Preventing Child Deaths in Missouri

MISSOURI DEPARTMENT OF SOCIAL SERVICES
STAT
STATE TECHNICAL ASSISTANCE TEAM

The Missouri Child Fatality Review Program

Annual Report for 2006

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State of Missouri

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Children's Trust Fund

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Dedication

This report reflects the work of many dedicated professionals throughout the state of Missouri. Through better understanding of how and why children die, we strive to improve and protect the lives of Missouri's youngest citizens. We will always remember that each number represents a precious life lost. We dedicate this report to these children and their families.

Missouri Child Fatality Review Program

Child Fatality Review In Missouri

Death rates for infants, children, and teens are widely recognized as valuable measures of child wellbeing, particularly when viewed within the context of a decade of demographic changes in our state. However, it is the accuracy of key factors associated with child deaths that provides the basis for identifying vulnerable children, and responds in ways that will protect and improve their lives. In 1995, the U.S. Advisory Board on Child Abuse and Neglect concluded that child abuse and neglect fatalities, and other serious and fatal injuries to children could not be significantly reduced or prevented without more complete information about why these deaths occur and how such tragedies might be avoided. It was widely acknowledged that many child abuse and neglect deaths were under-reported and/or misclassified. Scholars, professionals, and officials around the nation had agreed that a system of comprehensive Child Death Review Teams could make a major difference. In 1991, Missouri had initiated the most comprehensive child fatality review system in the nation, designed to produce an accurate picture of each child death, as well as a database providing ongoing surveillance of all childhood fatalities. The Missouri Child Fatality Review Program (CFRP) was presented in the Advisory Board's report as a state of the art model. While the program has evolved and adapted to meet new challenges, the objectives have remained the same-identifying potentially fatal risks to infants and children, and responding with multi-level prevention strategies.

In Missouri, all fatality data is collected by means of standardized forms and entered into a database. What is learned can be used immediately by the community where the death occurred. The sum of statewide data is used to identify trends and patterns requiring systemic solutions. The Missouri Child Fatality Review Program has succeeded in remaining effective, relevant and sustainable over ten years. The success of the program is due in large part to the support of panel members, administrators and other professionals who do this difficult work voluntarily, because they understand its importance. This work is a true expression of advocacy for children and families in our state.

Missouri legislation requires that every county in our state (including the City of St. Louis) establish a multidisciplinary panel to examine the deaths of all children under the age of 18. If the death meets specific criteria, or if requested by the coroner/medical examiner, it is referred to the county's multidisciplinary CFRP panel. The minimum core panel for each county includes: Coroner/Medical Examiner, Law Enforcement, Juvenile/Family Court, Emergency Medical Services, Prosecutor, Public Health and Children's Division. Optional members may be added at the discretion of the panel. The panels do **not** act as investigative bodies. Their purpose is to enhance the knowledge base of the mandated investigators and to evaluate the potential service and prevention interventions for the family and community.

Of all child deaths in Missouri, about 1100-1200 deaths annually, approximately one-third merit review. To come under review, the cause of the child's death must be unclear, unexplained, or of a suspicious circumstance. All sudden, unexplained deaths of infants one week to one year of age, are required to be reviewed by the CFRP panel. (This is the only age group for which an autopsy is mandatory.)

State Technical Assistance Team and Child Fatality Review Program

Missouri State Statutes

- Section 210.150 and 210.152 (Confidentiality and Reporting of Child Fatalities)
- Section 210.192 and 210.194 (Child Fatality Review Panels)
- Section 210.195 (State Technical Assistance Team - duties)
- Section 210.196 (Child Death Pathologists)
- Section 211.321; 219.061 (Accessibility of juvenile records for child fatality review)
- Section 194.117 (Sudden Infant Death; infant autopsies)
- Section 58.452 and 58.722 (Coroner/Medical Examiners responsibilities regarding child fatality review)

Confidentiality Issues (RSMo 210.192 to 210.196)

A proper Child Fatality Review Program (CFRP) review of a child death requires a thorough examination of all relevant data, including historical information concerning the deceased child and his/her family. Much of this information is protected from disclosure by law, especially medical and child abuse/neglect information. Therefore, CFRP panel meetings are always closed to the public and cannot be lawfully conducted unless the public is excluded. Each CFRP panel member should confine his or her public statements only to the fact that the panel met and that each panel member was charged to implement their own statutory mandates.

In no case, should any other information about the case or CFRP panel discussions be disclosed. All CFRP panel members who are asked to make a public statement should refer such inquiries to the panel spokesperson. Failure to observe this procedure may violate Children's Division regulations, as well as state and federal confidentiality statutes that contain penalties.

Individual disciplines (coroner/medical examiners, sheriff departments, prosecuting attorneys, etc.) can still make public statements consistent with their individual agency's participation in the investigation, as long as they do not refer to the specific details discussed at the CFRP panel meeting.

No CFRP panel member is prohibited from making public statements about the general purpose, nature or effects of the CFRP process. Panel members should also be aware that the legislation which established the CFRP panels provides official immunity to all panel participants.

When a Child Dies

The loss of a loved one...particularly a child...is perhaps the greatest loss an individual or family can experience. Many overwhelming feelings follow the death of a child. This grief and sadness is a natural and normal reaction to an irreplaceable loss.

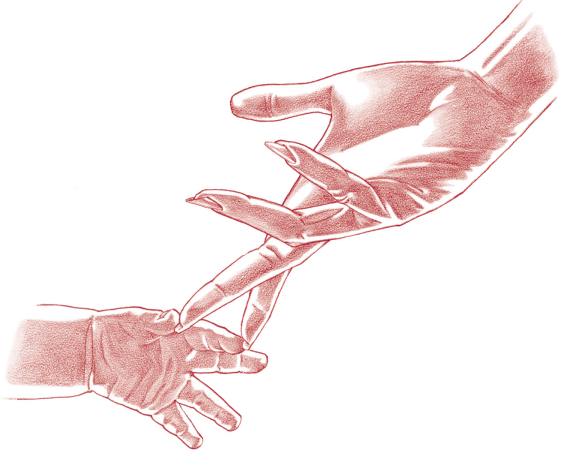
To better understand why and how our children die, the State of Missouri has implemented the Child Fatality Review Program. By reviewing child fatalities, we hope to identify causes and strategies that will ultimately lead to a reduction, in certain cases, of child fatalities. Missouri state law (RSMo 210.192) now requires that any child, birth through age 17, who dies from any cause, be reported to the coroner/medical examiner. The coroner/medical examiner is mandated to follow specific procedures concerning these fatalities. These include:

- All **sudden, unexplained** deaths of infants, from one week to one year, are required to be autopsied by a certified child-death pathologist. The most common questions for parents, "Why did our baby die?" can really only be answered by having an autopsy performed. During an autopsy, the internal organs are examined. This is done in a professional manner, so that the dignity of the child is maintained. The procedure will not prevent having an open casket at the funeral. Preliminary results may be available in a few days; however, the final report may take several weeks.

- In all other child deaths, the coroner/medical examiner may consult with a certified child-death pathologist regarding the circumstances of death. In some cases, an autopsy will be ordered.

- If the fatality meets certain criteria, the circumstances surrounding the death will be reviewed by the county Child Fatality Review Program panel. Facts regarding the death are discussed by the professionals who serve on the panel. The represented agencies on the panel have the responsibility to contribute information that will lead to a more accurate determination of the cause of death; they also try to identify ways to prevent further deaths from occurring. **All information is kept confidential.**

The Child Fatality Review Program is a true expression of child advocacy. Like you, we want to know why the death occurred. We will do everything we can to explain and help you understand why.



Missouri Incident Fatalities

"A simple child,
That lightly draws its breath,
And feels its life in every limb,
What should it know of death?"
-William Wordsworth

In reviewing this report, the reader should be aware of some important definitions and details about how child deaths are reported and certified in Missouri, summarized here: (Please refer to Appendix 6, Definitions of Important Terms and Variables, for additional information.)

- **"Missouri Child Fatalities"** refers to all children age 17 and under, who died in Missouri, without regard to the state of residence or the state in which the illness, injury or event occurred. (For example, a child who is a resident of Kentucky, injured in a motor vehicle crash in Illinois and brought to a Missouri hospital, where he or she subsequently dies, would be counted as a "Missouri Child Fatality." This death would be reported to the Child Fatality Review Program on a Data Form 1, Section A only, as an out-of-state event and reported to Illinois.)

- **"Missouri Incident Fatality"** refers to a *fatal illness, injury or event,* which occurs *within the state of Missouri*. (This is not necessarily the county or state in which the child resided.) If the death meets the criteria for panel review, it is reviewed in the county in which the *fatal injury, illness or event* occurred.

- *Every* Missouri incident child fatality is required to be reviewed by the coroner or medical examiner and the chairperson for the county CFRP panel. The findings of the review are reported on the Data Form 1.

- Any child death that is *unclear, unexplained, or of a suspicious circumstance, and all sudden unexplained deaths of infants one week to one year of age* are required to be reviewed by a county-based CFRP panel. Panel findings are reported on the Data Form 2. Panel members receive annual training on the investigation of child fatalities.

