


# Nebraska Child Death Review Report For 1996 – 2001

The third report of the  
Nebraska Child Death Review Team  
July, 2004

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Revised 9/04

July, 2004

The Honorable Mike Johanns, Governor  
Honorable Members of the Nebraska State Legislature  
Lincoln, Nebraska

This report on child deaths in the state of Nebraska is submitted in aggregate form for years 1996-2001. The Child Death Review Team is mandated under State Statute §71-3404 to report yearly on causes of child death in the state and recommendations for prevention of future deaths. However, the Team suffered from a lack of staffing for several years; its last report was produced in 1998 and was based on 1994-1995 data.

In July of 2002, I was tasked by Dr. Richard Raymond, Chief Medical Officer for the Nebraska Health and Human Services System, to bring the state up to date and the following is a report of our findings. To best meet the requirement for yearly reports, we have accumulated and compiled each year's data to look for trends over years. The Team and HHSS staff have dedicated countless hours to reviewing over 1,800 child deaths that occurred from 1996 to 2001. In addition, we have begun the more comprehensive reviews of 2002 and 2003 deaths.

We have tried to present this report in a meaningful way that will help protect Nebraska's present and future children. Our goal was to use complex and often contradictory information to produce meaningful interpretations for policy changes and educational efforts. We hope that our presentation of these results will in some small way ensure that every child who has been lost is remembered, and that they remain more than a number in our report.

Please note that these recommendations reflect the views of the Child Death Review Team, and are not necessarily those of Health & Human Services.

If I can be of any further assistance, please do not hesitate to contact me. We thank you for the continued support of the Child Death Review Team and of the children and families of Nebraska.

Sincerely,



Joann Schaefer MD  
Deputy Chief Medical Officer  
Nebraska Health and Human Services System

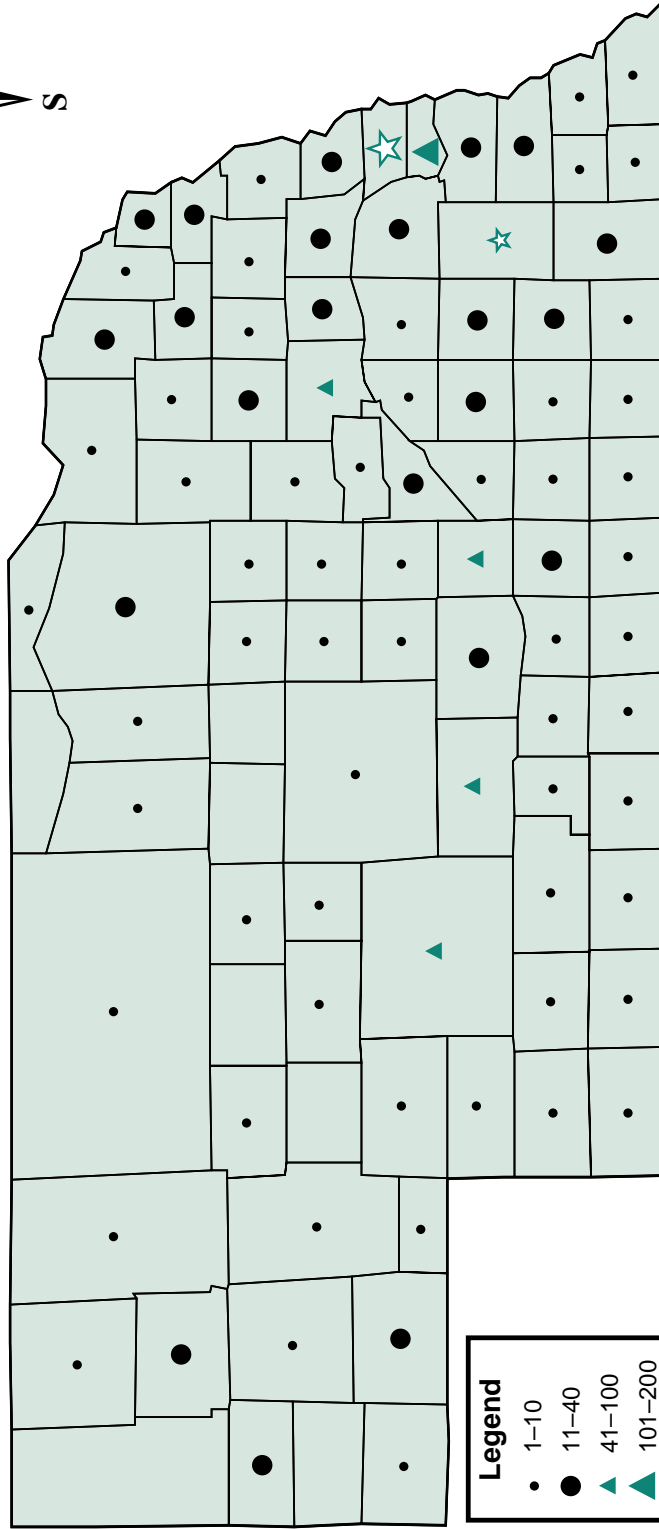
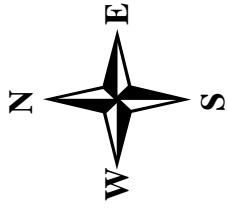
The Child Death Review Team would like to thank the County Attorneys and their staff, hospital Medical Records Departments, Tribal Authorities, State agencies, HHSS staff, family members and other individuals who graciously provided the information that made this report possible.

Providing useful information is the goal of this report. Any questions or comments regarding the report or the Child Death Review Team should be directed to:

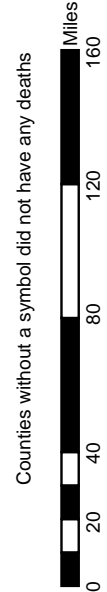
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A copy of this report may be found at: [www.hhs.state.ne.us/srd/srdindex.htm](http://www.hhs.state.ne.us/srd/srdindex.htm)

# Infant and Child Deaths (0-17) by County of Residence (N=1,845) Nebraska, 1996-2001



Legend	
•	1-10
●	11-40
▲	41-100
▲	101-200
☆	201-500
☆	501-550



Counties without a symbol did not have any deaths



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# Executive Summary

The Nebraska Child Death Review Team (CDRT) was established by the Nebraska Legislature in 1993 and charged with undertaking an ongoing, comprehensive review of existing information regarding child deaths in Nebraska. This report presents the CDRT's findings and recommendations based on review and analysis of deaths of the 1,845 Nebraska resident children (newborns through 17 years of age) who died from 1996 through 2001.

The overall death rate of children in Nebraska has gone down significantly since 1980, from a high of 112 deaths per 100,000 children to 65 per 100,000 in 2001. Apparent reasons for this decline include:

- Advancements in health care including diagnostics, medications and available treatments;
- Improved access to health care;
- Improved educational and preventive strategies for preventable diseases; and,
- Improved public education on the prevention of unintentional injuries.

Overall death rates for African-American, Native American and Hispanic children were higher than for White and Asian children, with this pattern generally true over the six year study period, 1996-2001. Further analysis of the records is needed to understand specific causes of death that contributed to these overall mortality disparities.

## Top Ten Causes of Death for Children in Nebraska, 1996-2001, and Key Recommendations for Future Prevention

### 1. Pregnancy-Related – 541 deaths

Pregnancy-related factors such as prematurity, maternal complications, and events of labor and delivery accounted for 29% of all infant and child deaths from 1996 through 2001. However, the underlying cause of death for most premature infants was not their prematurity - 66% had either a known reason such as maternal

pre-eclampsia for the premature birth, or a distinct cause of death other than their immature development. Among the infant deaths that were attributed to prematurity, over half were to multiple gestation infants who are known to have both higher prematurity and mortality rates.

- **All pregnant women should have access, including financial access, to high quality prenatal care.**
- **Providers who care for pregnant women should be aware of new treatments available for the prevention of preterm labor, and the situations for which they are appropriate.**
- **Maternal complications of pregnancy such as placental abruption are also significant contributors to prematurity, infant death and maternal illness; optimal medical management of these conditions is essential.**

### 2. Birth Defects, Inherited and Genetic Disorders – 380 deaths

Heart defects were the largest category of lethal birth defects, and hypoplastic left heart disease was the single most common diagnosis. The number of neural tube defect deaths decreased over the six year period, most likely from increased use of folic acid-containing multivitamins by women of child-bearing age.

- **Women of child-bearing age, whether or not they plan on becoming pregnant, should consume a daily multi-vitamin containing 400 micrograms of folic acid.**

### 3. Motor Vehicle-Related Incidents

Eighty-four percent of motor vehicle-related deaths occurred to children killed while riding in a motor vehicle. While the total number of children killed in motor vehicle-related incidents has declined over time, underuse of age-appropriate restraints (safety belt or child safety seat) continues to be a leading factor. The percentage of crashes where alcohol was involved increased over the six year time period.

- **Nebraska’s safety belt law should be upgraded to primary (standard) enforcement.**
- **Parents should limit the number of teenage passengers a teen driver may carry.**
- **Better enforcement of the state law against serving alcohol to intoxicated bar and restaurant patrons would likely reduce alcohol-related crash fatalities by approximately 11%.**
- **Enhance communities’ awareness of the need to improve safety for child pedestrians.**

#### **4. Sudden Infant Death Syndrome – 160 deaths**

The number of SIDS deaths in Nebraska has dropped by one-half since 1993 but the trend appears to have leveled off, particularly among African-American infants. Similar circumstances among cases diagnosed as SIDS and others diagnosed as accidental suffocation emphasize the need for educational campaigns on multiple infant sleep-related safety issues rather than focusing solely on SIDS prevention. Fourteen percent of Nebraska’s SIDS deaths were known to have occurred while the child was in a child care setting (licensed or unlicensed) and an additional 10% with a non-family member babysitter.

- **State regulations should require that infants in licensed child care facilities be put to sleep on their backs unless there is a documented medical reason for the child to sleep in a different position.**
- **Smoking during and after pregnancy is a risk factor for multiple infant illnesses, and state-supported efforts to reduce prenatal and postpartum smoking should be supported and expanded.**
- **A standardized death scene investigation should be conducted for all unexpected child deaths.**
- **Existing SIDS prevention regulations, messages and initiatives should be expanded to include other “Safe Sleeping” issues and options, and continue to be widely promoted.**

- **Parents who choose to bed share with their infants need to be aware of the risks involved and how to reduce them.**

#### **5. Infectious, Chronic and Other Medical Conditions – 138 deaths**

“Other medical” cases include a wide mix of preventable and non-preventable conditions. Although there was only one documented death from a vaccine-preventable disease (chickenpox), many deaths from “pneumonia” were likely due to influenza. The 17 deaths from asthma imply an over-reliance on inhalers and injectors rather than an effective medical plan.

- **Children with persistent asthma should be taking a daily prevention medicine, the most effective being inhaled corticosteroids. Reliance on albuterol-based inhalers in an emergency should not be considered effective control of asthma. All children with asthma should have a customized, written asthma action plan developed in conjunction with their primary care provider.**
- **Annual influenza vaccine is now recommended for healthy children ages 6 to 23 months, and for older children with specific health conditions.**

#### **6. Unintentional Injuries – 95 deaths**

The majority of unintentional injury deaths were from drowning, sleep-related suffocation other than SIDS, being hit by a vehicle not in traffic, residential fires, accidental hanging and playing with firearms.

- **Pool fencing ordinances, in combination with comprehensive assessments of building codes and enforcement ability, are effective in reducing child drowning deaths**
- **Young children should never be unsupervised in or near water, even shallow wading pools.**
- **Communities should examine their enforcement of building codes and laws requiring landlords to maintain smoke alarms in rental units.**
- **Children who are in the vicinity of moving**

motor vehicles or machinery should be under focused adult supervision at all times.

- **Eliminate potential safety hazards for young children.** Thorough home “child-proofing,” from a child’s perspective, can avoid needless tragedies.
- **Parents who keep firearms in the home must understand the importance of storing unloaded firearms and ammunition in separate, locked and inaccessible locations.**
- **Local law enforcement agencies have access to trigger locks for community giveaway programs and should be used as a resource.**

### 7. Suicide – 70 deaths

Although the number of suicides is apparently decreasing over time, at least 70 children ranging in age from 11 to 17 took their own lives during the 6-year period. Over half of the children used a firearm to commit suicide. Motivating factors included perceived academic failure, fear of parental retribution for various incidents, and the aftermath of personal embarrassment.

- **All teenagers need access, including financial access, to confidential, professional mental health services.**
- **Any suicidal gesture, no matter how “harmless” it seems, demands immediate professional attention.**
- **Parents who keep firearms in the home must understand the importance of storing unloaded firearms and ammunition in separate, locked and inaccessible locations. Trigger locks are an important component of firearm safety.**

### 8. Cancer – 64 deaths

The number of child cancer deaths dropped from 1996 through 2001, but cancer remained the most common cause of disease-related mortality. Leukemia and brain tumors were the most common causes of child cancer deaths in Nebraska.

- **Providers should stay up-to-date on findings regarding the risk factors, symptoms, and treatment and referral options for childhood cancer.**

### 9. Homicide / Criminal Child Abuse

– 63 deaths

Sixty-three children suffered violent or abusive deaths from 1996 through 2001. Thirty-two children between the ages of 12 and 17 were shot, beaten or strangled in disputes with friends or peers. Of the 31 children not killed by peers, 30% died from blunt force trauma, e.g., having their head hit against a hard surface. At least five of these children were intentionally killed, caught up in disputes between their mothers and their current or former male partners.

- **Schools, communities and others concerned about youth violence should be aware of and take advantage of the substantial resources available to help develop effective, community-based prevention programs.**
- **Never leave a child in the care of someone who is abusing drugs, especially methamphetamines.**
- **“Never, never, never shake a child©” is an excellent starting point for developing community norms against child abuse.**
- **Nebraska law should be amended to reflect current knowledge that exposure of children to domestic violence is harmful and constitutes child abuse.**
- **Relatives, friends and neighbors should follow their instincts – and the law - when they suspect substance abuse, child abuse and/or neglect by the caretakers of young children.**

### 10. Caretaker Neglect – 29 deaths

There were 29 child deaths where local prosecutors chose not to bring charges against the caretaker, but where the Team felt that the death would not have occurred under reasonable standards of supervision or care. Although not specifically abandoned, two new-

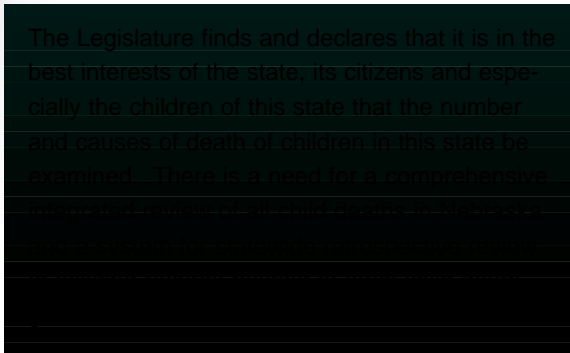
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borns were left without food and/or medical care and were clearly not wanted by their mothers. Other cases included drowning in tubs, pools or open water, and children who were left alone in buildings that caught fire. Eight additional cases were considered “Inconclusive Neglect,” where reviewers were not comfortable with the unintentional injury classification but did not have sufficient information to clearly determine neglect.

- **A “Safe Haven” law, with funding for public awareness, may save the lives of a small number of Nebraska newborns who are abandoned or neglected by their mothers and should be passed by the Nebraska Legislature.**
- **Young children should never be left unsupervised.**
- **Safe and affordable child care will reduce the number of children left unattended for long periods of time.**
- **Young teens should not be left alone in potentially hazardous situations such as when swimming in lakes and rivers. The ability to swim does not replace the need for supervision, even into the teenage years.**

# B Background

## Review of 1996-2001 Nebraska Child Deaths



This report presents the findings and recommendations of the Nebraska Child Death Review Team, based on the review and tabulation of 1,845 deaths of Nebraska resident children from 1996 through 2001. The traditional belief that “things will happen” ignores the reality that many of these deaths could have been prevented.

## BACKGROUND

The Nebraska Child Death Review Team (CDRT) was established by the Nebraska Legislature in 1993 and charged with undertaking a comprehensive, integrated review of existing records and other information regarding each child death. At that time, the Nebraska Commission for the Protection of Children had found that about 300 children died each year in the state, but that there was no systematic process in place for consistent review of those deaths to determine contributing circumstances.

The purpose of the CDRT includes developing an understanding of the number and causes of child death, and advising the Governor, Legislature, other policy makers and the public on changes that might prevent them. All child deaths are reviewed, not just “suspicious” or violent ones. The Team uses information in written records and the expertise of its members to identify situations where, in retrospect, reasonable

intervention might have prevented a death. Members of the original Team determined that the specific goals of these reviews would be to:

- Identify patterns of preventable child deaths;
- Recommend changes in system responses to child deaths;
- Refer to law enforcement newly-suspected cases of abuse, malpractice, or homicide; and,
- Compile findings into reports designed to educate the public and state policy makers about child deaths.

Two previous reports have been issued, covering child deaths in 1993 and in 1994/1995. However, no reports were completed after the 1998 report on 1994/1995 deaths, and the Team stopped meeting in 1999. In 2002, the Nebraska Health and Human Services System (HHSS) committed to the reinstatement of the CDRT and its work. New members were appointed in July 2002 and the Team resumed meeting that September. At that time, members decided to conduct an “expedited” review process and produce an aggregate report on deaths from 1996 through 2001; the comprehensive review process would resume with January 2002 deaths. This aggregate report thus covers child deaths from 1996 through 2001.



# M ethodology

In making its assessments, the Team obtains information from multiple sources, including:

- The Vital Records section of the Nebraska Health and Human Services System, which provides death certificates for all Nebraska resident children under the age of 18, and matched birth certificates for those under the age of one year;
- The HHSS Office of Protection and Safety and the Child Care Licensing section;
- County Attorneys, who are contacted annually for information on all deaths to children who resided in their respective counties;
- Hospitals, which are contacted annually for information on all deaths to children that occurred in those facilities;
- Additional sources as needed, e.g., private providers, public officials in counties or states where a death occurred but where the child was not a resident.

Using this information, the CDRT Coordinator reviewed all cases and classified them into one of 16 categories based on the “underlying” cause and circumstances of death<sup>1</sup>. Because information was incomplete for some children, some misclassification may have occurred. Team members discussed cases where the classification was not immediately obvious or was controversial. Most cases were not individually assessed for preventability; however, all unintentional injuries (“accidents”) to young children were reviewed by at least two Team members to determine whether caretaker neglect was involved.

The annual State of Nebraska Vital Statistics Reports provide categorized cause of death information for infants and older children. However, the CDRT review determined underlying causes that did not always correspond to those assigned by Vital Statistics. There were three main reasons for disagreement between the two systems:

- In a small number of cases, the official cause of death was found to be incorrect based on follow-up information received by the Team. For example, several official “accidental deaths” were deter-

mined to be suicides based on reports from local law enforcement; a death recorded as homicide had later been ruled self-inflicted and unintentional but not corrected in the Vital Statistics record.

- In a few cases, the official cause of death was left “undetermined / pending autopsy” on the death certificate, and not updated once the autopsy was performed.
- More often, however, the Team reached further back in the chain of events that led to the death to assign an underlying cause. As the goal of the CDRT is prevention of future deaths, this process was felt to better distinguish between preventable and non-preventable deaths.

Several types of data were used for this report. First, most records received by the Team were in paper format; most of the results presented in this report are based on multiple hand tabulations of these documents. A long-term goal is to have these 1996-2001 paper records entered into an electronic database. In the meantime, all cases beginning with 2002 deaths are being entered into a new CDRT database, which will allow more sophisticated analyses for future reports.

Secondly, the Team had access to several NHHSS electronic databases. Thus, aggregate information is presented on demographics and gestational age from analyses of the children’s computerized birth and death certificates. Numbers and names of Sudden Infant Death Syndrome (SIDS), suicide, homicide and criminal child abuse cases were compared to ensure that all children known to the state were listed appropriately in the CDRT files. Similarly, the state’s Cancer Registry was used to cross-check cancer deaths. The Nebraska Crash Outcome Data Evaluation System (CODES) database provided aggregate data on passenger restraint (e.g., seat belt) use and the involvement of alcohol in automobile crashes. The CODES data were not individually matched to CDRT cases, but do provide an aggregate assessment of the same children and incidents. Finally, in a small number of cases, the only information available was obtained from archived newspaper reports or local informants, most often County Attorneys’ staff.

<sup>1</sup> The underlying cause of death is the disease or condition that initiated the chain of morbid events leading directly to death, and may be many years removed from the actual occurrence of death. See Glossary for further discussion.





