

STATEWIDE CHILD FATALITY REVIEW COMMITTEE 2016 ANNUAL REPORT

**Sudden
Unexpected
Infant Death**

Prevention through
understanding



Table of Contents

Executive Summary	3
Introduction	6
Background	6
Methods: Selection Criteria and Case Review Process	8
Figure 1: Selection Criteria.....	8
Methods: SUID Case Registry	9
Figure 2: SUID Case Registry Process.....	9
Goal #1	10
<i>Determine whether SUID investigations are being conducted as recommended by the CDC Sudden Unexplained Infant Death Investigation (SUIDI) protocol.</i>	
Figure 3: The Autopsy Begins at the Scene.....	10
Goal #2	12
<i>Classify the cause and manner of death for all 2014 SUIDs, using the CDC SUID Case Registry algorithm</i>	
Figure 4: SUIDs Rates by Cause, Indiana, 2009-2015.....	13
Figure 5: SUID Case Registry, Decision-Making Algorithm.....	15
Goal #3	16
<i>Evaluate the quality and completeness of the data entered into the CDR-CRS.</i>	
Goal #4	17
<i>Identify prevalent SUID/SIDS risk factors and formulate prevention recommendations</i>	
Key Findings Goal #1	18
<i>Determine whether SUID investigations are being conducted as recommended by the CDC Sudden Unexplained Infant Death Investigation (SUIDI) protocol.</i>	
Figure 6: Who Conducted the Autopsy?.....	18
Table 1: Investigation Practices.....	19
Key Findings Goal #2	19
<i>Classify the cause and manner of death for all 2014 SUIDs, using the CDC SUID Case Registry algorithm.</i>	
Figure 7: Infant Mortality Distribution by Cause – Indiana 2014.....	20
Figure 8: The Effect of Missing Investigation Data on Classification of SUIDs.....	20
Table 2: SUIDs by County of Residence (Vital Records compared to State CFR Committee).....	21
Key Findings Goal #3	22
<i>Evaluate the quality and completeness of the data entered into the CDR-CRS.</i>	
Figure 9: Presence of Unsafe Sleep Factors.....	22
Figure 10: Number of SUIDs Entered in the CDR-CRS.....	22
Table 3: Substance History, by Type.....	23
Figure 11: Core Variables with Lowest Missing/Unknown %.....	23
Figure 12: Core Variables with Highest Missing/Unknown %.....	24

Key Findings Goal #4	24
<i>Identify prevalent SUID/SIDS risk factors and formulate prevention recommendations</i>	
Figure 13: Child Age Range.....	24
Figure 14: Child Gender.....	25
Figure 15: Child Race.....	25
Figure 16: Child’s Insurance.....	26
Figure 17: Prenatal Care Utilized.....	26
Table 4: Mother’s Substance Abuse during Pregnancy.....	27
Figure 18: Percentage of Mothers that Experienced Intimate Partner Violence.....	27
Figure 19: Primary Caregiver at Time of Incident.....	28
Table 5: Primary Caregiver Age Range.....	28
Figure 20: Primary Caregiver Employment.....	28
Figure 21: Primary Caregiver Education.....	29
Figure 22: Secondary Caregiver Type at Time of Incident.....	29
Figure 23: Secondary Caregiver Education.....	29
Figure 24: Secondary Caregiver Employment.....	29
Table 6: Secondary Caregiver Age Range.....	30
Figure 25: Supervisor Type at Time of Incident.....	30
Table 7: Supervisor Age Range.....	31
Figure 26: Was There a Crib in the Home for the Child?.....	32
Figure 27: Incident Sleep Place.....	32
Figure 28: Place of Incident.....	32
Table 8: Infant Sleep Position.....	33
Table 9: SUID Risk Factors.....	34
 Key Recommendations	 34
Conclusion	36
References.....	38
Resources and Appendices	40
<i>Appendix 1: Indiana Statewide Child Fatality Review Committee Members</i>	
<i>Appendix 2: C-POD Guidelines</i>	
<i>Appendix 3: SUIDI Top-25</i>	
<i>Appendix 4: ICD-10 Code Definitions</i>	
<i>Appendix 5: Definitions and Criteria for Assigning Cases to SUID Case Registry</i>	

Executive Summary

This report summarizes the work and findings of the Indiana Statewide Child Fatality Review (CFR) Committee during calendar year 2016. In an effort to identify classification, coding and data collection inconsistencies in infant deaths across the state, and to inform efforts to standardize these practices, the Indiana Statewide CFR Committee reviewed all 2014 Sudden Unexplained Infant Deaths (SUIDs), and evaluated the quality of investigation, classification and coding of cause and manner of death, quality and completeness of the data collected by the local child fatality review teams, and prevalent SUID risk factors.

Key Findings Overview

Through this review process, the state CFR committee identified 19 (22%) SUIDs not previously recorded through epidemiological analysis of vital records information. The addition of these previously unreported SUIDs increased the percentage of SUIDs from 14% to 17% of the infant deaths in 2014. This additional data is important, as it shows more accurately the burden SUIDs have on our overall infant mortality distribution.

A thorough death scene investigation and complete autopsy are required to fully understand the circumstances surrounding the death of an infant. Based on case review conducted by the state CFR committee, a death scene investigation was conducted in 87% of the 105 deaths (N=91). While a majority of SUIDs had a partial death scene investigation, not all were complete or included the necessary documentation.

A complete autopsy is not based solely on gross examination but must also include toxicology, X-rays, and pathology. Indiana law also requires SUID autopsies be conducted by a forensic pathologist. The state CFR committee found that an autopsy was conducted in 99% (n=104) of the deaths, but only 48% (n=50) were completed by a forensic pathologist. Toxicology screening was completed for 90 (86%) of the 105 autopsies, but X-rays were taken in only 51 (49%) cases.

While the circumstantial information points to Accidental Suffocation and Strangulation in Bed (ASSB), only 10.5% (n=11) of the SUIDs could be unequivocally labeled ASSB based on available investigation data and strict adherence to the case-review algorithm utilized by the state CFR committee. The state CFR committee classified 89.5% (n=94) of the SUIDs as unknown cause. This result exemplifies the need for improved investigation and documentation protocols.

While unsafe sleep factors cannot be categorically linked to the cause of death in all 2014 SUIDs, 99 of the 105 deaths reviewed showed the infant was placed to sleep in an environment with at least one unsafe sleep factor. Of the remaining 6 SUIDs, four additional may have occurred in an unsafe sleep environment, but there was inadequate documentation in the case files to make this determination. There were only two SUIDs reviewed in which the case files documented the presence of no unsafe sleep factors.

Reviewing each sleep-related infant death is a critical first step toward understanding the burden, but it is not enough. It is imperative that local CFR teams track the data resulting from their reviews. The data collected in



Child Death Review Case Reporting System (CDR-CRS), if done consistently and accurately, is the most comprehensive death data available. Circumstances and risk factors associated with the child’s death are captured, and this information is only available through child fatality review. Although CDR-CRS reporting is crucial to inform prevention and measure outcomes associated with prevention strategies, out of the 105 SUIDs reviewed by the state CFR committee, only 37 (35%) were entered in the CDR-CRS by local CFR teams.

Many key variables associated with sleep-related deaths were missing, including information about substance abuse and misuse. This detail can be critical to informing prevention but was either marked unknown or not asked in 47 SUIDs (45%). Infant death investigators and local CFR teams should be encouraged to consistently capture information about impairment for each SUID.

Identifying potential risk factors for SUID is crucial to helping inform targeted prevention. A majority (n=91, 90%) of SUIDs in 2014 occurred in infants between the ages of 0 days and six months, with the most critical time period being between one to two months of age. Consistent with national data, male infants represented slightly more than half of all Indiana SUIDs (n=60, 57%) and total infant deaths (n=345, 58%). In the United States, non-Hispanic African American infants are two times more likely to die of SUID than White infants. This disparity was even more marked in Indiana, where 27% (n=28) of the 105 SUIDs in 2014 listed the infant’s race as African American, which represents a higher percentage (close to three times) that of the African American population in Indiana in 2014 (9.5%).

Per the state CFR committee case review, biological parents accounted for 62% (n=65) of the supervisors listed for the 105 SUIDs (figure 25), and babysitters accounted for 9% (n=9). This information helps validate the belief that parents need to be the focus for safe sleep education

efforts, but it also indicates educators may also need to aim educational messages on babysitters or child care providers.

The infant's sleeping position is a modifiable risk factor that can be addressed during prevention activities. Among the SUIDs reviewed by the state CFR committee, 34% (n=36) of infants were found on their stomach. The back to sleep position does not guarantee safety, however, if the child is not placed in a safe sleep environment. Of the 105 SUIDs reviewed, 26% (n=27) were found sleeping on their back but in an unsafe environment.

The state CFR committee reviewed the quality of data being collected and reported by local authorities on death certificates, as well as that being entered by local CFR teams into the CDR-CRS. Even examining data for only one calendar year highlights the need for standardized death scene investigation and data quality training at the local and state level and provides a basis for recommendations aimed at reducing the incidence of SUID in Indiana.

Summary of Recommendations

Public health educators and community leaders frequently make assumptions about the best programs or interventions for injury prevention and family resources. Funding is allocated to these efforts, and often the impact is minimal. Through comprehensive death scene investigation, consistent and accurate child death reviews and data collection, local CFR teams can offer well-informed, evidence-based and customized recommendations for more effective intervention plans. Based on the key findings from the review, the Statewide Child Fatality Review Committee recommends the following prevention activities. A detailed explanation of each recommendation can be found on page 35.

- 1) Utilize Sudden Unexplained Infant Death Investigation (SUIDI) protocol, including SUIDI Reporting Form, doll re-enactment and pre-autopsy conferences, for all SUIDs.
- 2) All Child Fatality Review teams should employ the SUID Case Registry Algorithm when reviewing SUIDs.
- 3) Death certifiers and coroners should adopt the Centers for Disease Control and Prevention (CDC) definitions for types of SUID: Sudden Infant Death Syndrome (SIDS), ASSB and unknown cause.
- 4) All Child Fatality Review teams should enter timely, accurate and complete data into the CDR-CRS.
- 5) Local Child Fatality Review teams should use CDR-CRS data, in addition to other mortality and morbidity data, to implement evidence-based programs/activities specific to the risk factors, trends and circumstances identified within the community.

Introduction

When we talk about health and safety, we hear a lot about rates. For example, Indiana’s infant mortality rate for 2015 was 7.3, which is significantly higher than the national rate of 5.9. But what does that really mean?

It means, on average, more than 600 Hoosier babies die before their first birthday. That is more than 50 babies every month and nearly 12 infants every week. In the past five years, more than 3,000 infants—the number of students in a large Indiana high school or the number of children who would fill 42 school buses—have lost their lives in our state.

