact with the media including through press releases, media kits, op-ed pieces, letters to the editor, PSAs and interviews.

## How to Build Relations With Your Local Media<sup>1</sup>

Having your story printed, televised or aired is an exciting achievement. A story featuring your organization increases the public’s awareness about SIDS and infant death. This can attract the attention of politicians, donors and volunteers who might be willing to support your project or take action. The [National Council of Nonprofit Associations](#) has some suggestions on how to interact and build relationships with the media:

1. Reporters and newspapers often specialize in writing about certain issues and topics. Try to contact a health editor, for example, and read their stories. Tell the reporter that you are contacting them because you read their stories and have information that could help them write a new story on your topic.
2. Build relationships with the media so it will be easier for your story to be printed or placed on the air. One way to build rapport is to regularly share your insights with reporters on stories that they have published about SIDS and infant death. Another way is to offer any additional information that you feel a reporter may

have omitted when covering a topic in which you have expertise.

3. Put reporters on your mailing list for annual reports, research reports and invitations to special events.
4. Respond to a reporter's call in a timely manner, typically within a few hours.
5. Develop a file with relevant infant mortality statistics and data.
6. Become a resource for information.
7. Help reporters find experts for their stories by referring them to experts who are good with the media and will support your message.
8. Help reporters find good graphics and images. Reporters often need charts, lists, photographs and graphics as illustrations for their stories.
9. Invite a reporter to lunch at your organization to meet with staff, a board member and your constituency.
10. Create and update a "For the Press" section on your Web site. This section should list key contacts, highlight your mission and list press releases and potential story ideas.
11. Thank reporters when they write a story featuring your organization.
12. Send them creative story ideas and be prepared to follow up on your suggestions if they are accepted.

If you want to have successful relationships with a reporter (and also great media coverage), you need to think, act and write like a reporter. Why? Because you will be making their job easier. The easier a story is to write, the greater chance it will be written.

## News Values

There are a handful of basic news values that the media uses to weigh stories. Included below are the major values:

- **Impact:** The media care most about the things that affect their audience such as stories about local families.
- **Controversy:** Anything controversial will bring media attention. The media loves a good fight because audiences love a good fight.
- **Emotion:** Reporters are often told to find not just the facts, but the "human interest" angle to a story. They may be more interested in writing about the mother losing a baby as opposed to just infant mortality statistics. This news value is often easy to underutilize, but can be the value that gets you the attention when you otherwise would not.
- **The Unusual:** The journalist's cliché goes: When a dog bites a man it is not news, but when a man bites a dog, it is news.
- **Prominence:** If you fall down the stairs, it is not news. If a politician or an actress falls down the stairs, it is. Big names count, even if they are just prominent in your community.
- **Proximity:** Media outlets are on a constant mission to take national stories and "localize" them. Local families or individuals who are affected are much more interesting to media.
- **Timeliness:** Newer is always better. Consider all the live coverage to which we are

now exposed.

- **Educational:** This is what people “should” know such as infant product safety recalls or new health promotion campaigns.

## “So what?”

This is a question that reporters often ask themselves and one that you should ask yourself as well. Reporters want to know why they should care about what you are telling them and, in essence, why their audience should care. Although seemingly harsh, asking yourself, “So what?” can help you find what makes your story newsworthy.

The more news values your story hits, the more likely you are to get media attention. News values are often intertwined. Proximity and impact often work together as do controversy and emotion. By examining the obvious news values your story has, you can tie in other ones that will make your story as appealing as possible.

For example, you have an upcoming training on SIDS risk reduction geared toward child care providers. The obvious news values here are proximity (it is local) and timeliness (it is soon/has not yet happened). This may or may not get you attention depending on how much of a slow news day it is.

With a little work, you can easily make the story have high impact, emotion and proximity. Ask yourself these questions:

- What is your State’s infant mortality rate?
- What is your area’s infant mortality rate?
- How many babies in your area die every year of SIDS?
- Do you know any local families that have been personally affected by SIDS?
- Do you know any local child care providers that have dealt with a SIDS death firsthand?

Include in your press release local—as well as national—infant mortality and SIDS statistics. Explain how your training will save local babies.

Also, put a human face on your training. If you have a SIDS relative or child care provider, doctor or trainer who dealt with a SIDS death and is willing to share his or her story with the media, use that resource.

## Press Releases

The press release is the most basic and common way to contact the media. Releases should follow a standard format, including:

1. The words “News Release” in large type at the very top of the release so that it is easily recognizable.
2. On the left-hand side: “For Immediate Release” with the date one line below.
3. On the right-hand side: contact information for person in charge of public relations, including telephone number and e-mail address.
4. **Headline:** make it concise and attention-grabbing.
5. **Lead:** include the most important information and information that will get a

reporter’s attention. Also, include the important who, what, where, when, why, how and how much of the story.

6. Body of release: include a luminous quote in one of the first three paragraphs.
7. Closing paragraph: include your organization’s mission and whom they should contact for more information.

Press releases should be double-spaced with margins large enough for scribbling. Releases should be written in AP style and as a news story that would appear in a news publication. This includes not using the word “you.”

Most professions have a writing style, and for reporters, it is AP style. As such, contact with reporters should also be written in AP style. AP style is the style set by the [Associated Press](#) and their guide, the AP Style Guide, is often referred to as the journalist’s bible and is available at local bookstores.

## Writing Your Press Release

Keep the following points in mind when writing your press release:<sup>2</sup>

- **Is your news newsworthy?** The purpose of a press release is to inform the world of your news item. Do not use your press release to try and make a sale. If you read your press release and it reads like an advertisement, rewrite it.
- **Start strong.** Your headline and lead should tell the story. The rest of your press release should provide the detail.
- **Write for the media.** On occasion, media outlets, especially online media, will pick up your press release and run it in their publications with little or no modification to what you send. More commonly, journalists will use your press release as a springboard for a larger feature story. In either case, try to develop the story as you would like to have it told.
- **Not everything is news.** Think about your audience. Think about news values and ask yourself, “so what?”
- **Stick to the facts.** Tell the truth. Avoid fluff, embellishments and exaggerations.
- **Pick an angle.** Try to make your press release timely. Tie your news to current events or social issues if possible. Make sure that your story has a good hook.
- **Use active, not passive, voice.** Verbs in the active voice bring your press release to life. Rather than writing “entered into a partnership” use “partnered” instead. Do not be afraid to use strong verbs as well. Avoid gerunds (-ing words). “We are helping...” versus “We help...”
- **Economics of words.** Use only enough words to tell your story. Avoid using unnecessary adjectives, flowery language or redundant expressions. If you can tell your story with fewer words, do it. Wordiness distracts from your story. Keep it concise. Make each word count.
- **Beware of jargon.** The best way to communicate your news is to speak plainly, using ordinary language. Make sure all medical terms are thoroughly explained.
- **Avoid the hype.** The exclamation point is your enemy. There is no better way to destroy your credibility than to include a bunch of hype. If you must use an exclamation point, use one. Never do this!!!!!!!!!!!!!!
- **Get permission.** Be sure that you have permission before including information or quotes from employees or other organizations.

## Media Kits

Media kits often include the following materials:

- Fact sheet about the organization (make sure your contact information is included on this document)
- Fact sheet about SIDS, stillbirth, miscarriage or infant death
- General press release or release for your special event
- Brochure about the issue or organization
- Risk reduction and bereavement measures
- Calendar of events
- Camera-ready logo sheet or CD with high-resolution logo
- Public service announcement

Media kits should be sent to television stations, newspapers and radio stations to give them written materials about the organization and to familiarize them on the subject of SIDS and infant death, especially before events you are promoting. Depending on the size of your organization, some of the materials may not be available or necessary for your individual media kit.

Some of these items, such as the logo sheet and advertisements, are helpful for television and print media because they can be easily scanned into computer images and used by the stations. It is good for stations to have hard copies of these items in their files so you will not have to scramble at the last minute to produce information for news stories.

## Op-Ed Pieces<sup>3</sup>

An opinion editorial (op-ed) is a section of a newspaper that allows readers to share their opinions. Normally, the author of an opinion editorial has direct experience or knowledge of a particular issue. Readers who see their op-eds published are usually well-known by the newspaper. Your background and perspective should make your opinion editorial distinctive.

Prior to writing an op-ed, consider these questions to ensure that you make the necessary points for an effective piece:

- What is the problem in the community that your organization is solving?
- How does your organization help to solve this problem?
- Describe your organization. How does it work?
- Why wasn't the problem solved before? What was the obstacle?
- How can you paint a picture in someone's mind through your words?
- Which community leaders, groups or people in the community agree with you? Why?
- Which community leaders, groups or people in the community disagree with you? Why?
- What is the urgency?
- Who does this affect?

- What is the history of this story? What has been done before?

A few guiding principles to consider when placing one an op-ed:

- Generally, op-eds are 800 words or less in length. Before writing an op-ed, contact the op-ed page editor of your local paper for submission policies and guidelines.
- An op-ed should argue a point and the point being made should be stated clearly up front. There should be a compelling hook to generate interest in the op-ed and demonstrate its relevance to the readers and the community.
- Make your case from the top down. Begin with the premise of your opinion and then back up your opinion with facts. Do not present the facts first and save your opinion for the conclusion.
- Submit a timely piece. It should relate to something in the news.
- Keep sentences and paragraphs short.
- Offer specific recommendations to address the issues you raise.

## Submitting Information to the Media<sup>4</sup>

Now that you have completed your press release or op-ed, the [National Council of Nonprofit Associations](#) suggests certain principles you must follow to ensure that your message is effectively communicated:

- Know a reporter's and newspaper's deadlines for submitting final stories. Reporters prefer to receive early notice for a news event so that they can plan ahead.
- When establishing contact with reporters, ask them how they and their newspaper prefer to receive information (fax, mail or e-mail).
- If you use e-mail, make the message and the subject line very direct.
- Never use attachments because they are likely to be deleted in case they have viruses.
- If possible, address the reporter individually and do not misspell his or her name.
- Give them accurate contact information and check e-mail and voice mail daily. You never want to miss an opportunity to have your story covered because the reporter had a wrong number or you failed to meet a deadline.
- Check a newspaper's Web site. Often a paper's Web site allows you to post news tips.
- Respond to a reporter's inquiry quickly. Often the worst time to contact reporters is after 2 p.m., as the hours afterwards are spent polishing and editing their stories. This is not a time when they typically want new information.
- (For op-eds only) Propose a meeting with the editorial board explaining why you want your piece published.
- After meeting a deadline, check the status of the story.
- Follow up the submission of your story with a telephone call to the reporter or editor to make sure it was properly submitted.
- Update the reporter with any changes to the story.

There are several companies that will distribute press releases for you. They vary in cost

and can easily be found online. Examples include:

- Bacon's, [www.bacons.com](http://www.bacons.com)
- PR Web, [www.prweb.com](http://www.prweb.com)
- [www.press-release-writing.com](http://www.press-release-writing.com)
- [www.ereleases.com](http://www.ereleases.com)

## Spokespeople

The goal and purpose for training spokespersons to work with the media is to provide individuals with clear, concise messages for public consumption. Interviews are done in various media outlets with the most popular being radio, television and print. Communicating the organization's message in a manner that is professional, informative and credible is a critical element for successful media encounters.

Here are some things to think about before you set up a media interview:

- What message do you want your spokesperson to convey?
- Is the spokesperson you have chosen the most appropriate person to convey your message?
- What is the most effective media outlet for your information?
- Have you identified a specific targeted audience for your message?
- Is your message appropriate for your audience?
- Is your message informative, compelling, newsworthy, timely, accurate or interesting?
- What message do you want your spokesperson to give to the public?
  - SIDS risk reduction measures
  - Bereavement resources
  - New research findings
  - SIDS and child care information
  - SIDS and grandparents information

Prepare your spokesperson for the interview by providing him with the most up-to-date, evidence-based information and help him anticipate questions that are relevant to his expertise or experience. Below is a list of topics you may suggest your spokesperson discuss.

### Physicians

- Risk reduction measures
- Medical definitions
- Why back sleep is recommended
- Improvement of SIDS/ID rates
- Concern that babies may choke on spit-up while back sleeping

### Parents & Siblings

- Personal story
- Risk reduction measures
- How a bereavement center supported them
- How friends and family or church supported them

### **Counselors**

- Anecdotes about how they have helped families
- How to work with siblings
- The bereavement process and how people grieve differently
- Tips on how to help families in bereavement

### **Organization Spokesperson**

- Highlight the mission and goals of your center
- Risk reduction measures
- National and Statewide statistics on SIDS, infant death and fetal death

### **Tips for the Interview**

Interviews for television generally may last from 3 to 5 minutes. This may not seem like a long time, but it can be forever in front of a camera. Radio interviews may be from 10 to 30 minutes. Newspaper interviews vary in time and may be done over the telephone or in person. Make sure you have all of the necessary information to complete a successful interview. Remember to:

- Speak clearly and audibly.
- Maintain eye contact with the interviewer. Do not allow eyes to wander around the studio.
- Have correct facts and figures.
- Be compelling. Make the audience believe and care about what is being said.
- Know what you are talking about.
- Be positive and informative.
- Address all issues that are identified as key messages.
- Dress well, but do not over-dress. Too much “costume” will take the viewer’s attention away from the message.
- Know the organizational mission and goals.
- Provide viewers or listeners with a “call to action,” what you want them to do with the information they are being given.
- Do not use professional or medical jargon.
- Be enthusiastic about getting the message to the public.
- If a family is being interviewed in their home, remind them to clean the room in which the interview will take place.
- Use verbal and nonverbal language and signs to emphasize key points.
- Avoid over-answering questions during interviews. Be clear, concise and

compelling with your answers.

- Do not be afraid to repeat your message.

Tips for you to effectively answer a reporter's questions:<sup>4</sup>

1. When a reporter contacts you, reply back immediately. Be prepared to ask him or her:
  - What is your deadline?
  - What questions do you have?
  - Who else have you contacted?
  - Do not be afraid to ask, "Can I call you back in an hour to research your questions and find the right spokesperson for you?"
2. Know your message.
  - It is important that everyone in your group is clear about the message being conveyed. Have your message points written out and practice saying them before being interviewed. Do not be afraid to repeat your message.
3. Your response to any question should tie back to your message.
4. If you are able to schedule an interview, prepare yourself through a role-play.
5. Do not be afraid to say you do not know.
  - If you are unable to answer a reporter's question, refer him/her to someone who can.
  - If you realize you stated an incorrect fact or misstated your thoughts, immediately let the reporter know.
6. Provide any information that you may have for an upcoming story.
  - Reporters appreciate the gesture and this helps to build connections with media outlets.
  - Building rapport with a reporter will give you a better opportunity to frame your story for the public.

## Awareness Months

Awareness months are great times to get press coverage. September is Baby Safety Month and October is SIDS Awareness Month as well as Pregnancy and Infant Loss Awareness Month. October 1 is Child Health Day. Awareness months are also great times for fundraising. For more information on fundraising, see [Chapter 9: Fundraising & Development](#).

## Public Service Announcements

Public service advertising is commonly defined as "advertising that serves the public interest." The majority of PSAs run as a community service at no charge by the media. The objectives of these ads are education and awareness of significant social issues in an effort to change the public's attitudes and behaviors and stimulate positive social change.

PSAs encompass all ads running in donated ad time and space and some PSAs running in purchased time and space. Some nonprofit organizations and government agencies, such

as the [Office of National Drug Control Policy](#) and the [CDC](#), have begun purchasing media time and space for some of their PSAs, in addition to relying on donated media, in order to have more control over placement and scheduling.<sup>5</sup>

## Sample Radio PSAs

Try to record voice PSAs with the State/local health commissioner, local celebrity, local radio personality, television reporter, governor, mayor, councilperson or local sports figure. This text can also be used for video PSAs. PSA examples are from NICHD's Back to Sleep Resource Kit - African American Outreach, which can be found at [www.nichd.nih.gov/sids/Resource\\_kit.htm](http://www.nichd.nih.gov/sids/Resource_kit.htm).

**:30-Second Radio PSA.** Did you know that the safest way for babies to sleep is on their backs? This small change in the way you care for your baby is the best protection against Sudden Infant Death Syndrome—SIDS, sometimes called “crib death.” African American babies are two times more likely to die of SIDS as White babies. Remember, back sleeping is safest. To find out more about SIDS, call 800-505-CRIB. That's 800-505-2742.

A public service of this station and the [insert name of your organization].

**:15-Second Radio PSA.** Help protect African American babies from Sudden Infant Death Syndrome—SIDS, sometimes called “crib death.” All babies should sleep on their backs. To learn more about SIDS, call 800-505-CRIB.

A public service of this station and the [insert name of your organization].

**:30-Second Radio PSA.** Placing babies to sleep on their backs is the most important thing you can do to reduce the chance that your baby will die from SIDS—Sudden Infant Death Syndrome, sometimes called “crib death.” Nearly 3,000 babies die from SIDS each year. African American babies are two times more likely to die of SIDS as White babies. Remember, back sleeping is safest. To find out more about SIDS, call 800-505-CRIB. That's 800-505-2742.

A public service of this station and the [insert name of your organization].

**:15-Second Radio PSA.** Reduce the risk of SIDS—Sudden Infant Death Syndrome, sometimes called “crib death,” by placing babies on their backs to sleep. To learn more about SIDS, call 800-505-CRIB.

A public service of this station and the [insert name of your organization].

## Publications

Publications are a key component to any educational campaign. Literature may be distributed or placed at community events, health fairs, senior community centers, social service offices, churches, health departments, child care centers, doctor's offices and hospitals. Throughout this manual, resources for free or low-cost publications are included.

If, however, you are going to design some or all of your own publications, you should have some background in basic graphic design principles. [The Center for Health Care Strategies](#) suggests that written materials should:

- Include graphics and videos along with written materials to reinforce learning.
- Emphasize behavioral change rather than the medical facts.
- Focus on a few educational objectives.
- Use ample white space, bullets, clear headings and short sentences.