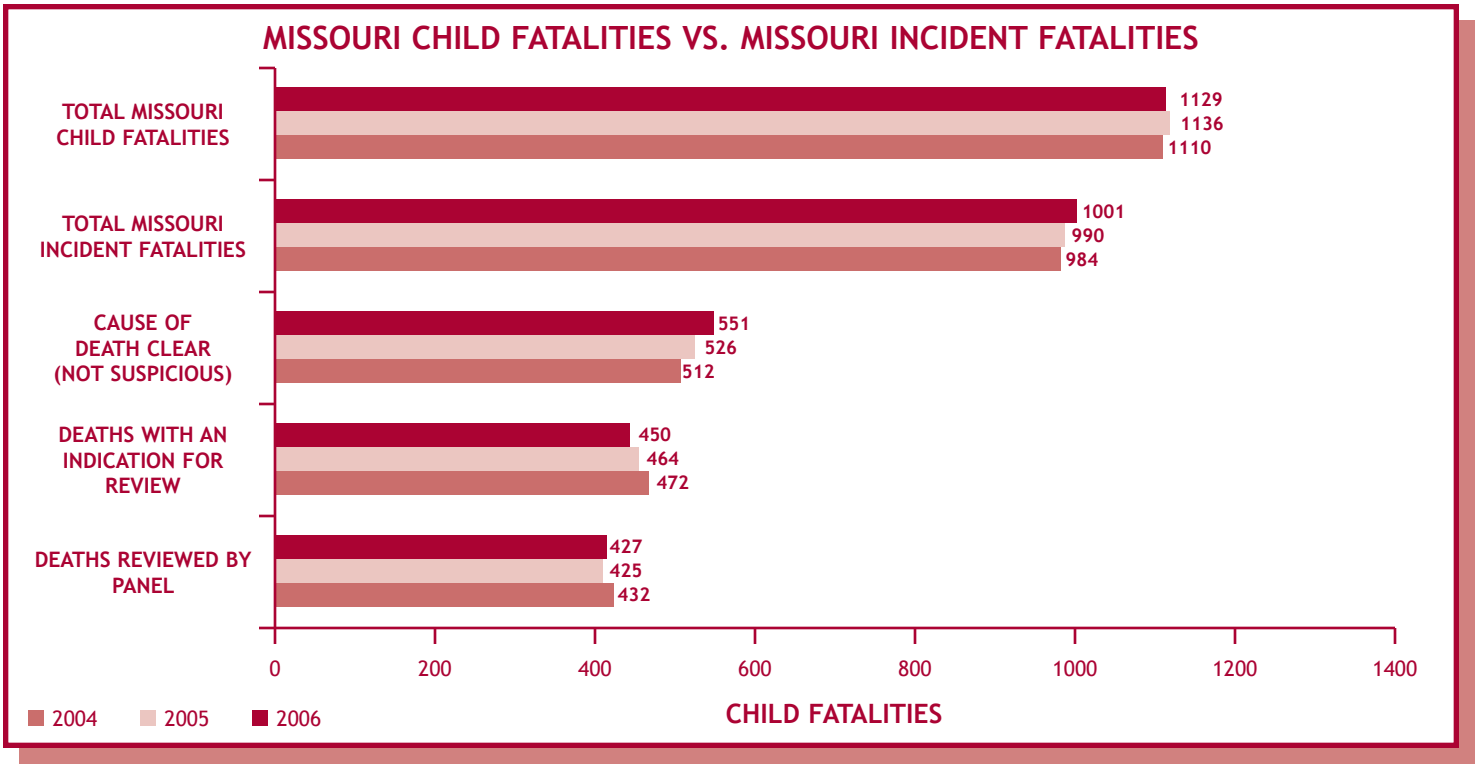
- **Multiple-Cause Deaths:** *Cause of death* is a disease, abnormality, injury or poisoning that contributed directly or indirectly to death. However, a death often results from the combined effect of two or more conditions. Because the Child Fatality Review Program is focused on the prevention of child fatalities, the precipitating events are of particular concern. Therefore, deaths are categorized according to the *circumstances of death,* which may not be the immediate cause of death listed on the death certificate. (An example would be a child passenger in a car that runs off the road and lands in a ditch full of water; the "immediate cause of death" is listed on the death certificate as "drowning," but the precipitating event was a motor vehicle accident. This death would be reported in the Motor Vehicle Fatalities section, with a footnote indicating that the death certificate lists "drowning" as the immediate cause of death.)

- The Child Fatality Review Program data management unit links data collected on the Data Forms 1 and 2 with the Department of Health and Senior Services birth and death data. Every attempt is made to reconcile the two systems; however, in some cases, crucial data components are incomplete and are noted, as appropriate.

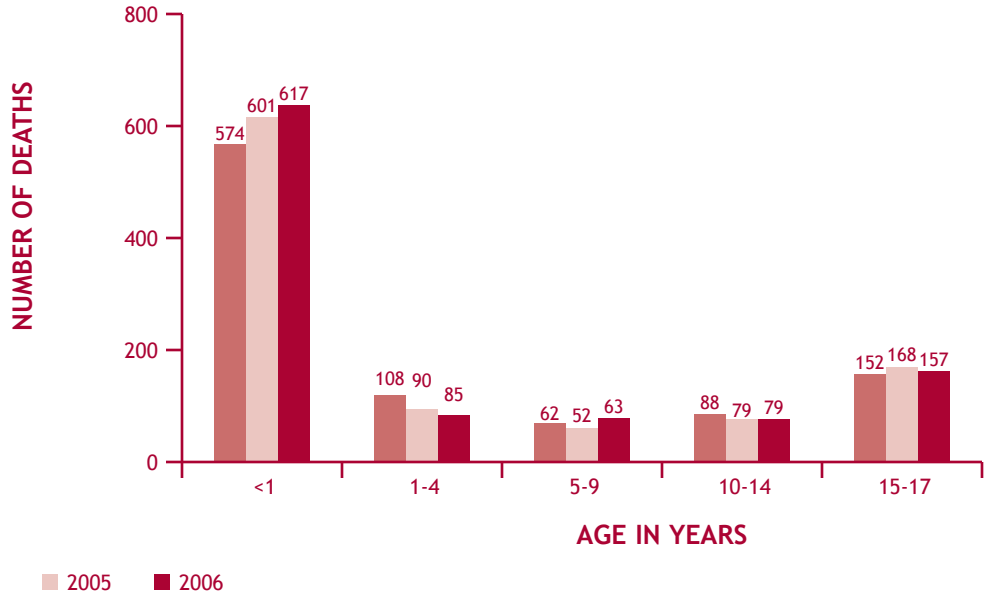
- All deaths included in this CFRP Annual Report occurred in calendar year 2006. Some of the cases reviewed may not have been brought before a county panel until the year 2006.
- In some cases, panels did not complete all of the information requested on the data form.
- Of the **450** Missouri Incident Fatalities reported on Data Form 1 in 2006, with indication for review, **23** did not receive required CFRP panel review, or panel findings were not submitted on Data Form 2. These **23** fatalities are included in this 2006 CFRP Annual Report because the data, though incomplete, is useful and accurate within the limitations on the Data Form 1 information.
- In 2006, **70** Missouri Incident Fatalities were not reported on either a Data Form 1 or Data Form 2, but were reported to CFRP by death certificates from the Department of Health and Senior Services. From information provided by the death certificates, **34** of those **70** fatalities (49%) had at least one indication for review; among those, **26** motor vehicle fatalities, **two** drownings, **two** suffocations, **one** child abuse, **one** firearm, and **one** illness/natural cause and **one** SIDS. These fatalities are not included in the data for this annual report.

Summary of Findings
Missouri Incident Fatalities, 2006

In 2006, **1129** children age 17 and under died in Missouri. Of those deaths, **1001** were determined to be "Missouri incident fatalities" and, therefore, subject to review by the coroner or medical examiner and county CFRP chairperson. Of the 1001 deaths, **450** had indications for review by a county CFRP panel, and of those **427** were reviewed and a Data Form 2 completed.