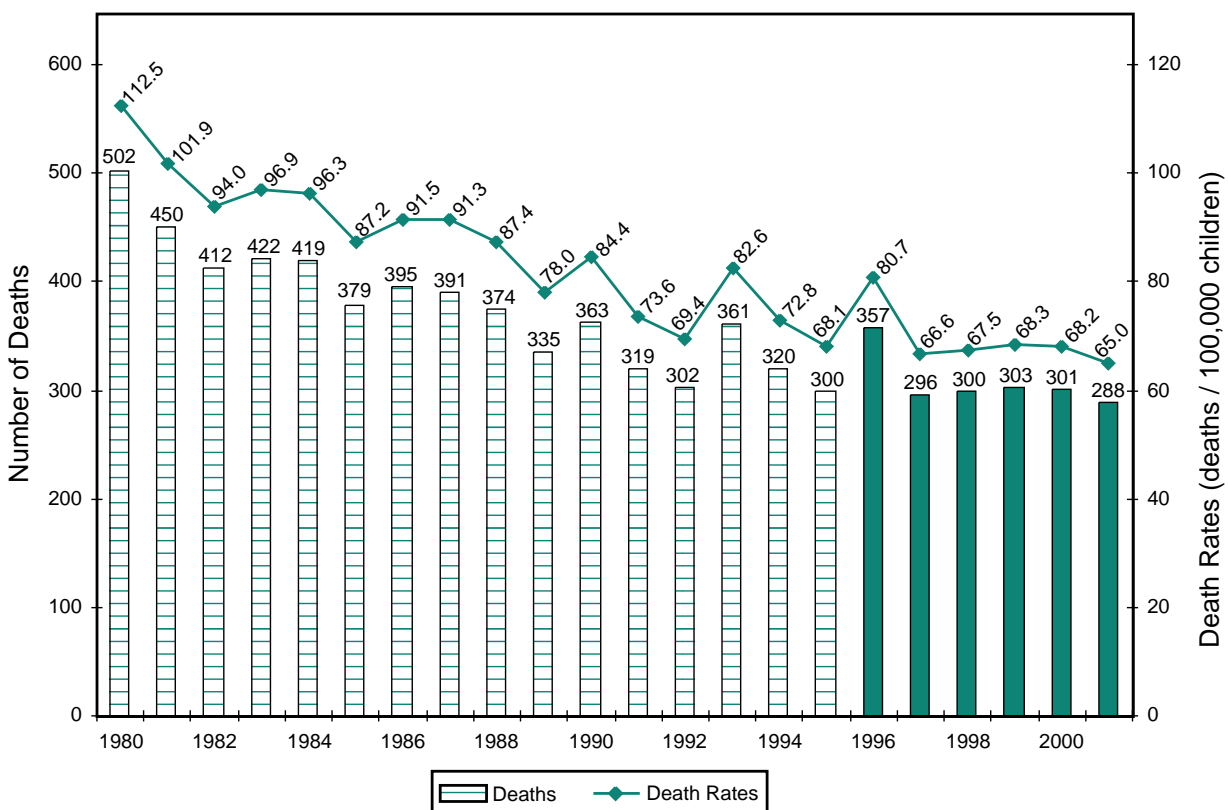
# Findings

A total of 1,845 Nebraska children ages 0 to 17 died from 1996 through 2001 (Table 1). This reflects a 19 percent decrease in the annual number of deaths over

that six year period, but a relative plateau when considering the 20-year trend of decreasing deaths (Figure 1).

**Figure 1**

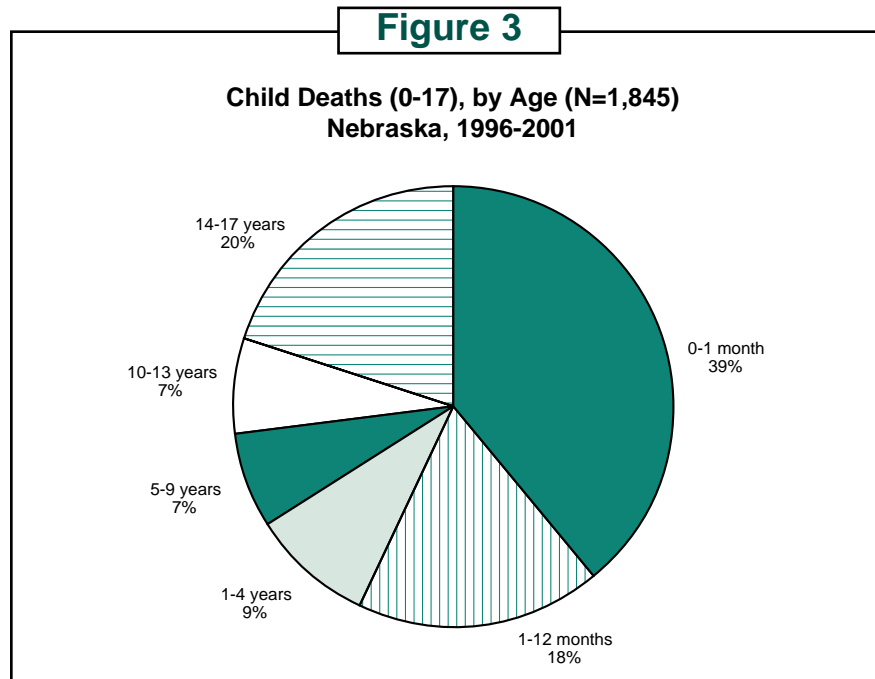
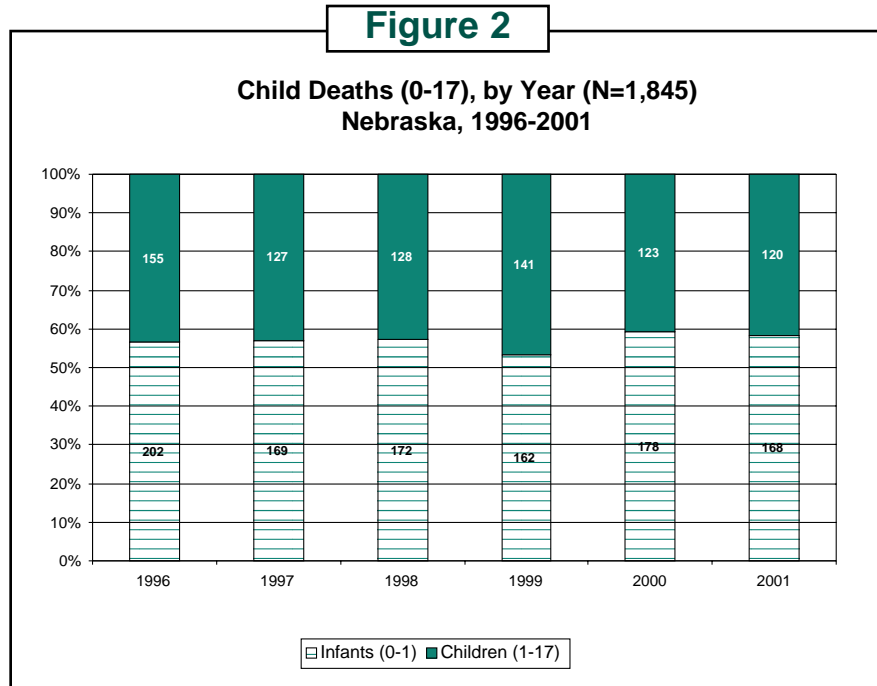
**Child Deaths (0-17) and Death Rates  
Nebraska, 1980-2001**



## Demographics

Infants less than 12 months old accounted for a fairly constant 57% of all deaths (Figure 2). Of these, about two-thirds died in their first month (Figure 3). Overall

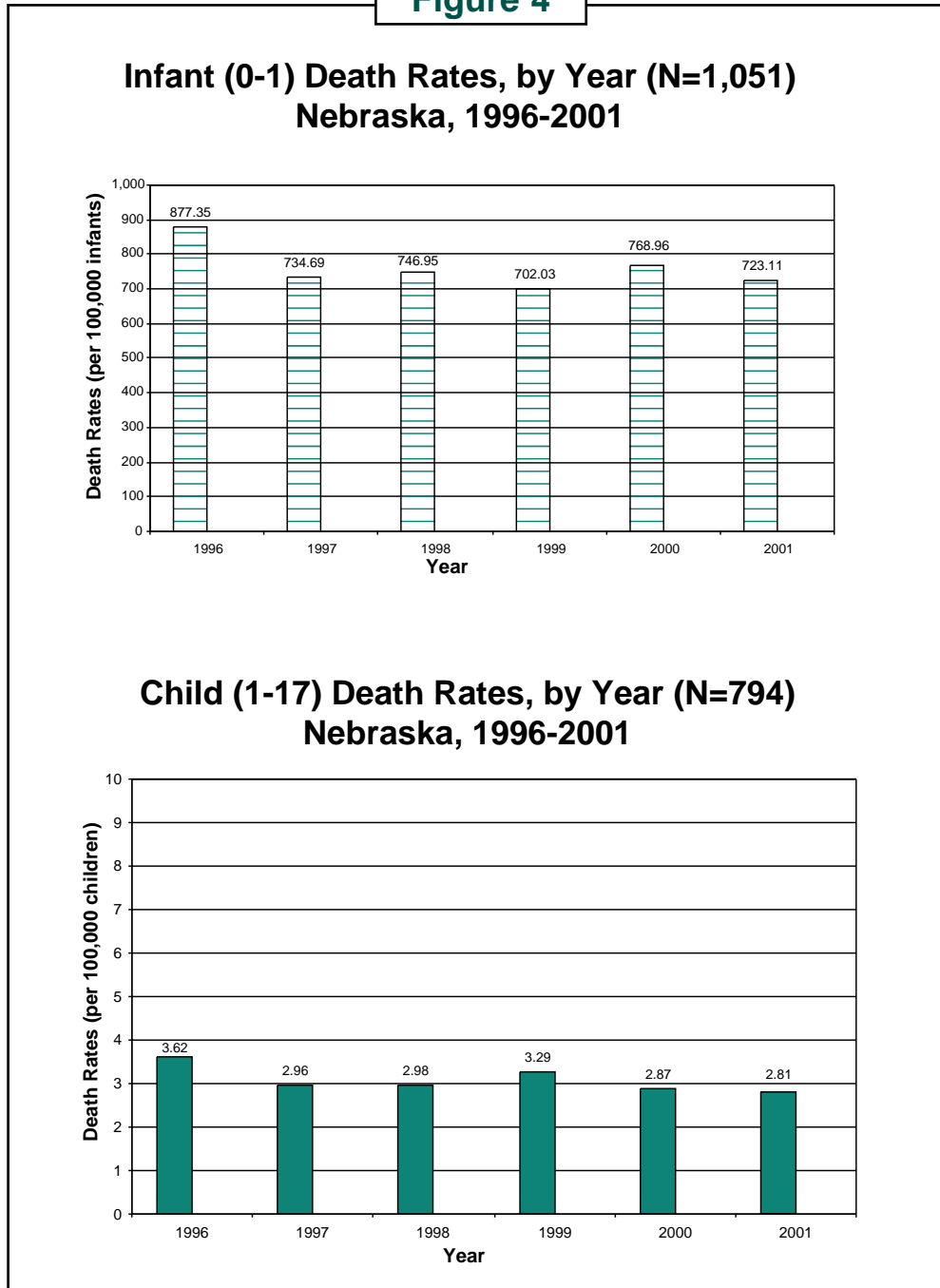
death rates for infants and for children declined slightly from 1996 through 2001 (Figure 4).



The children were predominantly male (58.5%) and White (85.4%) (Figure 5). African-American children made up 10.9% of deaths, Native American 2.8%, Asian 1% and Hispanic<sup>2</sup> children 8.7%. However, when calculated as a rate per 100,000 children,

African-American, Native American and to a lesser extent Hispanic children had significantly higher death rates with some variation over time (Figures 6 & 7). It was not possible for this report to determine the specific causes of death that account for these differences.

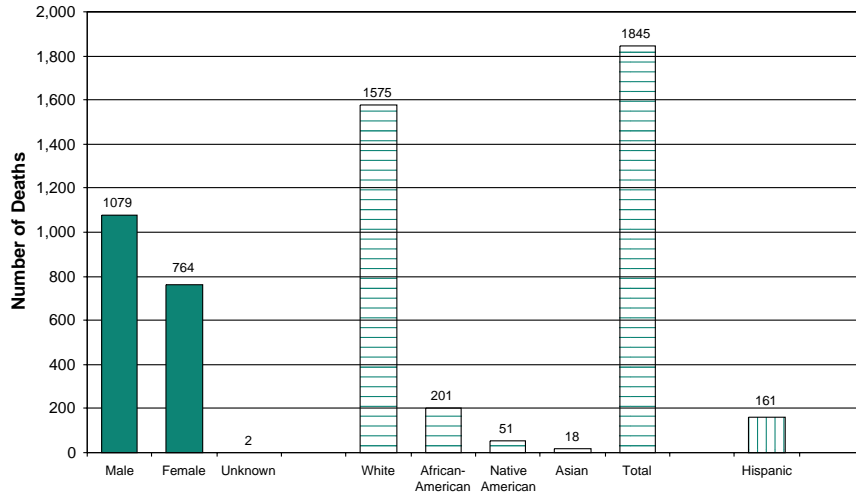
**Figure 4**



<sup>2</sup> Persons of Hispanic origin may be of any race, thus race and ethnicity percentages sum to greater than 100 percent.

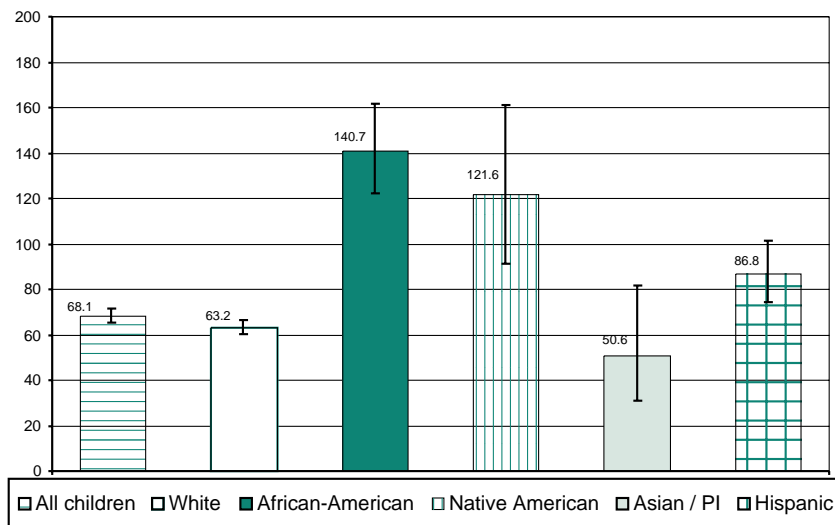
**Figure 5**

**Child Deaths (0-17), by Sex, Race and Ethnicity (N=1,845)  
Nebraska, 1996-2001**



**Figure 6**

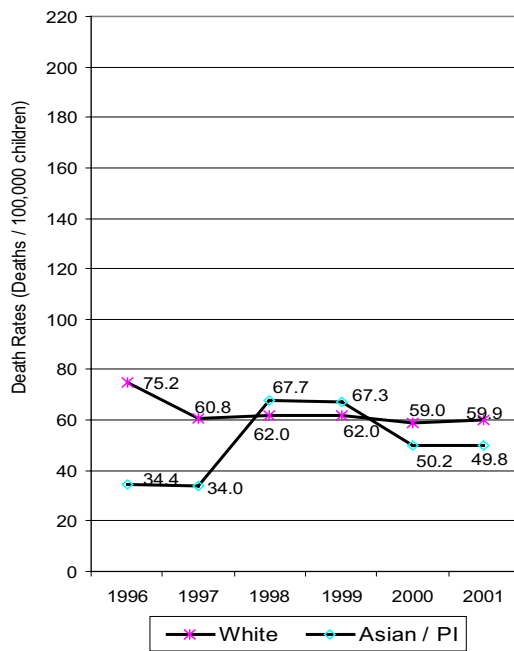
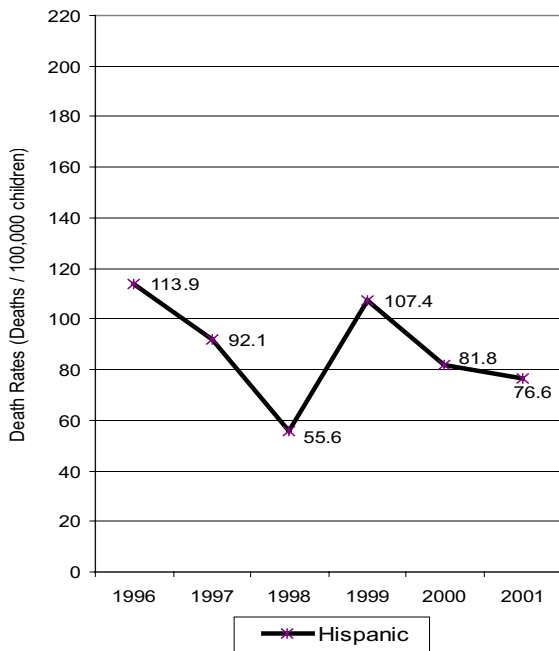
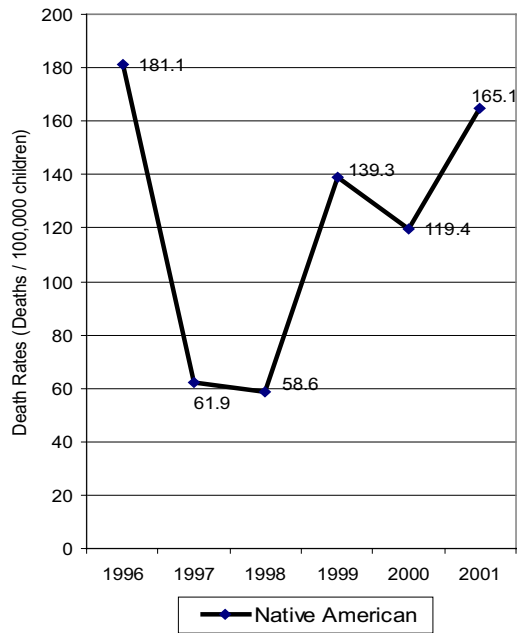
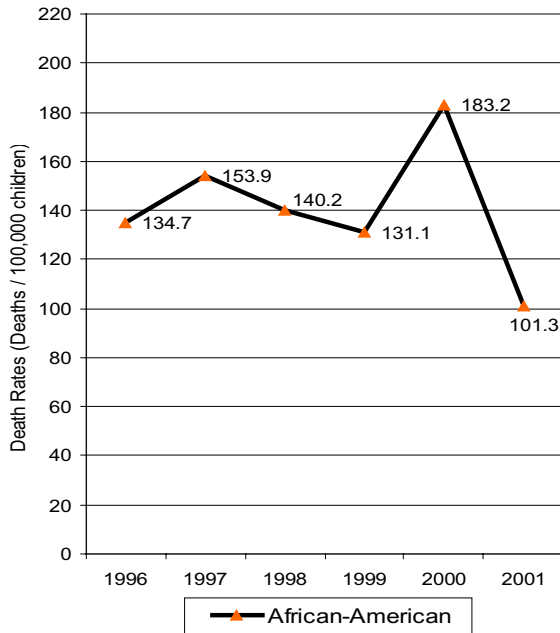
**Child Death Rates (0-17), by Race/Ethnicity (N=1,845)  
Nebraska, 1996-2001**



Hispanics can be of any race.  
Thin bars represent 95% confidence intervals.  
Source: Centers for Disease Control and Prevention.