## Public Relations and Media Resources

<b>Design</b>	The Non-Designer's Design Book	by Robin Williams
	Before&After Page Design	by John McWade
<b>General</b>	Bacon's	<a href="http://resources.mediasource.com/usefullinks_1.asp?plD=ul">http://resources.mediasource.com/usefullinks_1.asp?plD=ul</a>
	Communications Network	<a href="http://www.comnetwork.org">www.comnetwork.org</a>
	SPIN Project	<a href="http://www.spinproject.org">www.spinproject.org</a>
	Management Assistance Program for Nonprofits	<a href="http://www.mapnp.org/library/pblc_rel/pblc_rel.htm">www.mapnp.org/library/pblc_rel/pblc_rel.htm</a>
<b>Press Releases</b>	PR Web	<a href="http://www.prweb.com">www.prweb.com</a>
	Publicity Insider	<a href="http://www.publicityinsider.com/release.asp">www.publicityinsider.com/release.asp</a>
	eReleases	<a href="http://www.ereleases.com/howtowrite.html">www.ereleases.com/howtowrite.html</a>
<b>PSAs</b>	The Ad Council	<a href="http://www.adcouncil.org">www.adcouncil.org</a>

# 8

# Fundraising & Development

**Critical Program Function:** To identify alternative and additional resources to expand the capacity of the health and social services systems to improve bereavement support services and risk reduction efforts.

Program staff may:

- Prepare and submit proposals for State and Federal funds.
- Collaborate with other community-based organizations, hospitals and professional organizations to develop and submit joint program proposals for State and Federal funds.
- Provide technical assistance to private community-based organizations to prepare and submit their own proposals to funders.
- Advocate and allocate for funding for local and State efforts.
- Develop relationships with businesses, private philanthropic organizations and community services organizations such as the Kiwanis.

These are critical activities that organizations must undertake to support program capacity and sustainability in order to serve their communities better. As most program staff are not trained in fundraising and development, the following section was included to review the basics for both public and private sector programs.

Building a healthy development function begins primarily with strong and valuable programming. *What kinds of services does your organization provide? Who are your key audiences? What is your impact?* These are just a few of the fundamental questions that will be asked by your potential donors time and time again.

Beyond your organization's programmatic strengths, there are three key strategies that you should employ: diversify, communicate and say thank you.

## Diversify

Diversification will help your organization grow, and it will prevent it from becoming too dependent on one revenue stream or another. For example, if your organization was formed largely as a result of a government grant, you will soon need to find alternate ways of generating revenue. Eventually, all revenue sources dry up and another one—or more, preferably five or six—need to be ready to take its place.

There are five key areas that will help you craft a well-diversified development function:

1. Individual giving
2. Corporate contributions
3. Foundation grants
4. Government grants
5. Special events

## **Communicate**

Another key to developing a strong development function is to be consistent and persistent in your communications. Your donors or potential donors need to be reminded about your mission, programs and accomplishments on a quarterly basis. If possible, use a newsletter to communicate with your constituency, or if a full newsletter is beyond your capacity, a simple one-page update letter will suffice. You should also issue an annual report or again, an annual letter, which provides an overview of the year's accomplishments. If possible, also include key numbers from your audit.

## **Saying Thank You**

Say thank you immediately and often. For each donation that your organization receives, be sure to send out a thank you letter signed by either your Board Chair or Executive Director. All of your donors—whether individual, corporate, foundation or government—want to be sure that their contribution is valued and that their support is making a difference.

## **Individual Giving**

The key to developing a strong individual giving campaign is to offer your prospective donors plenty of options for giving. Components of a strong individual giving campaign may include:

- Program-designated funds
- Memorial gifts
- Annual appeals
- Planned giving
- Workplace campaigns

## **Program-Designated Funds**

Many donors appreciate the ability to direct their dollars. For example, perhaps your organization can offer individuals the opportunity to designate their funds to various research projects, support specific target audiences (such as children, parents or health care providers), contribute to a capital campaign or support a memorial fund.

## **Annual Appeals**

A great way of raising funds from individuals is to conduct an annual appeal for support. Many nonprofit organizations conduct annual appeals at year-end or during the holidays. Remember, to optimize your appeal, make it personal. Is there a member of your board,

staff or constituency who can author the appeal letter, sharing a personal story that is connected to your mission?

Also, be sure to carefully review your prospect list. Are all of the addresses as up-to-date as possible? Are there new constituency groups that should be included this year? Is everyone coded appropriately within your database to maximize your reach?

**Workplace Campaigns.** Explore workplace giving campaigns that are run by organizations such as the [Combined Federal Campaign](#), [Community Health Charities](#) and [United Way](#). These campaigns will help you tap into individuals who otherwise might not be aware of your mission and programs. If you opt to join an organized workplace campaign, be sure to promote your designated number often and prominently. This is how potential donors will designate your organization as their recipient.

## Corporate Contributions

One misconception in fundraising is that securing sponsorship from a large company in your community is next to impossible. People are often intimidated by the corporate world and they ultimately sell themselves, and their organizations, short. Many large companies have policies to support local giving.

### How a Company Benefits

Keep in mind that corporate sponsorships provide an opportunity for companies to portray themselves as civic-minded within their respective communities. Your organization's mission could be the perfect way for companies to do this. In addition, remember that companies also sponsor nonprofit organizations because they are seeking:

- **Publicity.** The publicity that your organization can generate for its sponsors is probably the most valued benefit of sponsorship.
- **A Positive Image.** Supporting your organization can create a positive image for a company's employees, colleagues and customers.

### What a Company Wants

While each company is different, most companies ask the same key questions:

- Does the organization's mission match the company's philanthropic goals?
- Can they trust the nonprofit partner will address the sponsorship responsibly and professionally?
- Who else provides support to the nonprofit?
- Is there an opportunity for employee involvement in the sponsorship?
- Is the organization well run, both fiscally and in terms of its management?

### Making the Ask

Once you have determined the appropriate corporate prospects for your organization, the next step is actually asking for sponsorship. Try to keep these things in mind when soliciting their support:

- Whenever possible, use your connections. Even contacting a friend of a friend is

better than making a cold call.

- Talk to the most senior-level person at the business (Area Manager, Regional Manager, etc.).
- Offer them different ways to sponsor your organization:
  - Develop different sponsorship levels and name them (Silver, Gold and Platinum, etc).
  - Determine different dollar amounts and benefits for each level.
  - Offer opportunities to sponsor key programs such as special events, public education campaigns, etc.
- Do not forget to make your request a personal one. The company will want to know that its money will make a difference.
- If someone at a company has been extremely helpful to you, capitalize on it. Do not feel that you are asking too much if he or she can provide great networking opportunities. This person could turn into a champion of your efforts year after year.

## Saying Thank You

Once again, be sure that you say thank you early and often. Donors never tire of hearing that their contributions have made a difference. Send a thank-you letter upon receipt of the sponsorship check, include mention of the contribution (with a photo, if possible) in your newsletter or quarterly update, have one of your board members make a special thank you call or include the company's logo on printed materials such as brochures and fact sheets.

## Foundation Grants

Grants from foundations can provide a large source of revenue for nonprofit organizations. The best place to begin researching potential foundation matches is through the Internet. There are several great resources that you can tap including the [Foundation Center](#), [Fundsnet](#) and the [National Council of Nonprofit Associations \(NCNA\)](#). The NCNA most likely can guide you to an association of nonprofit organizations, including foundations, in your State. Many State associations also maintain extensive libraries with information on funding sources.

The key to securing foundation dollars is to find a foundation whose philanthropic goals match your organization's mission. Foundation boards generally establish very tight restrictions on the kinds of programs they fund and more importantly, on those they do not fund.

After you have found a match, be sure to follow closely the foundation's application process. This includes the kind of information they request through their application and grant submission process, as well as their desired format. Often, the omission of just one piece of information may disqualify your proposal for funding review.

## Government Grants

Like foundations, grants from Federal, State or municipal governments tend to be very specific in focus. You will have to review grant guidelines carefully to be sure that first your

organization and second your program will qualify for the grant.

The U.S. Department of Health and Human Services is the largest grant-making agency, awarding approximately 60 percent of Federal grant dollars. HHS manages more than 300 grant programs designed to promote research in basic and applied science, public health, income support, child development and health and social services. In Fiscal Year 2004, HHS awarded more than 75,000 grants totaling \$258 billion.

HHS awards two types of grants: mandatory and discretionary. Mandatory grants are those that a Federal agency is required by statute to award to States. Discretionary grants are those that permit the Federal government, according to specific authorizing legislation, to exercise judgment, or “discretion,” in selecting the applicant/recipient organization, through a competitive grant process. Discretionary grant awards fund health and social science research and social and health services throughout the country.

Each Federal agency, or operating division, has grants and program offices that jointly administer grant programs. These offices are the best sources of information on HHS grants. Program offices are responsible for the technical and/or scientific aspects of grant programs. Grants offices are responsible for issuing grant awards and overseeing the business and financial management of grant awards.

To find out more about Federal grants you can visit one Web site, [Grants.gov](http://Grants.gov), to access the annual grant funds available across the Federal government. This Web site provides:

- A single source for finding grant opportunities.
- A standardized manner of locating and learning more about funding opportunities.
- A single, secure and reliable source for applying for Federal grants online.
- A simplified grant application process with reduction of paperwork.
- A unified interface for all agencies to announce their grant opportunities, and for all grant applicants to find and apply for those opportunities.

In addition to simplifying the grant application process, Grants.gov also creates avenues for consolidation and best practices within each grant-making agency.

## Special Events

While special events can be quite time-consuming, they can also offer great benefit—both in terms of proceeds and public awareness for your organization. Great special event ideas include dinner/dances, walk-a-thons, bowl-a-thons, golf tournaments, scavenger hunts and auctions. If you are undertaking a special event for the first time, we recommend the following seven key steps:

- 1. Make Key Decisions Early.** Many factors will have to be considered before the commitment is made to have a fundraiser, such as what type of event you would like to have, how many volunteers can assist, how much time you have to dedicate to planning an event and what are the potentials for garnering publicity and raising money.
- 2. Develop a Timeline.** Once you have made the decision to move forward with your special event, the planning stage begins. Organization is vital during this process and we recommend that you create a timeline, which will be invaluable to you and your team. Your timeline should contain various tasks and task deadline dates, and

it should delegate those tasks to various members of your planning team.

- 3. Develop a Budget.** With a first-time event, budgeting can often be difficult. Keep in mind the type of event you are holding, the expenses you will incur and the resources available to you. Be realistic when creating your budget. We suggest that you overestimate your expenses while underestimating your income.
- 4. Seek Corporate Sponsors.** Special events provide opportunities for publicity to companies in your community. Be bold. Be sure to make it clear that by sponsoring your event, the company will receive a tremendous amount of exposure, as well as a chance to demonstrate its position as a good corporate citizen and even an opportunity to garner new clientele.
- 5. Create Supporting Materials.** Developing a few simple communications tools to introduce your event to potential sponsors or attendees is ideal. Consider developing a simple letterhead, which will convey a professional look and feel to your fundraiser. Also, a one-page fact sheet to have on hand when approaching potential donors or sponsors is vital. It should contain the basic information about your fundraiser: who, what, when, where, how and why.
- 6. Promote the Event.** Building exposure for your event can seem daunting, but with some organization and persistence, it can be quite painless. Call television and radio stations in your area and ask for a PSA to promote your event. Create colorful flyers to circulate within your community as well as posting an ad in the Community Events section of your local newspaper.
- 7. Don't Forget the Wrap-Up.** Not all of the work is done when the event is over. Be sure to thank your donors and volunteers, especially your larger sponsors. Provide some photos of the event (and which include their logos) to your corporate sponsors to show them how much of a difference their support meant to your event. Send copies of any newspaper articles on the event to your sponsors, too. Last impressions can mean the difference of their supporting your fundraiser next year.

## Fundraising Resources

Chronicle of Philanthropy	<a href="http://www.philanthropy.com">www.philanthropy.com</a>
Combined Federal Campaign	<a href="http://www.opm.gov/cfc">www.opm.gov/cfc</a>
Community Health Charities	<a href="http://www.healthcharities.org">www.healthcharities.org</a>
Federal Grant Opportunities	<a href="http://www.grants.gov">www.grants.gov</a>
The Foundation Center	<a href="http://www.fdncenter.org">www.fdncenter.org</a>
Fundraising for Non-Profits	by P. Burke Keegan
Fundsnet	<a href="http://www.fundsnet.com">www.fundsnet.com</a>
Guidestar	<a href="http://www.guidestar.org">www.guidestar.org</a>
IEG, Inc.	<a href="http://www.sponsorship.com">www.sponsorship.com</a>

## **Fundraising Resources**

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IEG's Guide to Sponsorship

by Lesa Ukman

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National Council of Nonprofit Associations

[www.ncna.org](http://www.ncna.org)

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Secrets of Successful Fundraising

Compiled and Edited by Carol Weisman

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Strategic Marketing for Nonprofit Organizations

by Philip Kotler & Alan Andreasen

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United Way of America

[www.national.unitedway.org](http://www.national.unitedway.org)

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9

# 9

# Appendix A

## History of SIDS

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### 10th Century

The Holy Bible 1 Kings 3:19 (King James Version) records an infant brought to King Solomon dead as a result of being “overlaid.” Originally, SIDS was described as overlaying. It was assumed the infant died as the result of a neglectful mother laying on him. In early history, a mother whose child died of overlaying was punished.

In Egypt, about the same time period of King Solomon, mothers judged responsible for overlaying were condemned to hug the infant for three days and nights as punishment for their neglect.

The practice of punishing a mother for overlaying lasted into the 17th century.

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### 17th Century

In Sweden, a mother whose child had died was judged by the church. If the church found the mother guilty of overlaying, she was placed in a pillory in front of the church and lost her standing in the church and community. After a public confession, she could be reinstated into the church and community.

In Florence, a device was invented to prevent overlaying. This device was placed over the child while asleep to prevent the mother from rolling onto the infant. A woman guilty of overlaying and found not using this device was excommunicated from the church.

Later, after cribs and cradles had been invented, the idea of accidental overlaying was gradually abandoned. The diagnosis of overlaying could not be applied to an infant who had died in a separate bed than the mother. The diagnosis was changed to “crib death” or “cot death.” This term, along with others, continued to be used well into the 20th century.

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### 1834

Dr. S.W. Fearn noted in a letter to Lancet his postmortem findings of two children which anticipate the current findings of SIDS.

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# A

## History of SIDS

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<b>1842</b>	Dr. C.A. Lee published an article in the American Journal of Medical Science on the abnormally large thymus gland in infants as a possible cause of sudden infant deaths.
<b>1892</b>	Dr. C. Templeman published an article in the Edinburgh Medical Journal based on his autopsy and investigative findings attributing sudden infant deaths to suffocation, but he describes typical pathological findings similar to SIDS.
<b>1945</b>	Dr. P.V. Woolley, Jr., published an article in the Journal of Pediatrics exploring the relationship of mechanical suffocation during infancy to the problem of sudden infant death. He argued that much evidence for the belief that healthy infants die from suffocation rests on folklore.
<b>1953</b>	Drs. J.J. Werne and I. Garrow of the Office of the Medical Examiner in New York City published the first systematic, documented, detailed and objective analysis of a series of SIDS autopsies in the American Journal of Pathology.
<b>1960s</b>	The Guild for Infant Survival and the National SIDS Foundation, voluntary parent support organizations, are founded.
<b>1963</b>	First international conference on causes of sudden infant death is held in Seattle, Washington.
<b>1969</b>	Second international conference on causes of sudden death in infants is held in Seattle, Washington.  The term SIDS is coined and defined as the sudden death of any infant or young child, which is unexpected by history, and in which a thorough postmortem examination fails to demonstrate an adequate cause of death.
<b>1972</b>	First U.S. Senate hearings held on sudden infant death.
<b>1973</b>	First Federal funds earmarked for SIDS research.

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<b>1974</b>	<p>Sudden Infant Death Syndrome Act of 1974 (PL 93-270) is passed by U.S. Congress. The law assigns responsibility to the National Institute of Child Health and Human Development (NICHD) to conduct SIDS research. The Maternal and Child Health Bureau (MCHB) is delegated the information and counseling component of the legislation.</p> <p>First SIDS Information and Counseling Project inaugurated at Loyola University Medical Center in Maywood, Illinois.</p> <p>Federal funds provided from MCHB for the establishment of 21 SIDS Information and Counseling Projects.</p>
<b>1975</b>	<p>The National Center for Health Statistics (NCHS) introduces the code for SIDS into the Eighth Revision of the International Classification of Diseases, adapted for use in the United States.</p>
<b>1976</b>	<p>Investigative protocol for examining SIDS infants is developed by a group of pathologists, toxicologists and other health professionals convened in New Mexico by the maternal and child health program. The report of this group's findings was published by forensic pathologists A.M. Jones and J.T. Weston in the Journal of Forensic Sciences.</p>
<b>1977</b>	<p>NICHD initiated a cooperative epidemiologic study of SIDS risk factors. This case-controlled study collected and analyzed data from six centers in the United States.</p> <p>NFSID changed name to the National Sudden Infant Death Syndrome Foundation, Inc.</p>
<b>1979</b>	<p>The World Health Organization recognizes SIDS as an official cause of death.</p> <p>Establishment of the National Clearinghouse for SIDS by MCHB. The clearinghouse became the National SIDS and Infant Death Resource Center.</p> <p>First promotion of October as National SIDS Awareness Month.</p>
<b>1981</b>	<p>International Conference on SIDS convened in Brussels, Belgium.</p> <p>Omnibus Budget Reconciliation Act transferred responsibility for the SIDS Information and Counseling Services from the Federal MCHB to State control through passage of the Title V MCH Block Grants.</p>
<b>1982</b>	<p>International Research Conference on SIDS convened in Baltimore, Maryland.</p>
<b>1986</b>	<p>NICHD Consensus Conference on Infantile Apnea and Home Monitoring.</p>