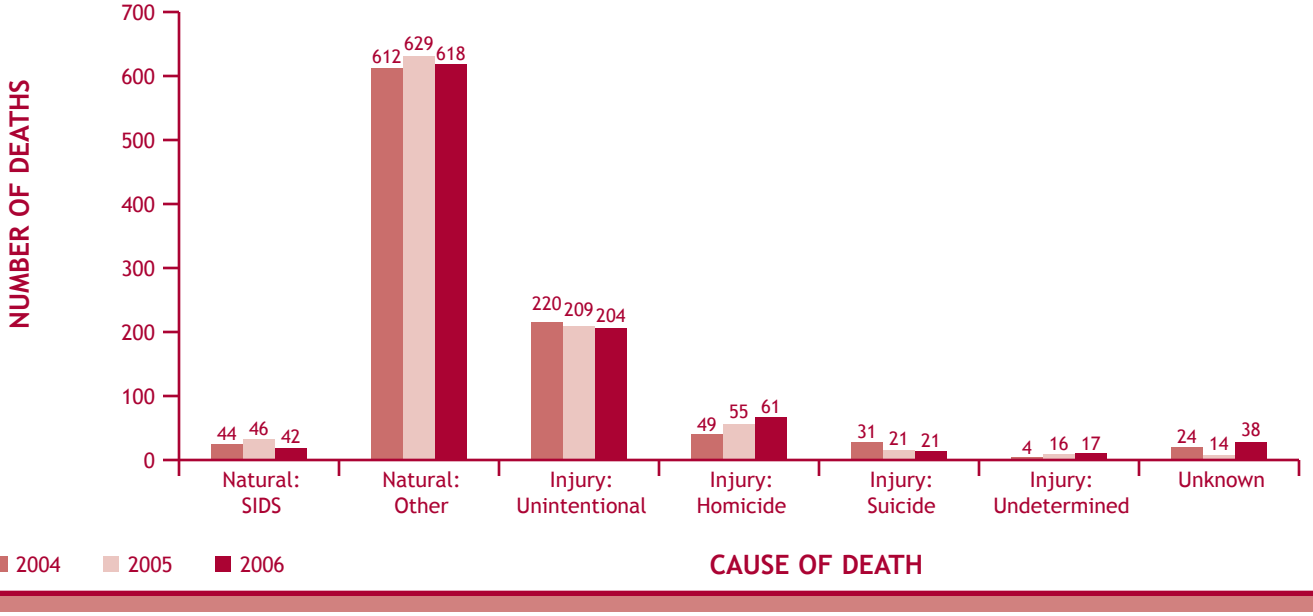
MISSOURI INCIDENT FATALITIES BY AGE



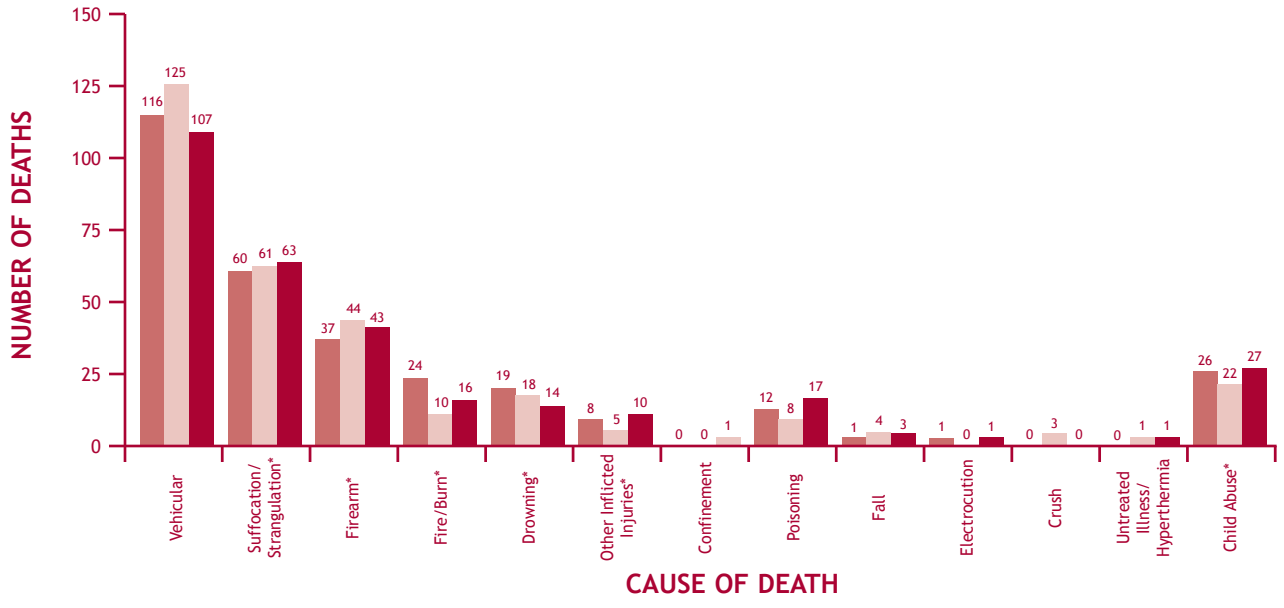
MISSOURI INCIDENT FATALITIES BY SEX AND RACE

SEX	2004	2005	2006	RACE	2004	2005	2006
FEMALE	422	590	419	WHITE	705	699	666
MALE	562	400	582	BLACK	257	275	310
UNKNOWN	0	0	0	OTHER	22	16	25
	984	990	1001		984	990	1001

MISSOURI INCIDENT FATALITIES BY MANNER



LEADING CAUSE OF INJURY DEATHS



*NOTE: All Shaken Deaths fall under the category of Child Abuse this category can also include deaths from the causes of Suffocation/Strangulation, Firearm, Fire/Burn, Drowning, Other Inflicted Injuries, and Other Cause

Illness/Natural Cause Deaths

All Illness/Natural Cause Deaths Other Than SIDS

"The infant mortality rate has declined steadily during the last decade, due in part, to improved medical technology and public health outreach...Infants are more likely to die before their first birthday if they live in unsafe homes and neighborhoods or have inadequate nutrition, health care or supervision."

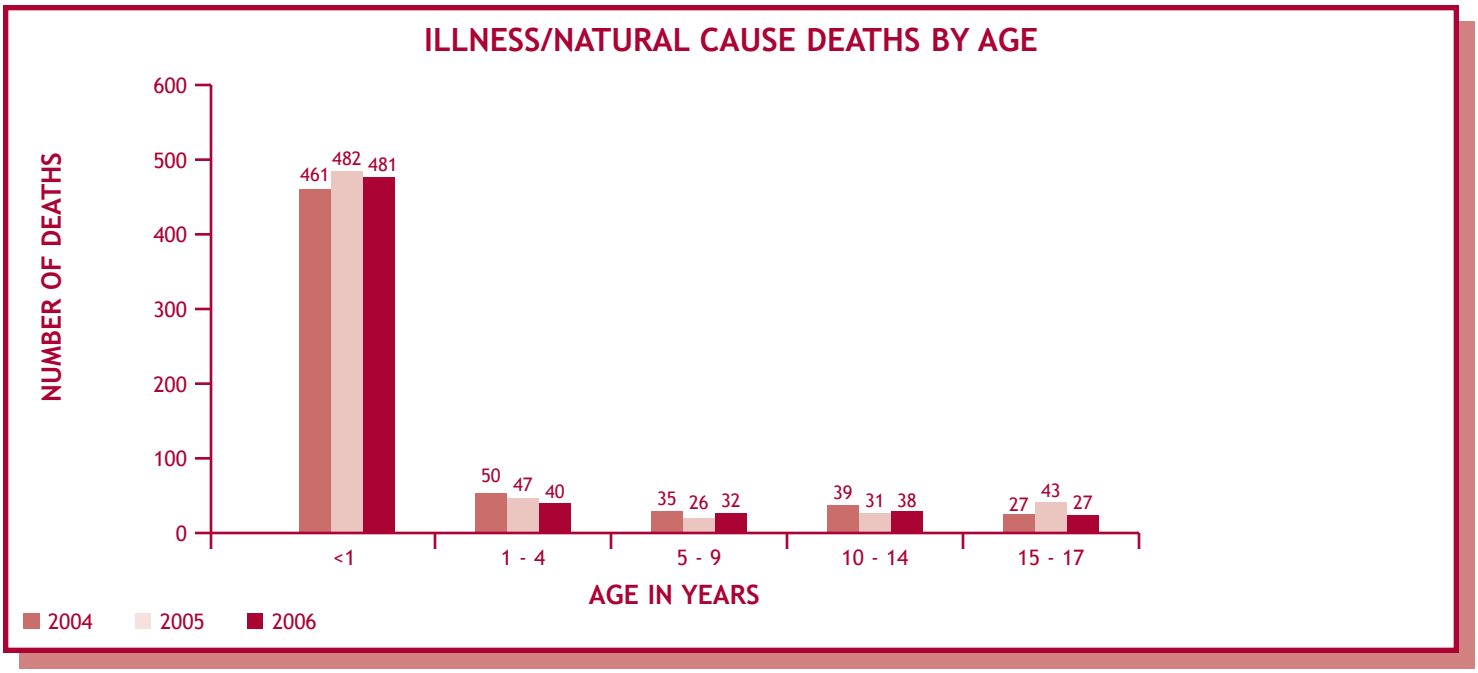
-Kids Count Missouri, Citizens for Missouri's Children and Children's Trust Fund

Illness/natural causes, other than SIDS, were responsible for the death of 618 Missouri children in 2006, representing 62% of all Missouri incident child fatalities.

Most child deaths are related to illness or other natural cause. Illness/natural cause deaths include prematurity, congenital anomalies, infection and other conditions. The vast majority of natural cause deaths occur before the first year of life and are often related to prematurity or birth defects.

ILLNESS/NATURAL CAUSE DEATHS BY SEX AND RACE

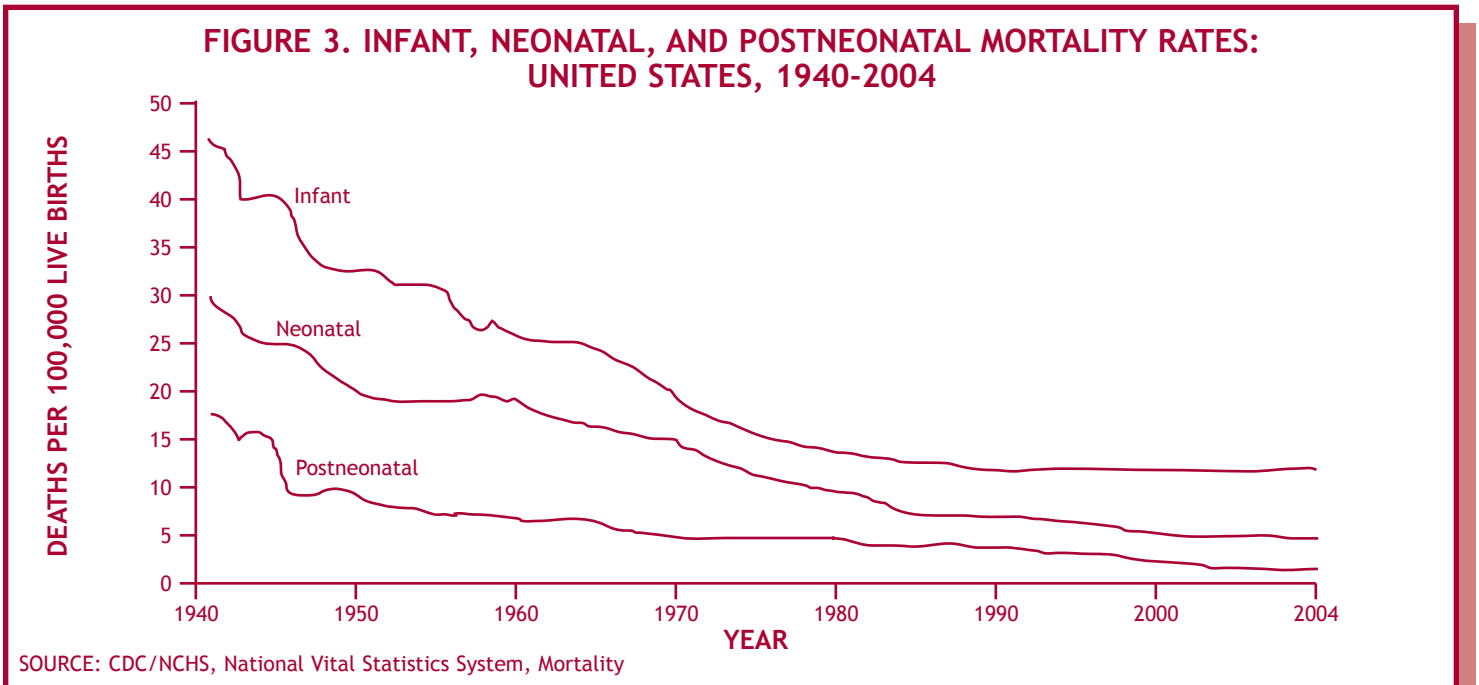
SEX	2004	2005	2006	RACE	2004	2005	2006
FEMALE	268	267	281	WHITE	424	436	406
MALE	344	362	337	BLACK	174	182	190
UNKNOWN	0	0	0	OTHER	14	11	22
	612	629	618		612	629	618



Leading illness/natural cause deaths among children over the age of one include cancer, congenital anomalies, and cardiac conditions.