Especially disturbing is the fact that Black infants in Indiana are 2.6 times more likely to die than White infants. In 2014, if Indiana lowered the Black infant mortality rate to that of the White infant mortality rate, 92 additional Black babies would have survived to see their first birthday.

It is not enough to understand the problem of a high infant mortality rate in Indiana. We also need to understand the causes of these deaths. While a majority of these deaths in the first year are due to things like low birthweight and extreme prematurity, the third-leading cause of infant death in Indiana is Sudden Unexpected/Unexplained Infant Death (SUID), and these deaths are mostly preventable.

Background

SUID is the death of an infant less than 1 year of age that occurs suddenly and unexpectedly, and whose cause of death is not immediately obvious before investigation. Most SUIDs are reported as one of three types 1) SIDS (Sudden Infant Death Syndrome), 2) Accidental Suffocation or Strangulation in Bed (ASSB), or 3) Unknown/Undetermined.

- ❖ **Sudden infant death syndrome (SIDS):** The sudden death of an infant less than 1 year of age that cannot be explained after a thorough investigation is conducted, including a complete autopsy, examination of the death scene, and a review of the clinical history. SIDS is a diagnosis of exclusion, made only after all other possibilities have been ruled out.
- ❖ **Unknown cause:** The sudden death of an infant less than 1 year old that remains undetermined because one or more parts of the investigation were not completed.
- ❖ **Accidental suffocation and strangulation in bed (ASSB):** The sudden death of an infant less than 1 year of age that can happen because of
 - Suffocation by soft bedding—for example, when a pillow or thick blanket covers an infant’s nose and mouth.
 - Overlay—when another person rolls on top of or against the infant while sleeping.
 - Wedging or entrapment—when an infant is wedged between two objects such as a mattress and wall, bed frame or furniture.
 - Strangulation—for example, when an infant’s head and neck become tangled in car seat straps or wrapped in blankets.

A safe sleep environment is one where the infant is placed on his or her back and on a firm sleep surface, including a crib, bassinet or portable crib. Sleep surfaces are free of soft objects, loose bedding, bumper pads or any objects that could increase the risk for entrapment, suffocation or strangulation out of the crib. Infants placed in unsafe sleep environments are at greater risk of SUID. Even after a thorough investigation, it can be hard to tell SIDS apart from other sleep-related infant deaths, such as overlay or suffocation by soft bedding. This is because these deaths are often unwitnessed and there are no tests to distinguish SIDS from suffocation. To complicate matters, people who investigate SUIDs may report cause of death in different ways and may not include enough information about the circumstances of the event from the death scene. Unfortunately, differences in classification and coding of causes and manners of infant death, as well as inconsistent investigation techniques, have led to an underreporting of SUIDs in Indiana.

In an effort to identify classification, coding and data collection inconsistencies in infant deaths across the state, and to inform efforts to standardize these practices, the Indiana Statewide Child Fatality Review (CFR) Committee reviewed all 2014 SUIDs and evaluated the quality of the investigative documentation being reported to the local CFR teams and the quality of the data being entered by local CFR teams into the National Center for Fatality Review and Prevention (NCFRP) Child Death Review Case Reporting System (CDR-CRS), a web-based reporting tool used to track child death review data.

The Centers for Disease Control and Prevention (CDC) Division of Reproductive Health supports SUID Case Registry monitoring programs in 16 states and two jurisdictions, covering 30% of all SUID cases in the United States. Participating states and jurisdictions use data about SUID trends and circumstances to develop strategies to reduce future deaths. The SUID Case Registry builds on the CDR-CDS and brings together information about the circumstances associated with SUID cases, as well as information about the investigations into these deaths (www.cdc.gov/sids/caseregistry.htm).

To ensure consistency with CDC case determination for the SUID Case Registry, the state CFR committee utilized the CDC SUID Case Registry decision-making algorithm (see Appendix 4) during the review process. The algorithm was published in 2014 by Shapiro-Mendoza et al and provides a standardized system to assign SUIDs to different categories, aids in the identification of gaps in infant death investigations, and helps detect high-risk groups.

Data for this review were pulled from Indiana death certificates, the official Indiana Department of Child Services (DCS) case assessment tool, data collected by local CFR teams in the CDR-CRS, and final autopsy reports.

This retrospective review process was comprised of four main goals:

Goal #1: Determine whether SUID investigations are being conducted as recommended by the CDC Sudden Unexplained Infant Death Investigation (SUIDI) protocol.

Goal #2: Classify the cause and manner of death for all 2014 SUIDs, using the CDC SUID Case Registry algorithm.

Goal #3: Evaluate the quality and completeness of the data entered into the CDR-CRS.

Goal #4: Identify prevalent SUID/SIDS risk factors and formulate prevention recommendations.

By better understanding specific risk factors and uncovering gaps in investigation and reporting processes, the state CFR committee will be more equipped to provide evidence-based recommendations for prevention efforts and process improvements. These recommendations can provide the basis for the training of investigators, local CFR teams, infant caregivers, community partners and statewide stakeholders who provide resources to infants, caregivers and families.

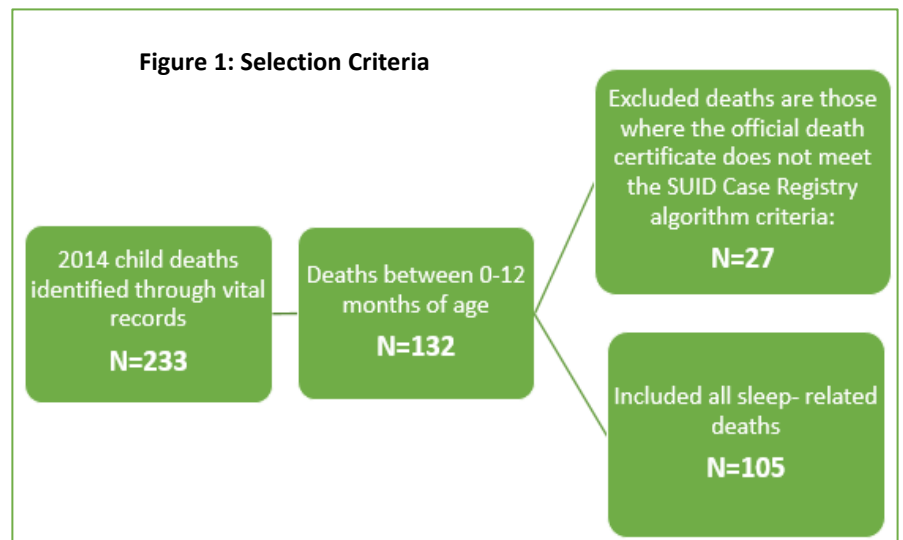
Methods: Selection Criteria and Case Review Process

The state CFR committee worked in conjunction with the Indiana State Department of Health (ISDH) Vital Records division to identify a total of 233 deaths of children in the year 2014 (figure 1). These data were then sorted further to isolate deaths of infants under one year of age (n=132). Because of possible errors in coding and cause of death determination, only using death certificates to isolate SUIDs could potentially lead to missed reviewable deaths, or infant deaths due to an unsafe sleep environment. For this reason, ISDH staff finalized case determination by individually examining each death through death certificates, DCS records, autopsy reports and coroner verdicts. Infant deaths did not meet the criteria for review if the death was determined to

- Be medical in nature;
- Be from an external injury (such as choking or those occurring as a result of motor vehicle collisions); or
- Not have occurred in the sleeping environment.

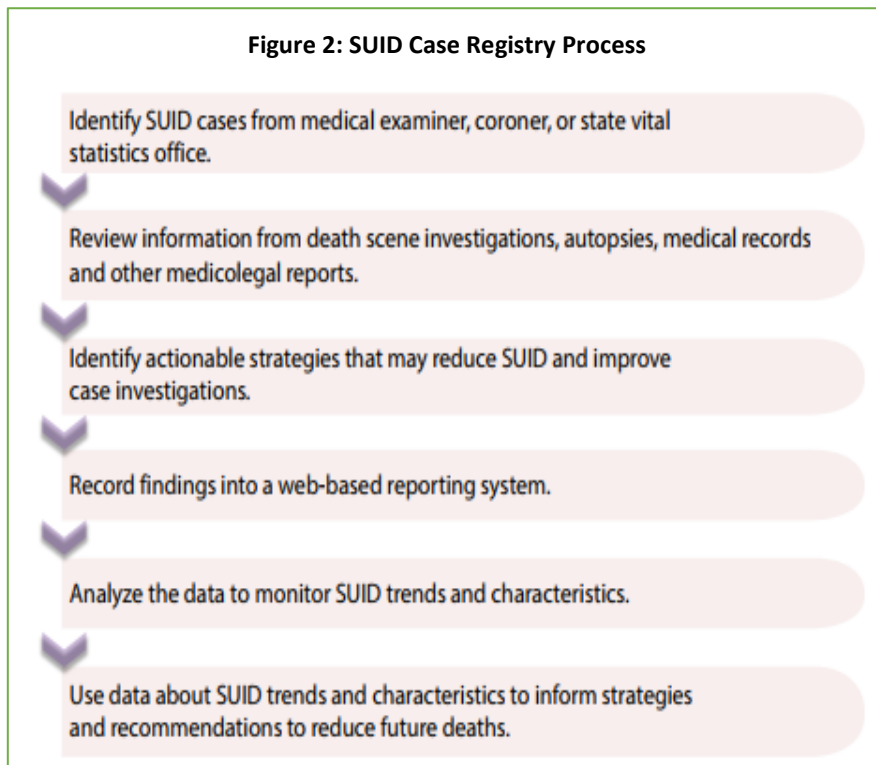
The remaining 105 SUIDs comprised

the deaths reviewed by the state CFR committee for this retrospective study and report.



Methods: SUID Case Registry

In 2012, the CDC began implementing the SUID Case Registry, a population-based surveillance system. Building upon the work of the NCFRP, the SUID Case Registry encourages existing multidisciplinary child death review programs to monitor and collect data on sudden unexpected infant deaths. Currently in use in 16 states, the SUID Case Registry provides a resource for understanding infant deaths by compiling comprehensive data surrounding the risk factors and circumstances associated with each death (figure 2). By monitoring SUID trends, the CDC and states can more effectively plan prevention programming and modify public health policy for maternal and child health programs. Further, understanding risk factors associated with infant death can lead to more targeted prevention efforts.



Source: CDC, 2017

The SUID Case Registry utilizes a standardized decision-making algorithm to identify SUIDs and collect, review and enter accurate, objective and comprehensive surveillance data linked from law enforcement reports, death certificates, coroner reports, DCS reports and infant and maternal medical records. By encouraging all local CFR teams to review SUIDs with the same protocol, standardized case determination is possible.

The state CFR committee used all data available to classify the 105 SUIDs to the best-fit category on the SUID Case Registry decision-making algorithm, including:

- Death certificates;
- Autopsy reports;
- DCS reports; and
- CDR-CRS data.