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	<p>International Research Conference on SIDS held in Lake Como, Italy.</p>
<b>1987</b>	<p>Association of SIDS Program Professionals (ASPP, now ASIP), representing SIDS information and counseling programs in the United States and Canada, is established.</p> <p>Formation of the SIDS Council by the NFSID, National Center for the Prevention of SIDS, Guild for Infant Survival, SIDS Resources and Southwest SIDS Research Institute. Name changed to Sudden Infant Death Syndrome Alliance.</p>
<b>1989</b>	<p>NICHD began implementation of the first five-year SIDS research plan, as mandated by Congress.</p> <p>An expert panel convened by NICHD revised the definition of SIDS to be the sudden death of an infant less than one year of age that remains unexplained after a thorough case investigation, including performance of a complete autopsy, examination of the death scene and review of the clinical history.</p> <p>A report on the conference and the development of the definition is published in <i>Pediatric Pathology</i>.</p> <p>First SIDS International Conference, held in United Kingdom.</p>
<b>1990</b>	<p>First SIDS national conference held in Santa Monica, California.</p>
<b>1991</b>	<p>SIDS definition revised to read “the sudden death of an infant under one year of age which remains unexplained after a thorough case investigation, including the performance of a complete autopsy, examination of the death scene and review of the clinical history.”</p> <p>Publication of the SIDS Alliance Standards of Excellence for Services to SIDS Families.</p> <p>Second SIDS Family International Conference and Global Strategy for SIDS Symposium are held in Sydney, Australia, in February. Perinatology Press published the proceedings in February 1994.</p>
<b>1992</b>	<p>First SIDS Alliance national conference in St. Louis, Missouri.</p>

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<b>1993</b>	<p>R. Kalaria found that SIDS victims had a decreased amount of dopamine in the brain when compared to controls. It was speculated that this change may be due to chronic or episodic hypoxia before death.</p> <p>J.S. Kemp and B. Thach reported their findings that infants placed on sheepskin to sleep have a higher risk of SIDS. This was reported to be the result of rebreathing exhaled carbon dioxide. Their study was based upon results obtained from anesthetized rabbits. This study was repeated the same year by B.A. Chiodini and Thach using human infants. They found no change in oxygen saturation in these infants.</p> <p>Formation of the Alliance of Grandparents, A Support in Tragedy (AGAST).</p> <p>The Tree of Hope National SIDS Memorial initiated.</p>
<b>1994</b>	<p>NICHD launched the Back to Sleep campaign with partners the AAP, SIDS Alliance, MCHB and ASIP.</p> <p>The Triple Risk Model was presented. This model remained in use and has evolved into the current theory of today.</p> <p>MCH Nationwide Assessment of SIDS Services Report released.</p> <p>CJ Foundation for SIDS established in Hackensack, New Jersey.</p>
<b>1995</b>	<p>Second five-year strategic plan released by NICHD.</p> <p>SIDS Network launched first online information Web site for SIDS.</p>
<b>1996</b>	<p>Publication of Guidelines for Investigation of Sudden Unexplained Infant Deaths by the CDC.</p> <p>Standardized autopsy and death scene investigation forms published in the MMRW.</p> <p>ASPP changed name to Association of SIDS and Infant Mortality Programs (ASIP).</p>
<b>1997</b>	<p>AAP revised recommendation regarding infant sleep position stating that back is the preferred position.</p> <p>SIDS Alliance awarded cooperative agreement from MCHB to establish National SIDS and Infant Death Program Support Center (NSIDPSC).</p>
<b>1998</b>	<p>Consumer Product Safety Commission (CPSC) convened meeting on hazards of soft bedding for infant sleep.</p>



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<b>2000</b>	<p>NICHD released third five-year strategic plan.</p> <p>AAP released policy statement from the Task Force for Infant Sleep Position stating “wholly on the back” as the preferred position.</p>
<b>2001</b>	<p>AAP revised its policy statement on Distinguishing Sudden Infant Death Syndrome From Child Abuse.</p>
<b>2005</b>	<p>First international conference to address both SIDS and stillbirth is held by First Candle/SIDS Alliance and the International Stillbirth Alliance. The conference, “Together Making A World of Difference,” was held in Arlington, Virginia.</p> <p>The AAP releases a new policy statement, “The Changing Concept of Sudden Infant Death Syndrome: Diagnostic Coding Shifts, Controversies Regarding the Sleeping Environment, and New Variables to Consider in Reducing Risk.” The AAP no longer recognizes side sleeping as a reasonable alternative to fully supine sleeping. The AAP also stresses the need to avoid redundant soft bedding and soft objects in the infant’s sleeping environment, the hazards of adults sleeping with an infant in the same bed, the SIDS risk reduction associated with having infants sleep in the same room as adults and with using pacifiers at the time of sleep, the importance of educating secondary caregivers and neonatology practitioners on the importance of “back to sleep,” and strategies to reduce the incidence of positional plagiocephaly associated with supine positioning.</p>

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Sources: W. Guntheroth, 1995; R.H. Raring, 1975

# Appendix B

## Glossary

**Acute Process:** Having a rapid onset and following a short, but severe course.

**Ammonia:** A colorless gas with a very sharp odor. Ammonia is irritating to the skin, eyes, nose, throat and lungs. Exposure to high concentrations in the air can severely burn the skin, eyes, throat or lungs. In extreme cases, blindness, lung damage or death can occur. Breathing lower concentrations causes coughing and nose and throat irritation. Swallowing ammonia may burn the mouth, throat and stomach.

**Apnea (central):** Episodes of cessation of breathing during sleep, caused by a temporary obstruction of the infant's airway due to relaxation of throat muscles.

**Apnea (obstruction):** Continuation of breathing movement despite obstruction of the airways.

**Apnea of Infancy:** An unexplained episode of cessation of breathing for 20 seconds or longer or a shorter respiratory pause associated with bradycardia, cyanosis, pallor and/or marked hypotonia.

**Apparent Life-Threatening Event (ALTE):** An episode that is frightening to the observer and is characterized by some combination of apnea (central or occasionally obstructive), color change (usually cyanotic or pallid but occasionally erythematous or plethoric), marked change in muscle tone (usually marked limpness) and choking or gagging. An infant will require significant intervention, such as vigorous shaking, mouth-to-mouth breathing or full CPR, to be revived from an ALTE.

**Arousal Response:** Awakening in response to some varying stimulation.

**Arsenic:** A metallic element that forms a number of poisonous compounds, arsenic is found in nature at low levels mostly in compounds with oxygen, chlorine and sulfur. Arsenic damages many tissues including nerves, stomach and intestines and skin. Breathing high levels can give you a sore throat and irritated lungs.

**Arterial Oxygen Saturation:** The point at which the level of oxygen and acidity in the infant's arterial blood supply exceeds a standard amount. This can be tested using a blood gas measurement test.

**Asphyxia:** Suffocation; a lack of oxygen that produces a potentially lethal build-up of carbon dioxide waste in the tissues. Asphyxia may arise from any one of a number of causes, including inhalation of smoke or poisonous gases, obstruction of the windpipe

(by water, food, vomit or a foreign object), strangulation or smothering. If it is not quickly relieved, brain damage or death ensues.

**Asthma:** A common disorder in which chronic inflammation of the bronchial tubes (bronchi) makes them swell, narrowing the airways. Asthma involves only the bronchial tubes and does not affect the air sacs (alveoli) or the lung tissue (the parenchyma of the lung) itself.

**Bedsharing:** Often used interchangeably with co-sleeping. For the purposes of this manual, it is when an infant shares the same sleep surface with another person, including the parents and or siblings.

**Bradycardia:** Slowed heartbeat.

**Brainstem:** Part of the brain at the base of the skull and the location for many control systems for functions such as breathing and heartbeat.

**Birth Rate:** Calculated by dividing the number of live births in a population in a year by the midyear resident population. Birth rates are expressed as the number of live births per 1,000 of the population. The rate may be restricted to births to women of specific age, race, marital status or geographic location.

$$\text{Birth Rate} = \frac{\text{Live Births} \times 1,000}{\text{Midyear Resident Population}}$$

**Birth Cohort Infant Mortality Rates:** Based on linked birth and infant death files. In contrast to period rates in which the births and infant deaths occur in the same period or calendar year, infant deaths comprising the numerator of a birth cohort rate may have occurred in the same year as or in the year following the year of birth. The birth cohort infant mortality rate is expressed as the number of infant deaths per 1,000 live births.

**Carbon Dioxide (CO<sub>2</sub>):** The gas formed when carbon is burned. It is eliminated by the lungs during breathing as a product of metabolism.

**Carbon Monoxide (CO):** A tasteless, odorless gas that is a by-product of combustion. Carbon monoxide acts as a poison by competing with oxygen for binding sites on hemoglobin, the molecule in red blood cells that carries oxygen from the lungs to the more remote tissues of the body and returns carbon dioxide from the tissues to the lungs.

**Choking:** An obstruction within the airway.

**Congenital Anomalies:** Birth defects; those conditions present in a child at birth that can sometimes be identified through genetic or metabolic screening procedures. Examples include spina bifida and cerebral palsy. A chromosomal abnormality (defect in a chromosome) is a specific type of birth defect that can lead to conditions such as Down's syndrome or Turner syndrome.

**Co-Sleeping:** Often used interchangeably with bedsharing. For the purposes of this manual, it is when infants are slept in close proximity to their parent/caregiver but on a separate sleep surface with a firm mattress and no pillows, blankets or toys.

**Cyanotic:** Showing cyanosis.

**Cyanosis:** Bluish discoloration of the skin and mucous membranes due to lack of oxygen in the blood.

**Death Rate:** Calculated by dividing the number of deaths in a population in a year by the midyear resident population. Death rates are expressed as the number of deaths per 100,000 populations. The rate may be restricted to deaths in a specific age range, race, sex or geographic groups or from specific causes of death.

$$\text{Death Rate} = \frac{\text{Number of Deaths in a Population in a Year} \times 100,000}{\text{Midyear Resident Population}}$$

**Diagnosis:** A judgment about what particular illness or problem is present; made after an examination.

**Diphtheria:** An acute infectious disease that typically strikes the upper respiratory tract including the throat.

**DNA:** Deoxyribonucleic acid; the chemical at the center of cells of living things that controls the structure and purpose of each cell and carries the genetic information during reproduction.

**DTaP Vaccines:** A vaccine for Diphtheria, Tetanus and Pertussis.

**Ectopic Pregnancy:** A pregnancy that is not in the uterus. The fertilized egg settles and grows in any location other than the inner lining of the uterus. The large majority (95 percent) of ectopic pregnancies occur in the fallopian tube. However, they can occur in other locations, such as the ovary, cervix and abdominal cavity. An ectopic pregnancy occurs in about 1 in 60 pregnancies.

**Epidemiology:** The study of the distribution and causes of disease in populations. Tracking the number of cases of disease by person, place and time allows public health authorities to better identify who is at risk, trends of occurrence and strategies for disease prevention and control.

**Erythematous:** Name applied to redness of the skin produced by congestion of the capillaries, which may result from a variety of causes.

**Etiology:** The scientific study of the causes of diseases. Currently, the etiology or cause of SIDS remains unknown. However, research has revealed many things about SIDS and what SIDS is not.

**Evidence-Based:** Proven to be effective through scientific study.

**Fetal Alcohol Syndrome (FAS):** The sum total of the damage done to the child before birth as a result of the mother drinking alcohol during pregnancy. Fetal alcohol syndrome always involves brain damage, impaired growth and head and face abnormalities.

**Fetal Death Rate:** The number of fetal deaths with stated or presumed gestation of 20 weeks or later or if they weigh 350 grams or more divided by the sum of live births plus fetal deaths, stated per 1,000 live births plus fetal deaths.

*Note: States are required to report fetal deaths in the 20th week or later of gestation or if they weigh at least 350 grams. Numbers of fetal deaths may be underreported because of variations in reporting requirements by States.*

$$\text{Fetal Death Rate} = \frac{\text{Number of Fetal Deaths (Gestation of 20+ Weeks)} \times 1,000}{\text{Live Births} + \text{Fetal Deaths}}$$

**Fertility Rate:** The total number of live births, regardless of age of mother, per 1,000

women of reproductive age (15 to 44 years of age).

$$\text{Fertility Rate} = \frac{\text{Total Number of Live Births} \times 1,000}{\text{Total Number of Women Ages 15 to 44}}$$

**Gene:** A part of the DNA in a cell that contains information in a special pattern received by each human, animal or plant from its parents and which controls its physical development and behavior.

**Genetics:** The study of how, in all living things, the characteristics and qualities of parents are given to their children by their genes.

**Gestation:** The period of an infant's development while it is inside the mother's body.

**Gestational Age:** The duration of time an infant spent in utero. Normal is 40 weeks.

**Hemoglobin:** Substance in red blood cells that carries oxygen and gives blood its red color.

**Histology:** The scientific study of the structure of tissue from plants, animals and humans.

**Hypothesis:** An idea or explanation of something that is based on known facts but has not yet been proven.

**Hypotonia:** Decreased tone of skeletal muscles; floppiness.

**Hypoxemia:** Low levels of oxygen in the blood.

**Hypoxia:** Low levels of oxygen in tissues.

**Incidence:** An event or the rate at which something happens.

**Larynx:** The hollow organ in the neck at the entrance of the airways.

**Lividity:** Dark, pooled blood on the dependent side of the body. May have the appearance of bruising. The pattern of lividity helps determine the position of the body at the time of and following death.

**Low Birth Weight (LBW):** Birth of an infant weighing less than 2,500 grams.

**Lymphocytes:** A type of white blood cell involved in the defense systems of the organism to fight infection.

**Mechanical Suffocation:** Occurs when external pressure is applied to the body preventing chest movement and respiration.

**Metabolic Disease:** Disease that involves complex biochemical processes. In the context of SUID, such diseases have been identified in a small percentage of cases.

**Metabolism:** All the chemical processes in the body, especially those that cause food to be used for energy and growth.

**Methane:** Colorless, odorless gas with a wide distribution in nature.

**Multi-Disciplinary Research:** Research of scientists and experts from different fields working together to address a complex problem.

**Miscarriage (Spontaneous Abortion):** Death of an embryo or fetus prior to 20 weeks of gestation.

**Neonatal:** The 0- to 28-day period of life.

**Neonatal Narcotic Withdrawal:** Infants who are born addicted to substance(s) often experience several withdrawal symptoms after birth. Some studies have suggested that the prone position helps to calm the increased fretfulness that is common among such infants.

**Neonatal Death:** Deaths that occur prior to four weeks (28 days) of age.

**Nicotine:** An alkaloid (a nitrogen-containing chemical) made by the tobacco plant or produced synthetically. Nicotine has powerful pharmacologic effects (including increased heart rate, heart stroke volume and oxygen consumption by the heart muscle) as well as powerful psychodynamic effects (such as euphoria, increased alertness and a sense of relaxation). As is now well-known, nicotine is also powerfully addictive. When someone becomes habituated to nicotine and then stops using it, they experience the symptoms of withdrawal including anxiety, irritability, restlessness, shortened attention span and an intense, sometimes irresistible, craving for nicotine.

**Otitis Media:** Inflammation of the middle ear characterized by the accumulation of fluid in the middle ear, bulging of the eardrum, pain in the ear and, if eardrum is perforated, drainage of purulent material (pus) into the ear canal. Otitis media is the most frequent diagnosis in sick children in the United States, especially affecting infants and preschoolers. Almost all children have one or more bouts of otitis media before age six.

**Pallid:** Deficient in color.

**Pallor:** An alternate name or description for symptom paleness.

**Passive Smoke Exposure:** Environmental tobacco smoke exposure (ETS). When non-smoking persons (mothers, infants) come into contact with tobacco smoke.

**Pathophysiological:** The theory that the pathway of the disease or the pathology is clearly connected to a physiological abnormality.

**Periconceptional Period:** The three months before pregnancy or during the first trimester.

**Perinatal:** The period immediately before and after birth.

**Petechiae:** Small red spots on the skin or on the surface of organs within the chest or abdominal cavity. The red spots are produced by blood outside vessels.

**Perinatal and Infant Mortality:** Critical measures of the quality of health status of the population. Comparisons of these statistics are used for numerous reasons including the allocation and targeting of resources. Variation in reporting and classification can result in inaccurate and misleading data, which can also make comparisons unreliable.

**Pertussis:** An infection of the breathing tract that is caused by a bacteria (Bordetella Pertussis). Pertussis is whooping cough's medical name.

**Placental Abruption:** The early separation of a normal placenta from the wall of the uterus. The placenta is an organ that grows in the uterus during pregnancy to provide nourishment and oxygen to the baby.

**Plethoric:** Florid; red-faced.

**Postneonatal:** The period of time in an infant's first year of life after the first 28 days.

**Positional Plagiocephaly:** An abnormal shape of an infant's head brought about by cranial

pressure experienced in the womb. One study tested the use of an assistive device on infants with this condition, but it did not evaluate the role of sleep position in the device's effectiveness.

**Positional Asphyxia:** Also known as postural asphyxia; a form of suffocation due to physical restriction of breathing mechanisms. For example, bedsharing and overlay can result in positional asphyxia. Children less than two years of age are more susceptible especially when sleeping on couches and adult beds.

**Prematurity/Preterm Birth:** Birth that occurs before 37 weeks of gestation.

**Mortality Rates:**

**Late Fetal Death and Infant Deaths During Perinatal Period Rate** is the number of fetal deaths with stated or presumed gestation of 28 weeks or more to 7 days after birth divided by the sum of live births plus late fetal and perinatal deaths, stated per 1,000 live births plus late fetal deaths.

$$\text{Late Fetal Death and Infant Deaths During Perinatal Period Rate} = \frac{\text{Number of Fetal and Infant Deaths (28 Weeks or More to 7 Days After Birth)} \times 1,000}{\text{Live Births} + \text{Late Fetal Deaths and Infant Deaths}}$$

**Infant Mortality Rates (IMRs)** are based on the number of infant deaths during a calendar year divided by the number of live births reported in the same year. It is expressed as the number of infant deaths per 1,000 live births. The Healthy People 2010 goal is 4.1 deaths per 1,000 live births.

$$\text{Infant Mortality Rate} = \frac{\text{Number of Infant Deaths During Calendar Year} \times 1,000}{\text{Number of Live Births in the Same Year}}$$

**Neonatal Mortality Rate** is the number of deaths of infants less than 28 days of age per 1,000 live births.

$$\text{Neonatal Mortality Rate} = \frac{\text{Number of Infant Deaths (0 to 28 Days)} \times 1,000}{\text{Number of Live Births in the Same Year}}$$

**Postneonatal Mortality Rate** is the number of deaths of infants that occur between 28 days and 365 days after birth per 1,000 live births.

$$\text{Postneonatal Mortality Rate} = \frac{\text{Number of Infant Deaths (28 to 365 days)} \times 1,000}{\text{Number of Live Births in the Same Year}}$$

**Perinatal Mortality Rate** is the sum of late fetal deaths plus infant deaths within 7 days of birth divided by the sum of live births plus late fetal deaths per 1,000 live births plus late fetal deaths. Perinatal relates to the period surrounding the birth event. Rates and ratios are based on events reported in a calendar year. Perinatal mortality ratio is the sum of late fetal deaths plus infant deaths within 7 days of birth divided by the number of live births per 1,000 live births.

$$\text{Perinatal Mortality Rate} = \frac{\text{Late Fetal Deaths} + \text{Infant Deaths (0 to 7 days)} \times 1,000}{\text{Live Births} + \text{Late Fetal Deaths}}$$

**Rebreathing:** Refers to breathing in exhaled air. Infants can experience excessive levels of carbon dioxide gas when they rebreath air trapped in soft bedding and pillows.