Infant Mortality

One of the most important health trends in the United States in recent decades, has been the reduction of high infant mortality rates. Between 1950 and 1996, the U.S. infant mortality rate was reduced by 75%. In the United States, the leading causes of infant mortality include congenital malformations, deformations and chromosomal abnormalities (congenital anomalies) and disorders related to short gestation and low birth weight, not elsewhere classified (low birth weight). Also among the leading causes of infant death are Sudden Infant Death Syndrome (SIDS), newborn affected by maternal complications, newborn affected by cord and placental complications, and unintentional injuries.



Infant mortality in the United States declined more than 45% between 1980 and 2000. However, the gap between black and white infant death rates has widened. Blacks continue to have a 2- to 3-fold greater risk than whites of giving birth to low-birth-weight (<2500 grams) and very low-birth-weight (<1500 grams) infants. *(CDC)*

In Missouri, in 2006, the infant morality rate increased slightly, from 7.5 to 7.7 per 1,000 live births. The increase in infant mortality primarily reflects an increase in very low birth weight babies weighing less than 1.1 pounds. Approximately 90% of these very small babies die, so even a relatively small increase or decrease has a major impact on infant mortality. *(Missouri Department of Health and Senior Services)*

In Missouri, in 2006, prematurity was the cause of **271** infant deaths, representing 44% of all illness/natural cause deaths, other than SIDS. Of those, **175** (65%) were born at 25 weeks or less gestation and **27** (15%) of those were born at less than 20 weeks gestation. In 2006, congenital anomalies were the cause of **150** infant deaths, representing 24% of all illness/natural causes, other than SIDS.

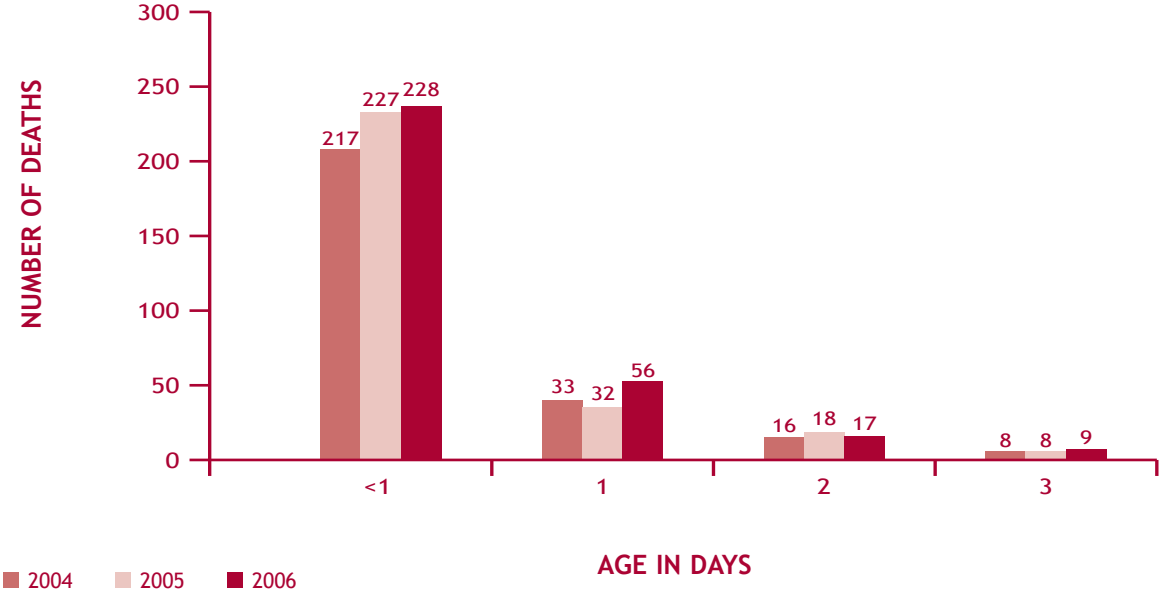
Infants less than one year of age comprised the majority (78%) of the illness/natural cause deaths in 2006, with **481**.

ILLNESS/NATURAL CAUSE DEATHS AMONG INFANTS <1 BY SEX AND RACE

SEX	2004	2005	2006	RACE	2004	2005	2006
FEMALE	197	208	217	WHITE	313	325	306
MALE	264	274	264	BLACK	136	148	159
OTHER	0	0	0	OTHER	12	9	16
	461	482	481		461	482	481

Of the 481 infant deaths <1 due to illness/natural cause, **310** (64%) occurred within the first three days of life and **228** (47%) occurred within 24 hours of birth.

CHILDREN AGE THREE DAYS OR LESS THAT DIED OF ILLNESS/NATURAL CAUSES



Natural Cause Deaths in Infants Less Than One Year as Reported on CFRP Data Forms

AGE AT DEATH	
0 - 24 hours after birth	264
24 - 28 hours	27
48 hours - 6 weeks	112
6 weeks - 6 months	54
6 months - 1 year	24
Not Answered	0

GESTATIONAL AGE AT BIRTH	
<20 weeks	30
20 - 25 weeks	179
26 - 30 weeks	45
31 - 37 weeks	72
>37 weeks	43
Unknown	60
Not Answered	52

BIRTH WEIGHT IN GRAMS	
<750 grams (<1lb 10oz)	159
750 - 1,499 grams (1lb 10oz - 3lbs 5oz)	60
1,500 grams - 2,499 grams (3lbs 5oz - 5lbs 5oz)	42
>2,500 grams (>5lbs 5oz)	43
Unknown	89
Not Answered	88

MULTIPLE BIRTHS	
Yes	71
No	331
Not Answered	79

The data on the following charts were collected only from those illness/natural deaths where the county panels completed a Data Form 2.

MEDICAL COMPLICATIONS DURING PREGNANCY	
Yes	3
No	5
Unknown	27
Not Answered	5

SMOKING DURING PREGNANCY	
Yes	2
No	3
Unknown	32
Not Answered	3

DRUG USE DURING PREGNANCY	
Yes	3
No	6
Unknown	28
Not Answered	3

ALCOHOL USE DURING PREGNANCY	
Yes	0
No	5
Unknown	32
Not Answered	3

"Infant morality is the most sensitive index we possess in social welfare."
-Julia Lathrop, Children's Bureau, 1913

Fetal and Infant Mortality Review (FIMR) in Missouri

The death of a child, especially the youngest, most vulnerable infant, is viewed as a sentinel event that is a measure of a community's overall social and economic well being as well as its health. During the last decade, two methods for examining these sentinel deaths at the local level have emerged: child fatality review (CFR) and fetal and infant mortality review (FIMR).

The rate of death among infants in Missouri has shown a steady decline during the last decade. In most communities, infant deaths due to natural causes such as prematurity, congenital anomalies, SIDS, infection, and other disease processes have traditionally been viewed as medically complicated and not preventable. Indeed, they are medically complicated, but research and experience have demonstrated that improvements in resources and systems that serve the needs of infants, mothers and families can produce significant improvements in outcomes. The emergence of FIMR in our state has the potential to bring about significant improvements in maternal and infant outcomes and further reduce infant deaths.

Fetal mortality is defined as the death of a fetus in utero at 20 weeks or more gestation. It is viewed as an important indicator of overall perinatal health. The health of the mother plays a significant role in maintaining a healthy pregnancy. Conversely, maternal medical complications of pregnancy are adversely associated with fetal deaths.

Infant mortality is defined as the death of a child before one year of age. The infant mortality rate is associated with a variety of social and economic factors, as well as medical/health conditions. Nationally, two-thirds of these deaths occur during the first 28 days of life, the neonatal period.

The FIMR process in our state conforms to the principles and guidelines set by the National Fetal and Infant Mortality Review Program, which is a collaborative effort between the American College of Obstetricians and Gynecologists and the Maternal and Child Health Bureau, Health Resources and Services Administration. The overall goal of Fetal and Infant Mortality Review (FIMR) is to enhance the health and well being of women, infants and families by improving the community resources and service delivery systems available to them.

Many sources provide information for FIMR reviews. A maternal interview is sought from the family. Medical records, including hospital and physician records, as well as any existing medical examiner records are abstracted. All identifying information; i.e., families, providers, and institutions, is removed. A summary of the case is prepared and presented to the case review team. Members of the FIMR case review team represent a broad range of professional organizations and public and private agencies (health, welfare, education and advocacy) that provide services and resources for women, infants and families. The reviews produce findings and recommendations that, typically, are presented to a community action team, comprised of other members of the community with the political will and fiscal resources to create large-scale system changes.

One of the first FIMR programs in Missouri was established in 2003 by the Infant Mortality Workgroup of the Maternal, Child and Family Health Coalition of Metropolitan St. Louis. "FIMR provides a voice for local families who have suffered the loss of an infant by working to improve the quality and scope of services for women and infants. FIMR provides a community-based, action-oriented, systematic way for diverse community members to come together and examine social, economic, health, educational, environmental and safety factors associated with fetal and infant loss in St. Louis." *(FIMR Annual Report 2006)*

In 2004, the Maternal, Child Health Coalition of Greater Kansas City piloted a Fetal and Infant Mortality Review program in the five zip codes served by the Kansas City Healthy Start project. As in the case of the St. Louis FIMR, these areas were chosen based on a combination of need and community capacity.