**Figure 7**

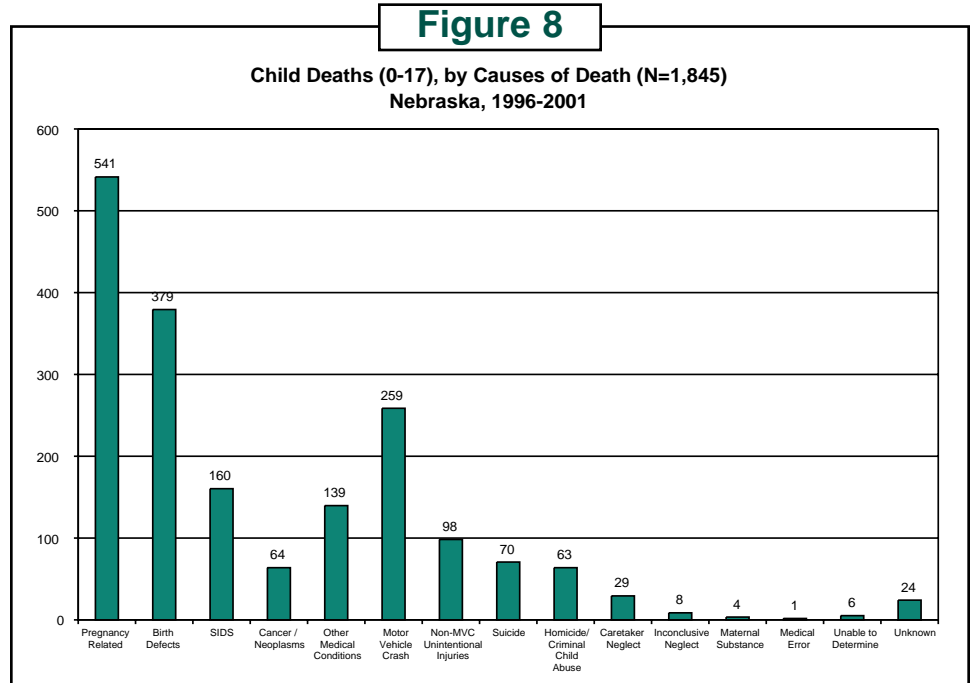
Child Mortality Rates (0-17), by Race / Ethnicity  
Nebraska, 1996-2001



Source: Centers for Disease Control and Prevention

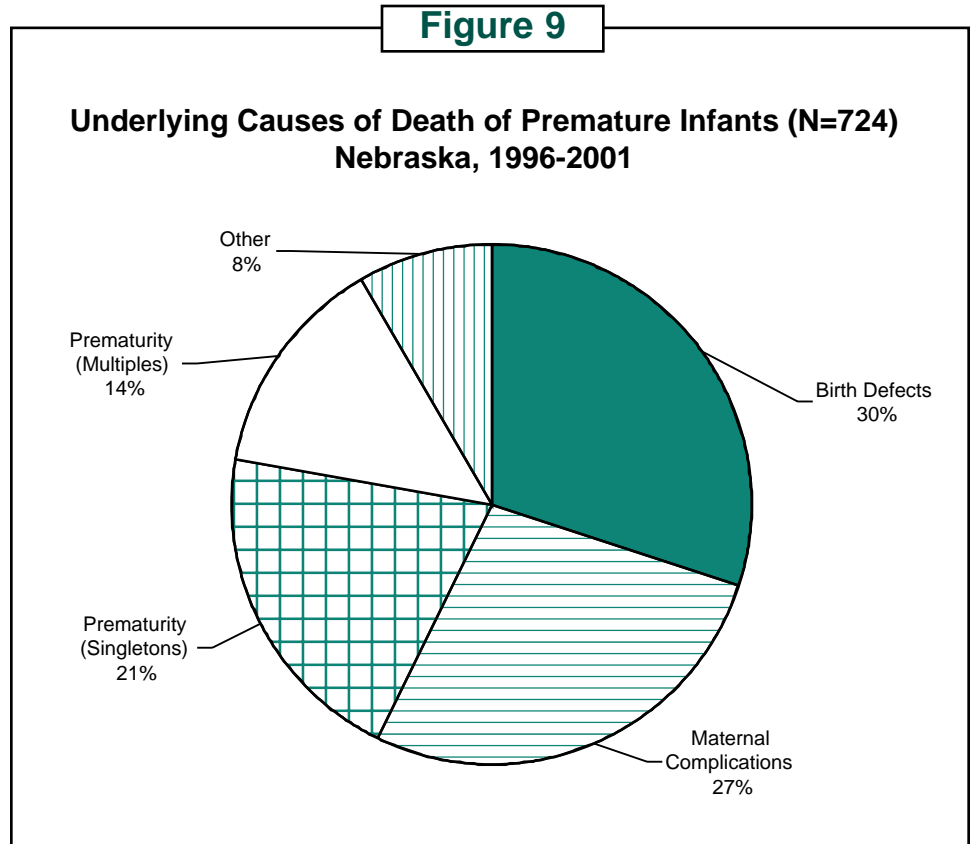
## Causes of death

Based on the Team’s reviews, over one-quarter of all deaths (29%) during the 6-year period were attributable to “Pregnancy-Related” causes, a combined category of maternal complications during pregnancy, labor and delivery problems, and prematurity (Table 1; Figure 8). Birth defects were the underlying cause for an additional 21% of all deaths. An additional one-quarter (29%) of deaths were attributed to non-medical conditions of which the majority were preventable.



## Pregnancy-Related

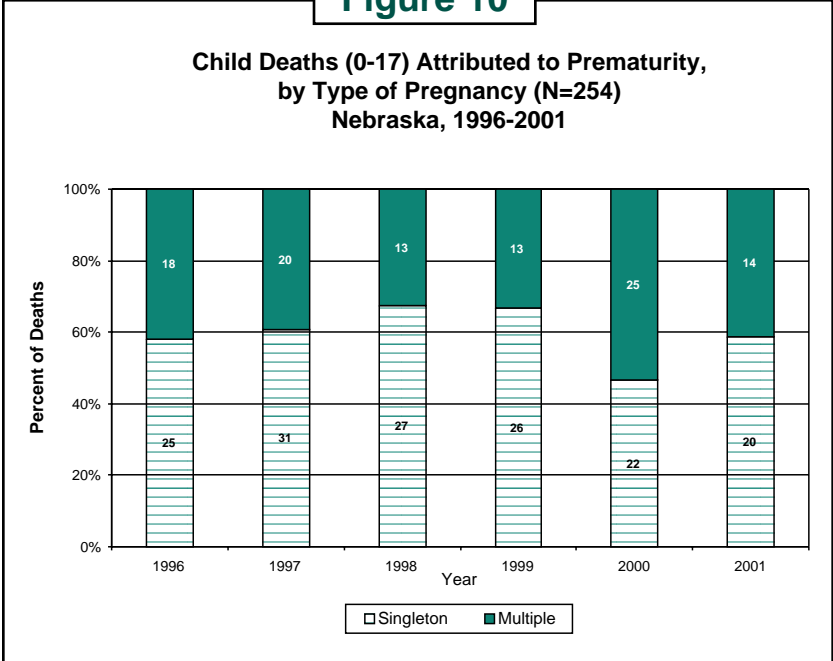
Factors related to pregnancy accounted for 29% of all deaths over the six-year period (Table 1). Prematurity, being born at a gestational age of 37 weeks or less, is widely considered a leading cause of infant death. Of the 1,051 Nebraska infants less than 12 months old who died from 1996 through 2001, 724 (69%) had been born prematurely. However, births of at least 28 weeks gestational age are generally considered “viable,” provided that specialized neonatal care is available. Correspondingly, of the 724 premature infants, 477 (66%) had either a known reason for their prematurity or a distinct cause of death other than their immature development (Figure 9). Thus, for example, maternal complications rather than prematurity were considered to be the underlying cause of death for an infant delivered at 23 weeks of gestation from a pre-eclamptic pregnancy.



Of the 254 deaths that the Team did attribute directly to premature birth, 151 (59.4%) were of multiple gestation infants<sup>3</sup> and 103 (40.6%) from singleton gestations (Table 2; Figure 10). Both prematurity and mortality

from maternal complications were of multiple gestation infants who were not premature. Although research shows that multiple gestation carries a higher risk of maternal complications, it is more useful from a prevention standpoint to categorize them with all maternal complications than in a separate multiple gestation category. Eight percent (45 deaths) of pregnancy-related deaths resulted from complications during labor and delivery, particularly from oxygen deprivation of the fetus during the birth process (Table 4). Thirty deaths did not fit into other cause of death categories, most often from neonatal infections (Table 1).

**Figure 10**



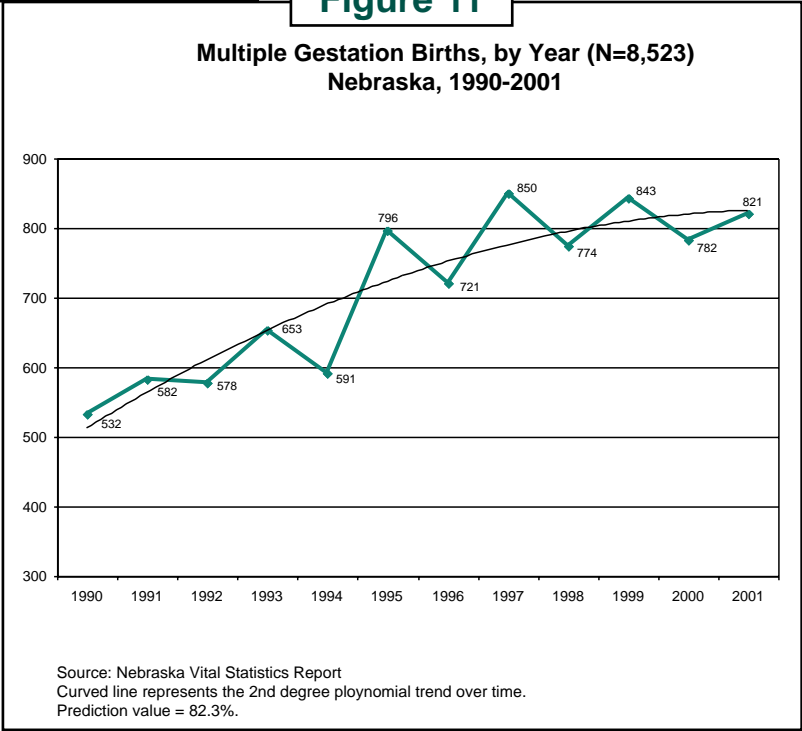
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**Discussion.** In at least three reviewed cases, the same delivery was issued both a live birth certificate and a fetal death certificate, reflecting a lack of agreement on the criteria for a live birth<sup>4</sup>. The Team also struggled with cases of children born with Apgar scores of “0”<sup>4</sup>, and subsequently put on a ventilator where a pulse and/or respiration was obtained. However, in many

rates for multiple gestation infants are considerably higher than for singletons, resulting in a significant impact of multiple births on Nebraska’s prematurity-related death rates. The annual number of multiple births in Nebraska increased significantly during the 1990s, although slowing towards the latter part of the decade (Figure 11). Assisted Reproductive Technology (ART) and other infertility treatments are more likely to result in multiple births, and are credited for much of the rise in Nebraska. However, infertility treatments were not consistently reported in the medical records available for this report, so their precise contribution to prematurity-related and multiple gestation deaths is unknown.

An additional 39% (210 deaths) of pregnancy-related deaths could be traced to maternal complications, the most frequent of which were incompetent cervix and placental abruption (Table 3). Four to five deaths each year

**Figure 11**



<sup>3</sup> Twins, triplets and quadruplets.  
<sup>4</sup> See Glossary for definitions.

cases when the ventilator was turned off no pulse or respiration returned. Was that child born “alive”? The Team chose to accept these cases as live births. However, aside from medical, ethical and/or legal issues involved, inconsistent use of live birth and fetal death definitions hampers the ability to understand and prevent perinatal death. Statewide efforts towards a consensus definition of “live birth” would improve understanding of perinatal health issues.

### ➤ **Recommendations for State Policy Makers**

**All pregnant women should have access, including financial access, to high quality prenatal care.** As state Medicaid eligibility is tightened and employer-provided health insurance trims benefits, the traditional issues of cost, transportation and quality of care once again become major barriers to healthy pregnancies and children. Women who do not receive prenatal care are more likely to have pregnancies and/or newborns that incur larger publicly-paid expenses.

### ➤ **Recommendations for Physicians, Coroners and Pathologists**

**Continuing education on cause of death determination should be provided to all persons who fill out death certificates.** Too many of the certificates reviewed were grossly inaccurate in distinguishing cause of death from manner of death, and in determining primary cause. As the State of Nebraska switches to electronic reporting of birth and death certificates (due in 2004 and 2005, respectively), training on accurate reporting of cause of death will be both timely and critical.

### ➤ **Recommendations for Health Care Providers**

**All pregnant women should receive early, regular and high quality prenatal care.** While it was not possible for this report to assess a possible association between maternal complications and a lack of prenatal care, it is generally accepted that prenatal care improves outcomes by detecting such complications early in pregnancy.

**All personnel who are involved in the care of pregnant women, their fetuses, and their neonates should be aware of the current Guidelines for Perinatal Care of the American Academy of Pediatrics and the American College of Obstetricians and Gynecologists.** These Guidelines are a comprehensive resource on the organization and content of perinatal health services.

The Nebraska Medical Association (NMA) periodically reviews neonatal deaths for the quality of their medical care. Their review of 126 deaths occurring in 1998 found:

- **Continuing need for physician education in recognition / management of high risk pregnancy;**
- **Continuing need for physician education in neonatal management of the very low birth weight infant;**
- **A need for perinatal pathologists to improve the quality of autopsy information and analysis; and,**
- **A need for physicians to be more proactive in support of preventive public health measures, e.g., smoking cessation, early prenatal care.**

Although based on deaths from several years ago, the NMA feels that these conclusions are still valid.

**Providers who care for pregnant women should be aware of new treatments available for the prevention of preterm labor, and the situations for which they are appropriate.** Maternal



complications of pregnancy such as placental abruption are also significant contributors to prematurity, infant death and maternal illness; optimal medical management of these conditions is essential.

### ➤ **Recommendations for Health Care Providers and Families**

**Parents should be informed about the potential importance of the neonatal autopsy, especially in selected circumstances.** Autopsies are not required in most cases, and can be a painful issue for grieving families. However, when not performed information is lost that could be used to prevent future deaths. Balancing family sensibilities and effective public health practice is a challenge. Primary care physicians may have the best opportunity to discuss with parents the importance of an autopsy after a child's death; this is particularly important for the large number of babies that die within their first few hours of life.

### ➤ **Recommendations for Families**

**Early and regular prenatal care is one of the best ways to promote a healthy pregnancy.** During prenatal care visits, women can discuss with their health care provider warning signs of preterm labor, and receive individualized assessments of other potential complications.

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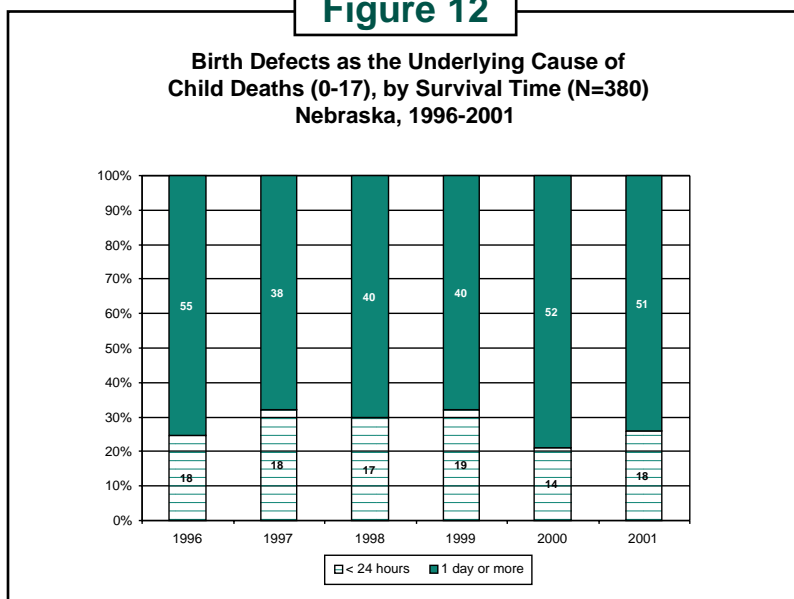
## Birth Defects / Congenital Anomalies

Birth defects accounted for one in five of the infant and child deaths (21%, or 380 deaths), comprising the second largest cause of death category. Between one-fifth and one-third of these deaths occurred within the first day of life (Figure 12). Heart defects were the largest category of lethal defects, and hypoplastic left heart disease was the single most common diagnosis

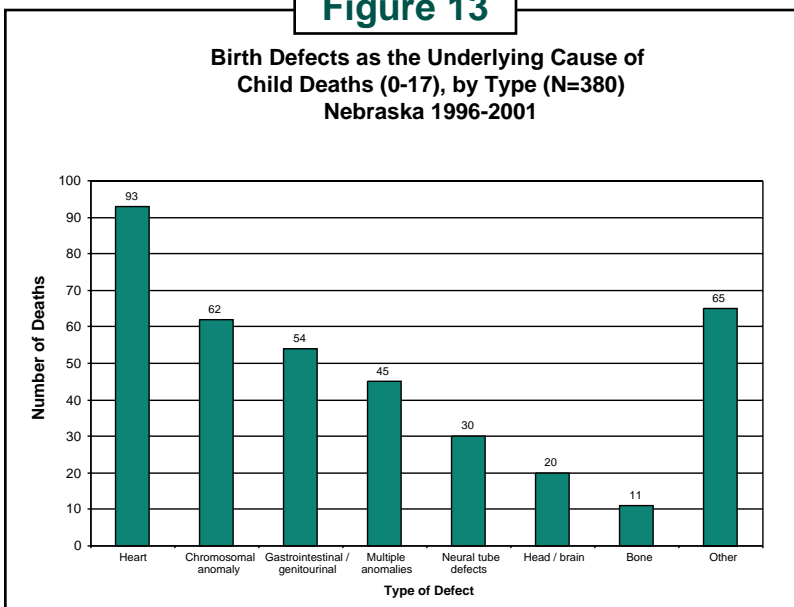
(Table 5; Figure 13). These observations are consistent with national trends.

Time trends in birth defect-related deaths are difficult to assess as the deaths are of children of different ages and birth years. However, 90% of neural tube defect-related deaths occurred within the first six

**Figure 12**

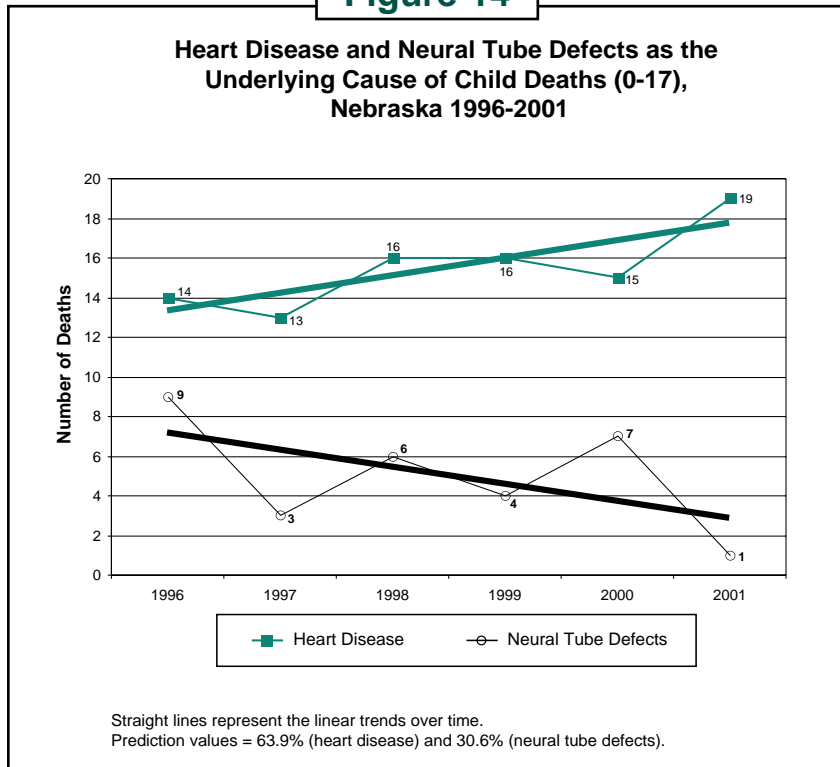


**Figure 13**



months of life and 84% of heart disease-related deaths within the first 12 months; they are thus more likely to reflect actual changes over time. The number of neural tube defect deaths showed a linear decrease over the six year period, while heart disease-related deaths increased (Figure 14).

**Figure 14**



**Discussion.** Nationally, about 1 in 30 babies is born with a birth defect. In Nebraska from 1996 through 2001, the rate varied between 1 in 25 and 1 in 36. The causes of most birth defects, including chromosomal anomalies, are unknown. However, women who do not take multi-vitamins, who use alcohol, tobacco or other drugs, who are overweight or who have diabetes are at higher risk of having a child with birth defects. The decline in the number of deaths to babies with neural tube defects is most likely a result of public health interventions to increase the regular use of folic acid-containing multivitamins by women of child-bearing age, and folic acid fortification of grain products.

Nationally, Down Syndrome (Trisomy 21), Edward Syndrome (Trisomy 18) and Patau Syndrome (Trisomy 13) are the most commonly occurring chromosomal anomalies. However, the survival rate of children with Down Syndrome is considerably higher than that for children with some of the other chromosomal anomalies, and

thus the number of Down Syndrome deaths is considerably lower than the actual number of affected children. In contrast, infants born with extra copies of chromosomes 13 or 18 have a much less favorable outlook and most die during their first year. Nationally, about 2 in 5000 babies are born with either Trisomy 13 or Trisomy 18. The 40 Nebraska infant deaths (1996-2001) from Trisomies 13 and 18 represent an incidence rate of approximately 1.3 per 5000 births. Increasing maternal age is the only commonly accepted risk factor for most trisomies.