**Respiratory Distress Syndrome (RDS):** Formerly known as hyaline membrane disease; a syndrome of respiratory difficulty in newborn infants caused by a deficiency of a molecule called surfactant. RDS almost always occurs in newborns born before 37 weeks of gestation. The more premature the baby is, the greater the chance of developing RDS. RDS is more likely to occur in newborns of diabetic mothers.

**Rigor Mortis:** Literally, the stiffness of death; the rigidity of a body after death.

**Risk Factors:** Factors that are found more frequently in a group of people with a certain problem than in a group of people without that particular problem. An expected connection between the risk factor and the problem is usually not obvious.

**Serotonin:** Neurotransmitter and hormone with multiple activities. The serotonergic system is known to modulate mood, emotion, sleep and appetite and thus is implicated in the control of numerous behavioral and physiological functions.

**Smothering:** Physical obstruction of the nose and mouth.

**Spontaneous Abortion:** See “Miscarriage.”

**Statistics:** The science of using information discovered from studying numbers. Statistics are information based on a study of the number of times something happens or is present or other numerical facts.

**Stillbirth (Fetal Demise/Fetal Loss):** Death prior to delivery of a baby with a gestation of at least 20 weeks or a birth weight of more than 350 grams.

**Supine:** Back; supine sleep position means sleeping on the back.

**Tetanus:** An often-fatal infectious disease caused by the bacteria *Clostridium tetani* (*C. tetani*) that usually enters the body through a puncture, cut or open wound. Tetanus is characterized by profoundly painful spasms of muscles, including “locking” of the jaw so that the mouth cannot open (lockjaw). *C. tetani* releases a toxin that affects the motor nerves, the nerves which stimulate the muscles.

**Thermal Stress:** Overheating; a condition that is a threat to the organism’s thermal regulation, but may be mild enough to permit core temperature to remain within normal limits. Hyperthermia has been used as a term equivalent to thermal stress, but hyperthermia should be reserved for conditions in which the core body temperature is elevated, such as with fevers. (*Pediatrics Vol. 107, No. 4, April 2001, pp. 693-698; Thermal Stress in Sudden Infant Death: Is There an Ambiguity With the Rebreathing Hypothesis? Warren G. Guntheroth, MD, and Philip S. Spiers, PhD, from the Department of Pediatrics, University of Washington School of Medicine, Seattle, Washington.*)

**Thymus:** The thymus produces lymphocytes and is therefore involved in the immune system. It is in the chest cavity just in front of the heart.

**Title V Program:** Title V of the Social Security Act is administered by the Health Resources and Services Administration, Public Health Service, Department of Health and Human Services. It is the Maternal Child Health Service grants which mandate services to families.

**Toxicology:** The scientific study of the characteristics and effects of poisons. In the context of SIDS and SUID, toxicology screening is used to determine whether abnormal levels of drugs or other substances are present in the blood.

**Tuberculosis:** A highly-contagious infection caused by the bacterium *Mycobacterium tuberculosis*, abbreviated as TB. Tubercles (tiny lumps) are a characteristic finding in TB. Diagnosis may be made by skin test, which if positive should be followed by a chest X-ray to determine the status (active or dormant) of the infection. Tuberculosis is more common in people with immune system problems, such as AIDS, than in the general population.

**Very Low Birth Weight (VLBW):** Birth of an infant weighing less than 1,500 grams.

**Vital Statistics:** A group of official facts that show such things as the number of births, deaths and marriages in a particular area.

**Vomitus:** Matter from the stomach that has come up into and may be ejected beyond the mouth, due to the act of vomiting.

Unless otherwise noted, these definitions have been adapted from the Webster's New World Medical Dictionary at [www.medterms.com](http://www.medterms.com) and the Centers for Disease Control and Prevention at [www.cdc.gov](http://www.cdc.gov).

# Appendix C

# C

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### Introduction

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# SIDS/ID Trainer's Guide



Health Resources and Services Administration  
Maternal and Child Health Bureau, SIDS/ID Program



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# Introduction

**T**he content of this training guide was guided by [Trainer’s Guide for Cancer Education](#) (NIH Publication No. 02-5052, 2001), by the [National Cancer Institute](#). The guide was adapted to provide trainers with the necessary skills, knowledge and materials to conduct effective trainings for multiple audiences on reducing the risk of sudden and unexplained infant death and how to cope with sudden and unexplained infant death. This guide assumes a certain level of knowledge and that users have reviewed the manual at some length.

There are hundreds of PowerPoint slides that can be used for multiple audiences. The slides and handouts include the latest national data available on infant mortality and SIDS. Sample State data slides have been provided with suggestions on how to obtain similar data for any State. Eight custom presentations targeted to specific audiences have been included. Additional resources, including handouts, for each of these trainings are available from [NSIDPSC](#). Included custom presentations are:

- Public health nurses
- First responders and emergency service personnel
- Child care trainers
- Child care providers (both center- and home-based)
- Community groups (risk reduction information)
- Community groups (risk reduction and bereavement information)
- Trainers
- Newborn nursery personnel

Training opportunities can range from a 20- to 30-minute keynote address to a one- to two-day workshop. This guide should prepare trainers for both experiences and anything in between. Depending on the audience and the time allotted, trainers may want to customize the workshop or presentation.

If you are interested in customizing your own training, contact the [NSIDPSC](#). To ensure the integrity of information, the [NSIDPSC](#) will happily support customization, but will not allow the original slides to be changed in any way.



# Basics

# 1

## Principles of Adult Learning

A fundamental responsibility of a trainer is to create an experience that enables another to learn. Malcolm S. Knowles, often referred to as the “father of adult education,” found that adult learning occurs best when it follows certain principles.<sup>1</sup> Experts in the field of adult education have found that people retain:<sup>2</sup>

- 20 percent of what they hear
- 30 percent of what they see
- 50 percent of what they see and hear
- 70 percent of what they see, hear and say
- 90 percent of what they see, hear, say and do

For participants to retain what they learn during a training, they need to hear a lecture or discussion, to see a demonstration or visual aids, to discuss the material and to do an activity with their new information and skills.

Participatory training is the hallmark of adult learning. It moves participants through the four phases of the adult learning cycle: experiencing, processing, generalizing and applying.

**Example:** A training program for health professionals on supporting families who have experienced an infant death.

### Phase 1: Experiencing

The trainer might first lead an activity designed to generate participants’ discussion about their own personal grieving styles.

**Trainer:** Please pull out the two-page handout called Personal Grieving Style Inventory. The purpose of this inventory is to help you, in a systematic way, reflect upon and better understand your own grieving style.

It is important to be honest with yourself, even if some of the memories are difficult and painful to recall. This information is for you only and does not have to be shared with others. Trust the first thing

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<sup>1</sup> Knowles, 1990

<sup>2</sup> Arnold et al., 1991

that pops into your mind rather than lingering on a particular answer.

## Phase 2: Processing

The trainer could then lead a discussion about what feelings arose during the completion of the *Personal Grieving Style Inventory*.

**Trainer:** I hope that this exercise helped you to identify your own grieving style and how your experiences may influence your interaction and connection to others. Let's quickly take a look at "Attitudes Toward and Beliefs About Grief and Bereavement."

As I explained earlier, there is really no right or wrong way to grieve, unless it causes harm to oneself or others. It is as unique as a fingerprint and shaped by our experiences. I am going to go over some of the common attitudes toward grief and bereavement and you can respond to your answers by show of hands if you agreed, disagreed or if you were not sure about the following statements.



## Phase 3: Generalizing

The next part of the discussion might lead to a comparison between participants' personal grieving styles and those of parents and grandparents whose baby or grandchild has died suddenly.

**Trainer:** Let's look at how your own personal grieving style is similar to and different from that of bereaved families. I'm going to make a chart of similarities and differences and list them here as you share.

## Phase 4: Applying

The trainer could then encourage participants to think of ways they might use these new insights. For public health nurses, the discussion may have generated ideas about how to effectively comfort grieving parents. For coroners or first responders, the discussion might provide insights that would help them be more compassionate and understanding with bereaved families during a crisis.

## Repeating the Cycle

The trainer would then move to the next activity and the adult learning cycle would be repeated using the same structure of experiencing, processing, generalizing and applying.

## Different Learning Styles

Trainers must be aware that in any audience, participants will learn in different ways. For example, health care professionals are often accustomed to learning from lectures, demonstrations and case studies. They may be less accustomed to learning through experiential exercises. On the other hand, community and family groups may prefer more interactive methods to lectures and PowerPoint presentations. This difference in ways of learning does not mean that health care professionals will never respond to experiential exercises or that community groups will never benefit from lectures.

Trainers will be most effective if they also carefully consider the culture of their audience when choosing appropriate training methods. See [Appendix B: Selecting Appropriate Training Methods](#) for more specific information about training methodologies. Although trainers can try to match appropriate training methods to the specific audience, it is best to assume that there are people with all learning styles in each group. Trainers should design a variety of strategies to meet the learning needs of all participants.

<b>For participants who:</b>	<b>Use:</b>
Learn best through abstract concepts and lectures	Case studies and discussions about theories and research
Learn best while observing others	Demonstrations and videos
Learn best from exercises	Role-playing and other experiential activities
Learn best through visual means	Videos, images and slides

## Resources for Adult Learning Information

Instructor Excellence: Mastering the Delivery of Training by Bob Powers and Malcolm S. Knowles

Planning Programs for Adult Learners: A Practical Guide for Educators, Trainers, and Staff Developers by Rosemary S. Caffarella and Malcolm S. Knowles

[www.hcc.hawaii.edu/intranet/committees/FacDevCom/guidebk/teachtip/adults-3.htm](http://www.hcc.hawaii.edu/intranet/committees/FacDevCom/guidebk/teachtip/adults-3.htm)



# Planning

## 2

### Setting Goals and Learning Objectives

To develop an effective training plan that achieves the goal and objectives of the educational session—to make changes in knowledge, attitudes, behaviors and skills—a number of key questions must be answered. Some of these questions will be addressed in the needs assessment. The answers to these questions will affect the content, format and logistics of the training.

#### Goals

Goals are broad, general statements of what a trainer hopes to accomplish as a result of the training. For example:

**Increased new parents' and grandparents' awareness of the importance of sleep safety measures.**

Attainment of training goals and objectives is one important aspect of the evaluation. Not all objectives are easily measured, but most can be evaluated using standard evaluation tools or other creative strategies.

Completing the following statements may assist you in customizing the goals and learning objectives for a particular audience:

- The goal for my training is \_\_\_\_.
- The changes I want to see as a result of my training are \_\_\_\_.
- Increase in knowledge of \_\_\_\_.
- Newly acquired skills of \_\_\_\_.
- Changes in attitudes toward \_\_\_\_.
- Increase in proficiency of existing skills of \_\_\_\_.
- Based on the above, the most appropriate objectives for my training are \_\_\_\_.

#### Objectives

Goals lead to the objectives which describe the desired changes in knowledge, attitudes, skills or behaviors in very precise terms. Learning objectives are written in a specific, action-oriented manner:

**By the end of this training session, participants will be able to (insert action verb).**

For objectives to be helpful in determining training effectiveness, they should be measurable. For example:

By the end of this training session, participants will be able to list five common myths about SIDS.

By the end of this training session, participants will be able to identify three ways to reduce the risk of SIDS.

There are seven types of objectives:

1. Fact
2. Understanding/Comprehension
3. Application
4. Analysis
5. Synthesis
6. Attitudinal
7. Skill

Depending on what you hope to accomplish during a training, some or all of these types of objectives may need to be developed. Keep in mind the adult learning cycle described earlier when developing your training objectives. When writing the seven different types of objectives, you might find the following chart of verbs helpful.

### Seven Objective Training Types

<b>Fact Objectives</b>	Define	List	Recall
	Name	Repeat	Recognize
	Record	State	Record
<b>Understanding/Comprehension Objectives</b>	Discuss	Identify	Express
	Describe	Translate	Convert
	Explain	Restate	Estimate
<b>Application Objectives</b>	Compute	Operate	Apply
	Demonstrate	Perform	Use
	Illustrate	Interpret	Practice
<b>Analysis Objectives</b>	Solve	Distinguish	Differentiate
	Compare	Contrast	Categorize
	Appraise	Classify	Critique

## Seven Objective Training Types

<b>Synthesis Objectives</b>	Synthesize	Diagnose	Propose
	Design	Manage	Hypothesize
	Summarize	Plan	Formulate
<b>Attitudinal Objectives</b>	Show sensitivity	Accept responsibility	Be willing to assist
	Respect opinions	Demonstrate commitment	
<b>Skill Objectives</b>	Perform	Compute	Operate
	Demonstrate	Teach	Complete
	Show	Role-play	Design
	Conduct	Take	Do

## Learning Objective Bank

The following bank of objectives has been developed as a sample using the seven types of objectives.

### At the end of this training, each participant should be able to:

<b>Fact Objectives</b>	Define Sudden Infant Death Syndrome (SIDS).
	List the actions that first responders should take at the scene of a suspected SIDS death.
	Describe key information collection and documentation for suspected SIDS cases.
<b>Understanding/Comprehension Objectives</b>	Describe important risk factors for SIDS.
	Discuss SIDS/stillbirth statistics and bereavement resources nationally and locally.
	Explain how to better handle the emergency in case an infant death occurs, including death scene investigation.
	Identify common responses of a family to death of an infant or child.
<b>Application Objectives</b>	Demonstrate ability to talk to children about infant death.
	Demonstrate ability to talk to families who have experienced a sudden and unexpected infant death/stillbirth/miscarriage.

**At the end of this training, each participant should be able to:**

<b>Analysis Objectives</b>	Describe how to distinguish SIDS from child abuse.
	Describe how to distinguish between SIDS death and stillbirth grief and mourning processes for families.
<b>Synthesis Objectives</b>	Summarize the stillbirth protocols in their hospital and registrar procedure.
	Plan a community-wide SIDS risk reduction awareness campaign.
	Summarize the responses of his/her particular community in the event of an infant death.
<b>Attitudinal Objectives</b>	Know what to expect from the other children in child care after an infant death.
	Demonstrate a commitment to sleep safety of infants by agreeing to develop a sleep safety policy for their child care center.
	Demonstrate a commitment to assisting families who have experienced a stillbirth.
<b>Skill Objectives</b>	Demonstrate how to more effectively comfort grieving families.
	Demonstrate ability to help himself/herself and others cope with SIDS and other infant deaths.
	Demonstrate knowledge of the needs of stillbirth families.

## Strengths and Needs Assessment

Before designing a one-size-fits-all program, it is important to conduct an assessment of participants' prior knowledge and experience as well as their hopes and expectations for the training. Participants will bring a number of strengths and experiences as well as needs for new information, insights and skills.

Often assessments focus on just needs, but a comprehensive assessment should include both the strengths and needs of participants.

### Before the Training

If the participants' backgrounds are known, an assessment can be conducted before the content and format are planned. The best-case scenario is to do this assessment with some or all of the participants. Assessment methods may include e-mail, fax or telephone surveys, focus groups and personal interviews.

If there is no roster of participants or time is limited, you can conduct an assessment with key informants. The key informant may be the person who invited you to present the training. Another option is conducting an assessment with people who may be

demographically matched to those who will be participating.

Assessments should include enough people to cover a variety of perspectives and experiences. This approach presents a fuller picture of the knowledge and experience the participants will bring to the training. The more specific the questions are, the more useful feedback will be.

This information can be used to develop the content and format of the training and guide decisions related to training logistics. If an assessment cannot be conducted, it is helpful to review evaluations from prior training programs.

## Hopes and Expectations of the Training

If you are not able to conduct an assessment before the training, there are a variety of techniques to determine participants' knowledge and expertise as well as their hopes for the training that day.

One quick way to conduct an assessment is to ask participants to write down their hopes and expectations about the training as they arrive:

- Post sheets of flip chart paper on the walls of the training room with titles such as *One or two things I hope to learn at this training* and *One or two concerns I have about this training*.
- Ask participants as they enter the training room to write his or her comments on the flip chart paper.
- Review all of the comments with the group.
- Let participants know which expectations will likely be met through the training and which may be beyond the scope of the training.

For example, if one of the participants writes that he is concerned that the trainer will use too much technical language or difficult scientific concepts, the trainer might say:

**Some people seem concerned that this training will have too many concepts that are difficult to understand. We are really going to try hard to make the concepts as user-friendly as possible.**

**However, if we start to use scientific jargon or talk about things you don't understand, please let us know at that time or talk with one of the trainers during a break. We really want this training to be meaningful for everyone, so please help us by asking questions and giving feedback.**

If someone writes that she wants to get detailed information about the latest research investigating the relationship between SIDS and smoking, the trainer might say:

**Actually, we won't be covering that specific information in detail, but I can refer you to the [National SIDS Resource Center](#), which prepares annotated bibliographies on topics such as smoking and SIDS. I'll give you the telephone number to call for more information.**

The trainer can then be a helpful resource for topics outside the scope of the training. However, if a number of participants have hopes and expectations that are not covered in a training plan, it is often helpful to take time to address these expectations before moving on with the training as you have planned.

This approach is respectful of people's perceived needs and eliminates one impediment to learning. If necessary, the training agenda can be revised to address the needs of

participants and discard less-important portions of the training. Flexibility is key in any training environment.

## Group Snapshots

Another quick way to assess participants' knowledge or experience is to take a group snapshot by asking participants to respond to a series of questions through a show of hands.

You might ask:

- How many of you know someone who has had a baby die from SIDS (or born premature, with a low birth weight, miscarriage, stillbirth, etc.)?
- How many of you have experienced the death of someone close to you?
- How many of you know the current American Academy of Pediatrics sleep safety recommendations for infants?