The presence of FIMR programs serving the major metropolitan areas in Missouri will bring about a more thorough understanding of the contributing factors of fetal and infant deaths, as well as a larger engagement of community health professionals and institutions to improve maternal and child health throughout our state.

While there are many similarities between CFRP and FIMR, there are distinct and important differences, including basic human concern and advocacy. In Missouri, FIMR and CFRP will be distinct, but complementary, systems, sharing a common mission and some promising opportunities for collaboration. It is anticipated that, when appropriate, the two systems will be able to collaborate in significant ways, such as joint reporting of aggregate findings, sharing recommendations with media and the public and improving systems and resources for children, mothers and families in our state.

For more information, visit:
www.dhss.mo.gov/FIMR
www.stl-mcfhc.org

Sudden Unexpected Infant Deaths

In 2006, there were 133 sudden, unexpected deaths of infants less than one year of age in Missouri.

Representative Cases:

- **Infants should be placed on their backs for every sleep.**

  The father of a 10-week-old infant put her to bed in her crib on her stomach with her face to the side. When the mother checked on the baby early the next morning, she was unresponsive.

  A daycare provider placed a two-week-old infant on his stomach in a playpen. When she checked on the child later, he was facedown into the sheet and unresponsive.

- **The safest place for infants to sleep is in a standard crib with a firm mattress and no soft bedding.**

  An eight-week-old infant was bedsharing with his mother. He was placed on his stomach. When the mother awoke, the baby was facedown into the bedding and he was not breathing.

  An infant was taken to the home of a childcare provider, who put him down for a nap on a full-size adult bed with a soft mattress, comforter and pillows. He was found later unresponsive.

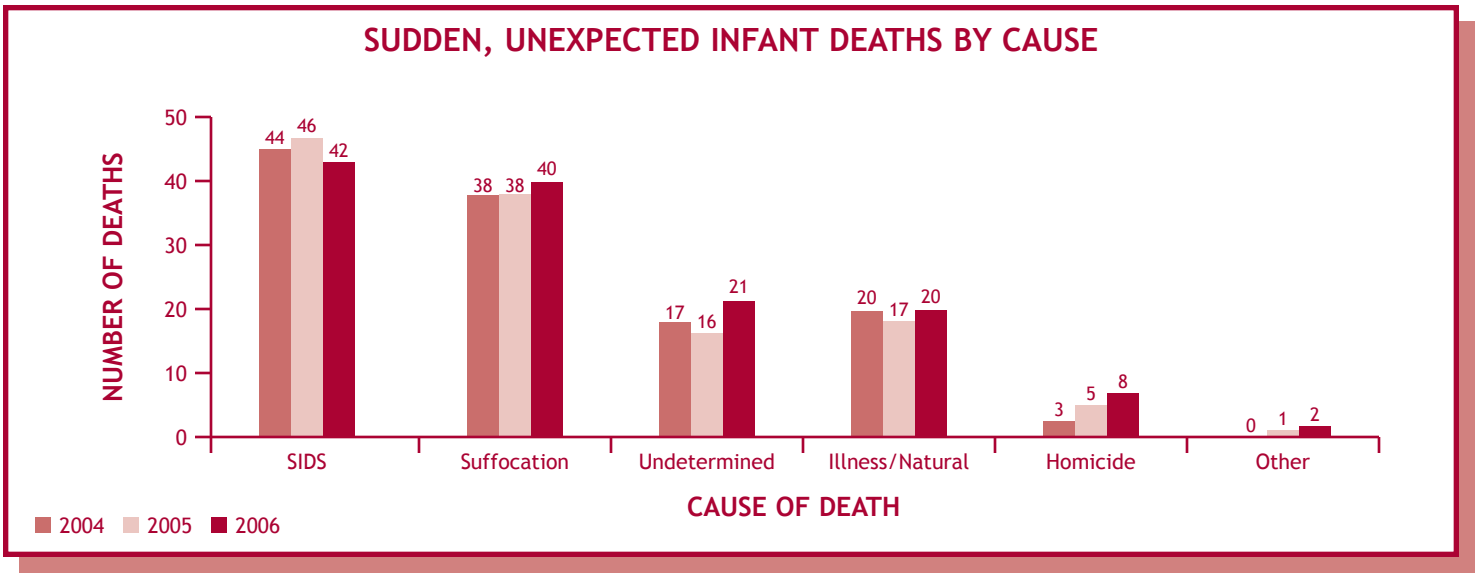
  A five-week-old infant fell asleep on her father's chest on a couch in the living room of their home. The father also fell asleep and awoke later to find the infant with her face wedged between his shoulder and the back of the couch.

  An infant was put to bed in a standard crib on his side. The crib contained a standard pillow, a blanket, bumper pads and a comforter. He was found unresponsive with his face against the pillow.

In 2006, there were **133** sudden, unexpected deaths of infants under the age of one year reported to the Child Fatality Review Program. Based on autopsy, investigation and CFRP panel review, **42** were diagnosed as Sudden Infant Death Syndrome (SIDS), **40** Unintentional Suffocation, **20** Illness/Natural Cause, and **21** could not be determined. **Eight** infants were found to be victims of Homicide and **one** infant's death was determined to be an Accident, resulting from exposure to excessive heat. Those nine deaths are discussed under "Fatal Child Abuse and Neglect." **One** infant was the victim of a poisoning of undetermined manner and is discussed under "Poisoning."

SUDDEN UNEXPECTED INFANT DEATHS BY SEX AND RACE

SEX	2004	2005	2006	RACE	2004	2005	2006
FEMALE	51	52	58	WHITE	87	84	93
MALE	71	71	75	BLACK	32	37	38
UNKNOWN	0	0	0	OTHER	3	2	2
	122	123	133		122	123	133



Investigation of Sudden, Unexpected Infant Deaths

Each year in the United States, more than 4,500 infants die suddenly of no obvious cause and about half of these sudden, unexpected infant deaths are diagnosed as Sudden Infant Death Syndrome (SIDS). Historically, the national Back to Sleep campaign's effort to reduce prone sleeping rates, SIDS rates resulted in a 50% decline in SIDS deaths between 1990 and 1999. However, studies have shown that since 1999, some deaths previously classified as SIDS are now classified as accidental suffocation or undetermined. This finding suggests that changes in reporting of cause of death may account for part of the recent decrease in SIDS rates and that, in fact, the rate of sudden, unexpected infant deaths in the United States has not changed significantly during this time period.

By definition, SIDS can be diagnosed only after a thorough examination of the death scene, a review of the clinical history, and performance of an autopsy fail to find an explanation for the death. Yet, we know that some sudden, unexpected infant deaths are not investigated and, when they are, cause of death data are not collected and reported consistently. The medical community has struggled to define universally acceptable guidelines for evaluation and certification of sudden, unexpected infant deaths. This causes concern because inaccurate investigation and classification of cause and manner of death impedes prevention efforts. Researchers cannot adequately monitor national trends or evaluate prevention programs.

In 2004, the CDC (Centers for Disease Control) launched an initiative to improve the investigation and reporting of sudden, unexpected infant deaths (SUID). CDC collaborated with federal and state agencies and organizations, representing medical examiners, coroners, death scene investigators, EMS, law enforcement, forensic nurses, SIDS researchers, and parents who have experienced the death of an infant. In March of 2006, CDC released the Sudden Unexplained Infant Death Investigation (SUIDI) reporting form for state and local use in infant death scene investigations. In collaboration with a team of national experts, CDC developed a comprehensive training curriculum and materials for infant death scene investigations. Training materials highlight infant growth and development, interviewing and investigative skills, scene recreation using a doll, and how to fill out a death certificate. *(CDC)*

Of the **133** sudden, unexpected infant deaths in Missouri in 2006, a scene investigation was completed in **118** cases (89%); **30** (25%) of those were completed by a medical examiner or coroner or their

investigator. The Death-Scene Investigative Checklist is one of the many tools available to professionals involved in the investigation and evaluation of all child deaths. Refined and updated over time, the Checklist provides a guide to the investigator, regardless of experience level, to consistently collect the information necessary for an accurate determination of the cause and manner of death. The Investigative Checklist and other tools and information are available at www.dss.mo.gov/stat or by calling 800-487-1626.

Sudden Infant Death Syndrome (SIDS)

The term Sudden Infant Death Syndrome (SIDS) was proposed in 1969 to describe a clinical entity with characteristic findings to diagnose the sudden unexplained deaths of infants, typically during their sleep. SIDS is the sudden death of an infant under one year of age, which remains unexplained after a thorough case investigation, including performance of a complete autopsy, examination of the death scene, and review of the clinical history. SIDS is a diagnosis of exclusion; there are no pathological markers that distinguish SIDS from other causes of sudden infant death. There are no known warning signs or symptoms. Ninety percent of SIDS deaths occur in the first six months of life, with a peak at two to four months. While there are several known risk factors, the cause or causes of SIDS are unknown at this time.

Current Research Findings and Theories

Most scientists now believe that infants who die of SIDS are born with one or more conditions that make them especially vulnerable to internal and external stressors. A team of researchers funded by the National Institute of Child Health and Human Development has discovered that infants who die of SIDS may have abnormalities in several parts of the brainstem. This finding builds on the results of an earlier study of SIDS infants that identified abnormalities in the region of the brain known as the arcuate nucleus and four other regions of the brain thought to play a crucial role in controlling breathing, heart rate, body temperature and arousal.