All infants born in the state of Nebraska must have a blood test that screens for specific metabolic and genetic diseases. In July 2002, Nebraska's newborn screening program began using tandem mass spectrometry (MS/MS), a relatively new, cost-effective technology, to screen for metabolic disorders. MS/MS increased the state's screening capacity from five to more than 30 different diseases. Although state law mandates screening for only six of the disorders, during the first year of operation more than 90% of Nebraska parents opted to have their newborns screened for the full panel. In 2002, 26 Nebraska newborns were diagnosed with a screened disorder. Although cases are rare, early detection allows early treatment of these potentially debilitating or lethal diseases. Of the five child deaths

(1996-2001) from metabolic disorders, three would have been detectable with the additional capacity of MS/MS.

Nebraska's Birth Defects Registry is administered by the Nebraska Health and Human Services System, and has consistently received a "B" grade in terms of quality and scope as measured by the Centers for Disease Control and Prevention (CDC). However, it does not have the resources to meet new criteria in the 2004 minimum standards, including the ability to track cases, and prevention, research and data use capacity. NHHSS projected the costs of upgrading at approximately \$200,000 per year over three years, but has been unsuccessful so far in obtaining federal funds for this purpose. While a high quality registry does not guarantee a reduction in birth defects and related deaths, it does improve the delivery of appropriate medical care and allows better forecasting of future need by schools and other systems that serve children with disabilities.

## ➤ Recommendations for State Policy Makers

**The Nebraska Birth Defects Registry will require additional resources to effectively and accurately meet the state's needs.** A well-functioning registry monitors birth defect occurrence, causation and related illness and mortality, provides data-based decision making for prevention activities, and monitors the provision of services to children living with congenital anomalies.

## ➤ Recommendations for Providers

**Every effort should be made to accurately identify and report congenital anomalies at birth, whether or not they are lethal.** Accurate and early detection of defects and anomalies will help ensure that the child receives appropriate medical care. It also allows better forecasting of future need by schools and other systems that serve children with disabilities.

## ➤ Recommendations for Communities and Families

**Women of child-bearing age, whether or not they plan on becoming pregnant, should consume a daily multi-vitamin containing 400 micrograms of folic acid.** Neural tubes close within the first four weeks of gestation, often before a woman knows she is pregnant. For folic acid supplementation to be effective, women should be taking it before they become pregnant. Folic acid may also prevent other birth defects, such as cleft lip/cleft palate and some heart defects (March of Dimes, 2003).

**Early and regular prenatal care is one of the best ways to promote a healthy pregnancy.** During prenatal care visits, women can discuss with their health care provider the risks to the fetus from certain foods, lifestyle and environmental exposures, as well as any immunization needs.

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Nebraska Health and Human Services System. Annual Vital Statistics Reports. Current data are available at <http://www.hhs.state.ne.us/ced/vs.htm>. Or, contact Mark Miller, Health Data Coordinator, Nebraska Health & Human Services System, P.O. Box 95007, 301 Centennial Mall South, Lincoln NE 68509-5007 or [mark.miller@hhs.state.ne.us](mailto:mark.miller@hhs.state.ne.us).

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## Sudden Infant Death Syndrome (SIDS)

The reduction in SIDS deaths that began around the early 1990s is one of the nation's public health successes. Nationally, the rate of SIDS dropped by 50% between 1983 and 2003<sup>5</sup>. Similarly, Nebraska's high of 47 cases in 1993 (20.3 deaths per 10,000 live births) dropped to 26 in 2001 (10.5/10,000) (Table 6; Figure 15). National and local "Back to Sleep" campaigns that encourage caretakers to put young babies to sleep on

child was in a child care setting (licensed or unlicensed) and an additional 10% with a non-family member babysitter, emphasizing the need for wide promotion of safe sleep messages (Table 7).

Although Nebraska requires an autopsy before a diagnosis of SIDS can be made, from 1996 through 2001 seven deaths were labeled SIDS without an autopsy.

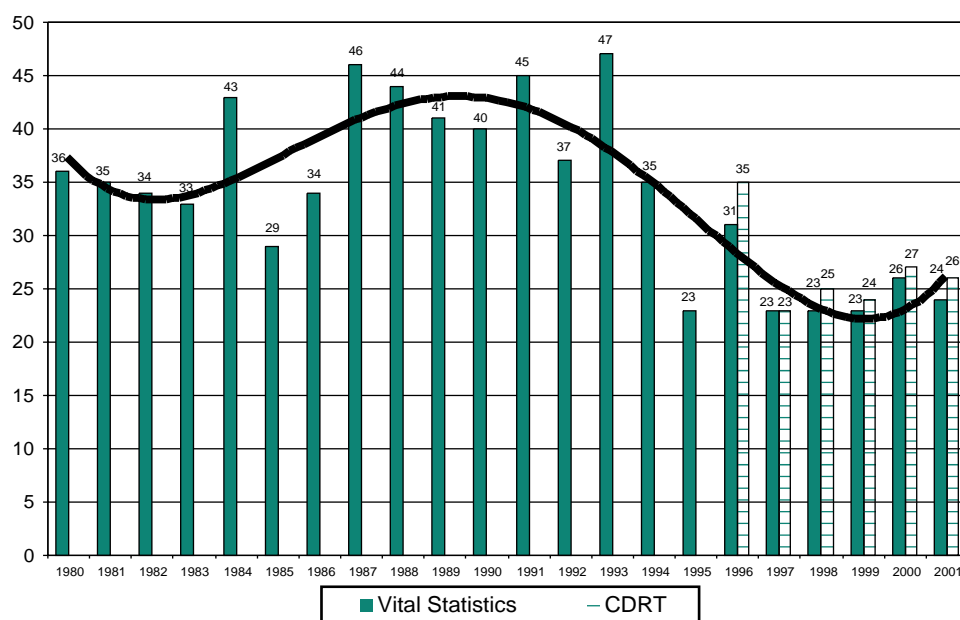
CDRT reviews detected from 0 to 4 more SIDS deaths per year than were recorded on death certificates; the discrepancy is most likely due to late filing of autopsy results. It is also possible that some autopsies were performed but never reported.

**Discussion.** The American Academy of Pediatrics defines Sudden Infant Death Syndrome (SIDS) as 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. In Nebraska only an autopsy is required<sup>6</sup>. The Unintentional Injury section of this report includes cases where infants suffocated while sleeping, either from someone sleeping in the same bed<sup>7</sup> rolling onto them or from their heads becoming

stuck between parts of a bed, crib or other furniture. Several of the cases diagnosed as SIDS, however, had similar circumstances. There are few differences between suffocation deaths and SIDS deaths that are detectable by autopsy. It thus seems likely

**Figure 15**

### Deaths from Sudden Infant Death Syndrome (SIDS), by Source Nebraska, 1980-2001



Source: Nebraska Vital Statistics Report and CDRT data.  
Curved line represents the 4th degree polynomial trend over time.  
Prediction value = 71.2%.

their backs are credited with a large part of these declines. In Nebraska, though, the decline appears to have leveled off, particularly among African-American infants (Table 6). Fourteen percent of Nebraska's SIDS deaths were known to have occurred while the

<sup>5</sup> At least part of the rise in SIDS deaths during the 1980s is thought to be related to increased use of the SIDS diagnosis.

<sup>6</sup> Nebr. Rev. Stat. §71-605.

<sup>7</sup> This practice is often called "co-sleeping" or "bed-sharing." The Team found no reason to believe that any of the sleep-related deaths were intentional.

that some of the SIDS cases were actually suffocations. Indeed, three of the autopsy reports noted the examiner's inability to determine whether the death was a consequence of parental "overlay" or other suffocation, or should be considered SIDS. A recent study from St. Louis, Missouri recommended that public health campaigns target multiple sleep-related safety issues rather than having a sole focus on SIDS prevention.

The number of non-White SIDS deaths is small and it is difficult to make accurate comparisons across race and ethnicity. However, African-American infants represented 17.5% of all SIDS deaths (Table 6), higher than their overall percentage of all deaths (10.9%; Figure 4). Recent surveys of Nebraska mothers show that so far the "Back to Sleep" message has been less

successful in some racial and ethnic communities than others; such campaigns may need to adapt their messages to better reach diverse caretakers<sup>8</sup>.

In addition to sleep position, exposure to cigarette smoke is a significant risk factor for SIDS. The Nebraska Legislature has prohibited or restricted smoking in licensed child care and preschool settings, and home-based settings when client children are present<sup>9</sup>. However, in 2001 15% of Nebraska mothers reported that they smoked during the last three months of their pregnancy, and 10% reported that their newborns were exposed to tobacco smoke. In 2001, the Tobacco Free Nebraska Program began funding community-based tobacco cessation initiatives and in 2003 implemented an educational campaign focusing on pregnant women.

## ➤ Recommendations for State Policy Makers

**Infants in licensed child care facilities should be put to sleep on their back unless there is a documented medical reason why the child should sleep in a different position. Regulations for licensed child care facilities that require crib "bumper pads" and that allow stuffed toys in cribs should be repealed.** Nationally, 20% of SIDS deaths occur in child care facilities, emphasizing the importance of prevention practices in these settings. Improperly secured pads pose a risk of suffocation to infants. The federal Maternal and Child Health Bureau, the American SIDS Institute and other SIDS prevention organizations have taken the position that any items in infants' cribs increase the chances of a SIDS death. Recommendations against bumper pad regulations and supporting back sleeping in child care facilities were also made by the Nebraska Governor's Blue Ribbon Panel on Infant Mortality (2000).

**State-level funding should support work to reduce the prevalence of smoking among pregnant and postpartum women.** Smoking during and/or after pregnancy is a risk factor for multiple infant and childhood illnesses, as well as for SIDS. Current funding resulted from a recommendation made by the Governor's Blue Ribbon Panel on Infant Mortality (2000), and needs to be supported and expanded.

**A standardized death scene investigation should be conducted for all unexpected child deaths.** The American Academy of Pediatrics' standard protocol for investigating unexpected child death requires an autopsy, a thorough death scene investigation and a comprehensive review of the child's medical history. Only the autopsy is currently required in Nebraska. A thorough investigation improves understanding of the events surrounding the death, and can help dispel suspicions of possible caretaker malfeasance.

<sup>8</sup> Back sleeping in the Nebraska PRAMS survey was reported by 65% of White respondents, 35% of African-American respondents, 64% of Asian respondents, 55% of Hispanic respondents and 59% of Native American respondents (2001 data except for Native Americans which are from 1999).

<sup>9</sup> Nebr. Rev. Stats. §71-5707; LB 1005 (2004).

## ➤ Recommendation for Community Organizations and Child Advocates

Existing SIDS prevention regulations, messages and initiatives should be expanded to include other “Safe Sleeping” issues and options. These messages should be tailored to racially, ethnically, culturally and financially diverse audiences. Additional emphasis is needed on including grandparents and other extended family members as targets of safe sleep messages.

“Safe Crib” programs have been successfully implemented in communities around the country to provide low income families with cribs that meet current safety standards.

## ➤ Recommendations for Parents

Parents who choose to bed share with their infants need to be aware of the risks involved. Babies should not be in the same bed with a sleeping adult who:

- Is excessively tired;
- Is overweight;
- Is a smoker; or,
- Has used alcohol, drugs, or medications that cause drowsiness.

Practices shown to reduce the risk of sleep-related deaths to infants include:

- Putting babies to sleep on firm surfaces only – waterbeds are particularly dangerous;
- Identifying places where a baby’s head could become trapped;
- Removal of soft toys, pillows and blankets from the baby’s sleeping area;
- Avoiding exposure of the baby to tobacco smoke, including on clothing;
- Keeping the baby warm but not hot; and,
- Always putting babies to sleep on their backs, unless there is a documented medical reason not to.

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Tobacco Free Nebraska. 2003. A Snapshot Progress Report on Tobacco Free Nebraska (TFN). Available at <http://www.hhs.state.ne.us/tfn/03TFNSnapMain.pdf>. Accessed 4/26/04. For more information on Nebraska's tobacco control program, contact Judy Martin, Program Administrator, Nebraska Health & Human Services System, P.O. Box 95044, 301 Centennial Mall South, Lincoln NE 68509-5044.



Childhood cancer is not one disease, but rather a spectrum of different malignancies with different causes. Leukemia and brain tumors were the most common causes of child cancer deaths in Nebraska. Although overall the number of child cancer deaths dropped from 1996 through 2001 (Table 8), cancer remained the most common cause of disease-related mortality.

**Discussion.** National statistics show that childhood cancer kills more children each year than asthma, diabetes, cystic fibrosis and AIDS combined. However, new treatment options have greatly improved overall survival rates over the last several decades. As was

true in these data, nationally, leukemias (blood cell cancers) and brain and other central nervous system tumors account for over 50% of new cases. The cause of most childhood cancers is unknown. A few medical conditions such as Down Syndrome, other specific chromosomal and genetic abnormalities, and ionizing radiation exposures explain a small percentage of cases. Recent research suggests an association between maternal vitamin intake during pregnancy and a lower occurrence of certain childhood brain tumors. However, environmental and non-medical causes of childhood cancer have been difficult to demonstrate conclusively.

### ➤ Recommendations for Families, Health Care Providers and Health Educators

**In the absence of significant advances in the prevention of childhood cancer, providers should stay up-to-date on findings regarding risk factors, symptoms, and treatment and referral options.**

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## Infectious, Chronic and Other Medical Conditions

The 138 “other” medical cases (Table 9) cover a wide range of causes. Infectious disease-related deaths in infants at least one week old and who were not preterm are included here, recognizing that there is some overlap with pregnancy-related conditions. However, children who died from complications resulting from maternal infections, e.g., HIV or herpes virus, are considered in the Pregnancy-Related section, again recognizing the overlap between categories.

Influenza is typically the leading cause of vaccine-preventable death in children. However, many of the children’s medical records and/or death certificates merely listed the cause of death as “pneumonia” without specifying a specific causal agent. It was thus not possible to quantify the number of influenza-related deaths although they are likely a large part of the 11 known pneumonia deaths.

The single death from chickenpox does, however, testify to the dramatic reduction in illness and death from other once common, vaccine-preventable infectious diseases - polio, measles, mumps, rubella, diphtheria, tetanus, pertussis, and hepatitis B. The organisms that cause these diseases have not disappeared, however,

and both the diseases and related deaths will reemerge if vaccination coverage drops. Currently, more than 70 percent of Nebraska two-year olds have received the chickenpox vaccine. Children who are not vaccinated risk getting the disease as adults when complications are more severe. Complications from chickenpox can include bacterial infections, pneumonia, dehydration, central nervous system problems and death.

Notable in this category are 16 deaths due to asthma (Table 9). These deaths occurred almost entirely in children who were receiving medical care and who were regular users of inhalers. Only one case was attributed to the caregiver’s being unable to find the child’s “EpiPen®” during the crisis<sup>10</sup>. More often, use of an inhaler or emergency injector did not avert the fatal attack.

**Discussion.** Asthma deaths can occur in children with either mild, moderate or severe persistent asthma; there is no relationship between severity and the risk of an asthma-related death. Recent studies have shown that regular use of inhaled corticosteroids will decrease asthma deaths. Reliance on albuterol inhalers and emergency injectors is a warning that a child’s asthma is not being properly controlled.

### ➤ Recommendations for Providers

**Pediatricians and other providers should stay current with the Standards for Child and Adolescent Immunization Practice, and the disease-specific Recommendations of the Advisory Committee on Immunization Practices (ACIP).** Recent shortages of vaccines, although not posing imminent danger to the public, require providers to be aware of changes in scheduled vaccines so that as many children as possible can access vaccine.

### ➤ Recommendations for Communities

**There are many resources available to help improve community health and prevent disease.** For example, the Guide to Community Preventive Services addresses the effectiveness of three population-based strategies to increase vaccination coverage: 1) Increasing community demand, 2) Enhancing access to vaccination services, and 3) Provider-based interventions.

### ➤ Recommendations for Providers, Communities and Parents

**The Centers for Disease Control and Prevention now recommend influenza vaccine for healthy children ages 6 to 23 months.** These changes are the result of recent reports demonstrating that otherwise healthy young children aged 6 to 24 months are hospitalized for influenza and its

<sup>10</sup>EpiPen is the registered trademark of a specific brand of self-injectable epinephrine.

complications at rates comparable to those for whom influenza vaccination is already recommended, including the elderly.

**Parents should consult their providers about which vaccines their children should have and when, and keep track of their children's immunization status.** The Centers for Disease Control and Prevention (CDC) consider vaccinations some of the most important tools available for preventing disease. Vaccinations not only protect children from developing a potentially serious disease but also protect the community by reducing the spread of infectious disease.

**Beginning July 1, 2004, all Nebraska students enrolled in Kindergarten or 7th grade, and out-of-state transfer students, must either receive the varicella (chickenpox) vaccine, provide documentation that they have had chickenpox, have previously received the vaccine, or be excused for religious reasons.**

**Children with persistent asthma should be taking a daily prevention medicine, the most effective being inhaled corticosteroids. Reliance on albuterol-based inhalers in an emergency should not be considered effective control of asthma.** Frequent use of albuterol inhalers or an emergency injector, disturbed sleep or a decrease in activity levels are warnings that a child's asthma is not being properly controlled. A customized, written asthma action plan developed in conjunction with the child's medical provider should be on file at the child's school and/or child care facility.

**All children with asthma and their caregivers should receive standardized asthma education and training from a qualified, licensed, or certified health care professional.** Training should include use of a physician-directed Asthma Action Plan designed to properly control the child's asthma.

## ➤ Recommendations for Parents

**Call the doctor for acute symptoms of abdominal pain, fever and vomiting or nausea.**

Appendicitis is a common condition that affects six percent of the population sometime in their lifetime; younger patients have higher rates of complications. The two deaths from ruptured appendix occurred when parents were uncertain about the severity of the child's illness. An urgent medical evaluation should be done at a doctor's office or a hospital Emergency Department whenever severe abdominal pain, fever and vomiting or nausea continue for more than four hours.

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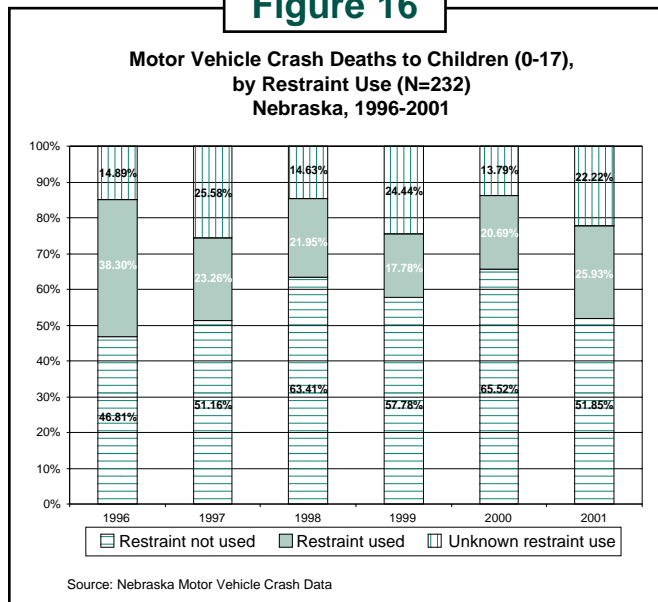
The Community Guide. 2003. Guide to Community Preventive Services – Vaccine Preventable Diseases. Available at <http://www.thecommunityguide.org/vaccine/default.htm>. Accessed 1/15/04.

## Motor Vehicle-Related Incidents

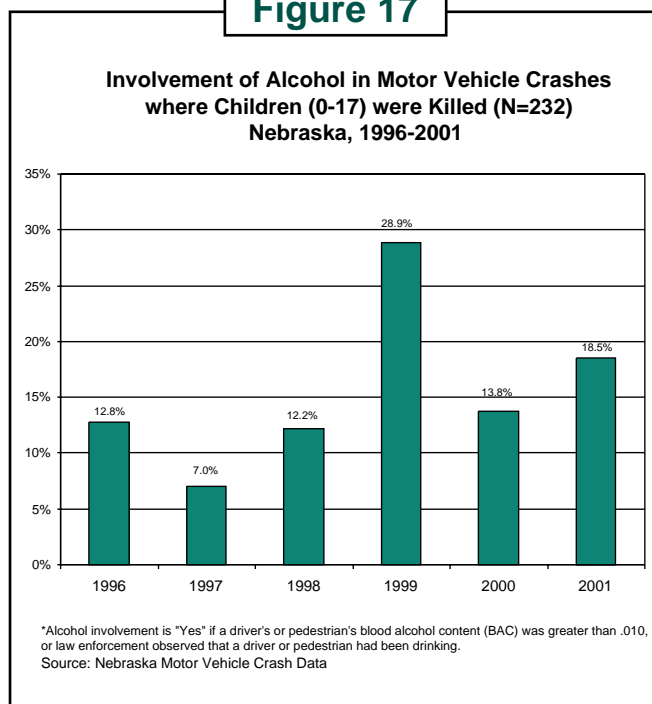
The third most frequent cause of death to Nebraska's children from 1996 through 2001 involved motor vehicles in traffic situations. Some of these deaths occurred out of state and details were not available. 218 children were killed while in a motor vehicle either as driver or passenger, representing 84 percent of all motor vehicle-related deaths (Table 10). An additional thirty children (11.6%) were struck and killed by motor vehicles while they were walking or riding a bicycle. The majority of these involved children between ages five and 10 darting out into traffic or attempting to cross a street against the light. Three young pedestrians were struck by trains. Six children were killed while riding all terrain-type vehicles, while an additional three were killed in a (single) school bus accident.