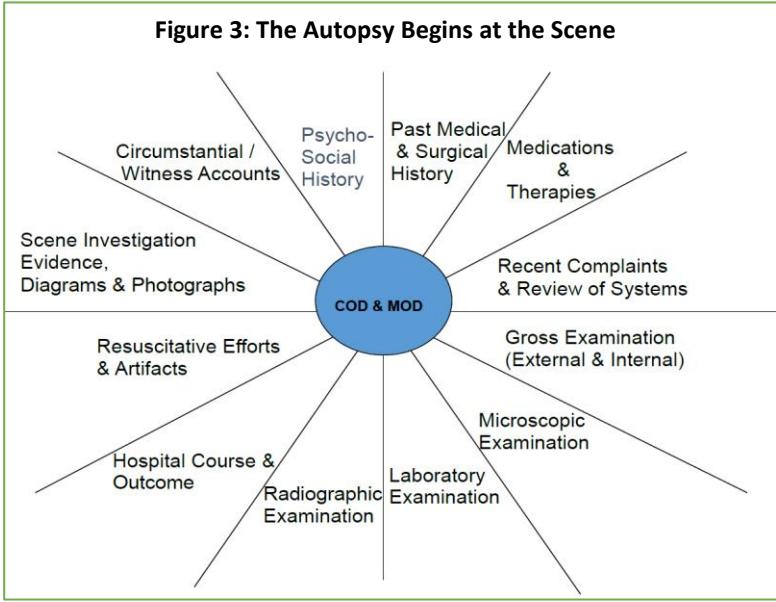
Consistent application of CDC definitions is imperative to creating standardization and consistency. Per the SUID Case Registry definitions:

- A complete death scene investigation and autopsy should be conducted and documented in the case report.

- For a death scene investigation to be considered complete, detailed information about where and how the body was found should be available.
- For an autopsy to be considered complete, all three should be performed and documented:
 - Toxicology
 - Radiograph
 - Pathology (including tests such as histology, microbiology and genetic testing).

Goal #1 - Determine whether SUID investigations are being conducted as recommended by the CDC Sudden Unexplained Infant Death Investigation (SUIDI) protocol.

The autopsy begins at the scene, so standardizing and improving data collection during infant death scene investigations is essential to help medical examiners and coroners accurately report the cause of death. To ensure valid and reliable data, which are required to support research and prevention efforts, standardized techniques and data collection at infant death scene investigations and consistent translation of findings into cause-of-death on the death certificate are crucial (figure 3). Inaccurate reporting and non-standard practices of classifying infant deaths hinder the ability to (1) monitor trends in SUID, (2) conduct research to identify risk factors, (3) design interventions to prevent these deaths, and (4) evaluate programs aimed at prevention.



SIDS is one of several causes of SUID. However, SIDS, unlike the other SUID causes, is a diagnosis of exclusion.

Although most conditions or diseases are usually diagnosed by the presence of specific symptoms, SIDS is a diagnosis given only after all other possible causes of sudden, unexplained death have been ruled out through a careful case investigation, which includes a thorough examination of the death scene, a complete autopsy and a review of the infant’s medical history. Suffocation (asphyxia), drowning, electrocution, hyperthermia, hypothermia, carbon monoxide poisoning and homicide are examples of other causes of SUID that can be explained after a careful case investigation. A comprehensive death scene investigation is often the only way to make a distinction between SIDS and suffocation as a cause of death.

Sudden Unexplained/Unexpected Infant Death Investigation (SUIDI), created by the CDC in 2006, aims to standardize and improve data collected at infant death scenes and to promote consistent classification and reporting of SUIDs (CDC, 2006). First introduced in Indiana in 2007, consistent trainings were conducted across the state through 2010. While trainers and agencies conducting SUIDI protocols remained in the state after this, no further training sessions were offered prior to 2014, the year the SUIDs examined through this process occurred.

SUIDI protocol emphasizes the importance of collaboration from all agencies involved at the death scene. In order to promote this team concept during the investigation of an infant death, Indiana has adopted guidance known as Collaboration-Preservation-Observation-Documentation (C-POD) (Appendix 2). C-POD helps guide investigators to conduct a coordinated infant death investigation using recommended practices and demonstrates how to report consistent, detailed scene information to the pathologist conducting the autopsy.

Collaboration during infant death scene investigations is critical. Immediate, coordinated investigations of all SUIDs will not only result in the most accurately collected scene information, but also will ensure the families are treated with respect, are not subjected to questioning by multiple investigators, and that the work is being done by the most appropriate agency/investigator for each task.

Preservation recommendations focus on maintaining an infant death scene as it was when the child was discovered, until all necessary evidence is seized, documented and/or circumstances are demonstrated or reconstructed. Observation recommendations emphasize the collection of the most detailed and accurate case information from all investigators at each scene.

Like all components of C-POD, documentation is crucial. All observations and details about the scene and witnesses should be immediately recorded. Investigators are guided by the SUIDI Top 25, a list of critical details necessary for complete investigations (Appendix 3). While assigning at least one investigator to the task of documenting infant death scene information is important, the combined details from all parties present at any and all scenes is critical to creating the most accurate picture of what caused the infant's injuries. These reports, coupled with medical records from both the infant and mother, will aid investigators in hypothesizing a probable cause of death to present to pathologists.

Documentation of the death scene should also include photographs of a doll re-enactment with the caregiver(s) who placed the child in the sleep environment (Placer), the caregiver(s) who found the child in distress (Finder) and the last caregiver to hear/see the infant alive (Last Known Alive). Each of these witnesses should be asked to utilize a SUIDI doll to demonstrate to investigators the body, head and neck positions of the infant, as well as the position of any environmental factors that may have contributed to the death. These re-enactments should be photographed from multiple angles and clearly labeled for the pathologist to review prior to the autopsy.

The documentation collected at the scene should be presented to the pathologist during a pre-autopsy conference. The pre-autopsy conference is a meeting of investigators, prosecutors and the forensic pathologist and should take place prior to the autopsy. It provides an opportunity for all members of the investigative team to share information collected at the scene and conduct a thorough records review. Not only does it give the pathologist a description of the circumstances surrounding the infant death and alert him/her to possible suspicious circumstances, but it makes him/her aware of evidence on or in the infant's body for which he/she should be searching.

Autopsies conducted for infant deaths should not rely solely on gross examination (IC 36-2-14-6.3). The autopsy should always include complete X-rays of the body. A complete skeletal series is the gold standard; however, in jurisdictions where this is not an option for financial or technical reasons, a single film would show documentation of gross findings. In Indiana, an autopsy on any child less than three years of age who dies suddenly, unexpectedly or whose death is unexplained must be done by a forensic pathologist (IC 36-2-14-6.7). Toxicology, histology, microbiology and other pathology, including genetic and metabolic testing, should also be conducted.

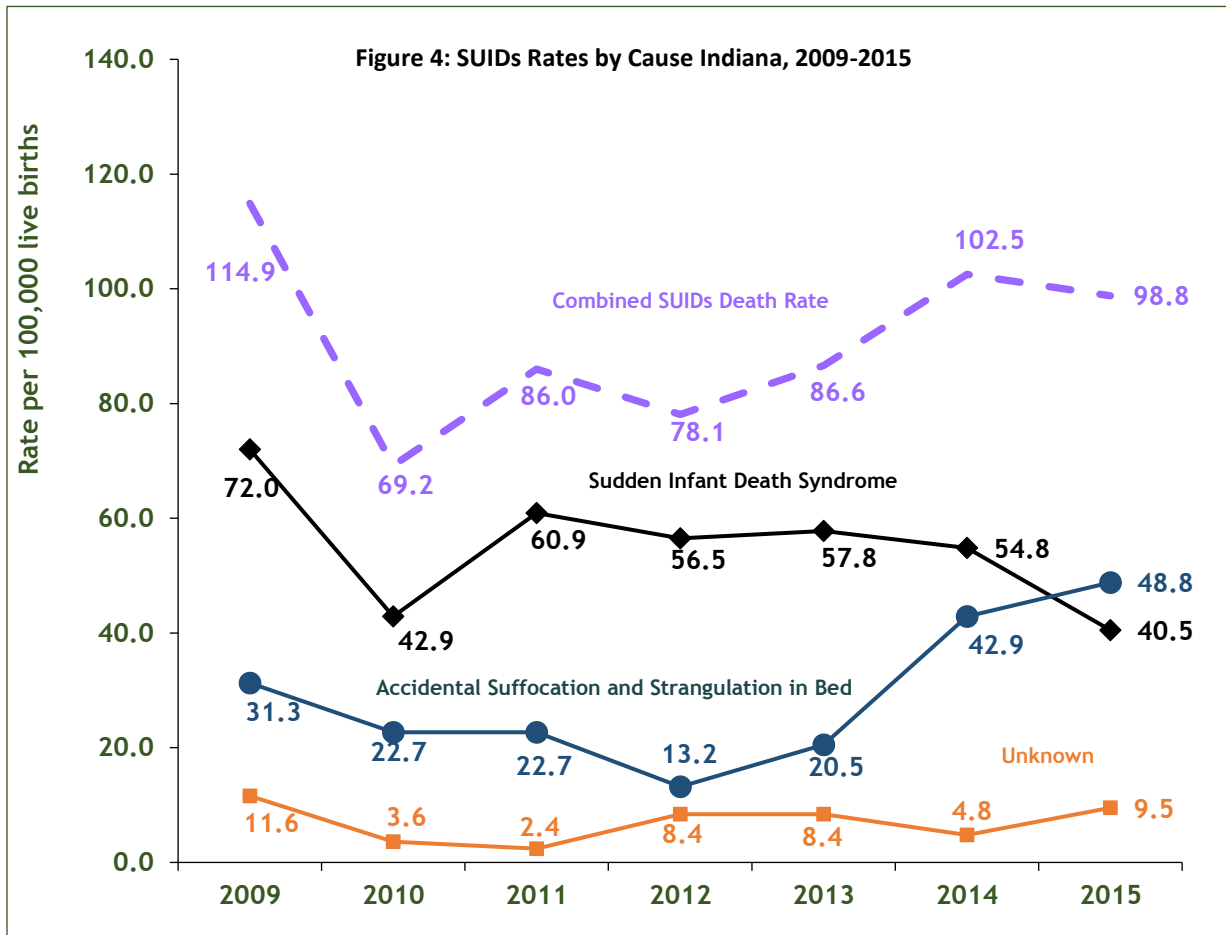
While all components of the C-POD guidelines are crucial, the state CFR committee focused on case documentation during their examination of calendar year 2014 SUIDs to determine which, if any, followed the complete SUIDI protocol for cause and manner of death determination.

Goal #2: Classify the cause and manner of death for all 2014 SUIDs, using the CDC SUID Case Registry algorithm.