This information can help the trainer structure or restructure activities to more closely draw on the participants' experiences and knowledge and to meet their needs.

## Throughout the Training

An experienced trainer is often able to read the body language of the participants to ascertain the appropriateness of the content, the pace of the training and the energy level of the group. It is important to do this throughout any training and adapt the training to accommodate participants if necessary. This technique is further discussed in 3: [Training](#).

## Evaluating the Training

Participants should always be given an opportunity for feedback. Ideally the evaluation should relate back to the training goals and objectives. Evaluation strategies should be chosen with the audience in mind. For example, health care professionals might be familiar with Likert-type scales. For an in-depth description of Likert scales, visit [www.uic.edu/classes/idsc/ids270sls/likert.htm](http://www.uic.edu/classes/idsc/ids270sls/likert.htm).

Read each evaluation carefully and then review them for recurrent themes. Trainers learn most from observing and noting the reactions of the majority of the participants rather than focusing on one or two comments.

If you use a quantitative or Likert scale evaluation form, review the average scores for each item. If you use a qualitative evaluation tool, summarize participant comments and reactions. For evaluations to be most useful, trainers need to develop an action plan for incorporating useful feedback into future trainings.

## Rehearsing the Training

Consider videotaping your rehearsal and then review the videotape for distracting mannerisms and other signs of nervousness. Remember that the best cure for nervousness is confidence, and confidence comes with practice.

If possible, rehearse multiple times, trying out new ideas and new techniques for

delivering the material. Choose the techniques that you are most comfortable with.

Rehearse the timing of your presentation to be sure that it falls within your time limits. Be sure to allow time for questions if appropriate. Practice your presentation in front of a small audience or a colleague and ask for feedback on the content and style of your presentation.

Things to consider:

- Is your message clear?
- Does your evidence support your key points?
- Are your graphics and illustrations clear, appealing and relevant to the topic?
- Are you within your allotted time frame?

## Planning the Training: Early Stages

Task	Notes
	Decide who should help plan this training.
	Decide who will be the presenters or trainers.
	Find out how much time you have for the training.
	Decide what topics can be reasonably covered in that time. Think in terms of topics' importance.  Assess which topics can be presented in an abbreviated fashion.
	Decide how to sequence the topics.
	Decide what you expect participants to do. For example, just listen, work in small groups or give feedback.
	Decide whether you will distribute any handouts. What handouts? Who will be responsible for photocopying these? How many will you need?
	Assess how much time you have to devote to questions and answers.
	Decide what type of training evaluation you want to conduct.  Decide who will prepare the evaluation form and analyze the forms after the training.
	Decide what action you would like to see come out of the training.

## Planning the Training: Logistics of the Training

Task	Notes
	Set the date and time for the training.
	Decide what type of facilities and arrangements need to be made for the training.  Think in terms of convenient location, adequate parking, good lighting, sufficient space, comfortable chairs, easy access for persons with disabilities and availability of audiovisual equipment.
	Decide who will be responsible for locating and reserving the space.
	Decide whether food and refreshments will be provided.  If so, decide who will be responsible for coordinating refreshments and what will be provided.
	Decide whether or find out whether continuing education hours/units (CEUs) be available to professionals and who will be responsible for coordinating this.

# 2

## Planning the Training: Six Weeks Prior

Task	Notes
	Set date and arrange location.
	Develop flyer(s).
	Develop registration form.
	If applicable, make arrangements to provide CEUs for nurses, child care workers, emergency medical personnel or other professionals.
	Set up registration spreadsheet/database.
	Send out confirmation letters or e-mails.

## Planning the Training: Two to Three Weeks Prior

Task	Notes
	Confirm training with all registered participants through e-mail.
	Review your materials and your plan.
	<p>If possible, visit the site where your training will take place. Note any potential problems or needs and develop strategies for resolving them.</p> <p>If you cannot visit the site yourself, call someone at the site and ask questions about the space. Make sure you have adequate outlets and extension cords for any equipment you will use.</p>
	Make sure that the room and your presentation will be accessible to any participants with disabilities.
	Gather any special equipment you'll need for the presentation, such as marking pens, flip charts, a microphone, an overhead projector, blank transparencies, extra bulbs, extension cords, name tags and masking tape.
	Organize your PowerPoint presentation or overheads by customizing the presentation for the specific audience.
	Review your content, rehearse and get feedback on your presentation.
	Prepare participant packets/folders including PowerPoint handouts and other materials.
	Prepare the sign-in sheet, pre- and post-tests and evaluation forms.
	Prepare certificates of completion detailing continuing education units.

## Planning the Training: Day of the Training

Task	Notes
	If the training room is not easy to find, post signs indicating the location.
	Make sure there are enough chairs, handouts and a name tag for every participant and any unanticipated attendees.
	Make sure the ventilation and the temperature of the room is comfortable.
	Have a registration table where participants can sign in and pick up handouts.
	Post Back to Sleep campaign and other sleep safety/risk reduction posters in the training room.
	Check to make sure that the equipment you need is there and working smoothly.
	Test all equipment. Make sure that the LCD projections, overhead projections or flip chart can be seen from all vantage points in the room.
	Perform a last-minute check of all training materials and handouts.
	Confirm set-up of refreshments for breaks, if applicable.
	Place any miscellaneous items you might need within easy reach, such as a pen, note pad, videotape, watch, glass of water or tissue.

# Training

# 3

## Opening the Training

When starting your training, it is important to introduce yourself and have the audience participate in some warm-up activities.

### Introducing Yourself

The first contact a trainer has with training participants makes a lasting impression and sets the tone for the entire experience. To make this first impression a positive one:

- Be sure to smile. Write your name down, if possible, and include a business card with participants' handouts.
- Pronounce your name slowly and clearly. If your name is unusual or difficult to pronounce, you may want to talk about the origin of your name.
- Talk about your professional background. Be creative.
- Communicate your expectations. You are there to teach, but you are also there to learn.

### Icebreakers

Icebreakers can be a good way to start a training. They warm up participants, put them at ease, get them involved and open up communication. Icebreakers create a positive learning climate within the group. They foster interaction, build group identity, stimulate creative thinking, acquaint participants with each other and help establish comfort. For examples of icebreakers, see [Appendix F: Icebreakers, Energizers & Closing Activities](#).

When selecting an icebreaker, consider:

- **The group's composition.** Consider participants' ages, cultural backgrounds, educational levels, occupations and personalities.
- **Time constraints.** The length of the icebreaker depends on the length of the training. More time can be devoted to icebreakers when the training is a full day or longer.
- **Comfort.** Icebreakers should make people feel comfortable. Do not use an icebreaker that would embarrass someone or that would make participants fail. Use an icebreaker that makes participants feel comfortable, not one that raises anxiety.

- **Participation.** Choose icebreakers that encourage everyone to speak. This is especially important for shy or timid participants. After their voice is in the room, shy participants are more likely to contribute to subsequent discussions.
- **Topic.** Icebreakers are best when they are related to the topic of the training. However, sometimes, it is important to have a fun icebreaker not related to the topic to lighten the mood or create a comfortable environment.

## During the Training

As a trainer, your goal is to help participants learn new information and build skills. The best way to help people learn is to use techniques that recognize and build on participants' knowledge, skills and experiences.

For detailed information on different training methods, see [Appendix B: Selecting Appropriate Training Methods](#). However, there are some general considerations to keep in mind:

- **When speaking, be natural.** Speak in a conversational tone. Slow down and emphasize important points, and pause before and after key points to set them apart.
- **Be sincere and build rapport with your audience.** Involve them in the presentation. Ask your audience questions to be sure that they're following you. If appropriate, get feedback from them after the presentation and use this feedback to make your next presentation even better.
- **Be respectful of your participants' schedules.** Start on time and keep a discrete eye on a nearby clock or watch as the presentation progresses.
- **Inform the group about the schedule,** even if you have provided a written agenda. For example, you might say something like: *Next, we'll discuss the basic facts about AIDS. After that, we'll have a 10-minute break.*
- **Announce any changes in or adaptations to the schedule** as soon as you are aware of them.
- **Have a glass of water close at hand,** just in case you need to relieve a dry throat during the presentation.
- **Training team composition sends a message.** Whenever possible, trainers' cultural backgrounds should be representative of participants' backgrounds. Diverse groups of participants will benefit from seeing people from their own communities among the trainers. In addition, a multicultural training team models cooperation and sharing among cultures.
- **Trainer styles differ, just as learning styles do.** Therefore, be careful in designing the training on the basis of an individual trainer's preferred style.
- **Acknowledge areas of weakness and expertise.** If given a direct question, make an attempt to answer it in an accurate and forthright manner. If you do not know the answer, say so. If you can get back to the questioner with the correct answer at a later date, say so.
- **Keep training goals and objectives in mind at all times, but especially when processing.** Be aware of participants who might take over or seek to control. If you are uncomfortable with conflict, or uncertain about how to address it, seek training in conflict resolution.

## Questions and Answers

Question-and-answer sessions present a unique set of challenges, but they also offer the opportunity for you to clarify your message and reinforce key points. Questions also allow resistance to exist out in the open where it can be dealt with.

- Plan for questions and answers by writing down questions you expect from the audience. For example:  
**Do babies have a greater tendency to choke or aspirate if placed on their backs to sleep?**  
**My baby has bad reflux and sleeping on the tummy seems to help. Is this okay?**
- State in advance whether you will take questions at any time during the presentation, at the end of each topic or at the end of the presentation. If you decide to take questions during the presentation, be sure not to get sidetracked. If a question takes you off track or is of interest to only a few members of your group, deal with it at the end of the training instead.
- Have participants write their questions down and hand them in at break time.
- At the beginning of your question period, state how much time you have for questions and then ask for the first question. If no one has any questions, suggest one yourself. You could also consider planting someone in the audience to ask the first question.
- Repeat questions so that everyone can hear them. Rephrase the question if necessary. If you do not know the answer to a question, it is best to be honest. Try to find some way to follow up with the person asking the question to get an answer to them.
- End the question period by restating your summary, close or action that you want your audience to take.

## Energizers

Energizers can be used at anytime during training when the energy or attention of the participants is low. Energizers should take no more than five to ten minutes. They are really intended to get people up and moving, not to spend a long time discussing ideas. They are especially helpful right after a meal when people are often sluggish. Introduce energizers with enthusiasm because some participants may be reluctant to act silly.

Model the activity first and be an active participant yourself. Your participation gives participants permission to get involved, too. For examples of energizers, see [Appendix F: Icebreakers, Energizers and Closing Activities](#).

## Encouraging Group Participation

When participants take an active role in their learning, they are more likely to own the information and skills covered during the training. People are more likely to participate actively in a training session if you:

- Maintain relaxed body language.
- Use an icebreaker to help participants relax, get to know each other and get ready to learn. Specific examples of some icebreakers are described in [Appendix F: Icebreakers, Energizers and Closing Activities](#).

# 3

- Set group norms, sometimes called ground rules, to help make the training a safe, comfortable and productive learning environment.
- Ask participants to give examples to illustrate a point. This strategy ensures that examples are relevant to participants.
- Bounce back to the group questions you receive from participants, as appropriate. *What do other people think about this?* and *What other ideas do you have?* are ways to show participants that you recognize their expertise.
- Show participants that you appreciate their contributions by saying things such as, *That's a good point*, *Thank you for bringing that up*, or *Many people have that same question*.
- Link discussion back to comments participants made earlier in the session, such as, *As Monique said earlier, this is a very emotionally-charged subject*.
- Bridge forward to what comes next, by saying things like, *After break, we're going to practice putting these new insights into action*.
- Move around. If you stand behind a podium, you are likely to appear distant or inaccessible to participants.

## Open-Ended Questions

Whenever possible, ask questions instead of talking at participants. You can do this by asking open-ended questions, or questions that cannot be answered with a simple *Yes* or *No*. These questions usually begin with words like *where*, *when*, *what* and *how*. The word *why* can be used if it is said in a questioning way rather than a confrontational one.

For example, when speaking to a first responder audience, asking, *Why do you think some first responders are reluctant to let parents hold their deceased baby?* would be appropriate, but asking, *Why aren't you letting parents hold their deceased baby?* might be seen as confrontational.

Open-ended questions can be used early in a training to get a sense of participants' expectations and baseline knowledge levels. Open-ended questions send the message that participants' input is welcome. You also can use open-ended questions to review information already covered. For example, have participants review or summarize parts of the training by asking the following questions:

**What new information have you learned today?**

**How will you apply what you have learned today as a law enforcement officer who might be called to a home where an infant has died suddenly and unexpectedly?**

In addition, you can use open-ended questions to help participants share ideas, experiences, barriers and solutions when you process activities or discuss content. For example:

**What has been your experience in encouraging safe sleeping arrangements for newborns?**

**What are some of the barriers you may face in setting a back only sleep position policy for newborns in your child care center?**

**How can you overcome the barriers you have identified?**

Open-ended questions are a simple way for trainers to acknowledge that participants have valuable information and experience to share. However, using open-ended questions often takes more time than lecturing. If you find that you are running out of time in a session, you may need to limit responses from participants by saying things like, *We have time for one or two more comments.*

## Active Listening

Active listening skills can help participants feel like their ideas are truly an important part of the training experience. In addition, active listening helps the trainer understand participants' concerns. This greater understanding helps you tailor the training to better meet their needs. An effective active listener uses both verbal and nonverbal skills to acknowledge participation, clarify information and encourage dialog.

Verbal active listening skills include:

- Repeating what participants say to emphasize their points.
- Rephrasing participants' words to see if you understand what they are saying.
- Connecting participants' points to something covered earlier in the training.
- Asking for clarification if you are not sure what a participant means.
- Thanking participants for their contribution.

Nonverbal active listening skills include:

- Maintaining open, receptive body language.
- Making eye contact with the speaker.
- Leaning forward.
- Nodding when appropriate.

## Managing Time

Time management can be one of the most challenging aspects of conducting a training session. It takes a skilled trainer to cover content in a way that involves and engages participants within a limited time frame. Some ways to manage time effectively are:

- Make clear that participants and trainers will be expected to respect start, end and break times.
- Help participants who wander off the topic to tie in their comments with the discussion at hand.
- Ask participants' permission to table questions, suggestions or comments.
- Limit comments on any given topic, but encourage participants to continue their dialog on breaks or after the training session.

If you run into a situation in which you have too little time to cover all topics on the agenda, you may need to negotiate with participants about what they most want to cover. By allowing them to identify what is most useful to them, you make the most of the time remaining and meet participants' needs.

## Giving Feedback

It is important to give positive feedback to participants throughout the training. However,

it may be necessary to give corrective feedback at several points in the training, as you help participants build their skills and knowledge. Effective corrective feedback, which is always given in a supportive manner, helps participants improve. To give effective corrective feedback:

- Focus your comments on the participants' behavior rather than on the individual.
- Always point out something the participant did well.
- Point out something specific on which the participant could improve.

Corrective feedback is never a personal attack on an individual. It is always offered as a way of helping someone increase knowledge or improve skills.

### **Checking-In With Participants**

An experienced trainer is able to read the body language of the participants to ascertain the appropriateness of the training content, the pace of the training and the energy level in the group. This step can be done informally on an individual basis during breaks or more formally with the entire group.

Asking questions like, *How is everyone doing?* and allowing time for honest responses or asking people to summarize the key points from a particular segment of the training will help trainers assess whether participants are grasping new information.

Mid-training adjustments may need to be made if it appears that many of the participants have not understood the material, appear bored or need additional help with concepts or skills. Trainer observations during role-plays, demonstrations or small-group activities can provide assessments of how well new material is being understood and integrated.

### **Working With Challenging Participants**

There is always the possibility that there will be participants who pose some challenges to a smooth and effective training process. In [Appendix C: Creating a Safe and Comfortable Learning Environment](#), a table summarizes some of these challenges and techniques to work effectively when challenging participants are part of a training group.

## **Strategies for Working With Multicultural Training Groups**

Many public and private health-related organizations are struggling to understand what cultural competence means and what they need to do to be culturally competent. Cultural competence is a complex issue that trainers need to consider.

### **Ensuring Cultural Competence**

To be effective, trainers must be aware of cultural issues that can affect the training environment. Culture can influence people's values, attitudes, beliefs and behaviors. Culture, therefore, has an impact on how people learn, communicate, make decisions and interact within groups.

Many people think of culture simply as a person's race or ethnicity. However, culture includes many different aspects of people's lives. People's cultural background may be

influenced by their:

- Race/ethnicity
- Gender
- Regional differences
- Language
- Sexual orientation
- Level of formal education
- Profession or job
- Spiritual beliefs and practices
- Physical ability
- Age

When working with multicultural groups, keep in mind that although people from a specific cultural group may share common traits, all members of a cultural group are not alike. Individuals within cultural groups have their own personal experiences, personality traits, values and belief systems. It is important to respond to people's needs and not assume that people will respond in a certain way because they belong to a particular cultural group.

If you train health professionals, keep in mind that there is a culture of medicine as well. People who work in health care have a common language and view of health and illness. These views may or may not be shared by community and patient groups.

When training audiences that are made up of both health professionals and others who do not work in health care, make sure that acronyms, medical jargon or other abstract concepts are not used unless they are well explained.

Also, it is important to be alert for biases and assumptions that health professionals may share, but which may conflict with community members' cultural values, attitudes and beliefs.

## **Considering Power Differentials**

In training groups where participants might come from diverse backgrounds or positions of power, be alert for ways that power imbalances might affect the training.

For example, if you are training a group of health professionals, some may be supervisors of others in the room. The supervisee might feel awkward about sharing certain feelings or revealing a lack of skill or knowledge related to the topic with his or her supervisor in the room. Likewise, patients may feel awkward discussing health care concerns if their nurse, physician or social worker is in the same audience.

Some tips for dealing with power differentials within an audience include:

- Acknowledge that the situation exists.
- Emphasize that each person's unique perspective and experiences is equally valued and refer to other ground rules that address issues such as these.
- Avoid participant introductions that emphasize academic degrees or professional status. Instead ask people to describe their connection to the topic.

## Self-Awareness

To fully appreciate cultural power and differences, trainers must:

- Recognize their own culture's influence on how they think and act.
- Understand the complexities of cross-cultural interactions and fully appreciate, value and respect participants' diversity.
- Be aware of the impact of institutional and societal racism, sexism, ageism and other such *-isms*, and acknowledge how these forms of oppression can influence group dynamics.
- Share appropriate personal experiences from your own culture while not attempting to be an expert on other cultural groups.
- Acknowledge that everyone in the room has something important to share and that you, as the trainer, hope to learn from the group as well.