Information on the use of restraints (safety belt or child safety seat) or the involvement of alcohol was not available for all of the incidents. However, at least 42% of the children killed in car crashes were documented either as having been unrestrained or as having been ejected from the vehicle (Table 10). Given that restraint use was unknown in nearly half of the cases that the CDRT reviewed, the true percentage of unrestrained children is likely higher. This is consistent with Nebraska Department of Roads (NDOR) motor vehicle crash data showing that for five out of the six years, restraints were not used over 50% of crashes where children died (Figure 16).

**Figure 16**



**Figure 17**



The NDOR data also show that the involvement of alcohol in crashes where children were killed increased over the six year time period (Figure 17). Data were not available to consistently determine whether the alcohol use was by the child, someone else in the child's vehicle, or a person in a different vehicle involved in the crash. However, nationally, nearly two-thirds of children age 15 and younger who died in alcohol-related motor vehicle crashes were riding with the drinking driver.

**Discussion.** The NDOR crash data include deaths to non-residents but not deaths to residents that occurred out-of-state, and thus Figures 16 and 17 have slightly different total numbers of deaths than Table 10. Clearly though, many motor vehicle crash deaths could be prevented through better application of safety measures and improved enforcement of existing laws. The Nebraska Injury Prevention State Plan provides a comprehensive assessment of motor vehicle injuries and recommendations to prevent future injuries; for more information contact the Injury Prevention Program, Nebraska Health and Human Services System (402/471-2101; <http://www.hhs.state.ne.us/hpe/injury.htm>).

## ➤ Recommendations for State Policy Makers

**Nebraska's safety belt law should be upgraded to primary (standard) enforcement.** States with primary enforcement laws have a safety belt usage that is estimated at 15% higher than those without. Safety belts cut the risk of death or serious injury in a crash by 45 to 50%. Children riding with unrestrained drivers are much more likely to be completely unrestrained compared to children riding with belted drivers.

**Child endangerment laws should be considered that provide special sanctions for drivers convicted of DUI with a child in the vehicle.**

**Better enforcement of existing laws against serving alcohol to intoxicated bar and restaurant patrons would likely reduce alcohol-related crash fatalities by approximately 11%.**

**Stronger legislation, prevention activities such as checkpoints, and more strict enforcement of laws designed to prevent driving under the influence (DUI) have been shown effective in reducing the incidence of drinking and driving.**

**Upgrade Nebraska's graduated licensing provisions.** Research shows that unsupervised driving with teenage passengers increases crash risk compared with driving alone - the more passengers the greater the risk. Provisions that would make Nebraska's graduated licensing more effective include:

- requiring at least 10 hours of nighttime driving as part of the required 50 hours of supervised drive time; and,
- limiting the number of teenage passengers to one or none during some or all of the intermediate phase, when an adult is not present.

## ➤ Recommendations for Communities

**Existing laws that all children ages six to 18 use a seatbelt in all seating positions should be enforced. Parents must impress upon teens the importance of wearing safety belts every time they drive or ride in a vehicle.** The 2001 Nebraska Youth Risk Behavior Survey (YRBS) indicated that only 25% of teens surveyed always wore a safety belt when they drove or rode in a car.

**Consider local ordinances for safety belts and bicycle helmets.** The National Highway Traffic Safety Administration reports that local ordinances, when coupled with appropriate levels of public awareness and law enforcement, can be very effective in increasing safety belt use and reducing the severity of injury.

**Examine the need for community-specific programs and ordinances that improve pedestrian and driver safety. Communities should continue to closely examine their roads, intersections and train crossings for modifiable hazards.** At least two communities made modifications to dangerous intersections following some of the deaths reported here.

**Enhance public awareness about the need to improve safety for child pedestrians.**

## ➤ Recommendations for Parents

**Parents should limit the number of teenage passengers a teen driver may carry.**

**Children should always use age-appropriate restraints when in a motor vehicle:**

- **Child safety seats.** When used correctly, child safety seats reduce the risk of death by 71% for infants and by 54% for children ages 1 to 4.
- **Child booster seats.** A child who has outgrown a child safety seat (generally at 40 pounds) should use a booster seat until approximately age 8 or 80 pounds and/or 4'9" tall. Children ages 4 – 8 years old are four times more likely to suffer a serious head injury while being restrained only in a safety belt rather than a booster seat.
- **Safety belts.** For children who are large enough to fit in them properly, safety belts reduce the risk of death or serious injury in a crash by 45 to 50%.

**Children ages 12 years and younger should not ride in the front seat.** This eliminates the risk of injury from front passenger-side airbags, and places children in the safest part of the vehicle. Riding in the back seat is associated with a 46% reduction in the risk of fatal injury in cars with a front passenger-side airbag and at least a 30% reduction in the risk of fatal injury in cars without one.

**Bicycle helmets should be worn by all persons (i.e., bicycle operators and passengers) of any age whenever and wherever they ride a bicycle.** Bicycle helmets reduce the risk of serious head injury by as much as 85% and the risk of brain injury by as much as 88%.

**Teach children pedestrian safety.** The most important thing parents can do to teach their children safe pedestrian behavior is to practice it themselves: crossing streets at corners, using traffic signals and crosswalks whenever possible, and making eye contact with drivers prior to crossing in front of them.

**Children under six should never ride all terrain-type vehicles (ATV).** No child under 16 should ever operate an adult-sized all-terrain vehicle. ATVs should be operated only on designated trails, not on public roads or paved surfaces. Personal protective equipment for ATV operators should include a U.S. Department of Transportation-approved helmet with face protection, goggles (if the helmet does not have face protection), a long-sleeved shirt or long pants, non-skid boots and gloves.

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**Drowning**

The most common cause of non-motor vehicle-related, unintentional death was drowning; water-related deaths made up 17% of the 98 total accidental deaths (Table 11; Figure 18). Of these, all but five occurred to

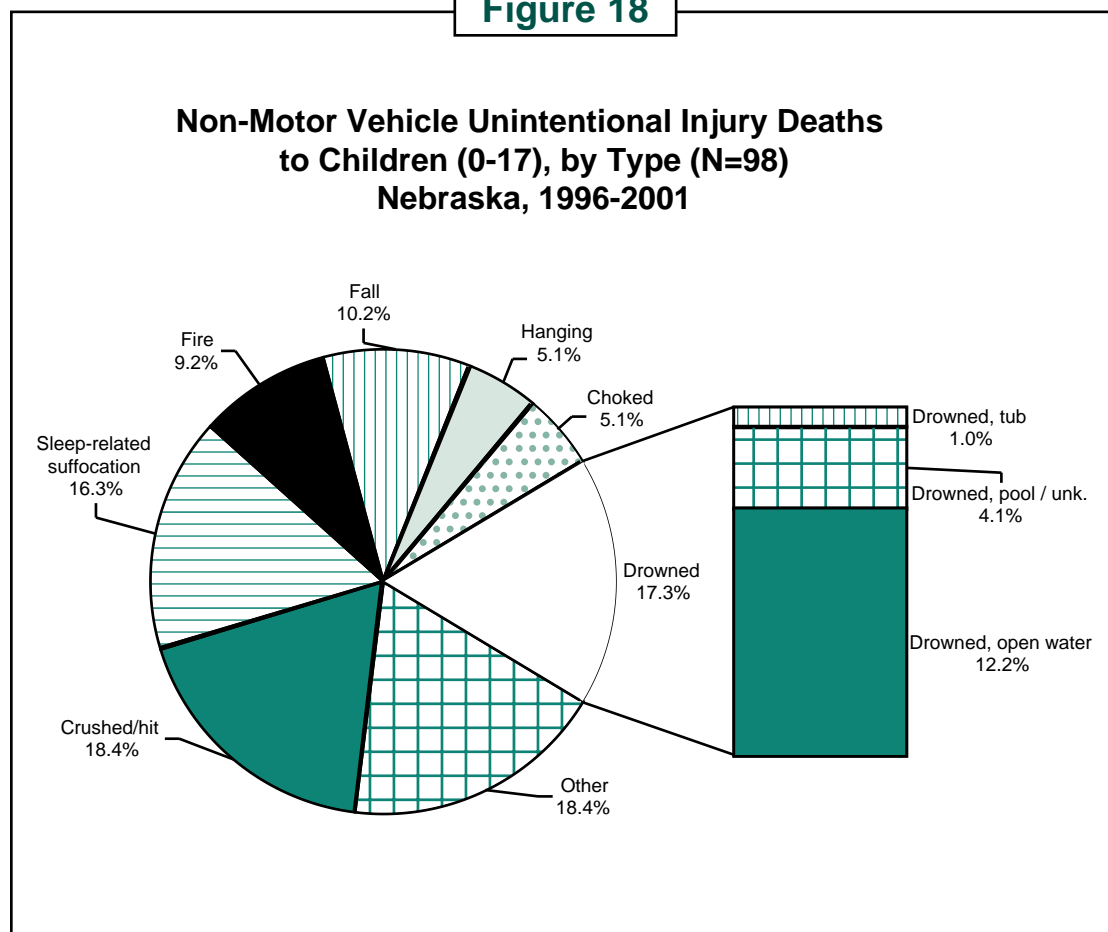
under the age of two are included in the Caretaker Neglect section.

**Sleep-Related Suffocation**

Sleep-related suffocation occurred most often to children under the age of two whose heads became trapped between their crib rails or wedged between pieces of furniture (Table 11). Four infants died while sleeping with a parent or sibling in a bed or reclining chair when their face either became pushed into a cushion or the other person's body, or was covered with an arm or other body part. In two cases the infant suffocated after being placed face down in bed linens. These cases are separate from those officially diagnosed as SIDS.

**Figure 18**

**Non-Motor Vehicle Unintentional Injury Deaths to Children (0-17), by Type (N=98) Nebraska, 1996-2001**



children ages 11 and older playing or swimming in lakes, streams or irrigation ditches. Nine children were revived subsequent to their water exposure, but eventually died from the effects of oxygen deprivation ("near-drowning"). Of the drowning deaths of children age two and younger, one was in a bath tub and one fell into a swimming pool. In a further case of tub drowning, local law enforcement chose to prosecute the caretaker (see under Homicide / Criminal Child Abuse). Six additional drowning deaths to children

under the age of two are included in the Caretaker Neglect section.

**Discussion.** "Safe sleep" for infants involves many more issues in than simply back sleeping. Although only a small number of children were unintentionally suffocated while sleeping, it is important that parents understand the risks to their infants' health associated with various sleeping practices, and how to reduce these risks. A more thorough discussion on sleep safety and recommendations to prevent further deaths can be found in the SIDS section of this report.



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## Fire

Of the children who died from home or other building fires, half were attributed by the Team to Caretaker Neglect, and are discussed in that section. After reviewing the nine remaining cases, caretaker negligence was not felt to have been a predominant factor in those children's deaths. Causes of these fires included faulty electrical switch boxes, a faulty propane oven, and older children playing with matches or lighters (Table 11). In at least two cases young children became scared and confused, and ran away from the parent trying to get them out of the burning home.

**Discussion.** According to the U.S. Fire Administration (USFA), "Nearly half of all children have engaged in fire play. While the majority of the child-set fires are set out of curiosity, not malice, the damage they cause, both in economic and human costs, are real and devastating." The USFA's Fire Safety Campaign for Babies and Toddlers is a public awareness and education campaign designed to draw attention to the increased risk of fire death for young children, and to teach parents and caregivers how they can avoid the tragedy. A child under the age of five is twice as likely to die in a residential fire than the rest of the population. The campaign's slogan: "Prepare. Practice. Prevent the Unthinkable." urges parents and caregivers to prepare by installing and maintaining working smoke alarms; safely storing lighters and matches out of children's reach and sight; and practicing a fire escape plan with small children, which should include helping toddlers understand how to quickly respond in case of fire, and planning how adults can escape with babies. Caregivers send the wrong message to children when they disable smoke alarms.

## Other

Four hanging incidents were considered to be unintentional (Table 11). The Team deferred to the judgment of the local investigators as to whether hanging deaths were unintentional or suicides. One of the deaths apparently resulted from the practice of autoerotic asphyxiation<sup>11</sup>. At least two more resulted from the child attempting to play a joke on family and/or friends.

Eleven children were killed by a motor vehicle backing up, by farm machinery loading or unloading grain, or by construction equipment. In nearly all of these cases, the child had been out of sight less than a minute. Typically, the vehicle operator lost sight of the child and/or the child escaped supervision long enough to get into or create a hazardous situation.

Children were distressingly easily able to access firearms, including finding the keys to gun cabinets and trigger locks and knowing where their parents "hid" loaded weapons. In addition to three deaths related to playing with a firearm, another 40 teens used a firearm to commit suicide.

**Discussion.** Children struck by a motor vehicle or machinery were among the most tragic of the deaths reviewed. Nationally, among non-traffic fatal incidents to children under 14 (1999-2003) reviewed by the Trauma Foundation's Kids 'n Cars program, 42% were of children backed over by a motor vehicle. Children are very quick, small and easily out of sight when in front of or behind farm machinery or a motor vehicle, particularly as personal vehicles get larger and longer. Adults operating motor vehicles or farm machinery can not adequately monitor the whereabouts and movements of young children.

Trigger locks are safety locks designed to prevent a gun's trigger from going off accidentally. However, the Consumer Product Safety Commission found that many of the locks currently on the market could be easily opened by children. While there is no national safety standard for gun locks, the State of California recently adopted very stringent standards for locks sold in the state. A list of locks that have been tested and approved is available at <http://caag.state.ca.us/firearms/fsdcertlist.htm>.

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<sup>11</sup>Self-strangulation for sexual arousal, sometimes called "pass out." A non-professional but thorough discussion of the practice can be found at <http://members.aol.com/bj022038/index.html>.

## ➤ **Recommendations for State Policy Makers**

**A comprehensive assessment of building codes and enforcement ability in combination with fencing ordinances may reduce child drowning deaths.** Ordinances requiring secure fencing around home swimming pools reduce the access of young children to these dangerous areas. However, without enforcement, enactment of fencing ordinances alone is insufficient to prevent pool deaths.

**Improve enforcement of building codes and laws requiring landlords to maintain smoke alarms in rental units.**

## ➤ **Recommendation for Community Organizations and Child Advocates**

**Existing SIDS prevention regulations, messages and initiatives should be expanded to include other “Safe Sleeping” issues and options. These messages should be tailored to racially, ethnically, culturally and financially diverse audiences.** Additional emphasis is needed on including grandparents and other extended family members as targets of safe sleep messages.

## ➤ **Recommendations for Communities**

**Communities are encouraged to implement smoke alarm distribution programs.** Homes with smoke alarms typically have a death rate that is 40% to 50% less than do homes without them.

**Consider implementing firesetter prevention and fire intervention programs.** The Juvenile Firesetter Intervention Program, available through the Nebraska Fire Marshal’s Office, strives to intervene with children who play with or deliberately set fires, as well as effectively teach fire prevention to the community. Family-oriented videos are also available for agency use.

**Local law enforcement agencies have access to trigger locks for community giveaway programs and should be used as a resource.**

## ➤ **Recommendations for Parents**

**When near a pool or body of water, parents and other caretakers should always designate one adult to keep sight of all children, at all times. A child should never be unsupervised in or near water, even shallow wading pools.** Devices such as bathtub seats or “water wings” can not be relied upon to keep children afloat and alive. Children can drown in as little as 1 inch of water, very quickly.

**The ability to swim does not replace the need for supervision of children or the use of personal flotation devices (PFD; “life vests”) on boats and around deep or moving water, even into the teenage years.** Swimming lessons are an important step, but do not make a child “drown proof.” Older children should be taught to always swim with a buddy. **U.S. Coast Guard-approved life vests should always be used on boats for children and teens; on docks and**



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**riverbanks for young and school age children; and at beaches and swimming pools for young children and nonswimmers.** Nebraska law requires children of all ages to wear a Coast Guard type I, II, III or V PFD when operating or riding a personal watercraft<sup>12</sup>.

**Smoke alarms should be installed and maintained on every floor of a home. Smoke alarms are recommended in each sleeping room.** Alarms need to be tested frequently and the batteries replaced at least once a year. The entire alarm should be replaced every 10 years as the sensors wear out even though the alarm will still sound when tested. Devices are currently available to assist individuals with sight and/or hearing impairment to recognize warnings provided by smoke alarms.

**Family discussions on fire safety will help familiarize young children with what to do during a fire.** These discussions can also help adults recognize and correct any hazards that would delay or block escape.

**Matches and lighters should be stored in safe places that are unknown to young children.** All children should be taught about the dangers of matches and lighters. Children who are known firestarters or fascinated by fire require constant supervision, and may benefit from counseling.

**Children who are in the vicinity of moving motor vehicles or machinery should be under focused adult supervision at all times.** Adults operating motor vehicles or farm machinery can not adequately monitor the whereabouts and movements of young children.

**Home hot water heaters should be set no higher than 120 degrees F.** Children's skin is thinner than adults' and burns more quickly. It takes just three seconds for a child to sustain a third degree burn from water at 140 degrees Fahrenheit, requiring hospitalization and skin grafts.

**Eliminate potential safety hazards for young children.** Thorough home "child-proofing," from a child's perspective, can avoid needless tragedies. Safety, not convenience, should be the first consideration when child-proofing the home. Buckets, containers and wading pools should be emptied immediately after use, and stored upside-down and out of children's reach. Keep toilet lids shut; toilet locks may be helpful. File cabinets with non-latching drawers should be considered a hazard.

**Parents and caregivers should be aware of the types of foods and objects that pose a choking risk for children, become familiar with methods to reduce this risk, and be able to treat choking in children.** Children under five should not be expected to be able to swallow pills.

**Parents who keep firearms in the home must understand the importance of storing unloaded firearms and ammunition in separate, locked and inaccessible locations. Trigger locks are an important component of firearm safety.** If a child obtains an improperly stored, loaded firearm and causes injury or death, the adult owner is potentially criminally liable.

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<sup>12</sup>Nebr. Rev. Stats. §37-1241.02; LB 176 (1999).

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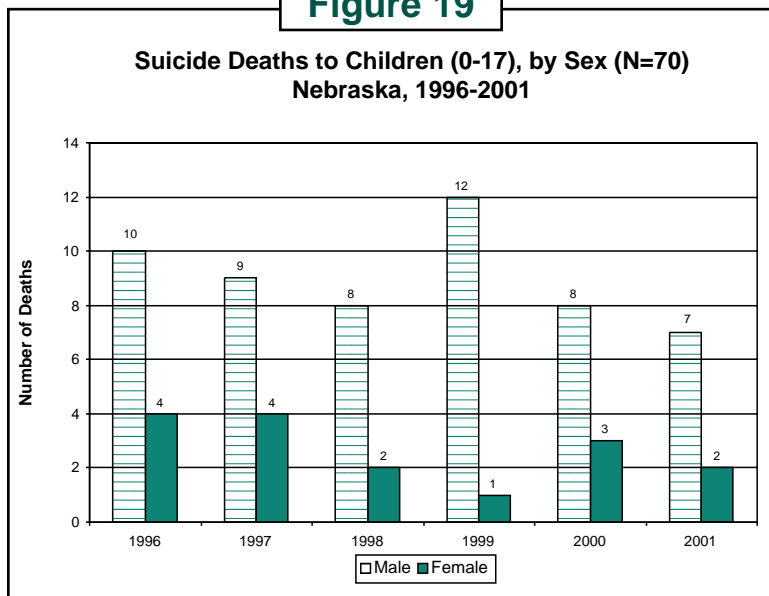
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## Suicide

Although numbers are apparently decreasing over time, at least 70 children ranging in age from 11 to 17 took their own lives during the 6-year period (Table 12; Figure 19). Seventy-eight percent of the suicides were boys; the most common age was 16 (30%) for both sexes (Figure 20). Over half (53%) of the children used a firearm to commit suicide. Triggering factors

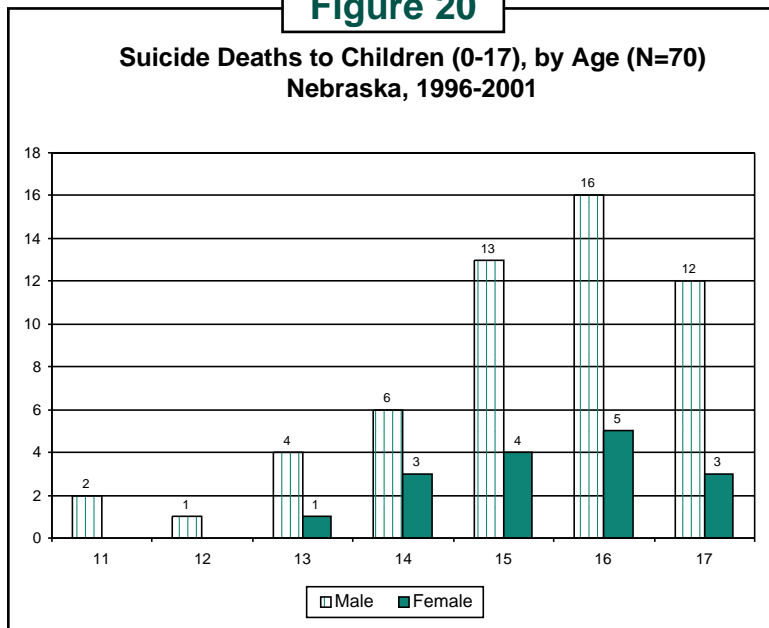
for the cases reviewed by the Team include perceived academic failure, fear of parental retribution for various incidents, and the aftermath of personal embarrassment. Some of the youth had documentation of chronic depression, other mental health issues and/or previous suicide attempts. Two children had been using a prescription medication that has been linked to suicidal behavior in depressed children. In several cases the Team could not find documentation of a motivating factor.