Death certificate data is often the only basis for state and national mortality statistics. While this does provide a snapshot of the burden of various causes of death, vital records data are often not calculated for more than a year, which limits real-time prevention efforts. Further, forms are often incomplete or contain inaccurate information and do not provide facts about the "who, what, where, when and how." These critical details are needed to identify risk factors and prevent future deaths.

Child death review experts and local CFR teams know the incidence of SUID is larger than what vital records data show. Per the CDC, there has been a shift in the types of SUIDs reported. Rates of deaths reported as unknown cause and ASSB have increased and deaths reported as SIDS have decreased. The exact cause for this shift is unknown but could be due to stricter adherence to SIDS definitions by death certifiers, more complete death scene investigation and autopsy data, or more detailed information on the circumstances surrounding each death resulting from child death reviews (CDC, 2017). In Indiana specifically, between 2013 and 2014, ASSB rates nearly doubled, while SUID rates remained stable (figure 4). This significant change

may be due to local CFR teams reviewing infant deaths, as it coincides with CFR legislation and CFR team formation across the state.



Source: Indiana State Department of Health, Maternal & Child Epidemiology Division [November 14, 2016]
 Indiana Original Source: Indiana State Department of Health, PHPC, ERC, Data Analysis Team

While SIDS is an assignable cause of death, SUID is not. SUID is the umbrella term by which infant deaths are categorized; thus, when SUID is placed in the cause of death field, it is automatically coded as SIDS. This means the SIDS rates will look higher than what is accurate and the deaths due to ASSB or unknown causes will be lost in reporting.

Infant sleep-related deaths should be coded as one of the cause of death determinations under the SUID umbrella: SIDS, ASSB, or unknown. SIDS, as a diagnosis of exclusion, denotes there was no evidence of cause or mechanism of death. The manner of death should be coded as undetermined because death investigators have no evidence to show whether it was, or was not, a natural death.

By definition, if a death is caused by injury, the manner of death is not considered natural. For this reason, the manner of death for ASSB will not be natural because death was hastened by injury (suffocation).

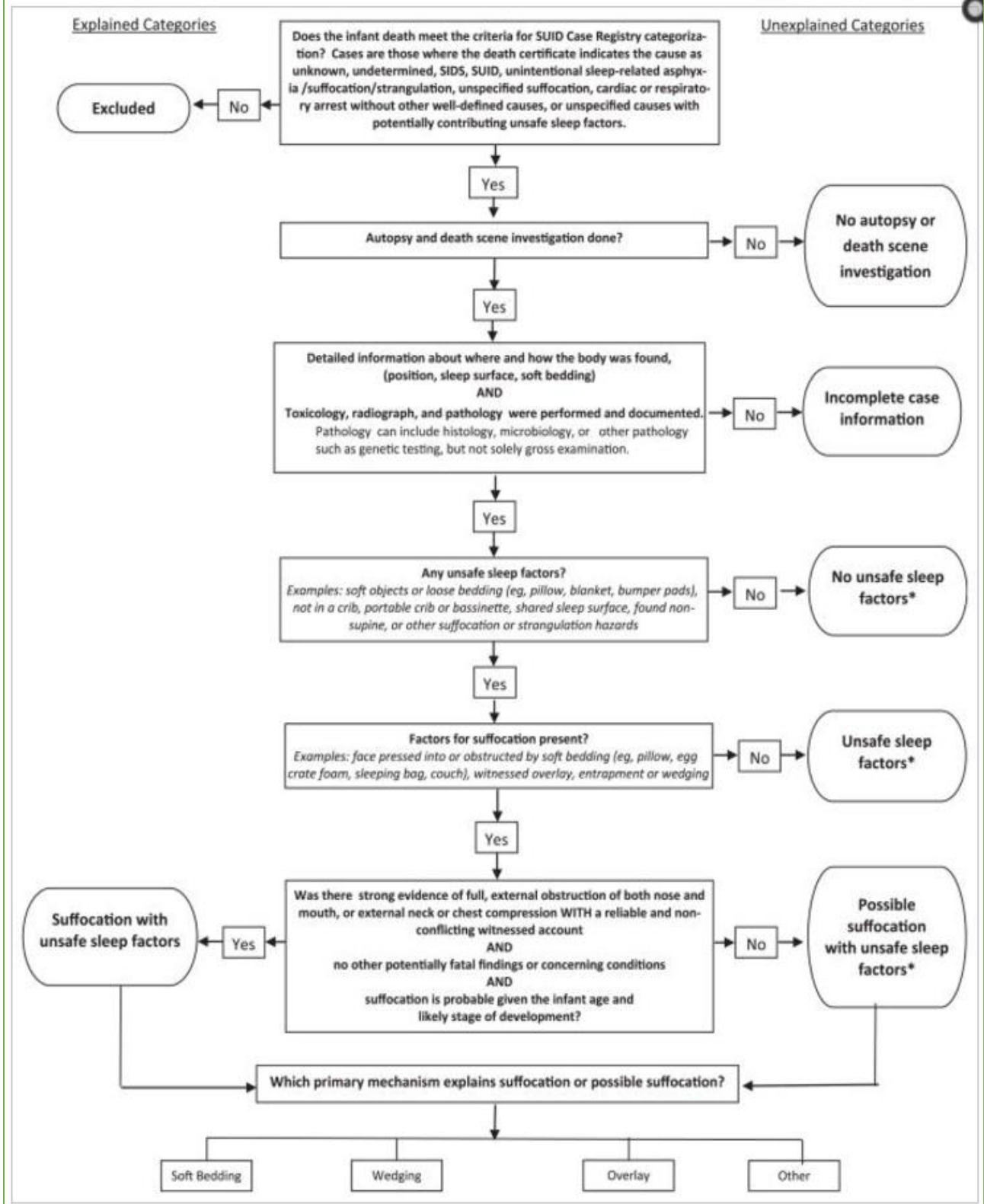
If one or more parts of the investigation were not completed— including a thorough death scene investigation or complete autopsy — the cause and manner of death should be classified as undetermined.

Death certifiers should make every effort to include contributing factors, such as possible suffocation and unsafe sleep factors, as those fields on a death certificate provide key words by which epidemiologists can further examine and categorize SUIDs.

The state CFR committee classified the cause and manner of death for the 105 SUIDs from 2014, using the SUID Case Registry algorithm. While this decision-making algorithm is new to Indiana, it should be the gold standard by which these classifications are made. Not only does the algorithm aid in cause and manner of death determinations, it also incorporates all investigative processes and the work of pathologists and coroners and can help inform the need for improved death scene training and protocols.

According to the algorithm, the cause and manner of death on the death certificate helps establish whether or not the infant death meets the SUID Case Registry criteria (Appendix 5). If there are no factors found relating to the algorithm, it is not a SUID and the death is excluded from review. All SUIDs meeting case criteria then are examined to determine if they are SIDS, ASSB or Undetermined causes of death. A series of progressive questions are answered with case documentation to make these determinations (figure 5).

Figure 5: SUID Case Registry: Decision-making Algorithm



Source: Shapiro-Mendoza et al., 2014

Goal #3: Evaluate the quality and completeness of the data entered into the CDR-CRS.

The death of a child is a sentinel event and should catalyze local and state action to prevent other deaths. While child death review is crucial to inform prevention, it is also important to systematically collect data from these reviews, compare review findings with child mortality data from vital statistics and other official records, and report on the findings from these reviews over time.

Utilizing standardized, consistent data collection and reporting practices will further enhance knowledge and identification of trends and patterns of risk, lead to improved child death investigations and lead to data-driven prevention programs. Local child fatality review (CFR) teams gather as much information as possible to determine the most accurate cause and manner of a child's death. Team members have the opportunity to share information, discuss and prioritize risk factors and promote local education and community-based prevention programs.

When data from local teams is collected, combined and analyzed over time, trends, risk factors or patterns in child injury and safety can be identified. The collection of findings from case reviews and the subsequent reporting on these findings can help:

- Local teams gain support for local interventions.
- State teams identify trends, major risk factors and to develop recommendations and action plans for state policy and practice improvements.
- State teams match review findings with vital records and other sources of mortality data to identify gaps in the reporting of deaths.
- State and local teams use the findings as a quality assurance tool for their review processes.
- Local teams and states use the reports to demonstrate the effectiveness of their reviews and advocate for funding and support for their CDR program.
- National groups use state and local CDR findings for national policy and practice changes.

Programming for topics such as seatbelt use in motor vehicles, suicide prevention in schools and water or fire safety education have all stemmed from the data entered by local CFR teams across the country. Access to this data has allowed entities such as the Consumer Product Safety Commission (CPSC) to use child death review data to inform its work with products marketed or recalled to families and children.

Local CFR team members are volunteering their time to do this difficult work, and by entering data into the CDR-CRS, the tragic loss endured by the family can result in systems

improvements protecting the lives of other Hoosier infants. Not only does it give purpose to the work local CFR teams continue to do, but it also honors the memories of the infants and children.

The state CFR committee evaluated the 2014 SUID data entered into the CDR-CRS by the local CFR teams for quality and completeness. This baseline information will guide training and support of local CFR teams across the state.

Goal #4: Identify prevalent SUID/SIDS risk factors and formulate prevention recommendations.

The goal of the Indiana State Child Fatality Review Program is to ultimately decrease child injury and death through prevention efforts. This is done by monitoring data, identifying trends, injuries, and deaths that may be preventable in Indiana and reviewing and learning from the reported deaths. In collaboration with key partners, this learning is applied to developing recommendations and interventions that may help prevent injuries and future child deaths.

While all case information and details were not available for this retrospective review, the state CFR committee felt it was prudent to examine each case for risk factors identified by the American Academy of Pediatrics (AAP) and social factors recognized by the CDC as contributing to significant gaps in mortality, such as race and socioeconomic position, and determine if trends could be identified on which recommendations and prevention efforts could be focused. With the increased use of the CDR-CRS by local CFR teams, this data will become more robust, and successful prevention responses can be created in real time.

Other potential risk factors could be uncovered with quality investigations (including SUIDI protocol), timely reviews and well-collected and well-documented data. These include:

- 1) Is substance abuse/misuse during pregnancy a risk factor for SUID?
- 2) Is substance abuse by caregiver a risk factor for SUID?
- 3) What substances, if any, are being abused by caregivers of infants who die in sleep-related events?
- 4) Is Intimate Partner Violence (IPV) a risk factor for SUID?
- 5) Is appropriate receipt of prenatal care protective for SUID?
- 6) Is a mother/father's employment status indicative of the risk for SUID?
- 7) Is a mother/father's education level indicative of the risk for SUID?
- 8) Is a mother/father's income level indicative of the risk for SUID?
- 9) Is age range for the infant caregiver a risk factor for SUID?

Understanding how these factors contribute to or protect against SUID in Indiana infants would assist local CFR teams and agencies in creating targeted, appropriate interventions for families.