## Cross-Cultural Communication

To improve cross-cultural communication skills, trainers should:

- Avoid statements based on stereotypes. If generalizations are used, they should be clearly labeled as such and modified with terms such as *many* or *some*.
- Appreciate the different ways that people from various cultures engage in group discussions. Silence, for example, has a different meaning, depending on personal experience and cultural background.
- Ensure that all participants have an opportunity to express their ideas to the group during discussions.
- Remember that participants have different levels of proficiency in reading, writing, speaking and understanding the language used in a training session.

Even with all cultural considerations in mind, there is no substitute for exercising judgment in considering how, what and when to address various issues during a training. Almost any training activity has the potential to be culturally offensive when facilitated by someone who does not demonstrate respect for participants. Demonstrating respect for participants is crucial and opens the door for mutual growth and learning.

## Body Language and Movements

Trainers must also be aware of the different ways people share information. In addition to speaking, people use body language, physical contact and body movements to express themselves. Be aware that the appropriateness of personal space, touching, physical contact and eye contact can vary depending on cultural norms, personal experiences and personal preferences.

## Closing the Training

It is important to close the training. Often this step is overlooked due to time constraints. Some trainers feel that the evaluation serves as the closing activity. However, closings are different from conducting an evaluation of the program. They provide a way to summarize or wrap-up the training content as well as an opportunity to close out the emotional aspects. Done well, closings help participants draw a boundary between the training and

the rest of their lives.

- If at all possible, allow time for participants to fill out evaluation forms before the end of the session. This time allowance will greatly increase your response rate. You also may wish to have participants exchange the evaluation for a certificate of completion or continuing education documentation.
- Remind participants of the handouts you've provided for their future reference or to share with others.
- If appropriate, refer the participants to the appropriate local resources for further questions. Make sure you have the correct addresses and telephone numbers for any organizations to which you refer participants. The PowerPoint presentation contains referral information about several national resources. You can customize the presentation with the local information.
- If you are willing to be contacted after the session, distribute business cards, include your information on a handout or customize the title slide to the PowerPoint presentation with your name and telephone number.
- Thank participants for their participation, attention and comments. If the presentation is sponsored by an agency or organization, or if you are there because of an individual's invitation, be sure to mention these individuals and organizations by name and thank them as well.

## **Put Closure on the Content of the Training**

Participants should experience a sense of closure with the content of the training. For example:

- Ask for a volunteer to summarize the key take-home messages.
- Conduct games that review concepts or information learned during the training.
- Do a post-test.
- Develop an action plan describing how the participants will use the new knowledge, attitudes or skills.
- Review expectations from the beginning of the training, and ask if all have been met.
- Address any lingering questions or concerns.

## **Put Closure on the Emotional Component of the Training**

Trainings where there has been significant personal sharing or where participants have formed strong emotional bonds need closure so that participants are not left with unfinished feelings. Examples of ways to put some closure on the emotions that were generated by the training include:

- Take a group photo.
- Have participants stand in a circle and say one thing they have appreciated about the other participants. A variation is to have people write comments on small pieces of paper and put their contributions in cups marked with each participant's name. This strategy works best when participants have been together over a two- to three-day training or are part of a group who meets over several months.
- Give participants an opportunity to plan a reunion or another time to get back

together. Again, this strategy is most appropriate for groups that have met over time or where deep bonding has occurred.

- Give certificates of participation or completion.

## **After the Training**

Even though your training is complete, your work is not. Make sure to:

- Review training evaluations. Use feedback—both positive and negative—to guide future training. Identify follow-up needs.
- Send required sign-in roster and other required documentation to agency providing continuing education hours/units (CEUs).
- Send a written thank-you note to the individual who invited you to conduct the training.

# 3

# Training Media

## Overview of Types of Training Media

There are a number of different types of training media that you may use including handouts, flip charts, overhead projectors, slides, computer presentations and videos.

### Handouts

Handouts are supplementary materials that provide a detailed expansion or reiteration of one or more aspects of the presentation. When using handouts, remember:

- Handouts can be your worst distraction during a presentation if distributed while you are speaking. Whenever possible, provide handouts at the end of a presentation unless the audience will use them during the training. In that case, provide the handouts before the presentation to avoid distraction and consider stapling or binding them in such a way that they can not be shuffled around.
- Reduced-size reproductions of charts or slides used during the presentation can be extremely useful to participants as reference material. Adding brief interpretive statements can remind participants of your key points at a later date.

### Flip Charts

A flip chart pad can provide flexibility for developing and modifying simple sketches, diagrams and statements during the course of a presentation.

Color is extremely important. Green, blue and brown should be used primarily for words. Avoid visuals that are one color. Use red, orange or yellow for highlighting only. If you have five- or six-line visuals, use colors to separate them or to group them.

When using flip charts, remember:

- Maintain your flow of speech while you write.
- Avoid talking to the flip chart.
- Stand to the side when writing on a flip chart pad.
- Write large and neatly.
- Draw a faint outline of a diagram or model in pencil before the presentation to provide guidelines for the marker or chalk.
- Limit the number of words to avoid busy and distracting pages.

- If you prefer, have a co-trainer or participant write while you facilitate group discussion.

## **Overhead Projectors**

An overhead projector is used to project material from a book or a prepared transparency onto a screen. When using transparencies, remember:

- Do not use more than four or five words per line.
- Do not crowd too many lines onto one transparency.
- Design transparencies so that they can be read from the back row of the training room.
- Use dark letters on light backgrounds.

When using overhead projectors, remember:

- Place a transparency on the projector before the training in order to focus it.
- Always have a spare light bulb and extension cord with you.
- Designate someone to control the room lights.

## **Slides, LCD Projectors and Computers**

Slides are still the most common visual aid used during trainings. However, many health care professionals are switching to LCD projectors and computers to project computerized presentations onto a screen using presentation programs like Microsoft PowerPoint.

When designing slides or computer-generated presentations, remember:

- Keep each slide simple with bullet points and simple visuals. Each bullet point can be elaborated upon during the presentation.
- Use a large enough font (at least 28 point) so that the text can be read from the back row of the training room.
- Use colors and designs that are pleasant, but not distracting.
- Use colors that make text stand out on a slide. Use a light color for the text on a dark-colored background. The more color used, the less effective text will be.
- Use visual aids that complement the text.
- Use a uniform font throughout.
- Use text on no more than 75 percent of each slide.
- Use animation sparingly, if ever. Although it is interesting to have bullet points appear or cross the screen as you read them, animation can easily be distracting.

When using slides, remember:

- Make sure your slides are placed in the carousel so that they project right side up.
- Practice showing your slides before the training.
- Practice using the remote control for changing slides.
- Practice operating the electronic pointer if you will be using one during your presentation.
- Always have a spare bulb and an extension cord with you.

- Designate someone to control the room lights.

When using LCD projectors and computers, remember:

- If you do not have your own slide projector or LCD and portable computer, reserve one for your training.
- Make sure the computer is equipped with compatible software to run your presentation.
- Make sure that your presentation fits onto a diskette, CD or USB memory stick.
- Before the training, do a test run of your presentation to make sure that there are no problems using your disk in the computer.
- Always bring a copy of your presentation on overheads in case you have technical problems.

## Videotape & DVD Players

Videotape and DVD players are extremely versatile and a major tool in presentations.

When using videotapes and DVD players, remember:

- Use is limited for large groups (more than 20 participants) because multiple monitors or large video projection screens are needed.
- Most equipment is portable but cumbersome.
- Carefully consider compatibility of the type and size of the videotape and cassette and DVD to the available equipment.
- Have tapes set at the proper starting point so that only the *Play* button needs to be pushed.

## Using All Types of Training Media

Maximize the use of media by following slides, videos, audiotapes and photos with a targeted discussion. Consider the following format as one useful way to move participants from description, to feelings, insights and action steps:

- Describe what you see and hear happening in this video.
- What feelings does the video evoke in you?
- What are the key issues that are brought to light by this video?
- What do you think are some of the underlying causes that led to these issues?
- What are some possible strategies for dealing with these issues?
- How can we each make a difference in addressing these issues?

## Viewing a Slide Show

Generally, you will view the slide show in one of two ways. The following options are available when you click **Set Up Show** on the **Slide Show** menu.

1. **Presented by a live speaker (full screen).** This option runs a full-screen while a speaker directs the show. The presenter has complete control of the show and can run the show automatically or manually. If you are presenting in a large room using a monitor or projector, PowerPoint has a Projector Wizard that will

automatically set and restore correct screen resolution for the target projection system.

2. **Browsed at a kiosk (full screen).** This option runs a self-running presentation. This option is useful at conferences, for example. If you have a booth, kiosk or other location where you want to run an unattended slide show, you can set up the slide show so that it restarts automatically after each showing.

## Overhead Transparencies

You can create a presentation that uses overhead transparencies by printing your slides as black-and-white or color transparencies.

1. Go to **File** and click **Page Set-Up**.
2. Under **Slides Sized for**, click the **Overhead** option.
3. Choose the **Page Orientation** and click **OK**.
4. Go to **File**, choose **Print** and select the **Print Range** (whether a slide show or certain slides). Under the **Print What**, select **Slides**.

Make sure you select whether you would like to print in grayscale or pure black and white. Pure black and white is not recommended for graphs. Print out your transparencies on regular paper first to make sure that the slides are printing correctly.

## Paper Printouts

You can design your presentation so that it looks great both on the screen in color and when printed in grayscale or pure black and white on a laser printer. You can preview and change what your presentation will look like when it is printed in grayscale.

To adjust the colors so that they print best in grayscale, under **Format**, go to **Slide Color Scheme**, click **Standard** and go to **Grayscale Preview**. In **Normal View**, right-click any object on the slide, point to **Black and White** on the shortcut menu and then click the option you want.

The changes you make while working in grayscale view don't affect the colors in your on-screen presentation.

## 35mm Slides

A service bureau can transform your electronic slides into 35mm slides. Contact your local service bureau for instructions. If you are located in the United States, you can have [Genigraphics](#) prepare your slides.

Point to **Send To** on the **File** menu, click **Genigraphics** and then follow the instructions in the Genigraphics Wizard.

## Notes and Handouts

You may want to print your speaker's notes to assist you with your presentation. To support your presentation, you can also give your audience handouts, smaller versions of your slides that are printed two, three, four, six or nine slides to a page.

1. On the **View** menu, point to **Master** and then click **Handout Master** or **Notes**

**Master.**

2. To preview the layout you want, click the buttons on the **Handout Master** or **Notes Master** toolbar.
3. Add the items you want on the handout or notes master: art, text, headers or footers, date, time or page number. Items that you add appear only on the handouts or notes. No changes are made to the master slide.
4. On the **Master** toolbar, click the **Close** button.
5. On the **File** menu, click **Print**.
6. In the **Print What** box, click **Handouts** or **Notes**.
7. In the **Slides Per Page** box, click the number of slides you want on the handout. If you select three per page, there will be lines next to each slide where participants can write notes.
8. If you choose four, six or nine slides per page, click **Horizontal** or **Vertical** to specify the order in which you want the slides to appear on the page.

**Note:** You can also change the orientation of the paper when you print handouts. Click **Page Setup** on the **File** menu, and then click **Landscape** or **Portrait** under **Notes, Handouts and Outline**.

# 4

# Appendix A

## Principles of Adult Learning Chart

### Adults learn best when...

They feel valued and respected for the experiences and perspectives they bring to the training.

Therefore, they wish to speak, participate and contribute to the training. They dislike long lectures and one-way communication.

The learning experience is active and not passive.

Adults are accustomed to being active. They should be given an opportunity for active participation whenever possible.

### The role of the trainer is to...

Create activities that use participants' experience and knowledge. Don't ignore what they know. It is a resource for you.

Provide low-risk activities in small-group settings.

Validate and affirm their knowledge, contributions and successes.

Provide for the possibility of a need to unlearn old habits.

Avoid jargon and talking down to participants.

Share personal experiences when asked and when appropriate.

Provide a quality, well-organized experience that uses time effectively.

Listen before, during and after the event.

Ask for feedback on training and provide input opportunities.

Actively engage participants in their learning experience.

Encourage participation by all participants.

Allow sufficient time for all activities.

Ask open-ended questions to encourage discussion.

Use participants' names to encourage connection to the class.

# A

# Principles of Adult Learning Chart

## Adults learn best when...

## The role of the trainer is to...

The learning experience actually fills their immediate needs.

Identify participants' needs and tie training concepts into these identified needs.

Adults learn with relevance. The learning must connect clearly and directly with tasks faced by the learner on the job or in life.

Follow up on answers to questions you don't know.

Provide background and supporting evidence for course content.

Modify the teaching plan to accommodate learner experiences.

They accept responsibility for their own learning.

Make sure that training content and skills are directly relevant to participants' experiences so that they will want to learn.

Adults prefer learning situations that allow choice and self-direction.

Build training plans around their needs and compare goals and actual needs.

Share the agenda and assumptions and ask for input on them.

Ask what participants know about the topic.

Ask what participants would like to know about the topic.

Build flexibility into your plans so they can easily be shifted if necessary.

Suggest follow-up ideas and next steps for after the session.

Their learning is self-directed and meaningful to them.

Involve participants in deciding on the content and skills that will be covered during the training.

Adults prefer learning situations that are practical and problem centered.

Give overviews, summaries and examples and use stories.

Plan for direct application of the new information.

Include collaborative, problem-solving activities.

Anticipate problems applying the new ideas and offer suggested uses.

Guard against becoming too theoretical.

# A

## Principles of Adult Learning Chart

<b>Adults learn best when...</b>	<b>The role of the trainer is to...</b>
<p>Their learning experience addresses ideas, feelings and actions.</p> <p>Therefore, the material and the method of presentation must catch their interest, touch their feelings and stir creative and independent thought.</p>	<p>Use multiple training methods that address knowledge, attitudes and skills.</p> <p>Promptly address participants' concerns, conflicts or difficulties.</p> <p>Use a variety of educational methods such as discussion, role-play or videos.</p> <p>Use colorful slides or overheads.</p> <p>Use colorful newsprints and markers.</p>
<p>New material is related to what participants already know.</p> <p>Adults want courses that focus on real-life problems and tasks rather than academic material. A strong how-to focus is desired. They become restless if they believe their time is being wasted.</p>	<p>Find ways to assess participant knowledge before an event.</p> <p>Help them recall what they already know that relates to the new ideas.</p> <p>Help them see how the new information is relevant to them.</p> <p>Modify the teaching plan to accommodate participant experiences.</p> <p>Process role-plays in a manner that reflects real life.</p> <p>Use real-life problems and examples.</p> <p>Ask participants to relate their own stories.</p> <p>Minimize the use of statistics.</p>
<p>The learning environment is conducive to learning. Adults learn best in comfortable settings.</p> <p>Therefore, physical discomfort will distract or create negative feelings.</p>	<p>Provide for their needs through breaks, snacks, coffee and comfort.</p> <p>Allow frequent breaks during instructional time.</p> <p>Encourage participants to dress comfortably/casually.</p> <p>Orient yourself and participants to the facility, especially the locations of telephones and restrooms.</p> <p>Create a classroom set-up that is conducive to participant interaction and learning.</p>

# A

## Principles of Adult Learning Chart

<b>Adults learn best when...</b>	<b>The role of the trainer is to...</b>
Learning is reinforced.	Use training methods that allow participants to practice new skills and ensure prompt, reinforcing feedback.
Adults want positive reinforcement of desired behavior and feedback about errors at the moment they occur.	<p>Handle unexpected situations or disrespect with minimal confusion or emotion.</p> <p>Process after each exercise, activity or role-play.</p> <p>Give praise and encouragement.</p> <p>Provides specific behavioral observations about errors.</p>
Learning is applied immediately.	Provide opportunities during the training for participants to apply the new information and skills they have learned.
Learning occurs in small groups.	Use training methods that encourage participants to explore feelings, attitudes, and skills with other participants.
The trainer values their contributions as both a participant and a teacher. Adults learn when mistakes are honored as well as successes. People learn from mistakes.	<p>Encourage participants to share their expertise and experiences with others.</p> <p>Process by asking what was most difficult or challenging about the exercise/assignment.</p> <p>Ask participants what they liked or thought they did well in the exercise/assignment.</p> <p>Encourage participants to take risks and try new things.</p>

**A**

# Appendix B

## Selecting Appropriate Training Methods

To help people gain new awareness and information that will translate into changes in attitudes and behavior, you must choose training methods that correspond to the changes you hope to accomplish. A variety of training strategies will ensure that the learning needs of all types of participants are met. The list below provides some suggested training methods for accomplishing changes in each of these domains.

### Knowledge (Concepts, Facts)

- Computer-assisted instruction
- Field trips or tours
- Handouts
- Programmed instruction
- Discussion
- Films, VHS, DVD
- Lecture
- Readings

### Attitude (Feelings, Opinions)

- Brainstorming
- Creative arts
- Interview situations
- Role-playing
- Case studies
- Field trips
- Open-ended discussions
- Panel presentations of SIDS family members and health professionals

### Behavioral Skills

- Action plans
- Guided practice with feedback
- Role-playing
- Demonstrations
- Practicums
- Simulations

## Training Methods Overview

The following table summarizes which of the training methods described below can be used to achieve changes in participants' knowledge, attitudes and behavior skills.

<b>Training Method</b>	<b>Knowledge</b>	<b>Attitude</b>	<b>Behavior</b>
1. Lecture	x		
2. Small-Group Discussion	x	x	
3. Brainstorming	x	x	
4. Case Study	x	x	x
5. Demonstration	x		x
6. Role-Play	x	x	x
7. Creative Work	x	x	

## **Training Method # 1: Presentation/ Lecture/Panel Discussions**

A presentation or lecture can convey information, theories or principles quickly and easily. Some examples specific to SIDS and other infant death risk reduction might be reviewing the facts about SIDS and other infant death risk reduction methods. Presentations can range from straight lecture to some involvement from the participants through questions and discussion. Presentations depend on the trainer for content more than any other training technique does.

### **Uses**

- Introduces participants to a new subject.
- Conveys facts or statistics.
- Provides an overview or a synthesis.
- Addresses a large group.