**Figure 19**



**Discussion:** The Centers for Disease Control and Prevention cite suicide as the third leading cause of death for young people. The 1999 Surgeon General's Report on Mental Health called attention to suicide in the child and youth population, noting that "The incidence of suicide attempts reaches a peak during the midadolescent years," with mortality increasing steadily through the teen years. Pre-existing mental health problems, availability of firearms, substance abuse, youth-specific stressful life situations, and a focus on the drama of suicide by the news and entertainment industries are all considered factors contributing to the incidence of youth suicide. The impact of a friend's suicide is extremely strong.

**Figure 20**



A growing body of literature points to effective mental health interventions that reduce risk for suicide when youth considering suicide are identified and treated with therapy and medication. Effective reduction of youth suicide requires a focus on both prevention and intervention with the many professionals who interact with youth including primary health care professionals; school nurses and counselors; clergy; mental health providers; and child welfare, juvenile justice, corrections and law enforcement professionals. Additionally, communities need the ability to screen for and identify youth at risk for suicide, and to implement individualized intervention plans when needed.

In the past few years, the availability of resources for community-based interventions has grown dramatically:

- Nebraska's Suicide Prevention Task Force has developed suicide prevention curriculum

for educators, health care providers, and adult community members.

- The National Center for Suicide Prevention Training provides a workshop series, "Youth Suicide Prevention: An Introduction to Gatekeeping", designed for community-based planning groups, public health practitioners/officials, mental health practitioners/officials, and other interested individuals.
- The Youth Residential Treatment Center (YRTC) in Geneva (Nebraska) has a model

suicide prevention program that has been highlighted regionally and nationally.

- Pilot screening projects for children at risk of suicide based on the "TeenScreen® Program" are being considered by the YRTC, the University of Nebraska Medical Center and BryanLGH Medical Center.
- Project Relate, a statewide mental health anti-stigma public service campaign, began in April 2004.

## ➤ Recommendations for Communities

**All teenagers need access, including financial access, to confidential, professional mental health services.** Co-locating mental health professionals with health care providers or within other non-traditional settings may make youth more comfortable accessing these services.

**Broad-based public education efforts are needed to draw attention to suicide as a significant and preventable cause of death for youth, create awareness of signs that indicate risk for individual youth, and encourage help-seeking actions when at risk youth are identified.**

## ➤ Recommendations for Parents

**Parents who keep firearms in the home must understand the importance of storing unloaded firearms and ammunition in separate, locked and inaccessible locations.** A previous CDRT report included "lessons learned" regarding the need for youth suicide prevention and a specific recommendation regarding safe home storage of firearms to prevent their use in suicidal acts; these recommendations are still valid.

**Any suicidal gesture, no matter how "harmless" it seems, demands immediate professional attention.** Parents must be aware of signs and symptoms of depression and/or suicide ideation in teenagers, and not be afraid to talk to their children about them. No talk of suicide should be taken lightly.

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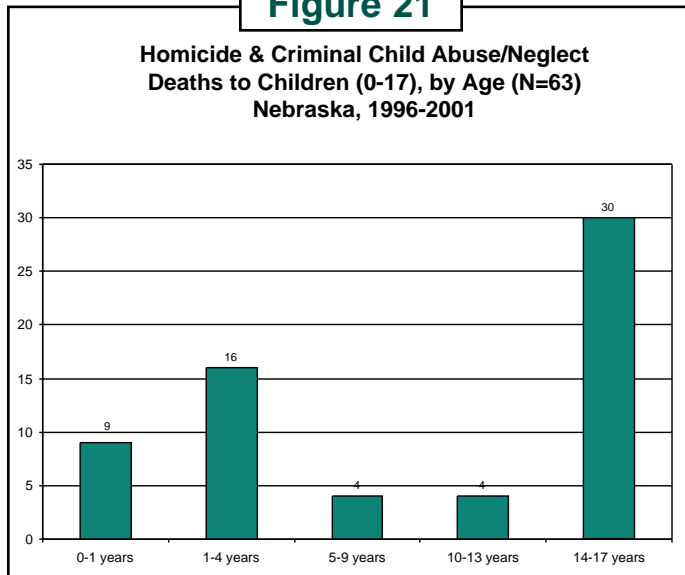
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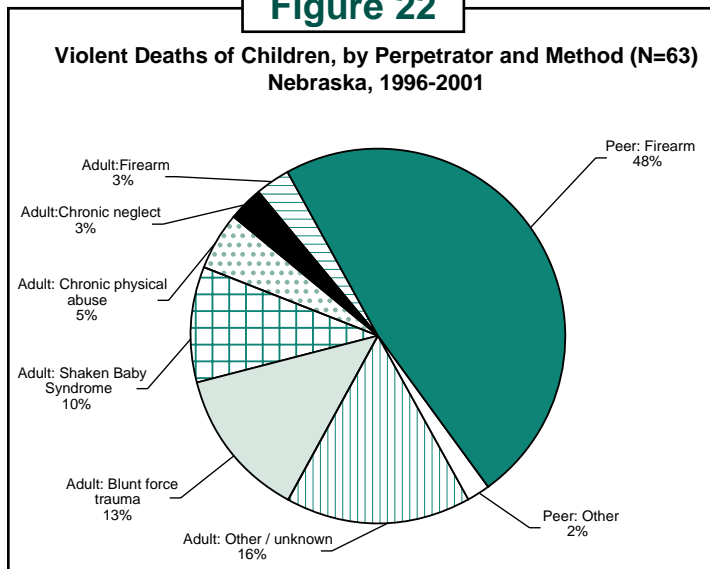
## Homicide – Youth Violence / Criminal Child Abuse & Neglect

Sixty-three children suffered violent or abusive deaths from 1996 through 2001; children under five and older teenagers were at highest risk of a violent death (Table 13; Figure 21). Thirty-two children between the ages of 12 and 17 were shot (n=30), beaten (n=1) or strangled (n=1) in disputes with friends or peers (Table 13, Figure 22). These 32 deaths occurred in 10 different counties around the state; all but two of the victims were male (94%).

**Figure 21**



**Figure 22**



Of the 31 children not killed by peers, 14 (45%; 22.2% of all deaths) died from being shaken or from blunt force trauma, e.g., having their head hit against a hard surface (Table 13, Figure 22). At least five of the children were intentionally killed, caught up in disputes between their mothers and their current or former male partners. Nineteen of these 31 victims were male (61%)

At the request of the 2003 Governor's Children's Task Force, a subcommittee of the CDRT reviewed in depth 30 deaths from child abuse that occurred in Nebraska between 1998 and 2003. Key findings from these 30 deaths include:

- Abusive head trauma was the most frequent cause of death (57%). These injuries occur when a child's head is slammed against a surface, is severely struck, or when a child is violently shaken.
- Young children are the most vulnerable victims.
  - Twenty-five (83%) of the victims were five years of age or younger.
  - Nineteen (63%) were two years of age or younger.
- Most fatal abuse occurred when a caregiver lost patience with a child (50% of known precipitating events); crying and toilet training accidents were the two most common explanations given for the abuse.
- Mothers and fathers were almost equally divided as being the perpetrator in the child's death. Seven mothers and eight fathers were responsible for the death of his/her child.
- Ten children were killed by their mother's current or former boyfriend.
- The majority of perpetrators had a history of substance abuse.
  - Seventeen (59%) had a history of drug/alcohol use.
  - Eight (28%) had a history of methamphetamine use.
  - Three (10%) were known to have used methamphetamines close to the time the injuries occurred.
- Domestic violence in one form or another was a factor in the perpetrator or family's history in a significant number of cases. Thirteen of the

twenty-eight families (46%) had a documented history of domestic violence in the home<sup>13</sup>.

It is important to note that at least 29 people were charged criminally for the death of these 30 children. The most frequent charge was for felony child abuse resulting in death. To date, sentences have ranged from termination of parental rights to surviving children, to the death penalty.

**Discussion – Youth Violence:** Nationally, homicide is the second leading cause of death for teenagers. The presence of guns turns “normal” adolescent conflicts into violent confrontations resulting in serious injury or death. Common risk factors for adolescent gun violence include:

- exposure to violence, including domestic violence and violent media (e.g., movies, song lyrics, video games);
- being victimized, including bullying;
- lack of knowledge of the legal consequences for using a handgun;
- lack of self-control;
- low self-efficacy;
- aggression;
- substance use; and,
- the availability of guns.

There are many resources available to communities wishing to reduce youth violence. The Nebraska

Department of Education maintains a school safety website, with links to the state’s Safe and Drug-Free Schools and Communities (SDFSC) Program which supports efforts to prevent violence in and around schools, to prevent the illegal use of alcohol, tobacco and other drugs, and to better involve parents and the community in schools’ prevention activities.

At the national level, the Surgeon General’s Report on Youth Violence (2001) examines youth violence from a public health perspective, with an important focus on protective factors and effective, research-based prevention strategies that can be implemented by parents, schools, and communities. The Guide to Community Preventive Services also reviews the effectiveness of community interventions that work to prevent violence through four main approaches: (1) behavioral change interventions, (2) health and education system level interventions, (3) legislation and public policy interventions, and (4) environmental interventions. Effective community-based programs to prevent youth violence typically include:

- clear goals and objectives;
- a broad base of community professionals, organizations and parents;
- an understanding of the source of firearms used in crimes; and,
- an understanding of the extent of violence-related injuries as well as deaths.

## ➤ Recommendations for Communities and Parents

**Schools, communities and others concerned about youth violence should be aware of and take advantage of the substantial resources available to help develop effective, community-based prevention programs.**

## ➤ Recommendations for Parents

**Limit children’s TV watching to 2 hours a day or less.** Know what your children are watching and help them choose programs that are less violent. If a program contains violence, talk about it with your child; questions you might ask include:

- Is this real or pretend?
- Is this the way to solve a problem?
- What would really happen if you did that?
- How would you feel if that happened?

<sup>13</sup>Two cases involved siblings.



**Discussion – Criminal Child Abuse & Neglect:** The 30 deaths (1998-2003) reviewed for the Governor’s Children’s Task Force overlapped with the deaths to young children (1996-2001) reported in Table 13. Causes and circumstances from the two time periods were similar, supporting an interpretation that the more detailed findings of the Children’s Task Force are broadly generalizable. Alcohol and drugs play large parts in child neglect, inappropriate child care, child

abuse and motor vehicle crashes. Being under the influence of alcohol or illegal drugs typically has a strong effect on a person’s judgment; methamphetamine in particular tends to decrease the ability to tolerate child-related frustrations. Actions taken to prevent child deaths resulting from abuse by a caretaker must include strategies to address the problems of substance abuse and domestic violence.

### **Selected Recommendations from the Governor’s Children’s Task Force\***

#### **Prevention:**

- **Statewide, voluntary home visiting programs are needed that provide support and assistance to expecting and new mothers in their homes.**
- **There is a need for parent education programs located, for example, in high schools that focus on teen parents, or within substance abuse treatment programs for mothers and families with young children.**
- **Respite care is needed for families that have children with special needs.**
- **Drug Courts which incorporate treatment in their program should be established locally and be funded by a combination of federal, state and local funds.** The use of Family Drug Courts to mandate treatment of all household members should be explored and the development of pilot programs encouraged.

#### **Investigation of Suspected Child Maltreatment:**

- **A multidisciplinary approach to the investigation of child maltreatment reports should be promoted by providing funding to local child abuse investigation teams for coordination, training and operating expenses.**
- **Increase the capacity of law enforcement professionals to investigate child maltreatment reports through increased training.**

#### **Prosecution of Child Maltreatment:**

- **Persons who perpetrate violent acts against children should be dealt with appropriately through the criminal justice system.** County attorneys should be given the necessary resources and assistance to successfully prosecute these crimes.

### **Recommendations from the Child Death Review Team**

#### **➤ Recommendations for State Policy Makers**

**Nebraska law should be amended to reflect current knowledge that exposure of children to domestic violence is harmful and constitutes child abuse.** Domestic violence was identified as either a direct factor or part of the family’s history in 46% of the cases studied where abuse by a caretaker led to a child’s death. Of all the information found by the CDRT in violent death cases, domestic violence was one of the most common occurring related factors. This is consistent with national figures that indicate domestic violence is the single most predictive factor for child abuse.

\* Implementation of many of the Task Force’s recommendations had begun at the time this report went to press.

**Local law enforcement should have the legal and financial ability to require immediate testing for illegal substance use when such use is legitimately suspected to have contributed to the death of a child.** It is impossible to assess the involvement of chemical substances in the death of a child if testing for these substances is not done immediately at the death scene on all care providers present when the child dies. Since this is a sensitive issue concerning individual privacy rights, substantial care and sensitivity would need to be exercised so that the constitutional rights of all involved are protected.

## ➤ **Recommendations for Communities and Parents**

**Never leave a child in the care of someone who is abusing drugs, especially methamphetamines.**

**Safe and affordable child care will reduce the number of children left in inappropriate and/or unsafe situations.**

**“Never, never, never shake a child<sup>14</sup>.”** Shaking is ineffective in stopping crying and causes tearing and bleeding of veins inside the brain. Severe damage from shaking can occur in children through age five. There are many resources available to help communities understand and publicize the dangers of shaking babies. The HHSS Office of Protection & Safety is currently developing brochures, ad campaigns and other printed materials on Shaken Baby Syndrome to be distributed to local communities.

**Holding a child in hot water should never be considered an acceptable form of punishment.**

**Relatives, friends and neighbors should follow their instincts – and the law - when they suspect substance abuse and/or child abuse/neglect by the caretaker(s) of young children<sup>15</sup>.** The State is working to expand Child Protection personnel so that all reports of abuse or neglect receive sufficient follow-up. Public awareness of the signs, symptoms and criteria of abuse and neglect will increase the quality of such reports.

## **References and further resources**

Child Death Review Team. 2003. Report to the Governor's Children's Task Force. Available through the Office of Family Health, Nebraska Health and Human Services System; 402/471-2907 or family.health@hhss.state.ne.us.

Governor's Children's Task Force. 2003. A Roadmap to Safety for Nebraska's Children. Available at <http://gov.nol.org/childtaskforce/index.html>, or through the Office of Family Health, Nebraska Health and Human Services System; 402.471.2907.

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Nebraska Department of Education, Safe and Drug Free Schools Program. <http://www.nde.state.ne.us/SDFS/>. Accessed 5/10/04.

Nebraska Health and Human Services System, Office of Protection & Safety, Child Abuse Prevention Project. Information and resources available at <http://www.hhs.state.ne.us/cha/chaindex.htm>, or contact Shirley Pickens-White, PO Box 95044, 301 Centennial Mall South, Lincoln NE, 68509.

SBS (Shaken Baby Syndrome) Prevention Plus. <http://www.sbsplus.com/>. Accessed 5/10/04.

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<sup>14</sup>“Never, never, never shake a child” is the copyrighted slogan of SBS Prevention Plus.

<sup>15</sup>State law requires any person to report suspected child abuse or neglect to law enforcement, an HHS local office, or the child abuse/neglect reporting number at 1-800-652-1999. All reports are confidential.



## Caretaker Neglect and Inconclusive Neglect

Deaths were attributed to caretaker neglect when a child's caretaker(s) knowingly did something that placed the child's life in danger or did not remove the child from a dangerous situation. The National Center for Child Death Review recognizes five types of supervisory neglect:

- Failure to protect from hazard
- Failure to provide necessities (food, shelter, other)
- Failure to seek medical care / follow treatment
- Emotional neglect
- Abandonment

Deaths where a caretaker was convicted of child abuse or neglect are reported above as Criminal Child Abuse / Neglect. Two child protection specialists from the Team individually reviewed all remaining injury deaths to young children for a possible fit with the categories of neglect listed above. Both reviewers had to agree before categorizing an otherwise "Unintentional Injury" as "Caretaker Neglect." In all, there were 29 cases where local law enforcement chose not to prosecute, but where the Team felt that the death would not have occurred under reasonable standards of supervision or care (Table 14). However, eight cases were left as "Inconclusive," where reviewers were not comfortable with the unintentional injury classification but did not have sufficient information to clearly determine or rule out neglect (Table 15).

**Discussion.** This report was written at a time when considerable attention was being paid to deaths of young children caused by adult caretakers. In some

cases the determination of caretaker neglect was straight-forward, e.g., a drug-impaired parent leaving a child in a burning building. More often, though, determining when a lack of supervision crossed the line between understandable and negligence was complicated; parental responsibility for supervision is constantly challenged by competing demands. Indeed, there was inconsistency across the state on the types of situations for which caretakers were prosecuted.

The determination of neglect was further hampered by a lack of objective data – an absence of "5 or 6 minutes" as reported by a distraught parent can be quite variable. Reviewers' intent was to make a reasonable assessment about the amount of time the child was unsupervised and why the caretaker was absent; clearly the younger the child the less time he/she should have been left unwatched.

At the other end of the spectrum, however, were at least two cases where newborns were left without food and/or medical care. Although not specifically abandoned, these infants were clearly not wanted by their mothers. Nebraska is one of only five states that, as of January 2004, does not have some form of a "Safe Haven" law which allows mothers to anonymously leave unwanted and unharmed newborns at specified locations. These laws are controversial, not a panacea for unwanted pregnancies, and only a relatively small number of mothers have taken advantage of these laws in states where they exist. However, they appear to have saved the lives of several hundred babies around the country over the past decade.

### ➤ Recommendations for Policy Makers

**A Safe Haven law, with funding for public awareness, may save the lives of a small number of Nebraska newborns who are abandoned or neglected by their mothers and should be passed by the Nebraska Legislature.**

## ➤ Recommendations for Communities

**Safe and affordable child care will reduce the number of children left unattended for long periods of time.** Although much of the emphasis in expanding child care opportunities has focused on the importance of nurturing and intellectual stimulation early in a child's life, safety-related issues should not be overlooked. The business community, policy makers, parents and child care providers working together may be needed to develop locally effective and sustainable solutions.

## ➤ Recommendations for Parents

**Young children should never be left unsupervised.**

**Young teens should not be left alone in potentially hazardous situations such as when swimming in lakes and rivers.**

**Matches and lighters should be stored in safe places that are unknown to young children.** All children should be taught about the dangers of matches and lighters. Children who are known firestarters or fascinated by fire require constant supervision, and may benefit from counseling.

## References and further resources

Evan B. Donaldson Adoption Institute. 2002. Unintended Consequences : Safe Haven laws are causing problems, not solving them. Available at [http://www.adoptioninstitute.org/whowe/lastreport\\_coverpage.html](http://www.adoptioninstitute.org/whowe/lastreport_coverpage.html). Accessed 4/25/04.

Gloria M. Silverio Foundation. 1993. Safe Haven Laws – by State. Available at <http://www.asafehavenfornewborns.com/laws.html>. Accessed 4/25/04.

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## Substance Use During Pregnancy

Nationally, between 5.5% and 18% of all births are thought to be affected by illegal drug use during pregnancy. Established delivery and neonatal complications from illegal drugs such as cocaine and methamphetamine include premature rupture of membranes (PROM), placental abruption, preterm delivery, and pre-eclampsia-like symptoms. However, because these problems also occur in non-drug using women, it is difficult to state with certainty whether an infant's or child's death was directly related to the mother's drug use. In contrast, infants affected by Fetal Alcohol Syndrome / Fetal Alcohol Spectrum Disorders (FAS/FASD) typically have distinct characteristics that

are sufficient for a diagnosis<sup>16</sup>. As a result, although several child deaths had indications that they were related to gestational exposure to cocaine, other illicit drugs and/or alcohol use, the Team only attributed death as due to maternal substance use in four cases (Table 16). One of these was a child documented as being affected by FAS; three other cases had known substance use and documented, distinct medical complications. As the CDRT is currently reviewing cases much closer to the time of death, the ability to acquire better information will improve and future use of this classification is expected to increase.

