

SUPPLEMENTAL REPORT  
TO THE  
GOVERNOR AND GENERAL ASSEMBLY

Iowa Child Death  
Review Team

October 2004

*Administrative Support Provided by:*

*IOWA DEPARTMENT OF PUBLIC HEALTH*

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## Iowa Child Death Review Team

### Supplemental Report to

### December 2003 Annual Report

The Iowa Child Death Review Team (CDRT) is required by law to publish an annual report to the governor and general assembly. Several recommendations that require legislative action are made in each year's annual report. In addition, the team describes areas where state agencies might revise their procedures and policies to ensure that each Iowa child will have a better chance of living a long and healthy life. Some suggestions are also made to the public, including health care and child-care providers, on ways to prevent future child deaths.

A report was published in December 2003 based on the team's review of child deaths occurring during calendar year 2002. Although the primary analyses of child death data are done prior to writing the annual report each year, staff and members of the CDRT continually evaluate data from previous years' deaths. As a result of these analyses, the Iowa Child Death Review Team determined that publishing a supplemental report to aid the governor and legislature in preparing for the 2005 legislative session is advisable. The CDRT has formulated a new recommendation regarding the sharing of information gathered and reviewed by the team when it can help to prevent future child deaths or hold responsible individuals who may have contributed to a child's untimely demise.

In addition, this brief addendum will alert health professionals and the public about emerging risk factors that are contributing to a large number of SIDS deaths in Iowa. Successfully decreasing the number of these deaths will take a collaborative effort of medical personnel, public health professionals, and other community members who teach parenting and child-care skills throughout the state.

### Issue Regarding Limited Sharing of Information

#### Background/Problem:

- Although essentially all state agencies and all bureaus at the Iowa Department of Public Health (IDPH) are under the same restrictions of confidentiality, the CDRT cannot share certain items of information with other programs. The CDRT collects all of these items and keeps them filed in locked file cabinets at one central location. This is the only program where all information on any child death is brought together to provide a complete picture and details of each death.

- When each separate program at IDPH must assess the information to be obtained, order it, organize and process the incoming data, staff effort is duplicated. In addition, costs of duplicate mail requests and/or telephone charges to get the exact same information are incurred.

This duplication uses Iowa taxpayer dollars to support identical work and stresses the workloads of state staff, the number of which has already been reduced due to budget crunches of the past several years. The current wording in the Iowa Code that relates to the Iowa Child Death Review Team contains very precise and strict language regarding sharing of information by the team and the penalties for disobeying the statute. Currently *for example*, if the CDRT coordinator requests and obtains an autopsy from the University of Iowa and the case falls under the State Medical Examiner's (SME) jurisdiction, the coordinator cannot give a copy of the report to that office. One of their staff people needs to re-request the autopsy report, and the staff at University of Iowa must again copy the report and forward it to yet another unit at the same state agency (IDPH). However, Iowa Code gives the CDRT coordinator the authority to request autopsy reports from the SME office, and that office must share any information they possess with the CDRT.

For child deaths occurring during calendar year 2002, the CDRT coordinator reviewed a list of child death cases reported to the State Medical Examiner's office. The coordinator knew of 19 additional deaths that should have been medical examiner cases but had never been reported to the SME. She could not give the names of the deceased children to the SME's staff, even though that agency is part of IDPH and operates under strict confidentiality guidelines.

- **Of great concern** to team members is their inability to protect surviving siblings of children who have died. The current legislation does not permit the team to refer a child whom they deem at risk to the Iowa Department of Human Services (IDHS) if that agency has not had previous involvement with the family. In other words, if the case is discussed at a CDRT meeting, and the IDHS liaison finds out from information gathered for team use that another child in the home may be in danger, their "hands are tied" by the current law. They cannot go into that home to assess what interventions are necessary to assure the safety of surviving siblings.
- Likewise, if the CDRT reviews the records for a child death and determines that the child died due to neglect or abuse, the team currently cannot refer the case to law enforcement for further investigation and possible prosecution.

**Proposed Change to Law: (Proposed new wording is underlined.)**

To rectify the aforementioned issues, the CDRT proposes that the Code of Iowa 135.43 be amended as follows:

The review team shall perform the following duties:

d. Recommend to the Department of Human Services, appropriate law enforcement agencies, and other child protective organizations and agencies interventions which may prevent harm to a child or children related to or living in the same home as the child under review.

e. Share information with the Attorney General's office, the office of the county attorney, and appropriate law enforcement agencies regarding a child under review only if the sharing of such information is necessary to initiate or assist in a death investigation or criminal prosecution and the office or agency does not otherwise have access to such information.

f. Share information with other divisions within the Iowa Department of Public Health for the purpose of assisting other divisions in performing the duties of that division, only if the division maintains the confidentiality of such information in accordance with this section and the division does not otherwise have access to such information.

g. Maintain the confidentiality of any patient records or other confidential information reviewed, subject to the limited releases of information authorized by this section.