The concept of underlying abnormalities that place certain infants at risk for sudden death is advanced by the Triple Risk Model, which is often used to describe the confluence of events that may lead to the sudden death of an infant. This model involves a vulnerable infant (one with a subtle defect involving the brainstem arousal responses), at a critical development period (less than six months of age), exposed to outside stressors, such as prone sleep position, overheating, and exposure to tobacco smoke. According to the model, all three elements must interact in order for a sudden infant death to occur. In and of themselves, outside stressors do not cause infant deaths, but in a vulnerable infant, "may tip the balance against the infant's chances of survival" *(Filiano and Kinney, 1994)*.

Other Risk Factors

Other risk factors, many associated with the mother's health and behavior, place the infant at significantly higher risk of sudden, unexpected infant death.

- Prematurity
- Low birth weight
- Less than 18 months between births
- Mother younger than 18
- Prenatal smoking
- Multiple birth
- Late or no prenatal care
- Alcohol and substance abuse

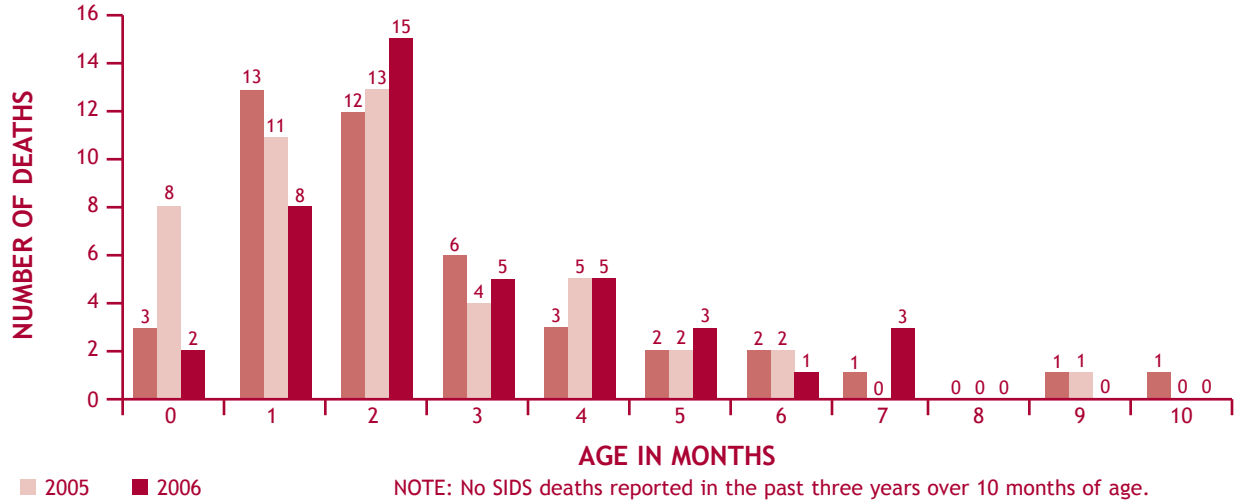
Certain environmental stressors have been shown to be highly significant risk factors. Environmental stressors are modifiable and the reduction of these risk factors through parent/caretaker education has great potential to save infant lives.

- Prone or side sleeping
- Soft sleep surfaces
- Loose bedding
- Bed sharing
- Overheating
- Exposure to tobacco smoke

SIDS FATALITIES BY SEX AND RACE

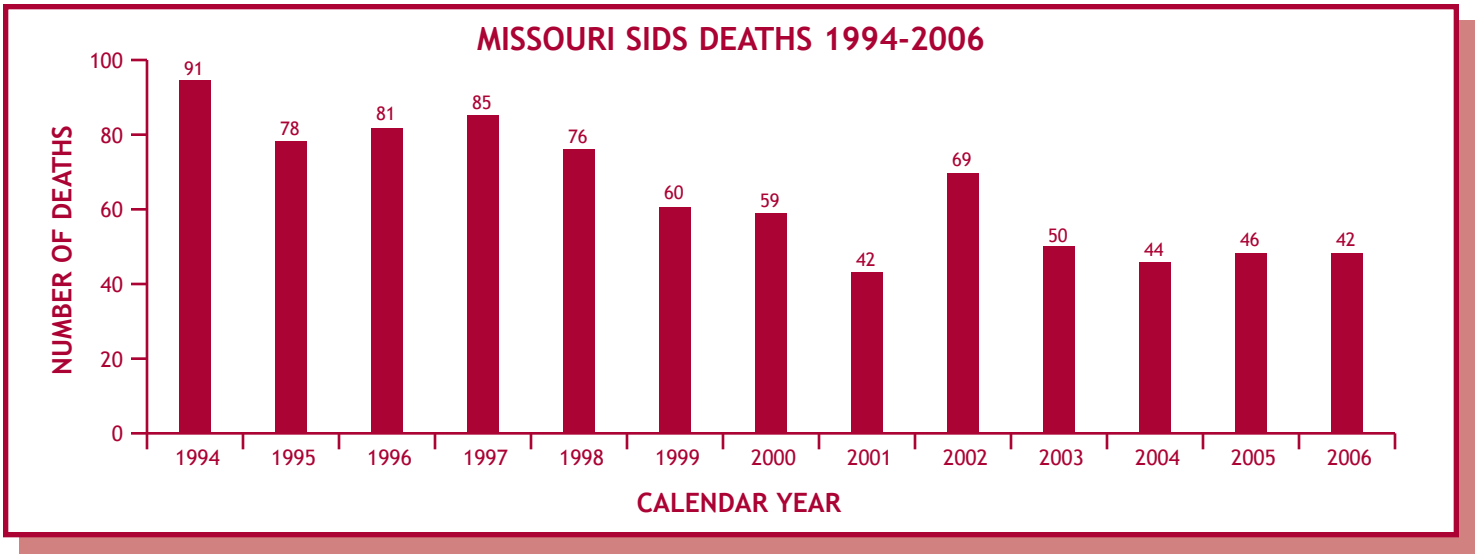
SEX	2004	2005	2006	RACE	2004	2005	2006
FEMALE	19	21	22	WHITE	28	34	28
MALE	25	25	20	BLACK	15	11	14
UNKNOWN	0	0	0	OTHER	1	1	0
	44	46	42		44	46	42

SIDS BY AGE (IN MONTHS)



NOTE: No SIDS deaths reported in the past three years over 10 months of age.

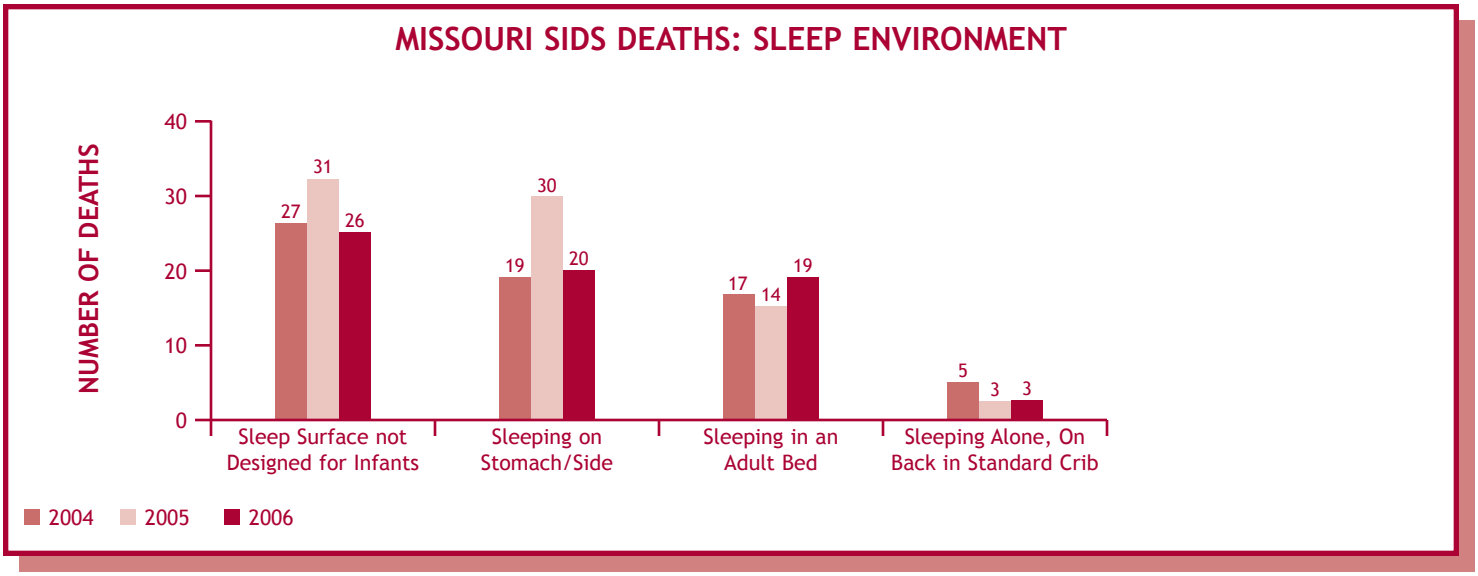
In 2006, Sudden Infant Death Syndrome (SIDS) was the cause of death of 42 Missouri infants.



It is estimated that as many as 900 infants, whose deaths are attributed to Sudden Infant Death Syndrome (SIDS) each year, are found in potentially suffocating environments, frequently on their stomachs, with their noses and mouths covered by soft bedding. *(Safe Kids)*

Unsafe sleep arrangements occur in the large majority of cases of sudden infant death diagnosed as SIDS, unintentional suffocation, and cause undetermined. Unsafe sleep arrangements include any sleep surface not designed for infants, sleeping with head or face covered, and sharing a sleep surface.

In Missouri, in 2006, of the **42** sudden, unexpected infant deaths reviewed by county CFRP panels and diagnosed as SIDS, **20** (48%) were known to be sleeping on their stomach or side. **Twenty-six** (62%) of those infants were not sleeping in a standard crib on a firm mattress and **19** (45%) were known to be sleeping in an adult bed. Only **three** (7.1%) infants who died suddenly and unexpectedly, whose deaths were diagnosed as SIDS were known to be sleeping alone on their backs, in a standard crib with head and face uncovered. This graph demonstrates that the safest place for an infant to sleep is in a standard crib, on his or her back, without soft bedding or toys of any kind.