### ➤ Recommendations for Health Care Providers

**Delivery personnel should be able to recognize and report Fetal Alcohol Syndrome and other disorders related to prenatal alcohol consumption.** The number of maternal alcohol-affected newborns is likely much higher than the three to five cases reported annually in Nebraska. Accurate knowledge of the prevalence of FAS will aid in its treatment and prevention.

### ➤ Recommendations for Communities

**Specialized resources should be available for substance addicted pregnant women who are trying to quit.** Providers need to be aware of available referral options.

### ➤ Recommendations for Parents and Communities

**Women should abstain from drinking alcohol at any time during pregnancy. Women are more likely to abstain from drinking during pregnancy when their partner also accepts the need to do so.** There is no known safe amount of alcohol to drink while pregnant, nor does there appear to be a safe time to do so.

## References and further resources

Centers for Disease Control and Prevention. Fetal Alcohol Syndrome. Available at <http://www.cdc.gov/ncbddd/fas/>. Accessed 5/10/04.

National Conference of State Legislatures. 2000. State Responses to Maternal Drug and Alcohol Use: An Update. Available at <http://www.ncsl.org/programs/health/forum/maternalabuse.htm>. Accessed 1/15/04.

Phillips, J. Detecting Maternal Drug Use through Meconium Testing: Pitfalls and Issues. 2001. University of North Carolina Hospitals, Chapel Hill, North Carolina. Available at [http://www.pathology.unc.edu/labs/resident\\_reports/resreportaug2001](http://www.pathology.unc.edu/labs/resident_reports/resreportaug2001). Accessed 1/15/04.

<sup>16</sup>FAS/FASD-affected newborns typically have a distinct pattern of facial abnormalities, growth deficiency and evidence of central nervous system dysfunction.

## Medical Error

Only one case was found where the Team's physicians felt that the records showed medical error as a prime contributor to the death (Table 1). In that particular instance, the hospital involved subsequently changed its protocols so that the medication dosage error would not re-occur.

**Discussion.** The Nebraska Medical Association (NMA) reviews all neonatal deaths (those that occurred in the first 28 days of life) occurring during selected time periods. Their more intensive reviews detected five to ten cases during 1998 alone where the quality

of medical care was felt to have contributed to the death. The need to review over 1,800 cases for this CDRT report in a relatively short time frame precluded the ability to make similarly detailed assessments. In the future, however, the CDRT will be working together with the NMA to incorporate the results of their intensive reviews with our overall reports, and to expand the level of detail with which all medical deaths are examined. Future increases in the determination of medical error are thus expected, but as a result of changes in the review process rather than necessarily from an increase in their occurrence.

## Unexplained

The deaths of six children remained unexplained, even after extensive law enforcement and medical investigations (Table 1). Circumstances in these cases were such that neither medical causes nor inflicted injuries could be ruled out.

## No information available

In 24 cases, HHSS databases did not list a cause of death, and the Team was unable to obtain any supporting information (Table 1). Many of the deaths were known to have occurred out of state; resources were not available for this report to pursue them further.

# Glossary

## Births

### Apgar Score

Newborn viability is most often assessed by the Apgar score. The Apgar score is a widely used assessment of the physical condition of a newborn infant based on heart rate, muscle tone, breathing effort, color and reflex responsiveness. Scores are assessed at 1, 5 and 10 minutes after birth. A score of 10 suggests the healthiest infant, and scores below 5 indicate that the infant needs immediate assistance in adjusting to his or her new environment. The Apgar test is non-invasive and does not involve risk to the newborn.

### Birth Defect / Congenital Anomaly

A birth defect is an abnormality of structure, function or metabolism (body chemistry) that is present at birth. Birth defects may be caused by chromosomal or “hereditary” errors, or by other influences on the fetus during gestation. They are the leading cause of death for infants. The March of Dimes groups birth defects in three main categories:

- Structural/metabolic (e.g., neural tube defects, missing organs),
- Congenital infections (e.g., Rubella (German measles), syphilis), and
- Other (e.g., Fetal Alcohol Syndrome (FAS)).

For this report, birth defects are only categorized as such if there was no known cause for their occurrence. For example, defects resulting from congenital infections are considered under Maternal Complications; defects resulting from FAS are under Maternal Substance Use.

### Gestation

The gestational age of the newborn is the interval between the first day of the mother’s last normal menstrual period (LMP) and the date of birth. It is typically determined by maternal recall, but can also be determined by clinical examination if the mother’s information is not available or is inconsistent with the fetus’ or newborn’s size.

### Live Birth

The state of Nebraska defines a live birth as “The complete expulsion or extraction of a product of conception from its mother, irrespective of the period of gestation, which, after such separation, breathes or shows any other evidence of life such as beating of the heart, pulsation of the umbilical cord, or definite movement of voluntary muscles, whether or not the umbilical cord has been cut or the placenta is attached, and is reportable.”

### Premature birth

Premature birth is a leading cause of infant mortality, yet little is known on how to prevent it. A normal gestation is considered to last from 37 to 41 weeks; an infant born at less than 37 weeks of gestation is considered premature. Through 37 weeks, major systems and organs are still developing. However, babies with at least 28 weeks of gestation are considerably more likely to survive; each additional week of gestation improves the likelihood of survival and decreases the probability of lifelong disabilities. Multiple gestation pregnancies (twins, triplets, etc.) are more likely to deliver prematurely. The prematurity rate is the number of live births of 37 weeks or less gestation divided by the total number of live births.

### Viable

Capable of living; born alive and with such form and development of organs as to be capable of living.

## Death / Mortality

### Cause of Death

The immediate cause of death is the disease (condition) or complication occurring closest to the time of death that leads to or contributes to death, and is classifiable according to the International Classification of Diseases (ICD) system. The State of Nebraska used the Ninth Revision for deaths up until 1998, and the Tenth Revision since 1999. However, the immediate cause of death does not necessarily reflect the complete set of reasons for the death. The underlying cause of death is the disease or condition that initiated the train of morbid events leading directly to death, and may be many years removed from the actual occurrence of death.

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Although immediate causes of death are often preventable, underlying causes are more informative for primary prevention purposes as defined by the Team. For example, pneumonia deaths are largely preventable. However, when pneumonia is the immediate cause of death in a child who is ventilator dependent due to cerebral palsy, prevention of infantile or childhood cerebral palsy becomes the larger, long-term focus. Similarly, while massive head trauma may be an immediate cause of death, prevention of the motor vehicle crash that caused the trauma is as important as improved emergency medical care.

### **Manner of Death**

The manner of death is important and distinct from the cause of death. Manner of death is classified on death certificates as:

- Natural
- Accidental
- Homicide
- Suicide
- Undetermined
- Unknown

### **Fetal Death / Miscarriage / Stillbirth**

The state of Nebraska follows the National Center for Health Statistics' definition of a fetal death as "... death prior to<sup>17</sup> the complete expulsion or extraction from its mother of a product of human conception, irrespective of the duration of pregnancy and which is not an induced termination of pregnancy. The death is indicated by the fact that after such expulsion or extraction, the fetus does not breathe or show any other evidence of life such as beating of the heart, pulsation of the umbilical cord, or definite movement of voluntary muscles."

A Fetal death that occurs before the 20<sup>th</sup> week of gestation is often called a miscarriage; a death prior to delivery but after 20 weeks is called a stillbirth. About 15 percent of recognized pregnancies end in a miscarriage, while another five percent end in stillbirth.

### **Neonatal Death**

Death of a live born infant under 28 days of age.

### **Perinatal Death**

Death of a fetus after 28 weeks or more of gestation or of a live born infant within seven days of life.

## **Medical Conditions**

### **Cancer / Malignant Neoplasms**

Cancer begins in cells, the building blocks that make up tissues. Normally, cells grow and divide to form new cells as the body needs them. When cells grow old, they die and new cells take their place. When new cells form that the body does not need and old cells do not die when they should, these extra cells can form a mass of tissue called a growth or tumor. Not all tumors are cancer. Tumors can be benign or malignant:

- Benign tumors are not cancer
- Benign tumors are rarely life-threatening.
- Usually, benign tumors can be removed, and they seldom grow back.
- Cells from benign tumors do not spread to tissues around them or to other parts of the body.
- Malignant tumors are cancer
- Malignant tumors generally are more serious than benign tumors. They may be life-threatening.
- Malignant tumors often can be removed, but they can grow back.

### **Hypoxia / Asphyxia**

Hypoxia is an insufficient supply of oxygen to the brain. The American Academy of Pediatrics states that an infant who has had "asphyxia" or hypoxia immediately prior to or during delivery that is severe enough to result in acute neurologic injury should demonstrate all of the following: (a) profound metabolic or mixed acidemia (ph <7.00) on an umbilical arterial blood sample, if obtained, (b) an Apgar score of 0 to 3 for longer than 5 minutes, (c) neurologic manifestation, e.g., seizure, coma, or hypotonia, and (d) evidence of multi-organ dysfunction. Because this level of detail was rarely available for this report, the physician's or pathologist's assessment was accepted.

### **Neural tube defect(s)**

The neural tube is the part of the developing fetus that becomes the spinal cord and brain. Neural tubes close within the first four weeks of gestation, often before a woman knows she is pregnant; neural tube defects (NTD) occur when the tube only closes partially or not at all. NTDs are among the most common of all serious birth defects.

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<sup>17</sup>Emphasis added.



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The two major types of NTDs are anencephaly and spina bifida. Anencephaly is the partial or complete absence of the baby's brain. This defect causes extensive damage, and most of these babies are stillborn or die soon after birth. Spina bifida occurs when an opening remains in the spine. These babies need surgery soon after birth to close the spine and prevent further damage. They also may need a shunt or a drain to prevent a build-up of spinal fluid in the brain called hydrocephalus. Babies with spina bifida may lack feeling in their legs and later develop problems with walking. In addition, these children may develop problems with their bowel and bladder control. They may also have learning problems, and some have mental retardation.

### **Sudden Infant Death Syndrome (SIDS)**

SIDS is officially defined as 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. In Nebraska, only the autopsy is required<sup>18</sup>. Major risk factors for SIDS are pre- or post-natal exposure to tobacco smoke, low birth weight, not breast-feeding, and the baby not sleeping on his/her back. SIDS is officially a diagnosis of exclusion, when no legitimate cause of death can be determined by autopsy or other means.

### **Trisomy**

Trisomies are genetic conditions present at birth where cells contain three copies of specific chromosomes instead of the normal two copies. For example, the presence of three copies of chromosome 21 is called Trisomy 21. A partial trisomy occurs when part of an extra chromosome is attached to one of the other chromosomes. A mosaic trisomy occurs when not all cells contain the extra chromosomal material. Trisomies can result in birth defects, miscarriage or early infant death.

## **Other Terms**

### **Preventability**

The Team focuses on identifying deaths that could have been prevented under Nebraska's definition:

“Preventable child death shall mean the death of any child which reasonable medical, social, legal, psychological, or educa-

tional intervention may have prevented. Preventable child death shall include, but not be limited to, the death of a child from (a) intentional and unintentional injuries, (b) medical misadventures, including untoward results, malpractice, and foreseeable complications, (c) lack of access to medical care, (d) neglect and reckless conduct, including failure to supervise and failure to seek medical care for various reasons, and (e) preventable premature birth; Reasonable shall mean taking into consideration the condition, circumstances, and resources available.”

§71-3405 Neb. Rev. Stat.

While preventability is often a straightforward assessment, it can also be quite challenging. For example, if a seizure disorder has been controlled with medications yet causes a 17-year old driver to have a fatal motor vehicle crash, preventability becomes problematic. Because of the large number of cases reviewed for this report, individual assessments of preventability were made only for potential “Caretaker Neglect.” Team members did feel that it is reasonable to assume that most motor vehicle-related deaths are preventable, particularly given the large numbers of deaths that occurred when an unrestrained child was ejected from the vehicle. Likewise, the unintentional and intentional injuries were largely preventable. On the other hand, most of the medical conditions appeared to have received appropriate medical care and thus the resulting deaths were perhaps not preventable.

Although the Team is comfortable with the generalized assessments of preventability made for this report, it is clear that determinations made on a case by case basis are preferable. This is the process that will be followed for subsequent years' reports.

### **Race and Ethnicity**

Nebraska assigns infant race and ethnicity at birth as that of the mother as reported on the birth certificate. Ethnicity and race are overlapping categories and are thus reported separately. For the time period of these data (1996-2001), Nebraska recognized four racial categories: White, African-American, Native American and Asian / Pacific Islander.

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<sup>18</sup>Nebr. Rev. Stat. §71-605.

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**Appendix – Detailed Data Tables**

**Table 1.**

<b>Underlying Cause of Death</b>	<b>1996 (N)</b>	<b>1997 (N)</b>	<b>1998 (N)</b>	<b>1999 (N)</b>	<b>2000 (N)</b>	<b>2001 (N)</b>	<b>Total (N) (%)</b>
Preterm Birth	43	51	40	39	47	34	<b>254 (47.0%)</b>
Maternal Complications	41	24	34	29	38	46	<b>212 (39.2%)</b>
Complications of Labor & Delivery	13	9	5	9	4	5	<b>45 (8.3%)</b>
Other Pregnancy & Neonatal-Related Conditions	5	9	6	4	1	5	<b>30 (5.5%)</b>
<b>Total, Pregnancy-Related</b>	<b>102</b>	<b>93</b>	<b>85</b>	<b>81</b>	<b>90</b>	<b>90</b>	<b>541 (100%)</b>
Pregnancy Related	102	93	85	81	90	90	<b>541 (29.3%)</b>
Birth Defects / Inherited & Chromosomal Disorders	73	56	57	59	66	69	<b>380 (20.6%)</b>
SIDS	35	23	25	24	27	26	<b>160 (8.7%)</b>
Cancer / Neoplasms	14	9	11	11	11	8	<b>64 (3.5%)</b>
Infectious, Chronic & Other Medical Conditions	24	17	26	29	20	22	<b>138 (7.5%)</b>
Motor Vehicle Crash	52	43	43	47	36	38	<b>259 (14.0%)</b>
Non-MVC Unintentional Injuries	15	17	17	19	19	11	<b>98 (5.3%)</b>
Suicide	14	13	10	13	11	9	<b>70 (3.8%)</b>
Homicide / Criminal Child Abuse & Neglect	11	14	9	8	14	7	<b>63 (3.4%)</b>
Caretaker Neglect	4	3	5	8	6	3	<b>29 (1.6%)</b>
Inconclusive Neglect	0	5	2	0	0	1	<b>8 (0.4%)</b>
Maternal Substance Use	0	0	0	2	0	2	<b>4 (0.2%)</b>
Medical Error	0	0	0	1	0	0	<b>1 (0.1%)</b>
Unable to Determine	1	1	0	1	1	2	<b>6 (0.3%)</b>
No Information Available	12	2	10	0	0	0	<b>24 (1.3%)</b>
<b>Total (N)</b>	<b>357 (19.3%)</b>	<b>296 (16.0%)</b>	<b>300 (16.3%)</b>	<b>303 (16.4%)</b>	<b>301 (16.3%)</b>	<b>288 (15.6%)</b>	<b>1,845 (100.0%)</b>

Table 2.

Preterm Births	1996 (N)	1997 (N)	1998 (N)	1999 (N)	2000 (N)	2001 (N)	Total (N) (%)
Singleton gestation	25	31	27	26	22	20	151 (59.4%)
Multiple gestation	18	20	13	13	25	14	103 (40.6%)
<b>Total (N)</b>	<b>43</b>	<b>51</b>	<b>40</b>	<b>39</b>	<b>47</b>	<b>34</b>	<b>254</b>

Table 3.

Maternal Complications	1996 (N)	1997 (N)	1998 (N)	1999 (N)	2000 (N)	2001 (N)	Total (N)
Diabetes, gestational or insulin-dependent	1				1	2	4
HELLP syndrome			5 <sup>1</sup>			1	6
Hypertension, pregnancy-induced or chronic		2	4	1		1	8
Incompetent cervix	7	6	14	6	12	10	55
Infection / chorioamnionitis	3	1	2	2	5	6	19
Infection, cytomegalovirus	1	1			2	2	6
Infection, herpes virus	1		1	1			3
Infection, HIV	1						1
Infection, other	2	1				1	4
Placenta previa		1		1	1	4	7
Placental abruption	8	2	4	13	11	9	47
Placental separation, other	2	1					3
Pre-eclampsia / eclampsia	4	2		2	2	3	13
Uterine bleeding	9	1	1	2		4	17
Uterine rupture		2			1		3
Other / unknown	2	4	3	1	3	3	16
<b>Total (N)</b>	<b>41</b>	<b>24</b>	<b>34</b>	<b>29</b>	<b>38</b>	<b>46</b>	<b>212</b>

<sup>1</sup> Includes one set of triplets.

Table 4.

Complications of Labor & Delivery	1996 (N)	1997 (N)	1998 (N)	1999 (N)	2000 (N)	2001 (N)	Total (N)
Perinatal hypoxia / asphyxia	11	8	5	5	2	3	34
Meconium aspiration	2	1		3		1	7
Delivery trauma				1	2	1	4
<b>Total (N)</b>	<b>13</b>	<b>9</b>	<b>5</b>	<b>9</b>	<b>4</b>	<b>5</b>	<b>45</b>

Table 5.

<b>Birth Defects / Inherited &amp; Chromosomal Disorders Neonatal (&lt; 1 day)</b>	<b>1996 (N)</b>	<b>1997 (N)</b>	<b>1998 (N)</b>	<b>1999 (N)</b>	<b>2000 (N)</b>	<b>2001 (N)</b>	<b>Total (N)</b>
Bone disorder <sup>2</sup>		2	1	1	1	1	6
Chromosomal anomaly, Trisomy 13 (Patau Syndrome)	2	1				1	4
Chromosomal anomaly, Trisomy 18 (Edwards Syndrome)			3	1	1		5
Chromosomal anomaly, Trisomy 21 (Down Syndrome)					1		1
Chromosomal anomaly, other	1		1	3	1	1	7
Gastrointestinal / genitourinary anomaly	2		1		1	4	8
Head / brain anomaly		1			2	1	4
Heart defect / anomaly	1	2	1	1		1	6
Hydrops fetalis, non-immune				1			1
Kidney anomaly	4	7	3	4	1	2	21
Liver defect / anomaly		1					1
Lung defect / anomaly				1		2	3
Mickel-Gruber Syndrome				1			1
Morquio's Syndrome		1					1
Multiple congenital anomalies	1	1	3	2	5	5	17
Neural tube defect - anencephaly	5	2	3	3			13
Neural tube defect - encephalocele	1		1				2
Neural tube defect -myelomeningocele / spina bifida	1				1		2
Turner's Syndrome				1			1
<b>Subtotal (N)</b>	<b>18</b>	<b>18</b>	<b>17</b>	<b>19</b>	<b>14</b>	<b>18</b>	<b>104</b>

<sup>2</sup> Dwarfism; chondrodysplasia; osteogenesis imperfecta.

**Table 5. (continued)**

<b>Birth Defects / Inherited &amp; Chromosomal Disorders Post-neonatal (1+ days)</b>	<b>1996 Age</b>	<b>1997 Age</b>	<b>1998 Age</b>	<b>1999 Age</b>	<b>2000 Age</b>	<b>2001 Age</b>	<b>Total (N)</b>
Anemia, Fanconi's						5y	1
Anemia, sickle cell					13y		1
Batten's disease				7y & 8y <sup>3</sup>			2
Bone disorders	4d	8d	2m, 10m	1d			5
Bowen Conradi syndrome	10y						1
Central Nervous System disorders	6wks, 9y					7y	3
Cerebro-costo-mandibular Syndrome	4y						1
Chromosomal anomaly, Trisomy 13 (Patau Syndrome)	1d, 3d			2d	2d, 3d, 4d, 5d,		7
Chromosomal anomaly, Trisomy 18 (Edwards Syndrome)	1d, 3d, 4d, 1m, 2m	1d, 1m, 2m	2d, 7d	2d, 4d, 4d	1d, 5d, 2m, 4m, 8m, 1y	1d, 5d, 22d, 1m, 7m	24
Chromosomal anomaly, Trisomy 21 (Down Syndrome)	3m, 6m	3y	3m, 2y	15y	8m	6y	8
Chromosomal anomaly, other	6d	1m		16d, 14y		2y, 3y	6
Coffin-Siris Syndrome					11y		1
Costello's Syndrome			6m				1
Cystic fibrosis				17y			1
Dandy Walker Syndrome			2y		9m		2
DiGeorge Syndrome			26d	4y	11m	1y	4
Gastrointestinal / genitourinary malformations	1d, 18d, 1y, 2y	17d	2d, 15d, 2m, 5m	1d, 3y	1d, 1m, 7y	4y, 14y	16
Head / brain anomalies, holoprocencephaly	6y			14y	9y		3
Head / brain anomalies, hydrocephaly	3m, 12y, 16y	10y, 14y					5
Head / brain anomalies, other		2y			2d, 7m, 2y, 7y	11m, 1y, 2y	8
Heart disease, hypoplastic left	1d, 7d, 8d, 14d, 1m	2d, 8d, 11d, 1wk, 1y, 2y	2d, 6d, 5m	10d, 2m, 4m, 7m,	1d, 9d, 10d, 1m, 2m	3d, 2m, 3m	26
Heart disease, other	2d, 25d, 3m, 5m, 11m, 1y, 2y, 16y	2d, 5d, 6m, 12y, 16y	5d, 7d, 10d, 15d, 21d, 1m, 1m, 3m, 4m, 5m, 5m, 2y	1d, 2d, 2d, 3d, 1m, 2m, 5m, 8m, 2y, 9y, 9y	5d, 5d, 6d, 15d, 1m, 2m, 5m, 9m, 1y, 6y	1d, 7d, 8d, 8d, 13d, 16d, 16d, 1m, 1m, 1m, 4m, 8m, 9y, 12y	61

<sup>3</sup> Siblings.