While this retrospective review process spanned only SUIDs from 2014, the trend data available from just one year was useful to identifying prevention opportunities.

Key Findings

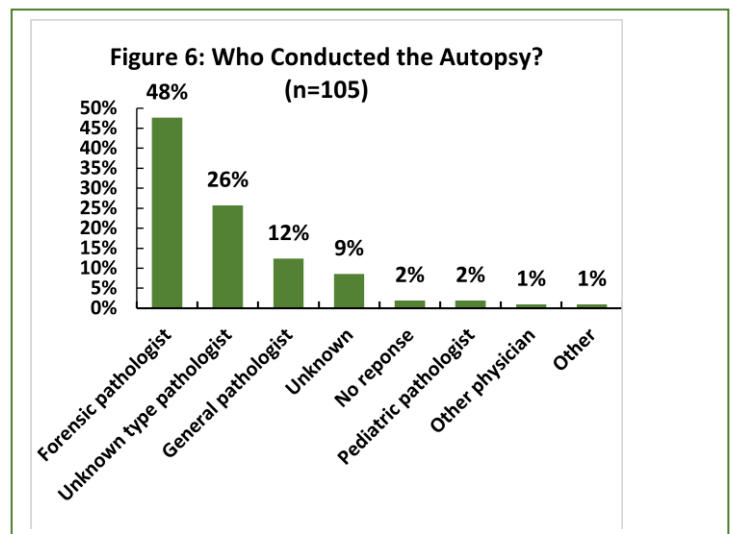
Goal #1: Determine whether SUID investigations are being conducted as recommended by the CDC Sudden Unexplained Infant Death Investigation (SUIDI) protocol.

Key Findings

A thorough death scene investigation and complete autopsy are required to fully understand the circumstances surrounding the death of an infant. Based on case review conducted by the state CFR committee, a death scene investigation was conducted in 87% of the 105 deaths (N=91). While a majority of SUIDs had a partial death scene investigation, not all were complete or included the necessary documentation. Completing a SUIDI Reporting Form (RF) during the investigation is critical to ensuring all of the information necessary for the pathologist is collected. In 2014, the SUIDI RF was only completed during 42 death scene investigations (40%). A scene re-enactment was conducted at 17 death scenes (16%), but only 10% (n=11) of those were completed with use of a doll.

A complete autopsy is not based solely on gross examination but must also include toxicology, X-rays and pathology. Indiana law also requires SUID autopsies be conducted by a forensic pathologist. An autopsy was conducted in 99% (n=104) of the deaths, but only 48% (n=50) were completed by a forensic pathologist (figure 6). Toxicology screening was completed for 90 (86%) of the 105 autopsies, but X-rays were taken in only 51 (49%) cases.

Another crucial component to ensure all relevant information is collected and presented to the pathologist is the review of Department of Child Services (DCS) records for prior history or contact with the family. According to the information collected from the review process found in the CDR-CRS, DCS records were not examined during 12 SUID investigations (11%).



Note: Due to rounding, percentages do not always add up to 100%.

Table 1: Investigation Practices

Table 1: Were These Investigation Practices Completed?	Number of SUIDs (n=105)									
	Yes		No		No response		Unknown		N/A	
	# of SUIDs	Percentage	# of SUIDs	Percentage	# of SUIDs	Percentage	# of SUIDs	Percentage	# of SUIDs	Percentage
Death Scene Investigation	91	87%	1	1%	1	1%	12	11%	0	0%
Autopsy	104	99%	0	0%	1	1%	0	0%	0	0%
Scene reenactment with a doll	11	10%	26	25%	18	17%	50	48%	0	0%
Scene reenactment without a doll	6	6%	27	26%	20	19%	52	50%	0	0%
SUIDI reporting form	42	40%	3	3%	16	15%	44	42%	0	0%
Toxicology Screening	90	86%	4	4%	1	1%	10	10%	0	0%
X-ray - complete skeletal series	51	49%	27	26%	6	6%	21	20%	4	4%

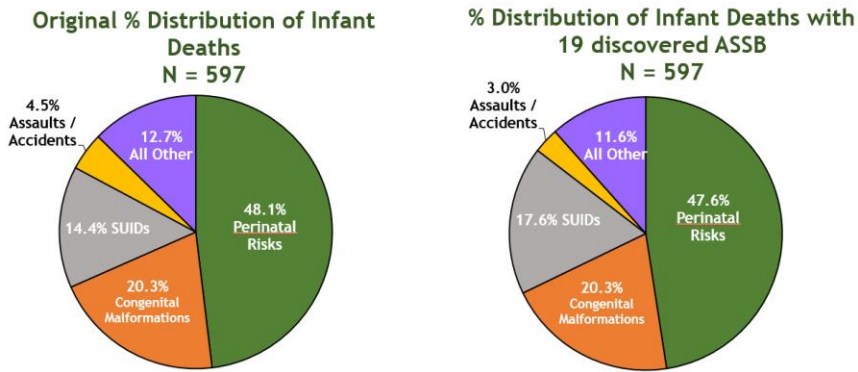
Because these deaths all occurred prior to a large-scale SUIDI training event in 2015, which resulted in more than 420 trained professionals, reviewing the investigative and autopsy techniques will aid in establishing a baseline of investigative practices prior to those efforts. From this knowledge, the state CFR committee and local CFR teams will be better able to create recommendations for continued SUIDI training, as well as compare previous practices to those occurring after 2015.

Goal #2: Classify the cause and manner of death for all 2014 SUIDs, using the CDC SUID Case Registry algorithm.

Key Findings

Through this review process, the state CFR committee identified 19 (22%) SUIDs that were not previously identified through epidemiological analysis of vital records information. The pie charts below (figure 7) shows the infant mortality distribution by cause for 2014. The addition of the 19 previously unreported SUIDs does not appear to change the distribution drastically, but the overall SUIDs percentage did increase from 14% to 17% of the infant deaths in 2014. This is much closer to the number deaths from congenital malformations (20%), which is the second most common cause of infant death in 2014. This additional data is important, as it shows more accurately the burden SUIDs have on our overall infant mortality distribution.

Figure 7: Infant Mortality Distribution by Cause – Indiana 2014

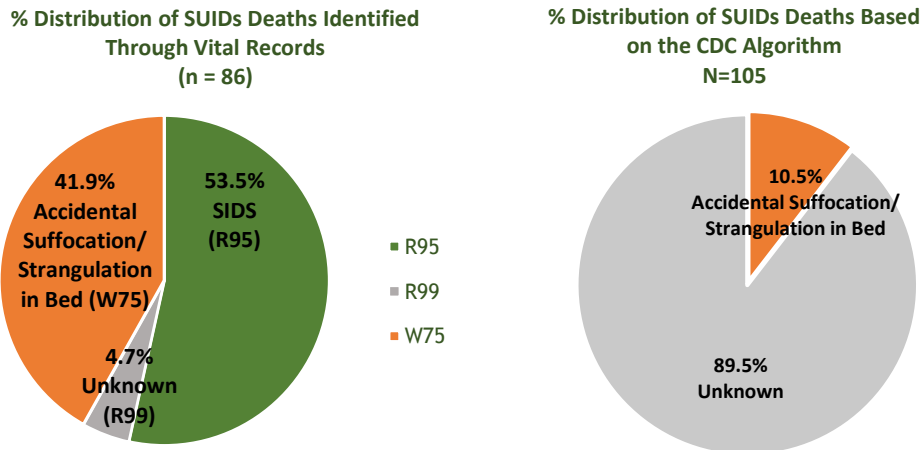


*Note: Cause specific mortality rates may not exactly equal the overall infant mortality rate due to rounding.
Source: Indiana State Department of Health, Maternal & Child Health Epidemiology Division (November 11, 2017)
Indiana Original Source: Indiana State Department of Health, PHPC, ERC, Data Analysis Team

It is critical to note that through this retrospective review process, there were some cause and manner of death determinations with which the state CFR committee agreed, given the anecdotal evidence. Nevertheless, the information available,

either from the investigation or from the documentation, was incomplete. Thus the SUID was identified as incomplete or undetermined, per the SUID Case Registry algorithm. Figure (8) compares the distribution of ASSB deaths from those 86 SUIDs gleaned from vital records to the determination of the state CFR committee using the SUID Case Registry algorithm (n=105). Not only did the number of SUIDs increase from 86 to 105, but anecdotally, the state CFR committee believes most of the SUIDs reviewed occurred as a result of ASSB. While the circumstantial information points to ASSB, only 10.5% (n=11) of the SUIDs could be unequivocally labeled ASSB based on available investigation data and strict adherence to the SUID Case Registry algorithm. The state CFR committee classified 89.5% (n=94) of the SUIDs as unknown cause. This result exemplifies the need for improved investigation and documentation protocols.

Figure 8: The Effect of Missing Investigation Data on the Classification SUIDs



Source: Indiana State Department of Health, Division of Maternal and Child Health [May 5, 2017]

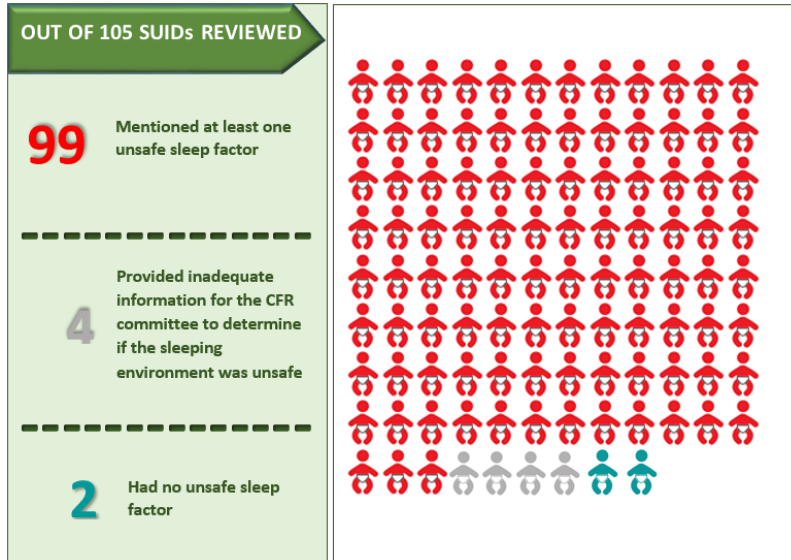
Epidemiologic analysis of vital records resulted in 86 SUIDs for 2014; however the state CFR committee identified a total of 105 deaths meeting the SUID inclusion criteria. Table (2) compares SUID counts from vital records and the state CFR Committee review by county of residence. This illustrates for local CFR teams how inaccurate SUID identification can impact infant mortality or SUID rates in a county or region.