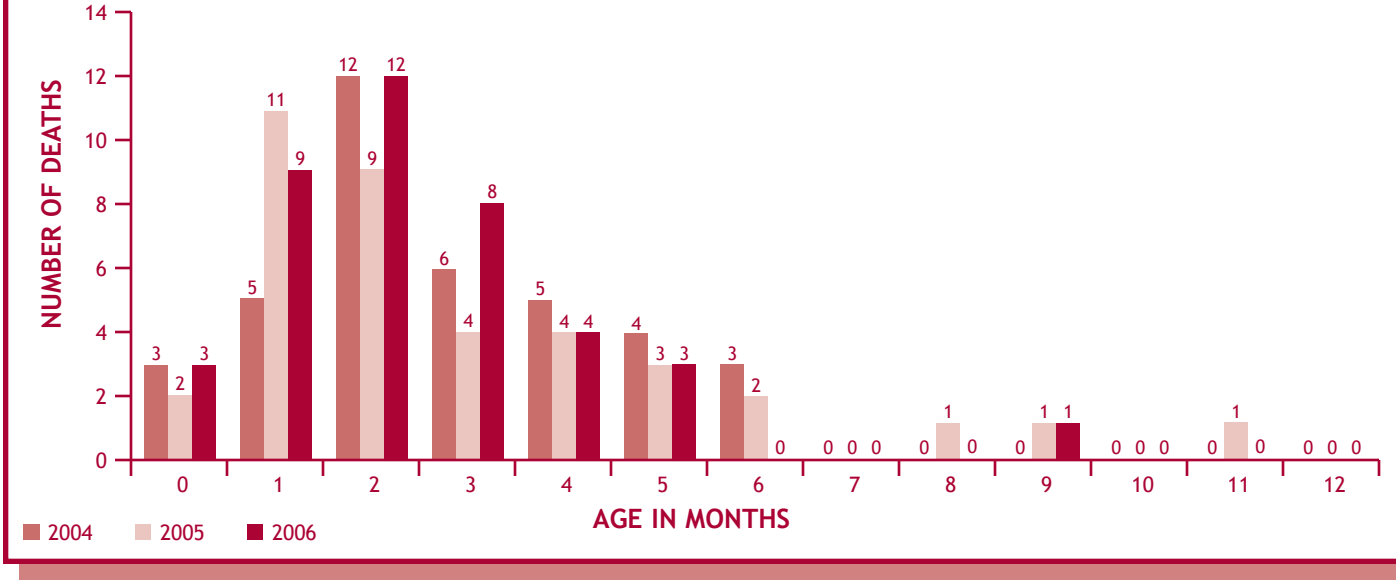
Suffocation in Infants

Unintentional Suffocation was the cause of death of 40 Missouri infants in 2006.

Most infant deaths due to **suffocation**, are directly related to an unsafe sleep environment. Many parents and caregivers do not understand the risks associated with unsafe sleeping arrangements. Infants can suffocate when their faces become positioned against or buried in a mattress, cushion, pillow, comforter or bumper pad, or when their faces, noses and mouths are covered by soft bedding, such as pillows, quilts, comforters and sheepskins. In most cases of unintentional suffocation, the sleeping environment is such that most normal infants would not have been able to move themselves out of the unsafe circumstances.

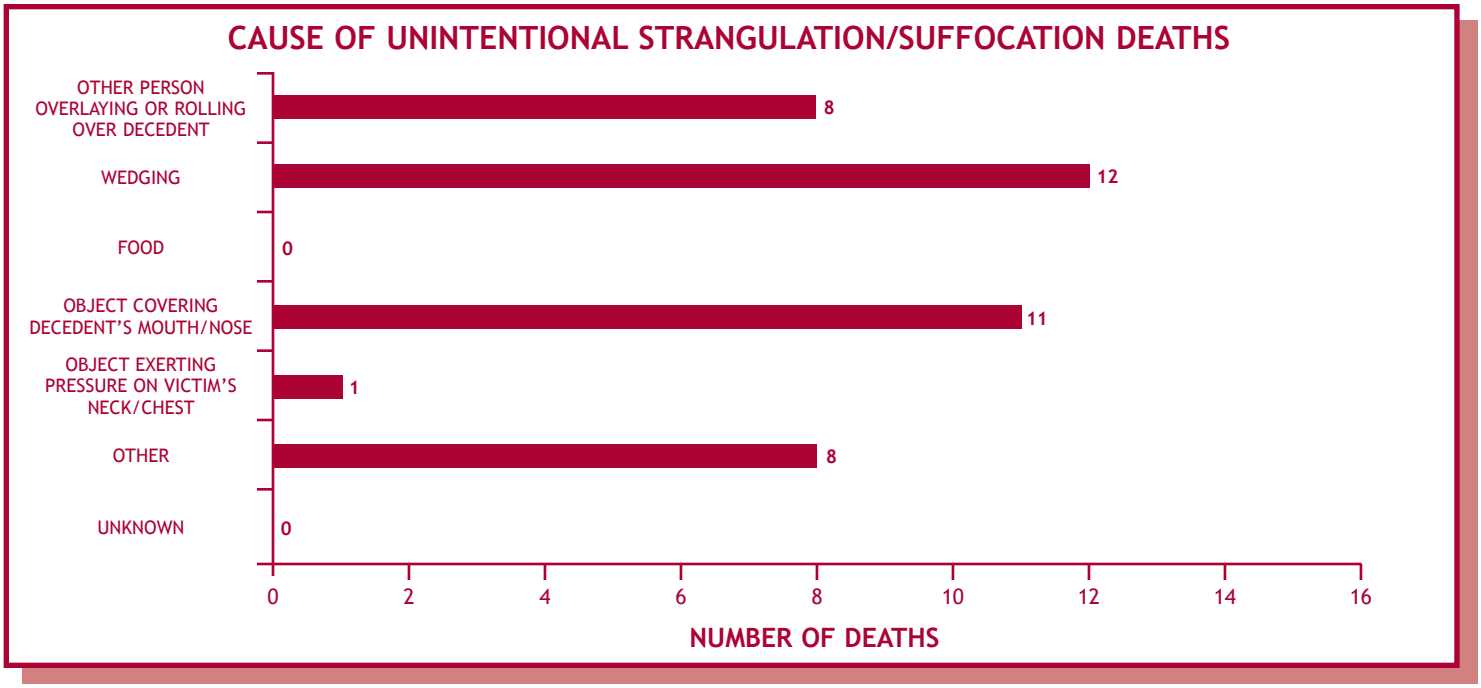
An **overlay** is a type of unintentional suffocation that occurs when an infant is sleeping with one or more persons (bed sharing with adults or other children) and someone rolls over on them. A suffocation due to overlay can be verified by one of the following means: (1) the admission of someone who was sharing the bed, that they were overlying the infant when they awoke or (2) the observations of another person. Most infant deaths involving possible or suspected overlay are classified as **undetermined** cause, because the actual position of the infant and other person at the time of death were not witnessed.

UNINTENTIONAL SUFFOCATION, UNDER 1 YEAR OF AGE BY AGE (IN MONTHS)



UNINTENTIONAL SUFFOCATION BY SEX AND RACE

SEX	2004	2005	2006	RACE	2004	2005	2006
FEMALE	16	12	15	WHITE	23	27	31
MALE	22	26	25	BLACK	14	10	9
UNKNOWN	0	0	0	OTHER	1	1	0
	38	38	40		38	38	40



UNDETERMINED

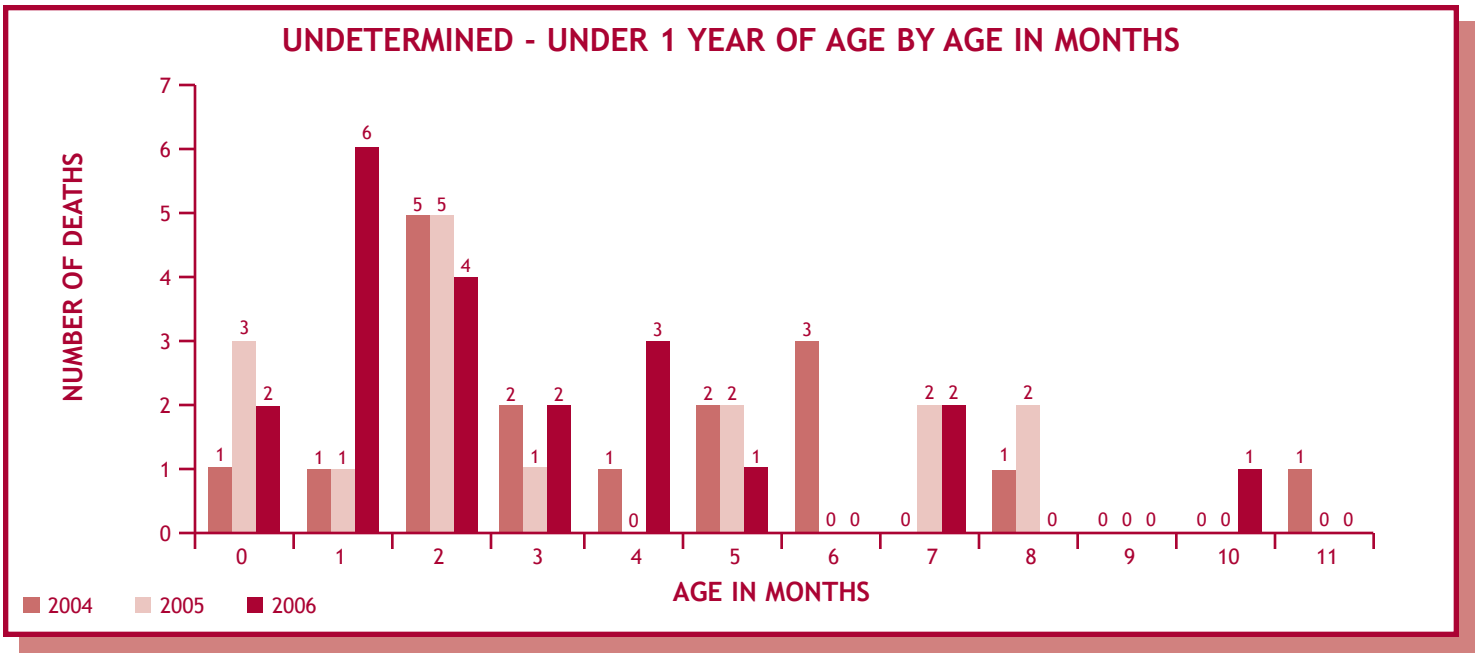
In 2006, the cause of death of 21 Missouri infants could not be determined.