**Issue Regarding SIDS Education**

During the past few years, particular attention has been given to information about child deaths due to Sudden Infant Death Syndrome (SIDS). While most states in the nation have reported a dramatic decrease in SIDS deaths since the "Back to Sleep" campaign began in 1994, Iowa saw a drop in SIDS deaths and then a leveling off of its rates. Iowa has experienced 37 to 38 SIDS deaths per year since 2000. Prior to the Back to Sleep Campaign, Iowa experienced an average of 85 SIDS deaths each year.

As better education of parents and other care providers of infants is the most feasible and efficient way to reduce deaths from SIDS, the CDRT reviewed records of SIDS cases to determine whether the risk reduction messages offered across Iowa should be revised. **One risk factor clearly emerged during this process: bed sharing increases the risk of a SIDS or SIDS like death.**

The CDRT re-evaluated data for SIDS cases for deaths occurring in the years 1999, 2000, 2001, and 2002. Each year a significant number of SIDS deaths occurred in a bed-sharing situation, and for 2000 through 2002, there was an increase of bed sharing each year (Table 1). **In 1999, 27.1 percent of the deaths occurred while the infant was bed sharing with one or more persons. That percentage rose to 28.9 percent in 2000, then to 40.5 percent in 2001. In 2002, a whopping 45.9 percent of infants who died from SIDS were bed sharing at the time of death.**

Table 1

SIDS Deaths by Bed-sharing Status  
1999-2002

Bed-sharing	1999	2000	2001	2002	Total
Yes	13	11	15	17	56
No	35	27	22	20	104
Total	48	38	37	37	160

In the majority of cases, the infant was sharing a sleeping surface with the mother, though there were deaths that occurred while the child was sharing with both parents, the father alone, or a sibling. In the vast majority of cases, the adult who shared the bed smoked, or there was other tobacco exposure in the home. Most of the mothers in the bed-sharing cases also smoked during pregnancy.

Many organizations and individuals have raised concerns about crib availability among bed-sharing families. For the 2001 SIDS deaths that occurred in a bed-sharing situation, the availability of a crib in the home was evaluated. Results showed that in the majority of cases, there was an appropriate sleeping surface available in the home, but parents opted not to use that place for the infant to sleep (Table 2).

Table 2

Availability of Crib in Home  
For 2001 SIDS  
Bed-sharing Cases

Crib Available	Bed-sharing Cases
Yes	9 (60%)
No	0 (0%)
Unknown	6 (40%)
Total	15 (100%)

For the SIDS cases occurring in 2002, the team was able to evaluate the use of illicit drugs and alcohol among the parents of the babies who died. The results are startling. **Of the 38 infants who died from SIDS during calendar year 2002, 12 (32.4%) had at least one parent who used substances.** Of these 12 children, eight died while sleeping with the user (Table 3).

Table 3

Parental Substance Use  
2002 SIDS Cases

Substance Use by Parent	Bed-sharing	Non-bed-sharing	Total Cases
Yes	8 (21.6%)	4 (10.8%)	12 (32.4%)
No	9 (24.3%)	16 (43.2%)	25 (67.6%)
Total	17 (45.9%)	20 (54.1%)	37 (100%)

Although information on substance abuse was not available for earlier SIDS deaths, it should be available for future years' deaths and will be reported upon in upcoming CDRT annual reports. **The CDRT has long recommended mandatory substance abuse testing of care providers at the time of any child's death.** Such testing would provide more complete information about substance abuse related to SIDS and other types of child deaths.

Most bed-sharing deaths occurred in an adult bed. However, infants also shared sleep surfaces with an adult on sofas, in recliners or other heavily stuffed chairs, and on the floor (Table 4).

Table 4

Shared Sleep Surfaces for SIDS Cases  
1999-2002

Surface	1999	2000	2001	2002	Total
Adult Bed	9	7	12	14	42 (75.0%)
Sofa	2	4	2	3	11 (19.6%)
Floor on Mattress	2	0	1	0	3 (5.4%)
Total	13	11	15	17	56 (100%)

During the years 1999-2002, Iowa experienced 160 SIDS deaths. Of these children, 100 (62.5%) were males, and 60 (37.5%) were females. The vast majority was white non-Hispanic (137), while 8 were Hispanic, 11 were black, 3 were Asian, and 1 was Native American. Although the SIDS rate is higher for blacks than for whites, the numbers are too small to reach a statistically significant conclusion. Many studies have shown bed sharing to be a cultural practice among many black, Asian, and Hispanic families. In addition, many lactation educators urge breastfeeding mothers to share their sleep surface with their infant to promote and expedite breastfeeding. The CDRT strongly supports breastfeeding, but urges mothers to put the baby in its own sleep surface after the feeding is completed.