Table 5. (continued)

Birth Defects / Inherited & Chromosomal Disorders Post-neonatal (1+ days)	1996 Age	1997 Age	1998 Age	1999 Age	2000 Age	2001 Age	Total (N)
Hemachromatosis					14y		1
Hurler's Syndrome	1y				5y		2
Hydromyelia			4m				1
Hydrops, non-immune			2d		5d	1m	3
Hystiocytosis X		1y					1
Kidney anomaly		1d, 3d		1d		15y	4
Lactic acidemia, congenital			3m				1
Leigh's encephalopathy		6m					1
Liver defect / anomaly	2y					2y, 3y, 11y	4
Lung defect / anomaly	2m			11d	2y		3
Menke's Disease		2y					1
Metabolic disorder	7d	6m	10m			2d, 3m	5
Multiple congenital anomalies	5d, 12d, 1m, 2y, 3y, 5y	1d, 6d, 9d, 28d, 3m, 5m, 7m, 7m	12d, 25d 10y	17d, 2m, 4m, 8m, 9m	3m, 2y	3d, 5y, 5y, 17y	28
Muscular dystrophy	15y			17y		17y	3
Myotonia, congenital	1m						1
Myotonic dystrophy						16y	1
Neural tube defect, anencephaly			1d		1d, 1d, 2d, 3d, 5d		6
Neural tube defect, encephalocele				4m		3d	2
Neural tube defect, myelomeningocele / spina bifida	9d, 21d	7y	13y		14y		5
Neurodegenerative disease						1y	1
Neuromuscular disorder	28d, 5m, 6y				2m, 4m	19d, 6m	7
Otahara Syndrome			9m				1
Pena Shokeir Syndrome	16d						1
Persistent pulmonary hypertension	5m						1
Seizure disorder, congenital				9y			1
Tay-Sach's Disease		3y					1
Tracheal stenosis			1y				1
Zellweger's Syndrome		2m	3d				2
<b>Subtotal (N)</b>	<b>55</b>	<b>38</b>	<b>40</b>	<b>40</b>	<b>52</b>	<b>51</b>	<b>276</b>
<b>Total (N)</b>	<b>73</b>	<b>56</b>	<b>57</b>	<b>59</b>	<b>66</b>	<b>69</b>	<b>380</b>

For birth defect-related deaths under one day old, the number of cases are given. For deaths greater than one day, ages are given in years (y), months (m) and days (d).

Table 6.

Sudden Infant Death Syndrome (SIDS) – Race / Ethnicity	1996 (N)	1997 (N)	1998 (N)	1999 (N)	2000 (N)	2001 (N)	Total (N) (%)
White	27	17	22	20	19	20	125 (78.1%)
African-American	5	6	3	4	6	4	28 (17.5%)
Native American	3	-	-	-	-	2	5 (3.1%)
Asian	-	-	-	-	2	-	2 (1.25%)
<b>Total (N)</b>	<b>35 (21.9%)</b>	<b>23 (14.3%)</b>	<b>25 (15.6%)</b>	<b>24 (15.0%)</b>	<b>27 (16.9%)</b>	<b>26 (16.3%)</b>	<b>160</b>
Hispanic Ethnicity	3 (8.6%)	1 (4.3%)	1 (4.0%)	2 (8.3%)	3 (11.1%)	1 (3.4%)	11 (6.9%)

Table 7.

Sudden Infant Death Syndrome (SIDS) – Caretaker	1996 (N)	1997 (N)	1998 (N)	1999 (N)	2000 (N)	2001 (N)	Total (N) (%)
Babysitter / Child Care	6	4	11	6	8	4	39 (24.4%)
Parents / Family member	19	15	11	15	16	18	94 (58.8%)
Unknown	10	4	3	3	3	4	27 (16.9%)
<b>Total (N)</b>	<b>35 (21.9%)</b>	<b>23 (14.3%)</b>	<b>25 (15.6%)</b>	<b>24 (15.0%)</b>	<b>27 (16.9%)</b>	<b>26 (16.3%)</b>	<b>160</b>

Table 8.

Cancer / Neoplasms	1996 (Age)	1997 (Age)	1998 (Age)	1999 (Age)	2000 (Age)	2001 (Age)	Total (N)
Astrocytoma	3, 7		11			15	4
Blastoma			2				1
Bone tumor					10		1
Brain tumor	6, 12, 15	1, 4, 11, 12		11	10, 11	4, 6, 11	13
Ependymoma	11, 11						2
Ependymoma vs. astrocytoma				13			1
Ewing's sarcoma			13		9		2
Glioblastoma			13	17			2
Glioma, brain stem			8	8			2
Glioma, posterior fossa			5				1
Hepatoblastoma		6					1
Hodgkin's Disease						17	1
Leukemia, acute or chronic	8	1	6m	1, 2, 15, 17	3, 12, 12	13, 16	12
Lymphoma, lymphoblastic			12				1
Medulloblastoma		15		5			2
Mesothelioma, peritoneal						17	1
Neuroblastoma		5	3, 9	10	3, 4, 4		7
Neuroendocrine tumor	11						1
Pineal gland dysgerminoma	9						1
Renal medullary carcinoma	11						1
Rhabdoid tumor of the kidney		1		11m			2
Rhabdomyosarcoma	17, 17		6		7		4
Unspecified type	17						1
<b>Total (N)</b>	<b>14</b>	<b>9</b>	<b>11</b>	<b>11</b>	<b>11</b>	<b>8</b>	<b>64</b>

Ages are in years and months (m).

**Table 9.**

<b>Infectious, Chronic and Other Disease Conditions</b>	<b>1996 (Age)</b>	<b>1997 (Age)</b>	<b>1998 (Age)</b>	<b>1999 (Age)</b>	<b>2000 (Age)</b>	<b>2001 (Age)</b>	<b>Total (N)</b>
"Cold injury syndrome of the newborn"	1d						1
"Collapsed during physical activity"					12y	17y	2
"Idiopathic vomiting and diarrhea"			3m				1
"Organic brain disease"			11y				1
"Probable viral respiratory disorder"				5y			1
Anemia, aplastic					11y		1
Appendix, perforated/ruptured			13y		12y		2
Asthma, unknown treatments <sup>4</sup>	10y, 14y	15y					3
Asthma, with inhaler and/or "EpiPen"	9y, 13y, 17y	11y, 14y		7y, 10y, 13y, 14y, 17y	16y, 15y	14y	13
Bronchitis / bronchiolitis/ bronchopneumonia	4m		1y	7m, 7m, 3y		1m, 5y, 14y	8
Cerebral palsy (complications)		5y, 8y, 10y, 10y	1y, 3y, 5y, 8y, 15y, 16y	3y, 5y, 11y	15y, 16y	4y, 5y, 17y	15
Chickenpox		9y					1
Cystic fibrosis			16y		13y		2
Dermatomyositis				13y			1
Diabetes mellitus <sup>5</sup>					1y	2y	2
Drug abuse (crank), chronic	17y						1
Encephalitis / encephalopathy		15y		15y		1y	3
Epilepsy					1y, 7y		2
Glomerulonephritis						11y	1
Heart arrhythmia	13y		16y				2
Heart disease, myocarditis		3m	18m	11m	5y	2y	5
Heart disease, other <sup>6</sup>	17y	2y, 13y, 15y, 17y		2y, 15y		2y, 12y	9
Hemolytic uremic syndrome					2y		1
Hemorrhage, subarachnoid				17y			1
Hepatitis C				17y			1

<sup>4</sup> An additional asthma death is included in the "Inconclusive Neglect" category.

<sup>5</sup> An additional diabetes-related death is included in the "Supervisory / Caretaker Neglect" category.

<sup>6</sup> Predominantly cardiomyopathy; cardiomegaly; arteriosclerotic heart disease; atherosclerotic heart disease.



**Table 9. (continued)**

<b>Infectious, Chronic and Other Disease Conditions</b>	<b>1996 (Age)</b>	<b>1997 (Age)</b>	<b>1998 (Age)</b>	<b>1999 (Age)</b>	<b>2000 (Age)</b>	<b>2001 (Age)</b>	<b>Total (N)</b>
Idiopathic inclusion body myopathy	3m						1
Laryngeal tracheitis				2y		3y	2
Leukodystrophy, adrenal			12y				1
Liver failure / probable fatal infectious mononucleosis	14y						1
Liver failure, unknown cause	16y		3m				2
Lung disease, unspecified			2y				1
Lymphoma, non-Hodgkins	16y						1
Meckel's diverticulum, perforation of				3y			1
Meningitis	1y	13d	12w, 1y		20d	6y	6
Mononucleosis	14y						1
Motor neuron disease						15y	1
Pneumonia / pneumonitis <sup>7</sup>	7m, 14y		2m, 12y		1m, 2m, 3m	12y	8
Pneumonia, aspiration	3y, 11y					3y	3
Reflux disease		3m	3m				2
Respiratory Syncytial Virus (RSV)			7y	6m, 6m, 4y	4		
Reye's Syndrome			10y				1
Seizure disorder	8m, 12y	11y		7y			4
Sepsis, bacterial / viral <sup>8</sup>	2y			5m, 10m, 2y		12d, 4y	6
Stevens-Johnson Disease				2y			1
Streptococcal arthritis, complications from						12y	1
Tonsillectomy, post-surgical complications	17y						1
Waterhouse-Friderichsen syndrome					1y		1
Undetermined medical cause			14d, 5y, 15y		1y, 15y		5
<b>TOTAL</b>	<b>24</b>	<b>17</b>	<b>26</b>	<b>29</b>	<b>20</b>	<b>22</b>	<b>138</b>

Ages are given in years (y), months (m), weeks (w), and days (d).

<sup>7</sup> Streptococcal; unspecified.

<sup>8</sup> Pneumococcal; streptococcal; enteroviral; rotavirus; unspecified.

Table 10.

Motor Vehicle-Related Incidents <sup>9</sup>	1996 (N)	1997 (N)	1998 (N)	1999 (N)	2000 (N)	2001 (N)	Total (N)
<b>Motor Vehicle Crash - Restraint status<sup>10</sup></b>							
Restrained	8	3	3	3	4	3	<b>24 (11.0%)</b>
Not restrained	14	5	9	6	5	2	<b>41 (18.8%)</b>
Ejected	4	10	8	12	9	7	<b>50 (22.9%)</b>
Unknown	15	21	14	21	16	16	<b>103 (47.2%)</b>
<b>MVC Subtotal</b>	<b>41</b>	<b>39</b>	<b>34</b>	<b>42</b>	<b>34</b>	<b>28</b>	<b>218 (84.2%)</b>
<b>Pedestrian</b>	7	2	4	2	1	3	<b>19 ( 7.3%)</b>
<b>Bicycle</b>	2	1	4	1	-	3	<b>11 ( 4.2%)</b>
<b>Motorcycle</b>	-	1	-	1	-	-	<b>2 ( 0.8%)</b>
<b>Other</b>	2	-	1	1	1	4 <sup>11</sup>	<b>9 ( 3.5%)</b>
<b>Total (N)</b>	<b>52 (20.1%)</b>	<b>43 (16.6%)</b>	<b>43 (16.6%)</b>	<b>47 (18.1%)</b>	<b>36 (13.9%)</b>	<b>38 (14.7%)</b>	<b>259</b>

Numbers of cases.

<sup>9</sup> Only includes motor vehicles engaged in traffic. Accidents in driveways and other non-traffic situations are in the Unintended Injury section. Categories refer to the location of the child.

<sup>10</sup> Age-appropriate restraints: carseat or booster seat for children through age eight; seatbelt and/or shoulder harness for older ages.

<sup>11</sup> Three deaths occurred in a school bus accident.

Table 11.

Unintentional Injury <sup>1</sup>	1996 (N)	1997 (N)	1998 (N)	1999 (N)	2000 (N)	2001 (N)	Total (N)
Animal-drawn vehicle <sup>2</sup>						9	1
Carbon monoxide poisoning			17				1
Choked on food/medication/toy		2	1	3	11	4	5
Crushed under falling object				3, 17			2
Drowned, <sup>3</sup> bath tub	2						1
Drowned, open water (swimming / canoeing / body surfing / wading / rescue attempt)	11, 17, 17	17, 17	14	11, 16	12, 16, 17, 17		12
Drowned, pool / unknown		13	1		17	13	4
Electrocution, playing around power lines	7		11	14			3
Explosion, building pipe bombs					17		1
Fall from and/or run over by vehicle		24 wk ga <sup>4</sup>	9	14	24 wk ga, 3		5
Fall from and/or stepped on by horse	2	12	10				3
Fall from railroad bridge		8					1
Fall from skateboard being towed by car			14				1
Fight				15			1
Fire, house/trailer/apartment <sup>5</sup>	14	2 & 3	6			4m & 2y, 3, 6 & 7	9
Hanging / strangulation, accidental			12, 12	10, 11	11		5
Hit / crushed by or between moving car(s), not in traffic		2	5, 16		5, 16		5
Hit / run over by farm or construction vehicle, not in traffic		3, 3		13	5	5, 16	6
Hit by object	13	10		5, 15	16		5
Hypothermia (cold), outdoor exposure		17					1
Knife wound	12			12			2

<sup>1</sup> Similar, separate events can be found under the Neglect and Child Abuse sections.

<sup>2</sup> Incident occurred out-of-state; no further details were available.

<sup>3</sup> Includes near-drowning, where child was resuscitated but later died from effects of oxygen deprivation.

<sup>4</sup> Weeks of gestational age.

<sup>5</sup> Children killed in same incident are separated by "&".

**Table 11. (continued)**

<b>Unintentional Injury<sup>1</sup></b>	<b>1996 (N)</b>	<b>1997 (N)</b>	<b>1998 (N)</b>	<b>1999 (N)</b>	<b>2000 (N)</b>	<b>2001 (N)</b>	<b>Total (N)</b>
Overdose, over-the-counter or prescription medication		17			16	17	<b>3</b>
Playing with firearm	13, 14	15	16				<b>4</b>
Rough play	3						<b>1</b>
Suffocation, crib / bed parts	1		1, 1, 9	5m, 4m	7m		<b>7</b>
Suffocation, other				6, 15, 17			<b>3</b>
Suffocation, overlay	1m	3wks			1m, 3m		<b>4</b>
Suffocation, placed faced down in crib	1m				1m		<b>2</b>
<b>Total (N)</b>	<b>15</b>	<b>17</b>	<b>17</b>	<b>19</b>	<b>19</b>	<b>11</b>	<b>98</b>

Ages are given in years, months (m), weeks (w) and days (d).

Table 12.

Suicide		Firearms (Age)	Hanging (Age)	Overdose (Age)	Other (Age)	Subtotal (N)	Total (N)
1996	Male	15, 16, 16, 16	11, 11, 13, 13, 17	-	16	10 (71.4%)	14 (20.0%)
	Female	13, 15, 17	15	-	-	4 (28.6%)	
1997	Male	12, 14, 15, 16, 16, 17, 17	13	-	17	9 (69.2%)	13 (18.6%)
	Female	17	-	14, 16, 16	-	4 (30.8%)	
1998	Male	14, 15, 15, 16, 16	14, 17	-	16	8 (80.0%)	10 (14.3%)
	Female	16, 16	-	-	-	2 (20.0%)	
1999	Male	15, 15, 16	15, 15, 15, 15, 16, 17, 17	-	14, 17	12 (92.3%)	13 (18.6%)
	Female	-	15	-	-	1 (7.7%)	
2000	Male	13, 17, 17, 17, 16	14, 16	16	-	8 (72.7%)	11 (15.7%)
	Female	14, 16	17	-	-	3 (27.3%)	
2001	Male	14, 15, 15, 15, 16, 16, 17	-	-	-	7 (77.8%)	9 (12.9%)
	Female	15	14	-	-	2 (22.2%)	
Subtotal (N)	Male	31 (57.4%)	17 (81.0%)	1 (1.9%)	5 (9.3%)	55 (77.5%)	70
	Female	9 (56.3%)	4 (19.0%)	3 (18.8%)	0	16 (22.5%)	
Total (N)		40 (57.1%)	21 (30.0%)	4 (5.7%)	5 (7.1%)	70	

Ages are given in years.

Table 13.

Intentional injury	1996 (Age)	1997 (Age)	1998 (Age)	1999 (Age)	2000 (Age)	2001 (Age)	Total (N)
<b>Criminal child abuse or neglect (convicted)</b>							
Blunt force trauma	1, 2	7wks, 1, 18m, 7 <sup>17</sup>	4			3	8
Chronic physical abuse		9m	1			2m	3
Dehydration / malnutrition	1, 3						2
Drown (tub)		8m					1
Illicit drug overdose (provided by parent)		17					1
Scald (tub)	2m			2			2
Shaken Baby / Shaken Infant Syndrome		2m	9m	3	2m, 3	4m	6
Smothered						2	1
<b>Subtotal (N)</b>	<b>5</b>	<b>8</b>	<b>3</b>	<b>2</b>	<b>2</b>	<b>4</b>	<b>24 (38.1%)</b>
<b>Homicide / manslaughter (alleged or convicted)</b>							
Firearm	13, 14, 15, 17, 17, 17	12, 15, 15, 16, 16, 17	15, 15, 15, 17, 17, 17	17, 17, 17	2, 3, 12, 14, 15, 16, 17, 17, 17	17, 17, 17	33
Stabbing				5 & 8 <sup>18</sup>			2
Strangulation					7 & 13 <sup>9</sup> , 17		3
Unknown				3			1
<b>Subtotal (N)</b>	<b>6</b>	<b>6</b>	<b>6</b>	<b>6</b>	<b>12</b>	<b>3</b>	<b>39 (61.9%)</b>
<b>Total (N)</b>	<b>11 (17.5%)</b>	<b>14 (22.2%)</b>	<b>9 (14.3%)</b>	<b>8 (12.7%)</b>	<b>14 (22.2%)</b>	<b>7 (11.1%)</b>	<b>63</b>

Ages are given in years, months (m) and weeks (wks).

<sup>17</sup> Trauma occurred at age 2.

<sup>18</sup> Siblings.

Table 14.

Parental / Caretaker Neglect	1996 (Age)	1997 (Age)	1998 (Age)	1999 (Age)	2000 (Age)	2001 (Age)	Total (N)
<b>Failure to protect from hazard</b>							
Drowned / near-drowning (tub, container, pool, lake)	8y, 11y		1y, 8y	1y, 6y	5m, 1y, 1y	1y	10
Residential fire		7y, 12y	10m, 2y	2y, 2y, 1y & 7y	8y		9
Other	7m	2y	1y	1y, 2y		3y	6
<b>Failure to provide necessities</b>							
Starvation / dehydration						12d	1
<b>Failure to seek medical care / follow treatment</b>							
Failure to provide medical attention					nb, 3 wks		2
Other	15y						1
<b>Total (N)</b>	<b>4</b>	<b>3</b>	<b>5</b>	<b>8</b>	<b>6</b>	<b>3</b>	<b>29</b>

Table 15.

Inconclusive (Not enough information to determine neglect)	1996 (Age)	1997 (Age)	1998 (Age)	1999 (Age)	2000 (Age)	2001 (Age)
Construction site accident						6y
Drowning / near-drowning, tub		5y				
Drowning / near-drowning, commercial pool			7y			
Drowning / near-drowning, pond			9y			
Drowning / near-drowning, shore collapse		7y				
Fall from motor vehicle		3y				
Medical neglect		4y				
Medical neglect / possible abuse		1y				
<b>Total (N)</b>	<b>0</b>	<b>5</b>	<b>2</b>	<b>0</b>	<b>0</b>	<b>1</b>

Table 16.

Maternal Substance Use	1996 (Age)	1997 (Age)	1998 (Age)	1999 (Age)	2000 (Age)	2001 (Age)	Total (N)
Alcohol				2y			1
Cocaine / crack				18d		7h	2
Methamphetamine						5m	1
<b>Total (N)</b>	<b>0</b>	<b>0</b>	<b>0</b>	<b>2</b>	<b>0</b>	<b>2</b>	<b>4</b>

Ages are given in years (y), months (m), days (d) and hours (h).