Table 2: SUIDs by County of Residence (Vital Records compared to State CFR Committee)

Table 2: Number of SUIDs (n=105)								
County of Residence	Vital Records	Identified by State CFR Committee	County of Residence	Vital Records	Identified by State CFR Committee	County of Residence	Vital Records	Identified by State CFR Committee
Adams	0	0	Fulton	0	0	Orange	1	2
Allen	7	9	Grant	2	2	Parke	1	1
Bartholomew	2	2	Hamilton	2	2	Perry	1	1
Boone	1	1	Howard	0	1	Porter	0	2
Brown	0	0	Huntington	1	1	Pulaski	0	1
Carroll	1	1	Johnson	1	1	Randolph	1	1
Cass	0	0	Knox	1	1	Ripley	1	1
Clark	2	2	Kosciusko	0	1	St. Joseph	2	7
Clinton	0	0	LaGrange	1	1	Starke	1	1
Daviess	2	2	Lake	5	7	Steuben	2	2
Decatur	0	0	Lawrence	1	1	Tippecanoe	3	5
Dearborn	1	0	LaPorte	1	0	Vanderburgh	0	1
DeKalb	1	1	Madison	3	3	Vigo	3	3
Delaware	2	2	Marion	21	22	Wells	1	1
Dubois	2	2	Marshall	1	0	White	1	1
Elkhart	1	3	Miami	1	2	Whitley	1	1
Fayette	1	1	Monroe	2	2	Unknown	0	0
Fountain	0	0	Montgomery	1	1	Total	86	105

The state CFR committee believes the majority of 2014 SUIDs examined were due to unsafe sleep factors but is unable to state this with certainty, per the rules of the SUID Case Registry decision-making algorithm. However, figure (9) illustrates the committee’s findings based on evidence from the review, which includes any mention of “unsafe sleep factors” in the available case files. These results are staggering and should be taken into consideration when conducting future reviews and data analysis to inform prevention. While unsafe sleep factors cannot be categorically linked to the cause of death in all 2014 SUIDs, 99 of the 105 deaths reviewed showed the infant was placed to sleep in an environment with at least one unsafe sleep factor. Of the remaining 6 SUIDs, four additional may have occurred in an unsafe sleep environment, but there was inadequate documentation in the case files to make this determination. There were only two SUIDs reviewed in which the case files documented the presence of no unsafe sleep factors.

Figure 9: Presence of Unsafe Sleep Factors

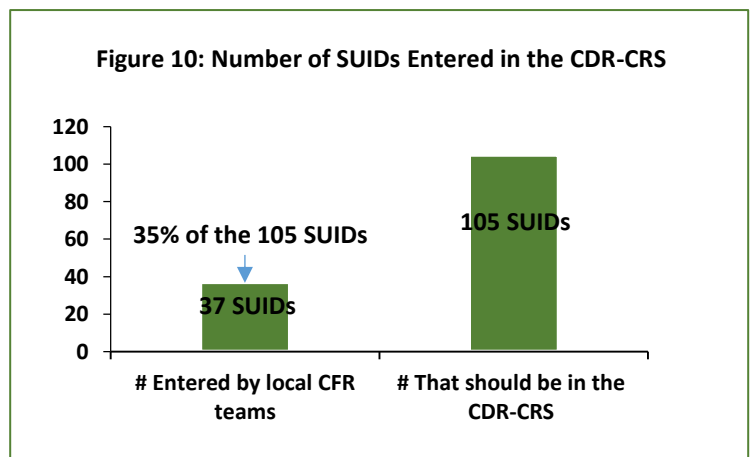


Goal #3: Evaluate the quality and completeness of the data entered into the CDR-CRS.

Key Findings

While reviewing each sleep-related infant death is a critical first step toward understanding the burden, it is not enough. It is imperative that local CFR teams track the data resulting from their reviews. The data collected in CDR-CRS, if done consistently and accurately, is the most comprehensive death data available. Circumstances and risk factors associated with the child’s death are captured and this information is only available through child fatality review. Vital records data does not capture this. Details about the quality of investigations and systems responses to a child death are often also documented. This allows national, state and local experts to identify trends related to child death, document the prevention activities and programs implemented at the local level and analyze the outcomes associated with these prevention programs. Evaluating CDR-CRS reporting trends is the first step toward improving the quality and consistency of the data collected and entered.

Although CDR reporting is crucial to inform prevention and measure outcomes associated with prevention strategies, out of the 105 SUIDs reviewed by the state CFR committee, only 37 (35%) were entered in the CDR-CRS by local CFR teams (figure 10). There are also key variables that are important to understand the circumstances and events associated with sleep-related deaths. Many of these key variables crucial to the focus of prevention activities or targeting

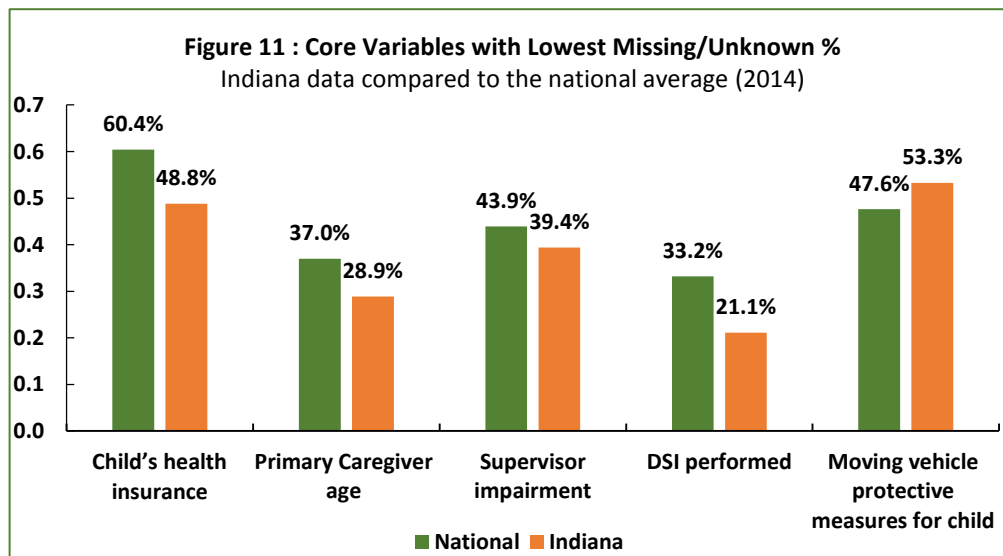


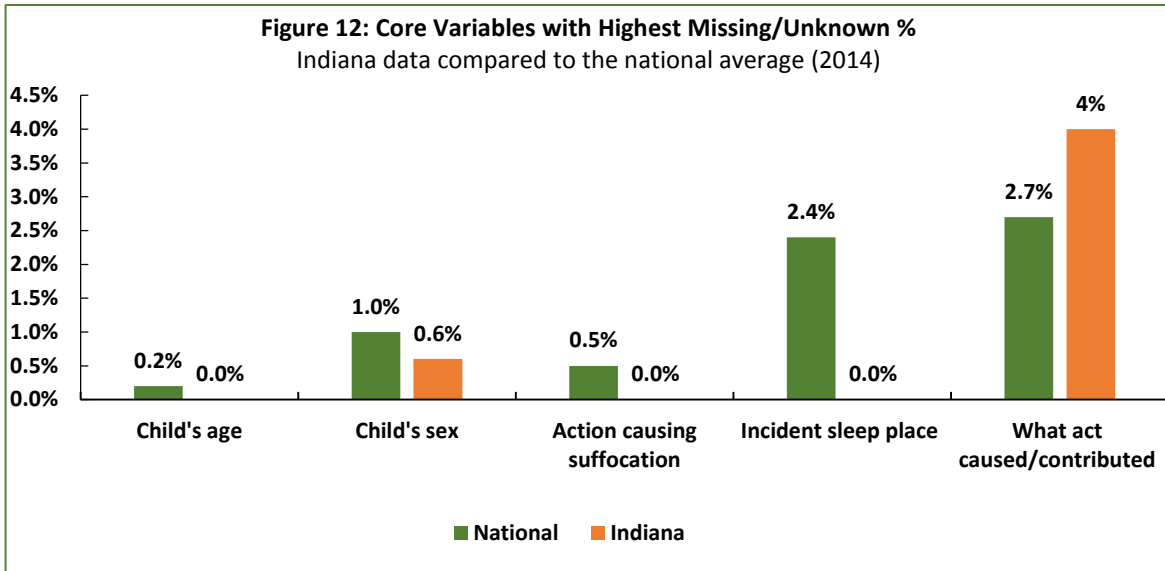
specific groups were missing, including such variables as insurance coverage of the infant, primary caregivers’ education and employment status, and whether or not there existed a history of intimate partner violence. Substance abuse and misuse is also a critical factor to examine with regards to prevention, but the questions regarding supervisor’s substance abuse history were either marked unknown or not asked in 47 SUIDs (45%) (table 3).

Table 3: Substance Abuse History, by Type

Table 7: Caregivers or Supervisors with a History of Substance Abuse - Substance Type (n=105)						
Substance Abused	Supervisor at Time of Incident	Percentage	Primary Caregiver	Percentage	Secondary Caregiver	Percentage
Alcohol	4	4%	5	5%	3	3%
Cocaine	1	1%	2	2%	1	1%
Marijuana	20	19%	25	24%	16	15%
Meth	6	6%	6	6%	2	2%
Opiates	7	7%	8	8%	3	3%
Prescription drugs	7	7%	7	7%	3	3%
Over the counter	2	2%	2	2%	1	1%
No response	3	3%	21	20%	27	26%
Yes	40	38%	22	21%	32	30%
No	25	24%	24	23%	26	25%
Unknown	37	35%	38	36%	20	19%

The National Center for Fatality Review and Prevention conducts periodic data quality analyses of the information entered into the CDR-CRS. Figures (11) and (12) graphically demonstrate the data entered by Indiana CFR teams, as compared to national averages. For most variables, local CFR teams in Indiana are in line with current national trends. However, more work needs to be done to improve the utility of the information housed in the CDR-CRS.





Goal #4: Identify prevalent SUID risk factors and formulate prevention recommendations.

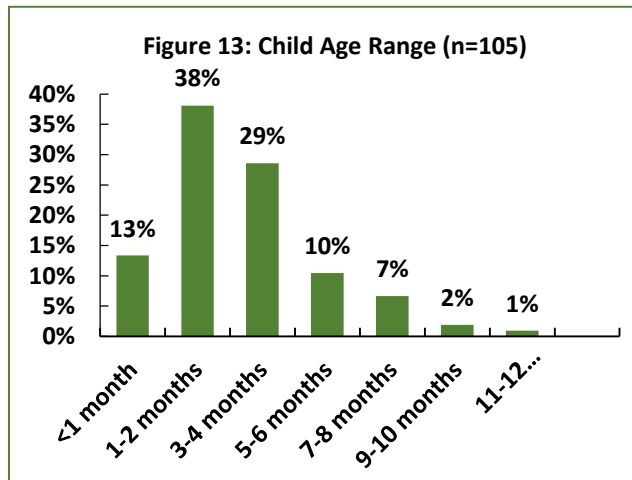
Key Findings

Infants

According to the American Academy of Pediatrics (AAP) (2016), a safe sleep environment is one where the infant is placed on his or her back and on a firm sleep surface including a crib, bassinet or portable crib. Sleep surfaces are free of soft objects, loose bedding, bumper pads or any objects that could increase the risk for entrapment, suffocation or strangulation out of the crib. Identifying the risk factors involved in SUIDs is crucial to helping inform targeted prevention. Knowing if infants of a certain age, gender, race or specific insurance coverage are more at risk help us focus prevention efforts.