Fluffy, soft bed coverings such as quilts, blankets, duvets, pillows, and pillow top mattresses, as well as adults or other children in the bed, provide the means for rebreathing or for suffocation. Anyone who uses drugs, legal or illegal, or alcohol, should never sleep with a child. The chances of suffocation or rebreathing greatly multiply in these situations since the adult may be unaware of bedding that is near the infant's face, and they may roll on to the child during a very deep sleep.

Parents who smoke greatly enhance the risks of SIDS in their babies. Peter Fleming, a renowned SIDS researcher from the United Kingdom, has noted that when prone sleeping position is removed as the primary risk factor for SIDS, tobacco exposure emerges as the next most significant risk. Studies conducted by Dr. Fleming from 1993-5, found that as the number of cigarettes smoked by parents each day increased and the number of hours per day that an infant was exposed to second hand smoke increased, so did the likelihood that the child would die from SIDS. For example, he found that with one to two hours of exposure to smoke each day, an infant's risk for SIDS was doubled. However, if the child was exposed to smoke for more than 8 hours each day, their risk was more than nine times that of an infant who was not exposed to second hand smoke on a usual basis.

Maternal smoking during pregnancy was found to increase the risk for SIDS, and the risk increased with the number of cigarettes smoked each day. If the pregnant woman smoked 1-9 cigarettes per day, the risk for SIDS was nearly five times greater than for infants of non-smokers. If the number of cigarettes smoked per day during pregnancy was increased to a pack per day (20 cigarettes), the risk increased to nearly eight times the risk of the non-smokers' offspring. Numerous studies from Norway, Austria, and New Zealand have confirmed these findings.

Table 5

Prenatal Smoking For SIDS Deaths  
While Bed-sharing  
Occurring During Years 1999-2002

Prenatal Smoking	1999	2000	2001	2002	Total
Yes	9	7	8	9	33(58.9%)
No	4	4	7	8	23(41.1%)
Unknown	0	0	0	0	0(0.0%)
Total	13	11	15	17	56(100%)

Table 6

Prenatal Smoking For SIDS Deaths  
Occurring During Years 1999-2002  
No Bed-sharing

Prenatal Smoking	1999	2000	2001	2002	Total
Yes	17	13	8	8	46(44.2%)
No	16	12	12	12	52(50.0%)
Unknown	2	2	2	0	6( 5.8%)
Total	35	27	22	20	104(100%)

Several studies conducted since 1995 have shown that bed sharing with a smoking parent significantly increases the risk for SIDS. Based on Dr. Fleming's research, since the infant would be exposed for more than 8 hours per day and at very close proximity to the smoker who would most likely have tobacco smoke residue on their clothing, this finding is quite plausible. Indeed, data from the CDRT case reviews substantiate Dr. Fleming's findings. **For years 1999-2002, 87.5 percent of the SIDS deaths occurring while bed sharing were in infants who were exposed to second hand smoke.**

Table 7

Secondhand Smoke Exposure for  
SIDS Deaths Occurring  
While Bed-sharing  
Occurring During Years 1999-2002

2 <sup>nd</sup> Hand Smoke	1999	2000	2001	2002	Total
Yes	12	10	12	15	49(87.5%)
No	1	0	1	1	3( 5.4%)
Unknown	0	1	2	1	4( 7.1%)
Total	13	11	15	17	56(100%)

Table 8

Secondhand Smoke Exposure for  
SIDS Deaths Occurring During Years 1999-2002  
No Bed-sharing

2 <sup>nd</sup> Hand Smoke	1999	2000	2001	2002	Total
Yes	19	17	13	12	61(58.7%)
No	7	4	3	4	18(17.3%)
Unknown	9	6	6	4	25(24.0%)
Total	35	27	22	20	104(100%)

With increased awareness of Sudden Infant Death Syndrome, parents may be bed-sharing because they think that they will more easily hear their infant if he/she has trouble breathing during the night. They may be following advice of child experts who claim that the “family bed” offers bonding opportunities. Parents may opt to bed share to expedite and ease breastfeeding. No matter what the reason for bed sharing, data show that the child is at increased risk for SIDS.

**Based on this information, the CDRT strongly recommends that all SIDS educational information, verbal and written, be updated to emphasize that bed sharing for any reason increases the chances an infant will die from SIDS, especially if the child was exposed to tobacco in the mother’s womb or after birth.**

The Iowa Department of Public Health has already established a work group to address SIDS materials it prints and to develop a strategy to update the public and professionals about bed sharing and tobacco exposure issues.

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