### **Advantages**

- Covers a lot of material in a short time.
- Provides context for more practical or hands-on training techniques.
- Works with large groups.
- Gives lecturer or presenter more control than in other training situations.

### **Disadvantages**

- Emphasizes one-way communication.
- Requires that participants take passive role in their learning.
- Is not experiential in approach.
- Requires that lecturer possess skills as an effective presenter.

- Is not appropriate for changing behavior or for learning skills.
- Limits participant retention unless it is followed up with a more practical technique.

## Process

1. Introduce the topic. Tell the participants what you are going to tell them. Use an opening that:
  - Explains the purpose of the presentation and why it is important.
  - Relates to the topic, situation, participants or speaker.
  - Involves and stimulates the audience.
  - Creates positive thinking and peaks interest.
  - Gets attention, for example, by using:
    - Questions
    - Illustrations
    - Brief stories
    - Subject matter of significance
    - Presents the topic
    - Unique facts
    - Quotations
    - Compliments
    - Serves as a preview to subject matter
2. Hold participant attention and interest by:
  - Being enthusiastic, dramatic or humorous.
  - Using specific examples that:
    - Provide clarity, color and credibility.
    - Make the impersonal become more personal.
    - Help a general thought become a specific one.
    - Avoid jargon.
    - Vary the pace.
  - Providing opportunities for participant involvement by:
    - Questioning both ways.
    - Acknowledging individuals, by name, if possible.
    - Asking for participant assistance.
    - Using references that show material is aimed at a specific group.
    - Using surprises and extras.
    - Inviting the participants to ask questions.
3. Use a closing that:
  - Summarizes the entire activity and emphasizes the key take-home message.
  - Makes a meaningful statement.
  - Relates to the topic, situation, participants or speaker.
  - Ties together the activity as an entity.

## Variations

A lecturette is a term used for a brief lecture of no more than 15 to 20 minutes. Often these are made more interactive by using a call-and-response format such as interspersing

questions to the participants in between lecture points made by the presenter.

For example, the trainer might ask, *Which communities or populations are most impacted by SIDS?*

After participants offer answers, the trainer could then validate the right answers, correct misinformation or wrong answers and then briefly summarize the take-home messages. In this manner, participants are acknowledged for what they already know while new and accurate information is offered by the trainer.

Another variation on the presentation method is a panel discussion. A group of experts such as SIDS parents, SIDS grandparents, health professionals or first responders, present their perspectives to the participants through prepared remarks or spontaneous answers to questions posed by a moderator or facilitator.

This approach can be made more interactive by allowing time for participants to ask questions or make comments. A moderator or trainer can model this interaction by asking one or two questions. Participants can also write their questions on index cards if the size of the training group makes it logistically difficult for participants to ask questions verbally.

## Training Method #2: Small-Group Discussion

A small-group discussion is an activity that allows participants to share their experiences and ideas or to solve a problem. It exposes participants to a variety of perspectives and experiences as they work together to accomplish a task. Some examples specific to sleep safety/SIDS risk reduction include breaking people into small groups to discuss ways to encourage new parents to use cribs or place their babies to sleep in the back position.

### Uses

- Enables participants to present their ideas in a small group.
- Helps participants learn from each other.
- Promotes teamwork.
- Enhances problem-solving skills.
- Clarifies personal values.
- Gives participants a greater sense of responsibility in the learning process.

### Advantages

- Allows participants to develop greater control over their learning.
- Encourages shy or less talkative participants to become involved.
- Builds group cohesion.
- Encourages participants to be less dependent on the trainer.
- Allows for reinforcement and clarification of the lesson through discussion.
- Elicits information from participants.

### Disadvantages

- Takes time to move people into groups.
- Compromises quality control if a trained facilitator is not in each small group.

## Process

1. Arrange the participants in small groups using some of the ideas listed on the next page. Introduce the task that describes what should be discussed in the small group and tell participants how much time they have.
2. Ask each small group to designate:
  - A discussion facilitator.
  - A recorder.
  - A presenter who will discuss the group's findings in front of the larger group.
3. Check to make sure that each group understands the task. Give groups time to discuss. Circulate among the small groups to:
  - Clarify any questions participants may have.
  - Make sure that participants are on task.
  - Make sure that a few participants are not dominating the discussion.
  - Bring all of the small groups together to have a large group discussion.
4. Have the designated presenters discuss a summary of their group's findings. (This could be a solution to a problem, answers to a question or a summary of the ideas that came out during the discussion.) Identify common themes that were apparent in the groups' presentations. Ask the participants what they have learned from the exercise and how they might use what they have learned.

## Determining Group Size

Participants learn through their own experience, especially by discussing questions posed by the trainer. Discussions can take place in a large group, in a small group, or between two participants. Keep in mind:

- Most people find it difficult to speak in a group of strangers. Also, there is usually not enough time for everyone to speak. Therefore, if everyone is to participate actively, small groups are essential.
- Most people find it difficult to listen attentively for long periods of time. Therefore, talks should be short, and people should be given an opportunity to discuss a topic or issue in small groups.
- We all remember much better what we have discovered and said ourselves than what others have told us. Therefore, participants should be given questions leading them to express all they have learned from their own experience first. This needs to be done in small groups.
- A resource person or facilitator can briefly sum up the points from each group and add his or her own insights later, instead of taking a long period of time to tell people what they know.

Pairs are useful for:

- Interviews
- Intimate sharing
- Practicing some skills (e.g., listening or feedback)
- A quick chat with a neighbor to stir passion or prompt a sleepy group into action

Triads (groups of three) are very useful for:

- Getting everyone to think and participate actively. A participant can be passive in a group of five, but it is unlikely to occur in a group of three.
- Testing out an idea one is hesitant to present to the full group

Groups of four, five or six will add a bit more variety for sharing ideas and insights. Four, five or six participants can be a good size for a planning team, a film discussion group or a more complex situation. However, the bigger the group becomes, the longer the discussion and the decision-making process.

## Dividing Groups and Assigning Roles

When facilitating an interactive training, it sometimes is necessary to divide participants into groups and assign them roles. The following are some imaginative ways to divide participants into groups:

- Deck of cards using the four suits to represent four groups
- Colored stickers or dots placed on or under chairs
- Different types of candy (e.g., peppermints, butterscotch, cinnamon or fruit flavors), which participants pick out of a basket
- M&Ms of different colors

If groups do not need to be exactly even, use things like types of cars participants drive, types of toothpaste they use, preferences for different types of music, etc.

## Selecting a Group Recorder/Reporter

- Select any date at random. The person whose birthday is closest to that date becomes the recorder.
- Choose a person who lives closest (or farthest) from the meeting site.
- Choose the person newest (or oldest) to the organization.
- Choose the person with the most pets (including fish).
- Choose the person who exercises the most.
- Choose the person who watched the least TV in the past week.

## Training Method #3: Brainstorming

Brainstorming is an activity that generates a list of ideas, thoughts or alternative solutions around a particular theme or topic. Creative thinking is more important during this activity than practical thinking. No idea is dismissed or criticized. Anything offered is written down. Often participants stimulate each other's thinking.

After the list of ideas is completed, the group clarifies, categorizes or discusses one item at a time, depending on the situation.

### Uses

- Introduces a problem or question. For example, *Let's brainstorm all the reasons new parents might sleep with their newborn infant.*

- Forms the basis of discussion.
- Can use in conjunction with group discussion.

## Advantages

- Generates ideas and leads to discussion quickly.
- Allows everyone's ideas to be expressed and validated without judgment.
- Generates energy to move forward with problem solving.
- Stimulates thought and creativity.

## Disadvantages

- Can be difficult to get participants to follow the rules of not diminishing or criticizing the ideas generated during the actual brainstorming activity.
- Affords opportunity for participants to get off track and develop a list too broad to guide discussion.
- Opens up the possibility that participants may feel badly if their idea meets with criticism.
- Requires that participants have some background related to the topic.

## Process

1. Establish the rules for brainstorming, including the following:
  - All ideas will be accepted for the list.
  - At no time should an idea be discussed or criticized.
  - Discussion occurs only after the brainstorming session is complete.
2. Warm up the group by doing a practice exercise such as having everyone write down on a piece of scrap paper everything you can do with a rule. Then go around the room and generate a group list.
3. Announce the SIDS- or sleep safety-related topic, problem or question.
4. Write the ideas and suggestions on a flip chart to prevent repetition and keep participants focused on the topic. Allow silence. Give participants time to think. Provide positive feedback to encourage more input from participants.
5. Review written ideas and suggestions periodically to stimulate additional ideas. Conclude brainstorming when no one has any more ideas to add to the list.
6. Review the final list before discussion.

**Note:** It is helpful for your co-trainer, if one is present, to record the ideas while you call forth the ideas from the group. If there is not a co-trainer, a trusted participant can function in this role.

Be sure, however, that the participant chosen for this recorder role can keep up with a fast-paced generation of ideas. Nothing impedes the brainstorming process more than a recorder who constantly asks for ideas to be repeated, words to be spelled or acronyms to be explained.

## Variation

A variation to the method described above is to ask each participant to write down his or her thoughts or ideas about the topic on Post-it notes. The trainer then collects all the notes and quickly organizes the categories and responses under each one and discusses the similarities, differences, consistencies, inconsistencies and take-home messages.

## Training Method #4: Case Study

A case study is a written description of a hypothetical situation that is used for analysis and discussion. It is a detailed account of a real or hypothetical occurrence (or series of related events involving a problem) that participants might encounter. It is analyzed and discussed, and participants are often asked to arrive at a plan of action to solve the problem.

Case studies can help group members learn to develop various alternative solutions to a problem and may help develop analytical and problem-solving skills. Some childcare provider and first responder-related examples are included in the PowerPoint slides on the included CD-ROM. You may wish to create additional case studies for other audiences.

## Uses

- Synthesizes training material.
- Provides opportunity to discuss common problems in a typical situation.
- Provides a safe opportunity for developing problem solving skills.
- Promotes group discussion and group problem solving.

## Advantages

- Allows participants to relate to the situation.
- Involves an element of mystery.
- Avoids personal risks by using hypothetical situations.
- Involves participants in an active manner.

## Disadvantages

- Requires a lot of planning time if you need to write case studies yourself.
- Requires careful design of discussion questions.

## Process

1. Introduce the case study to participants. Give participants time to familiarize themselves with the case. Present questions for discussion or the problem to be solved. Emphasize that there is not always only one right solution, if appropriate for the specific case.
2. Give participants time to solve the problems individually or in small groups. Circulate among the small groups to:
  - Clarify any questions participants may have.

- Make sure that participants are on task.
  - Make sure that a few participants are not dominating the discussion.
  - Bring everyone back together for a larger group discussion.
3. Invite participants to present their solutions or answers. Discuss all possible solutions or answers. Ask the participants what they have learned from the exercise. Ask them how the case might be relevant to their own lives. Summarize the points made.

## Tips for Developing Case Studies

- Develop a case study that is as realistic as possible.
- Describe the people in the case study.
- Use names, but be sure to indicate that they are not the names of real people.
- State their genders, ages, ethnicities and other relevant characteristics.
- Describe the specific situation.
- Think about the specific issues you want the participants to address.
- Use the case study to challenge assumptions. For example, illustrate that health care workers don't always know the answers or patients aren't always uninformed.
- Avoid giving solutions to the problems raised in the case study.
- Avoid making the case study too complex or too simplistic.

Some examples of discussion questions that use the adult learning cycle as a model include:

- Describe what you see and hear happening in this case study.
- What feelings does the case study evoke in you?
- What are the key issues that are brought to light by this case study?
- What do you think are some of the underlying causes that lead to these issues?
- What are some possible strategies for dealing with these issues?
- How can we each make a difference in addressing these issues?

## Training Method #5: Demonstration

A demonstration is a method for showing precisely how a skill, task, or technique should be done. The trainer or a skilled participant shows other participants how to successfully perform a given task by demonstrating it, describing each step, and explaining the reasons for performing it in a particular way.

It is often followed by a practice session in which the participants carry out the activity under the supervision of the trainer. The use of models or props, such as dolls, one-piece sleepers or a safe crib set-up, greatly enhances the training on sleep safety and leads to effective acquisition of these new skills.

## Uses

- Shows participants how to perform a skill.
- Shows how participants can improve or develop skills.
- Clarifies and corrects misconceptions about how to perform a task.
- Models a step-by-step approach.

## Advantages

- Provides learning experience based on actual performance and is relevant to the participant's job or personal experience, especially when combined with hands-on practice.
- Illustrates processes, ideas and relationships in a clear and direct manner.
- Requires low development costs.
- Helps participants focus their attention.
- Involves participants when they try the method themselves.

## Disadvantages

- Has limited usefulness.
- Requires lots of planning and practice ahead of time.
- Requires facilities and seating arrangements that are carefully planned so all members of the audience have an unobstructed view of the demonstration.
- Requires enough materials for everyone to try the skill being demonstrated.
- Does not ensure that participants will immediately be able to duplicate the skill after it is demonstrated.
- Requires that participants take a passive role during demonstrations, which may cause them to lose interest, particularly during afternoon hours and toward the end of the session.

## Process

1. Introduce the skill being demonstrated and explain its purpose.
2. Present the materials that are going to be used. Demonstrate the skill for participants. Repeat the demonstration, explaining each step in detail. Invite the participants to ask questions.
3. Allow participants to practice the skill themselves. Circulate around to each person to:
  - Observe participants as they perform the skill
  - Provide them with constructive feedback.
  - Bring participants back to the larger group.
  - Discuss how easy or difficult it was for them to perform the skill.
4. Summarize the take-home messages or key points.

## Training Method #6: Role-play

Role-play is a technique in which several individuals or a small group of participants acts out a real-life situation in front of the group. The scenario of the role-play is related to the training topic and must have a skill-based objective.

For example, in a training for childcare providers, two participants might role-play how to inform a mother who is seeking child care for her 8-week-old baby about the center's sleep safety policy. There is no script. However, the situation is described in as much detail as appropriate. The participants make up their parts as the situation unfolds. The role-play is then discussed in relation to the situation or problem under consideration.

### Uses

- Helps change people's attitudes.
- Enables people to see the consequences of their actions.
- Provides examples of possible reactions or behaviors.
- Provides a safe environment for exploring problems they may feel uncomfortable discussing in real life.
- Enables participants to explore alternative approaches to various situations.
- Explores possible solutions to emotion-laden problems.

### Advantages

- Provides opportunity for stimulating new ideas while having fun.
- Engages the group's attention.
- Simulates the real world.
- Provides a dramatic way of presenting a problem and stimulating a discussion.
- Allows participants to assume the personality of another human being.

### Disadvantages

- Requires that participants feel comfortable being in front of a group. Some participants may feel self-conscious, shy, or may fear looking ridiculous.
- Requires dyads or triads in which everyone is either acting or observing to address participant reluctance.

### Process

1. Prepare the actors so they understand their roles and the situation. Set the climate so the observers know what the situation involves.
2. Observe the role-play. Thank the actors and ask them how they feel about the role-play. Be sure that they get out of their roles and back to themselves.
3. Establish ground rules for having a group discussion about the role-play. As a group leader, your attitude and direction in this discussion are important. Try to protect the role-players from too much exposure to negative comments. In addition, try to get the observers to put their comments in the form of suggestions on how to improve the handling of the situation. The best way to do this is to set

the example yourself. Make your comments in a self-oriented, non-evaluative manner:

- Try to express your feelings as you were watching the role-play. For example, The interaction in the role-play made me feel...
  - Make your comments descriptive of what happened. For example, I noticed that the woman had eye contact twice with her friend.
  - Try not to interpret the behavior of the players in terms of why they did what they did. If this seems necessary, however, ask the players in an open-ended way rather than putting words into their mouths. For example, I was wondering why you asked the woman her marital status.
4. Discuss as a group the different reactions to what happened. Ask the participants what they have learned. Ask the participants how the situation relates to their own situation. Summarize the main messages or learning points and application.

## Handling Participant Resistance

There might be some resistance to role-playing. The most important thing in dealing with resistance is to allow it to be there and accept the feelings and thoughts behind it. At the same time, you should try to be clear that you want to do the role-play and why. If you feel good about it, the group will reflect this.

Types of resistance include:

- **Fear of exposure:** This type usually relates to a person's fear of being exposed to the total group and appearing as a fool. One way of handling this is to use multiple role-playing rather than single role-playing. Divide the group into pairs and ask them to do their own role-plays in different corners of the room. Using this method, you should walk around to get a feel for how each dyad is doing and whether the role-play is being used the way it was intended.
- **What is going to happen to me?** Generally, this type refers to a person's fear of not knowing the procedures involved in role-playing. This may be related to lack of knowledge about the topic or lack of role-playing skill. Usually a good explanation of the different steps in the session clarifies the issue. You should ensure that people won't be criticized by acknowledging how difficult role-plays can be and thanking participants for their bravery in being willing to step outside their comfort zone to provide an excellent learning experience for everyone.

## Training Method #7: Creative Work

Although some people believe that using the arts in training is unprofessional and not appropriate, others have found that this approach is well-received by many audiences. These training activities give participants an opportunity to think or act outside the box. Examples of creative activities include:

- Making a collage. For example, making a collage of ways you received support when you were faced with an infant death.
- Drawing or painting with markers, water colors, chalk, or colored pencils. For example, painting a picture of what fear of recurrence looks like.
- Modeling with clay. For example, making a sculpture of a baby.

- Composing songs, poems, stories or plays. For example, writing a play about expectant mothers who changed their behavior related to smoking tobacco while pregnant.

## Uses

- Encourages participants to engage the right brain (creative, non-linear part), especially important after a left brain training method.
- Explores other ways to think about familiar situations.
- Enables participants to explore emotionally-laden topics in a safe way.
- Encourages people to move beyond their comfort zone.

## Advantages

- Gives participants an opportunity to have fun while dealing with emotionally-laden issues.
- Allows participants to move around, which is especially good for kinesthetic participants.
- Provides a creative way of dealing with sensitive issues.
- Fosters interaction and emotional connections among participants.

## Disadvantages

- Requires additional space and materials.
- Intimidates participants who feel shy about artistic endeavors. However, don't assume that your audience won't respond well to this technique. You might try out the idea with a few people who are demographically matched to your potential participants before your training session.
- Might cause participants who are used to linear thinking and came to the training to get new information to question the usefulness of this approach.