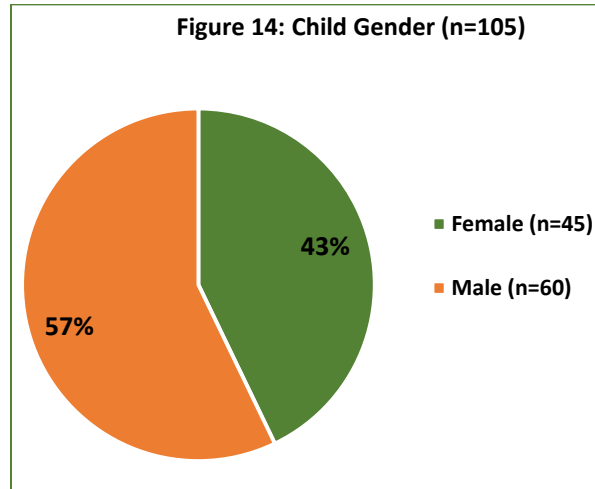
Infant Age

Through the state CFR committee's review of SUIDs in Indiana during calendar year 2014, some of these risk factors became apparent. For example, a majority (n=91, 90%) of SUIDs in 2014 occurred in infants between the ages of 0 days and six months; but the most critical time period was for those infants who were one to two months old at the time of death.



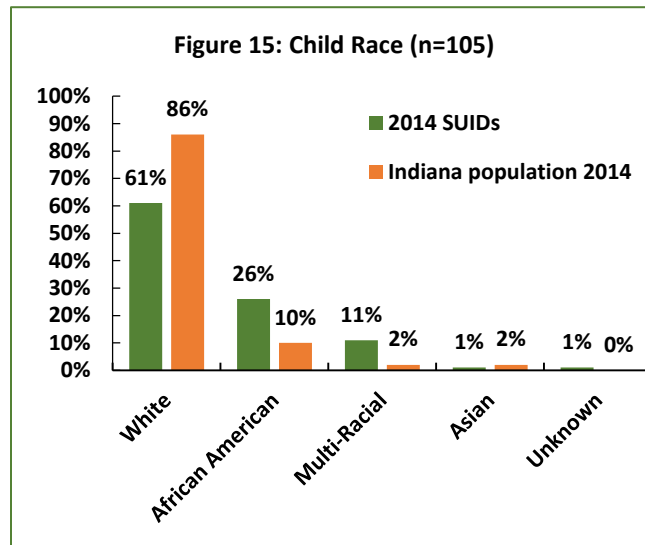
Infant Gender

In 2014, males represented slightly more than half of all Indiana SUID (n=60, 57%) and infant deaths (n=345, 58%) (figure 14). This data is consistent with national research on SUID demographics.



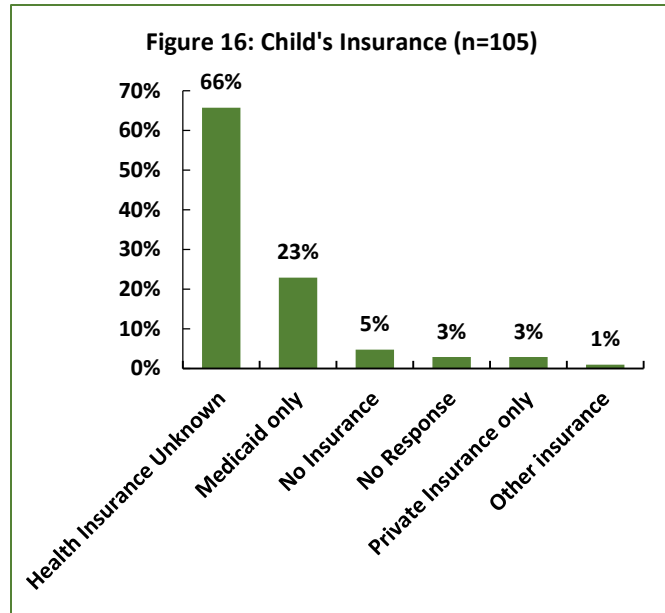
Infant Race

In the United States, non-Hispanic African American infants are two times more likely to die of SUID than White infants (CDC.gov). This disparity was even more marked in Indiana, where 27% (n=28) of the 105 SUIDs in 2014 listed the infant’s race as African American, which represents a higher percentage (close to three times) that of the African American population in Indiana in 2014 (9.5%) (figure 15).



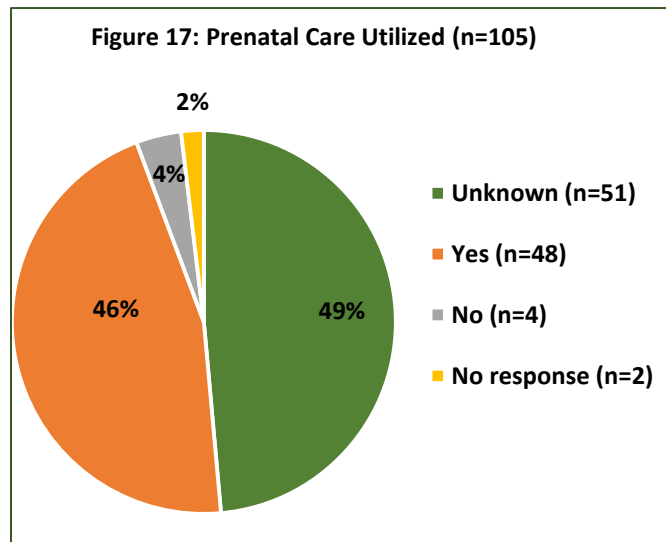
Infant Medical Coverage

According to the case records reviewed by the state CFR committee, 23% of infants lost to SUID were covered by Medicaid (n=24), representing a potential source for intervention and prevention services in Indiana. Unfortunately, the insurance coverage was unknown for 65% of SUIDs (n=69), demonstrating the challenges of incomplete investigation and data entry into the CDR-CRS when researching targeted prevention efforts (figure 16).



Mother Profile

The AAP 2016 recommendations for pregnant women are that they should 1) seek and obtain regular prenatal care; 2) avoid alcohol and drug use during pregnancy and after birth; and 3) avoid smoke exposure during pregnancy. Understanding the trends, challenges and risk factors associated with SUID can help policymakers target appropriate intervention for women of childbearing age and their partners.



Prenatal Care

Prenatal care data for 49% (n=51) of 105 SUIDs in 2014 was unknown (figure 17). With more complete case records, regional trends in access and utilization of prenatal care could be revealed to local and state CFR teams, thereby driving policy or resources available in those areas with underserved populations.

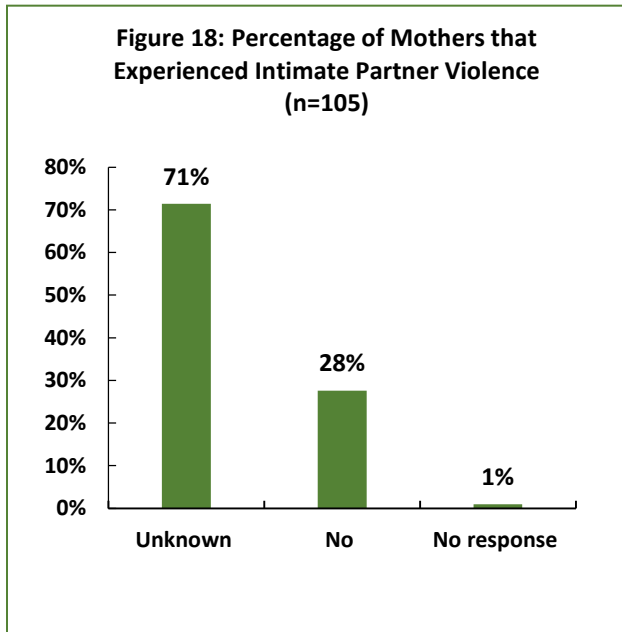
Substance Use during Pregnancy

The risk of SUID increases when the mother uses alcohol or drugs during pregnancy. The information on the mother’s alcohol and drug use during pregnancy was unknown for 64% (n=67) and 55% (n=58) of 105 SUIDs, respectively (table 4).

Table 4: Mother Substance Abuse during Pregnancy

Table 4: During Pregnancy Did Mother Abuse any Substances? (n=105)				
Answers	Tobacco	Illicit Drugs	Alcohol	Over the Counter or Prescription Drug
No Response	1	2	1	2
Yes	13	14	2	1
No	23	31	35	35
Unknown	68	58	67	67

The state CFR committee also attempted to track domestic violence as a potential risk factor for SUID, but the information collected and documented during the investigation was inconclusive. Questions about intimate partner violence during pregnancy were only asked in 28% of investigations (n=29) (figure 18). Discerning a correlation between intimate partner violence and the risk of SUID could be possible if this information was gathered during the course of each SUID investigation, as this is a data point collected in the CDR-CRS.



Caregiver at Time of Incident

Primary Caregiver

In the NCFRP data dictionary, primary caregiver is defined as person or persons (up to two) who had responsibility for care, custody and control of child a majority of the time (NCFRP, 2015, p. 18). These infant caregivers are crucial targets for prevention programs, safety resources and health information. Understanding their demographic may help local and state health educators tailor messages for SUID risk reduction. The biological parents accounted for 94% (n=99) of the primary caregivers listed for the 105 SUIDs (figure 19).

The average age of the primary caregivers was approximately 24.9 years (table 5), and 91% (n=96) were female. While the primary caregiver’s employment was unknown for 49% of SUIDs (n=51), a little over a quarter of them were employed (n=28) and 20% were unemployed (n=22). The primary caregiver’s education level was unknown in 73% (n=77) of SUIDs (figures 20-21).