In some cases, even the most thorough autopsy and scene investigation do not produce a definitive cause of death, yet risk factors are present that are significant enough to have possibly contributed to the death. One such risk factor is an unsafe or challenged sleep environment.

Recent studies of epidemiological factors associated with sudden unexpected infant deaths, demonstrate that prone sleeping and the presence of soft bedding near the infant's head and face pose very strong environmental challenges, by limiting dispersal of heat or exhaled air in the vast majority of cases. The extent to which such environmental challenges play a role in a particular sudden infant death, often cannot be determined. Therefore, a sudden unexpected infant death involving an unsafe sleep environment would be classified as **undetermined,** when unintentional suffocation is not conclusively demonstrated by the scene investigation.

UNDETERMINED BY SEX AND RACE

SEX	2004	2005	2006	RACE	2004	2005	2006
FEMALE	6	9	8	WHITE	16	6	15
MALE	11	7	13	BLACK	1	10	5
UNKNOWN	0	0	0	OTHER	0	0	1
	17	16	21		17	16	21



Sudden, Unexpected Infant Deaths in Child Care Settings

In the United States, twenty percent of SIDS deaths occur in a daycare setting *(Moon, Patel, and Shaefer, 2000)*. Although media and mailings have been largely effective in communicating safe sleep information to many childcare centers, back positioning and other risk reduction measures are not universally practiced among child care providers *(Moon and Biliter, 2000)*. *(HRSA)* In Missouri, in 2006, **13** sudden, unexpected infant deaths occurred in child care settings, including **seven** SIDS, **three** suffocation, **one** illness/natural cause, and **two** undetermined.

Reducing the Risk of Sids

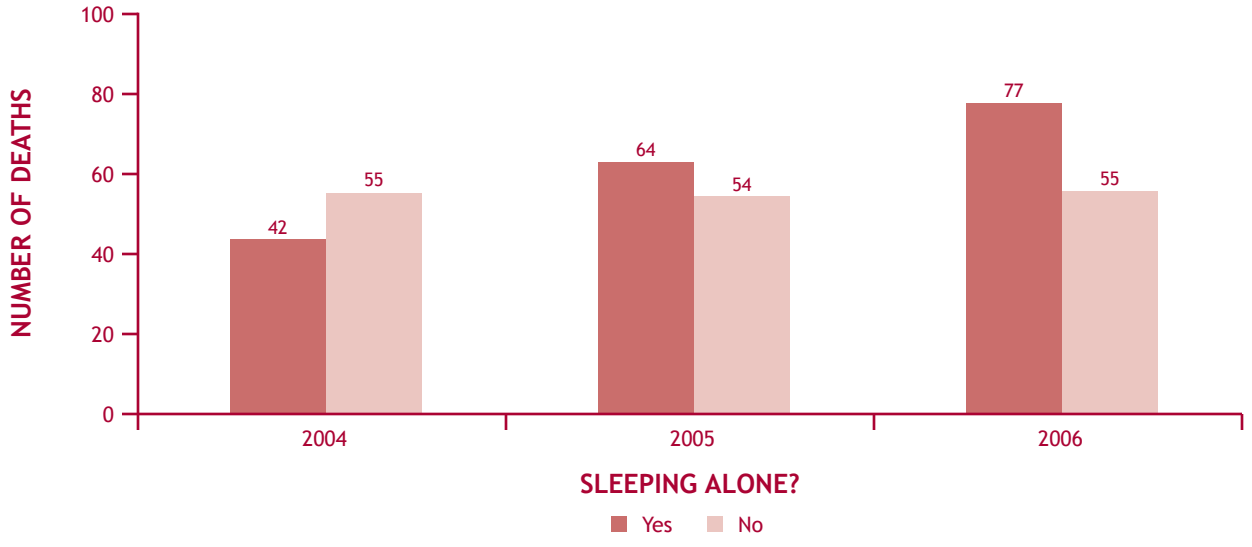
In an updated policy statement published in Pediatrics in November 2005, the American Academy of Pediatrics (AAP) addressed several issues that have become relevant since they published a statement in 2000.

- Back position during every sleep. Infants should be placed for sleep in a supine position (wholly on the back) for every sleep. Side sleeping is not a safe alternative to back sleeping and is not advised.

- Bed sharing is not recommended. 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 room sharing (infant sleeping in a crib in 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. The AAP recommend that a pacifier should be used when placing the infant down for sleep and not be reinserted once the infant falls asleep.

KNOWN BEDSHARING AMONG SUDDEN, UNEXPECTED INFANT DEATHS DIAGNOSED AS SIDS, SUFFOCATION AND UNDETERMINED



A Safe Sleeping Environment Infants

Physicians are the #1 influencer of patient health care choices. All pediatric health care providers should model safe sleep practices when working with patients and talk about safe sleep for infants. All parents and child care providers should have information about safe sleep for infants. The American Academy of Pediatrics has revised their recommendations on safe bedding practices when putting infants down to sleep. Here are the revised recommendations to follow for infants under 12 months.

Safe Sleep Practices for Infants

- Place baby on his/her back for every sleep. Side sleeping is not a safe alternative to back sleeping and is not advised.
- Bedsharing during sleep is hazardous and is not recommended. A separate but proximate sleeping environment is recommended, such as a separate crib in the parents' bedroom.
- Use a firm, tight-fitting mattress in a crib that meets current safety standards.
- Remove all fluffy and loose bedding from the sleep area; use a bottom sheet and no blanket. Consider a sleeper/sac rather than a blanket.
- Avoid commercial devices marketed to reduce the risk of SIDS (wedges, positioners, etc.)
- Avoid overheating and over bundling the infant.
- Offer a pacifier during nap and bedtime during the first year of life.

Courtesy of Missouri Children's Trust Fund.

Risk Reduction Recommendations:

The following risk reduction recommendations are from the American Academy of Pediatrics, SIDS Resources, Inc., and the SIDS Alliance.

For parents:

- *Safe Sleep:* Parents should be informed about safe sleep practices for infants, including the fact that bed-sharing is hazardous, and follow safe sleep recommendations.
- *Smoking:* Avoid smoking during pregnancy. Create a smoke-free environment around the baby after birth.
- *Breastfeeding:* Mothers should be encouraged to breastfeed. Infants may be brought into bed for nursing but should be returned to their own crib or bassinet when the parent is ready to return to sleep.
- *Maternal and infant healthcare:* Early prenatal care and recommended well baby care should be encouraged.

For professionals:

- All pediatric health care providers should be informed about current recommendations for safe sleep for infants, model safe sleep practices when working with patients, and talk about safe sleep for infants.

For community leaders and policy makers:

- Implement and support safe sleep campaigns.
- Require safe sleep education for all licensed child care providers.

For Child Fatality Review Panels:

- All sudden, unexplained deaths of infants <1 year of age require autopsy by a child death pathologist and review by a county CFRP panel.
- Encourage proper scene investigations in all sudden unexpected infant deaths.
- Remember that all data and information pertaining to any SUID is critically important in identifying risk factors and developing effective prevention strategies.

Something We Can Do: The Safe Crib-Safe Sleep Campaign

The safest place for an infant to sleep is in a standard crib, on his or her back without soft bedding or toys of any kind. The American Academy of Pediatrics, the Consumer Product Safety Commission and the National Institute of Child Health and Human Development have revised their recommendations on safe bedding practices when putting infants down to sleep to incorporate this new information. Unfortunately, many parents have not received this information and, for a variety of reasons, are unable to provide a safe crib for their infant.

The Safe Crib Project provides a safe, new crib to families in need, along with critical parent education about safe sleep arrangements for infants. In communities throughout Missouri, social service agencies, community health agencies, hospitals and similar organizations have collaborated to implement the Safe Crib Project, using funding from Children's Trust Fund. The goal of this innovative project is to save infant lives and support families. For additional information about Children's Trust Fund, active Safe Crib Projects or funding opportunities, please contact Children's Trust Fund at 573-751-5147 or visit www.ctf4kids.org.

Resources and Links:

American Academy of Pediatrics Policy Statement news release and a related reviewed article . . . . . www.aap.org/healthtopics/sleep.cfm
aappolicy.aappublications.org/cgi/reprint/pediatrics;116/5/1245.pdf

National SIDS/Infant Death Resource Center . . . . . www.sidscenter.org

St. Louis Safe Sleep Task Force . . . . . www.stlsafesleepforbabies.com

SIDS Resources, Inc., 135 West Monroe, St. Louis, MO 63122
Counseling and support, research, training and education . . . . . www.sidsresources.org

Missouri Children's Trust Fund
Safe Crib-Safe Sleep campaign www.ctf4kids.org

Fetal-Infant Mortality Review . . . . . www.dhss.mo.gov/FIMR

"The truth on how these deaths occur must be known and shared for there to be any opportunity to prevent the next infants' death. We need to work in a kind and caring way, but still need the truth on how the death occurred – nothing less...We have an obligation to our infants and their families to seek only truth – and offer only honesty."

- Pat Tackitt, RN, MS
Wayne County, Michigan CDRT Coordinator