## Process

1. Introduce the creative activity to participants. Discuss how the activity ties into the topics being covered. Provide participants the permission to take risks, be creative and not feel that they have to strive for perfection. Sometimes, asking people to remember what they were like in the fifth grade will help them to be less inhibited and let go of their inner critic.
2. Assure participants that these activities are not intended to be judged on artistic merit but rather to stimulate new ways of thinking about the topic. Review the materials that are available to complete the creative activity, such as clay, markers, magazines, scissors or glue. Tell participants how long they will have to work on their creations. Explain that you will give them a 10-minute warning before they have to finish their work.
3. Provide the allotted time for participants to create. Circulate around the room to see how participants are doing. Give the 10-minute warning. Bring everyone back together for a larger-group discussion. Discuss the ground rules for the discussion:

- Participants should support each other.
  - Comments made about another person’s creation should relate to how the creation makes them feel.
  - Comments should not be evaluative or judgmental.
4. Invite individuals to share their creations and how they are related to the topic. Ask participants to discuss both:
    - The process of creating
    - The meaning behind their work
  5. Summarize the discussion. Affirm participants’ work and ability to be creative.

**Example:** You might ask a group of public health nurses to draw a home visit scenario in which they visited a home and found that the infant had recently died. Each person would share his or her drawing with the group and talk about the images that were selected, the meaning behind them and how they relate to their role in supporting the bereaved family. Then they would talk about how it felt to create the drawing.

# Appendix C

# C

## Creating a Safe and Comfortable Learning Environment

Adults learn best when the training environment is emotionally safe and physically comfortable. There are a number of different strategies trainers can employ in order to create a positive learning environment.

## Setting Up: Ensuring a Comfortable Room Ambiance

Adults learn best in a pleasant environment where their physical needs are met. If possible, make sure there are adequate measures for controlling the temperature in the training room. Rooms with windows that provide natural lighting and contact with the outside world are preferable.

Beware of conditions that may distract from the training session:

- Windows that provide outside noise or visual distractions such as people walking by or nature scenes.
- Inadequate facilities including uncomfortable chairs, no tables to write on, inadequate lighting and poor acoustics.

**Note:** For large groups, a microphone may be needed. A lavalier microphone will allow the trainer to move freely around the room.

Sometimes, it is difficult to control room conditions. Simply acknowledge to the participants that you are sorry for their discomfort and state what you can and cannot control.

## Enhancing the Room

Even the drabest meeting room can be made more pleasing through the use of decorations. Bring in posters that pertain to your topic, wall hangings, flowers, tablecloths or candles. Use colorful markers to write on flip charts.

## Setting Up the Room With Chairs

How the room is set up will greatly affect participant interaction. Included are four common room arrangements and their benefits and drawbacks.

Set-Up	Benefits	Drawbacks
<p><b>Circle Seating</b></p> <pre>           X   X         X       X         X       X           X   X           </pre>	<p>Stimulates interaction.</p> <p>Promotes more equal role between trainer and group members.</p>	<p>Visual aids difficult to use.</p> <p>More difficult if large number of participants.</p> <p>No room to write. Materials must be balanced on laps.</p>
<p><b>U- Shape Seating</b></p> <pre>           X   X   X         X       X         X       X           X X X X           </pre>	<p>Leader more easily becomes part of group.</p> <p>Facilitates communication.</p>	<p>Participants at extremes may be distant from each other, which may hamper communication.</p> <p>Takes time to arrange furniture.</p>
<p><b>Workshop Clusters</b></p> <pre>           X         X X   X X         X   X   X           X X           </pre>	<p>Good freedom for participants.</p> <p>Good discussion and diverse communication.</p> <p>Lots of participant working space.</p> <p>Can accommodate large groups.</p>	<p>Takes lots of space.</p> <p>Visuals can be difficult to see.</p>
<p><b>Standard Classroom Seating</b></p> <pre>           X         X X X X         X X X X         X X X X           </pre>	<p>Easy to set up/rented facilities often set up this way.</p> <p>Can accommodate large groups.</p>	<p>Participants cannot easily talk with or see one another.</p> <p>Leader clearly apart from the group.</p> <p>Visuals may be difficult to see.</p>

**X** = Trainer    **X** = Participants

## Getting Started

After the training room is set up, you are ready to welcome participants to the training. As participants enter the training room, welcome them, ask them to sign in and give them name tags and any training materials or handouts for note taking. Remind them of the starting time and start the training as close to the scheduled time as possible to signal respect for participants' time.

## Help Participants Know What to Expect

Emotional safety is essential to creating a positive learning environment. For participants to feel comfortable in a new training situation they need to know what to expect from the training and what is expected of them as participants. The trainer should review:

- The goals and objectives of the training.
- An overview of the agenda including:
  - Stop and start times.
  - Times for breaks and meals (if appropriate).
  - The trainer's role. For example, as a facilitator rather than a speaker or presenter.
  - The participants' roles. For example, as active contributors to the group discussions and activities. The trainer should emphasize that the participants have a lot of wisdom to share with the group and that everyone will be greatly enriched if people participate fully in the training activities.
  - Where they can take care of their basic needs such as the location of restrooms, telephones and places to obtain food and drink.

## Create Ground Rules

Ground rules, also called group norms, are guidelines that help create a safe environment and enable tasks to be accomplished efficiently. Examples of ground rules include:

- Honor everyone's input regardless of educational degrees, professional or community status, or personal experiences with the topic.
- Value each person's unique opinions and perspectives.
- Agree to disagree, but do so respectfully.
- Speak one-at-a-time.
- Allow each person time to talk.
- Start and end on time. Come back from breaks promptly.
- Keep personal comments said during the training confidential.
- Support those who may have anxiety talking about emotionally difficult topics.
- Step outside your comfort zone.
- Speak for yourself, not other people. Use I statements rather than everybody or other people.
- Take charge of your own learning. Take breaks when you feel necessary or ask for clarification.

- Have fun even though the topic is a serious one.
- Ask questions.
- Feel free to pass when discussing a certain topic.

It is preferable for a training group to develop their own ground rules that reflect what is important for them to feel safe. However, if there is limited time, the trainer can suggest a set of ground rules and then ask the group for any additional ones.

For example, in professional audiences, it may be important to add the ground rule to put all cell phones and pagers on vibrate or turn them off. The trainer should address any participant concerns about the ground rules and then ask for people to follow these throughout the training. Tape the list of ground rules on the wall so all participants can see them. Refer to them if necessary during the training.

### Create a “Parking Lot”

Explain to participants that the parking lot is a place to put questions, comments or concerns that are important but slightly off the topic currently being discussed. Assure them everything in the parking lot will be addressed by the end of the training and keep your word, revisiting the parking lot as appropriate throughout the training.

After the trainer has set the stage for how the group will move through the training together, she or he can then move into the icebreaker or warm-up activities. Using Icebreakers and Energizers describes these in more detail.

### Dealing With Challenging Participants

Type of participant:	Why are they challenging?	Ways to work effectively with this type of participant:
<b>Know-it-alls</b>	May actually have a lot of information about the topic but still could benefit from the experiences and perspectives of others.	Acknowledge that they are a wealth of information.  Approach them during a break and ask for their assistance in answering a specific question.  At the same time, express your concern that you want to encourage everyone to participate and enlist his or her help in doing so.
<b>“I’m only here because I have to be.”</b>	May have been required to attend the workshop, yet has no particular personal interest in the topic.	Acknowledge that you know that some of the participants are present because they have to be.  Ask for their assistance in making this a meaningful experience.  Specifically ask, “How can I make this workshop helpful to you?”

<b>Type of participant:</b>	<b>Why are they challenging?</b>	<b>Ways to work effectively with this type of participant:</b>
<b>Questioners</b>	<p>May be genuinely curious.</p> <p>May be testing you by putting you on the spot.</p> <p>May have an opinion but not confident enough to express it.</p>	<p>Acknowledge that they seem to have a lot of questions about a particular topic.</p> <p>If the questions seem like legitimate attempts to gain content information that other members of the group already know, tell them that you will be happy to work with them later to fill in the gaps or put the question on the parking lot.</p> <p>Reframe or refocus. Send the questions back to the questioner.</p> <p>Establish a buddy system and ask for volunteers who would be willing to meet with them.</p>
<b>Talkers</b>	<p>May be eager or a show-off.</p> <p>May be exceptionally well-informed and anxious to show it, or just naturally wordy.</p> <p>May need to be heard because they are still working through difficult emotional issues.</p> <p>May take time away from other participants.</p>	<p>Don't be embarrassing or sarcastic. You may need their help later. Slow them down with some difficult questions or difficult tasks (such as group leader).</p> <p>Interrupt tactfully with something like: "That's an interesting point. Now let's see what the rest of the group thinks of it."</p> <p>In general, let the group take care of them as much as possible.</p> <ul style="list-style-type: none"> <li>• Avoid eye contact.</li> <li>• Give them a role.</li> <li>• State that your role is to keep people on time.</li> <li>• Quick interruptions - move to them and put your hand on his or her shoulder.</li> <li>• Paraphrase what they say and move on.</li> <li>• Acknowledge that their stories are important and you and others would love to hear them later or after the workshop.</li> </ul>

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<b>Type of participant:</b>	<b>Why are they challenging?</b>	<b>Ways to work effectively with this type of participant:</b>
<b>Arguers</b>	<p>Have combative personalities.</p> <p>May not want to be at the workshop.</p> <p>May be upset by personal/family health issues.</p> <p>May upset other participants.</p>	<p>Keep your own temper firmly in check. Don't let the group get excited either.</p> <p>Honestly try to find merit in one of their points, or get the group to do it, then move on to something else. Say something like, "That was a good point" or "We've heard a lot from (person's name), who else has some ideas?"</p> <p>If facts are misstated, ask the group for their thoughts. Let them turn it down.</p> <p>As a last resort, talk with them in private, find out what's going on, and ask for cooperation. For example, say, "Let's talk at break/end of session. How can we be on the same team?"</p> <p>Give them a role.</p>

# Appendix D

## D

### Trainer Skills Checklist

Think about your own skills as a trainer then read through the following statements. Determine whether the statements you feel describe your strengths or if they describe areas where you'd like to improve. Think about one or two things you could do to build on your strengths to address areas that need improvement.

- You know your subject matter. You have studied your topic and have experienced the events you speak about.
- You know your audience. You respect and listen to the participants. You call them by name, if possible.
- You are neutral and non-judgmental. You validate everyone's experiences and their right to individual perspectives. You respect differences of opinion and lifestyle.
- You are culturally sensitive. You are aware that your own views and beliefs are shaped by your cultural background just as your participants' cultures shape their perspectives.
- You are self-aware. You recognize your own biases and hot-buttons and act in a professional manner when your hot-buttons are pushed.
- You are inclusive. You encourage all participants to share their experiences and contribute to the group learning process.
- You are lively, enthusiastic and original. You use humor, contrasts, metaphors and suspense. You keep your listeners interested and challenge their thinking.
- You use a variety of vocal qualities. You vary your pitch, speaking rate and volume. You avoid monotones.
- You use your body well. Your body posture, gestures and facial expressions are natural and meaningful, reinforcing your subject matter.
- You make your remarks clear and easy to remember. You present one idea at a time and show relationships between ideas. You summarize when necessary.
- You enhance with illustrations. You use examples, charts, visuals and audio aids to illustrate your subject matter.
- You understand group dynamics and the stages all groups go through. You are comfortable with conflict resolution.
- You are flexible. You read and interpret your participants' responses, both verbal and nonverbal, and adapt your plans to meet their needs. You are in charge without

# D

being overly controlling.

- You are open to new ideas and perspectives. You are aware that you don't know all the answers. You recognize that you can learn from participants as well as offer them new knowledge or perspectives.
- You are compassionate. You understand that much of the material may have an emotional impact on the participants. You are empathetic and understanding about participants' emotional reactions.
- You are interested in evaluating your work. You encourage co-trainers and participants to give feedback.



# E

<b>Objectives:</b> At the end of the workshop, participants should be able to:	<b>Content:</b>	<b>Strategies to delivery:</b>	<b>Allotted time:</b>

# Appendix F

## Icebreakers, Energizers & Closing Activities

Included are a variety of icebreakers, energizers and closing activities to use during your training. Feel free to adapt them to better meet your needs or create your own.

### Icebreakers

#### Paired Interviews

**Time:** Allow one to two minutes per participant.

**Materials:** Scrap paper and pens for participants to jot down notes.

- Pass out postcards or playing cards that are cut in half.
- Instruct participants to find the person who has the other half of their card. This gets people up and moving around.
- When all pairs have matched up, ask them to take turns interviewing each other. Each person will have four minutes to learn the following things about his or her partner:
  - Name.
  - How they spend their day (e.g., job or other responsibility like care taking for a sick spouse).
  - Their interest in or connection to the training topic.
  - One hope for the training.
  - One interesting thing about them.
- Tell participants that they will be introducing their partner to the entire group when it reconvenes, so they may want to take notes.
- After four minutes, give participants a signal to change partners.
- At the end of eight minutes, or after each person has had a chance to be an interviewer and be interviewed, call the large group back together.

#### Go-Rounds

**Time:** Allow one minute per person.

**Materials:** None

- State the purpose of the exercise and ask each person to say his or her name followed by the answer to one of the following questions:
  - What is one thing you'd do if you were given \$100,000 with no strings attached?
  - What is one thing you'd like to change about the world?
  - Describe a strong feeling you've had in the past week and a reason for that feeling.
  - What is one thing you'd like to get from the training?
- Post the questions on a flip chart paper or overhead so that participants can focus on the discussion and not on remembering the question.

## **Finish This Sentence**

Time: Allow one to two minutes per participant.

Materials: None

- Go around the room and have each person say his or her name and complete one of the following sentences:
  - I am in this class because...
  - The best job I ever had was...
  - The riskiest thing I ever did was...

## **Truth or Lie**

Time: Allow two to three minutes per participant.

Materials: Index cards and pens

- Pass out index cards.
- Tell participants to write three statements about themselves. One must be true and the other two must be untrue. The more outrageous all three statements are, the better. Encourage participants to think of odd information about themselves that no one would be able to know if it were true or false.
- Have either the participant or a group leader read the card.
- After all three statements have been read, have the group vote on which statement they believe to be true.
- Have the participant read the truthful statement.

## **Famous People/Cities**

Time: Allow one to two minutes per participant.

Materials: Index cards and pens

- As participants arrive, tape an index card on their back with the name of a famous person or city.
- Ask participants to circulate the room and ask questions that can only be answered

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with a Yes or No to identify clues that will help them find out the name on their back.

## **Favorite Animal**

Time: 10 to 15 minutes

Materials: Nametags and a marker

- As participants arrive, ask participants to tell you their favorite animal and three adjectives to describe the animal.
- Write the three adjectives on a nametag before their name and omit the name of the animal.
- Ask participants to mingle with the crowd, sharing why these adjectives best describe their own personality.

## **Energizers**

### **Beach Ball Toss**

Time: 5 to 10 minutes

Materials: Beach ball, Nerf ball or Koosh ball

- Instruct participants to form a circle.
- Explain that you will throw the ball to someone within the circle. When that person catches the ball, he or she should mention a key message or concept heard during a previous session.
- Once he or she has made a statement, he or she should toss the ball to another person within the circle.
- Ask participants not to toss the ball to the person on their immediate left or right.
- Suggest that participants should step out of the circle once they have participated.
- Continue tossing the ball until all participants have had an opportunity to participate.

*Note: If this is the first session for the training program, you can ask the person to tell you what he or she expects to learn.*

### **That's Me**

Purpose: To get participants moving, standing up and down. It also allows participants to become acquainted with one another.

Time: 5 to 10 minutes

Materials: None

- Explain that:
  - You will ask a question, such as, *Who has grandchildren?*
  - If the characteristic fits participants will stand up, raise both arms outstretched over their head and shout, *That's Me!*

- Ask the group to practice standing up and shouting, *That's Me!* when you count to three.
- Ask the group as many of the following questions, or questions of your choice, as time allows. Mix in questions that are more personal with those that pertain to the topic of the training.
  - *Who lives in (State)?*
  - *Who traveled more than four hours to get here?*
  - *Who has grandchildren?*
  - *Who exercised this morning?*
  - *Who took a vacation last summer?*
  - *Who ate at least one serving of fruit this morning?*
  - *Who had a clinical breast exam within the last year?*
  - *Who watched at least one movie or videotape in the last month?*
  - *Who plans to shop while in (this city)?*
  - *Who knows someone who has a new baby?*
  - *Who has a pet?*
  - *Who has read a non-fiction book during the last three months?*
  - *Who is eager to learn more about (the topic)?*

## Traditions

Time: 10 to 15 minutes

Materials: None

- Have participants introduce themselves by ethnicity and ask them to talk about their ethnic heritage or their ancestors, like family stories about coming to the United States or traditions.
- Use this opportunity to discuss what traditions might be barriers to placing infants on their backs to sleep and other safe sleep practices.

## Closing Activities

### Calm Down

Time: 15 to 20 minutes

Materials: None

- Have participants get into a comfortable position and ask them to reflect on what they just learned.
- After about five minutes, say a key word or short phrase and have participants reflect for a few minutes.
- Repeat one or two more times.

Gather the group into a circle and have them share what they believe is the most important point of the workshop and how they can best use it at their place of work.

## Feedback Cards Exercise

Time: 5 to 10 minutes

Materials: Two colors of index cards

- Pass around two stacks of index cards. Each stack should be a different color. It is best to use colors that are easily distinguishable from each other.
- Ask each participant to take one card of each color.
- Ask participants to write one thing they really liked or appreciated about this training (or this day of training) on one color card and one thing they wished had been different on the other color card.
- When all participants have completed the cards, ask them to pass both cards to the front.
- Thank participants for their input and assure participants that the trainers will carefully consider their feedback.

## Head, Heart and Feet Exercise

Time: 15 minutes

Materials: Evaluation sheet for each participant, flip chart, markers and tape

- Hand out the evaluation sheet that follows. Explain its objective and how the information will be used.
- Invite participants to use the markers to draw their head, heart and feet on the paper. Ask participants to fill in the form individually or with someone else.
- If there is time, ask them to share something they learned or to give final comments.

**Variation:** Draw a large head, heart and feet on flip chart paper and post it. Distribute small slips of paper and ask participants to write down the major things they learned or got out of the event. Post these points in the appropriate position on the flip chart and discuss them.



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