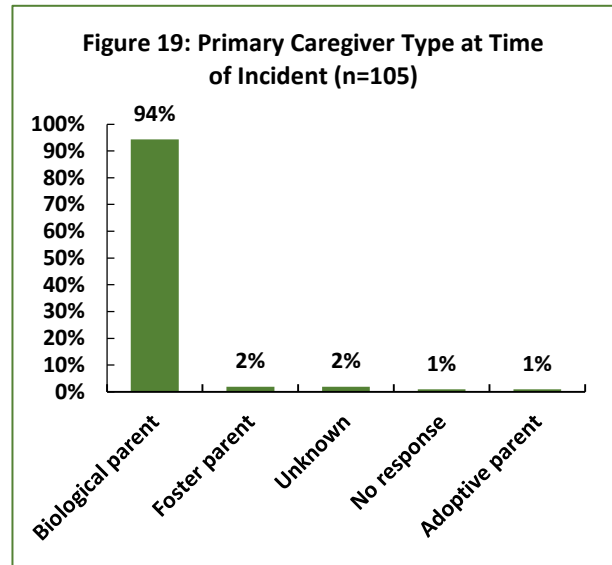


Table 5: Primary Caregiver Age Range

Table 5: Primary Caregiver Age Range (n=105)		
Age Range	# of SUIDs	Percentage
<18 years	1	1%
18-24 years	43	41%
25-34 years	42	40%
35-44 years	6	6%
45-55 years	1	1%
No response	9	9%
Did not apply	3	3%

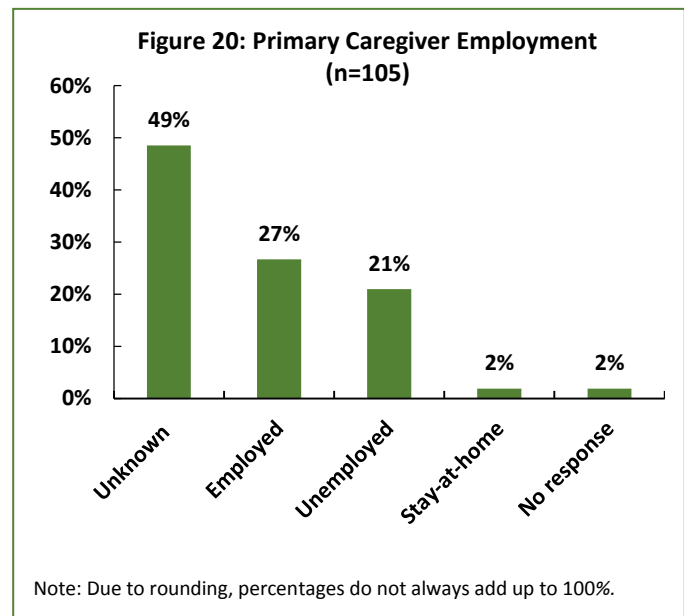
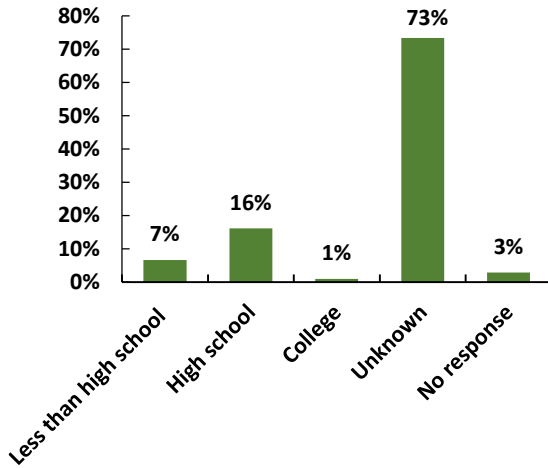
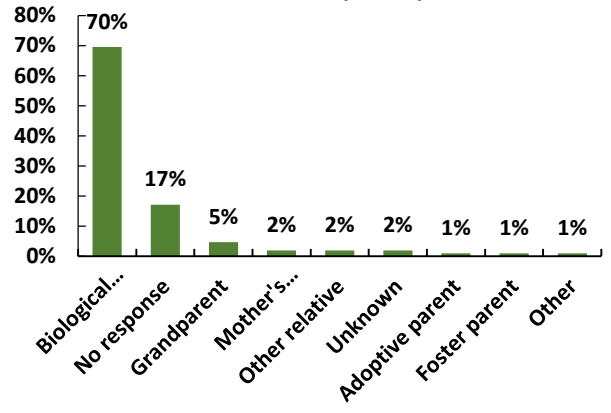


Figure 21: Primary Caregiver Education (n=105)



Note: Due to rounding, percentages do not always add up to 100%.

Figure 22: Secondary Caregiver Type at Time of Incident (n=105)



Secondary Caregiver

Any caregiver who spends the most time with the infant, after the primary caregiver(s), is considered the secondary caregiver. This includes parents and guardians, a grandparent, a sibling, an institutional staff, a step-parent, a friend, a relative, or mother's/father's partner. These critical adults in the infant's life should also be appropriately educated on SUID risk reduction. The type of secondary caregiver listed for 70% of the 2014 SUIDs (n=73) were biological parents, followed by 5% grandparents (n=5) (figure 22).

The average age of the secondary caregiver was 29.78 years (table 6). About 71% (n=75) were listed as male, but this question was skipped for 18% of the SUIDs (n=19). The secondary caregiver's employment was unknown for 36% of SUIDs (n=38), while 37% of them were employed (n=39) and 18% did not provide the employment status (n=19). The education level was unknown for 69% (n=72) of the 105 SUIDs (figures 23-24).

Figure 23: Secondary Caregiver Education (n=105)

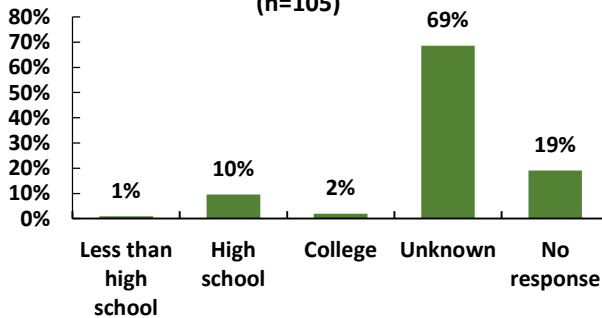
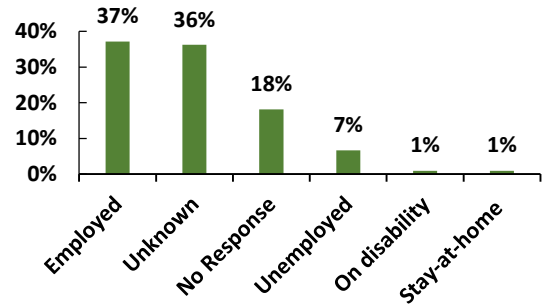


Figure 24: Secondary Caregiver Employment



Note: Due to rounding, percentages do not always add up to 100%.

Table 6: Secondary Caregiver Age Range

Table 6: Secondary Caregiver Age Range (n=105)		
Age Range	# of SUIDs	Percentage
18-24 years	21	20%
25-34 years	42	40%
35-44 years	12	11%
45-55 years	3	3%
>55 years	1	1%
No response	25	24%
Did not apply	1	1%

Supervisor at Time of Incident

Although it is important to collect information on the circumstance and risk factors of the parents and primary caregivers, it is also important to collect information on who had supervision of the child the time of the death. According to the NCFRP, supervision is defined as a person who has responsibility for care and control of child at time of incident (NCFRP, 2015, p. 21). Collecting this information helps us focus our prevention on the group(s) who were responsible for the infant when the death occurred.

Per the state CFR committee case review, biological parents accounted for 62% (n=65) of the supervisors listed for the 105 SUIDs (figure 25), and babysitters accounted for 9% (n=9). This information helps validate the belief that parents need to be the focus for safe sleep education efforts, but it also indicates educators may need to aim educational messages on babysitters or child care providers. While 61 (57%) were female, the supervisor sex was unknown in 24% of cases (n=25). The average age of the supervisor was approximately 27.06 years, however, a third of the SUID cases (n=31) did not list the age (table 7).

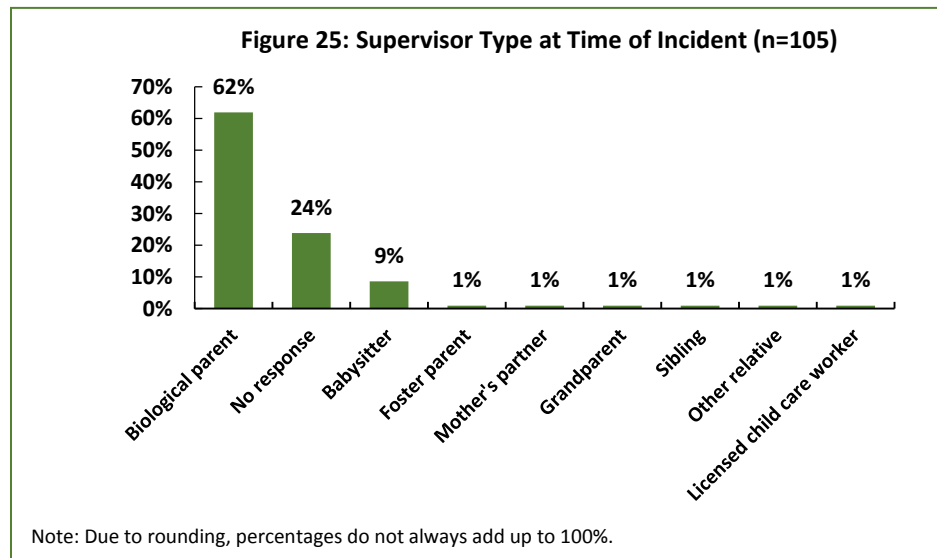


Table 7: Supervisor Age Range

Table 7: Supervisor Age Range (n=105)		
Age Range	# of SUIDs	Percentage
<18 years	2	2%
18-24 years	28	27%
25-34 years	29	28%
35-44 years	9	9%
45-55 years	3	3%
>55 years	1	1%
No response	31	30%
Did not apply	2	2%

Caregiver/Supervisor Substance Abuse History

Collecting information about caregiver and supervisor drug and alcohol use is imperative to connecting the risk factors that cause or contribute to the death and informing how and where to target prevention efforts. While this is important information to collect, the question regarding supervisor’s substance abuse history was either marked unknown or not asked in 45% of the SUIDs (n=47) (page 24, table 3).

The primary caregiver’s substance abuse history was unknown in 35% of the 105 deaths (n=37), but 38% of the primary caregivers (n=40) reported having a history of substance abuse, and a quarter reported abusing marijuana (n=25) (page 24, table 3).

The secondary caregiver’s substance abuse history was not reported in 36% of SUIDs (n=38), but 22% of the secondary caregivers (n=22) reported having a history of substance abuse, and 15% (n=16) abused marijuana (page 24, table 3).

Determining the number of SUIDs in 2014 that occurred while the supervisor was impaired could be a key piece of information toward understanding the impact that drug and alcohol use by caregivers can have on infants and small children. In 2014, when asked, 30% (n=32) of the supervisors at the time of the incident reported having a history of substance abuse and 14% (n=15) were impaired at time of incident. Additionally, 19% (n=20) of the supervisors reported having a history of abusing marijuana (page 24, table 3).

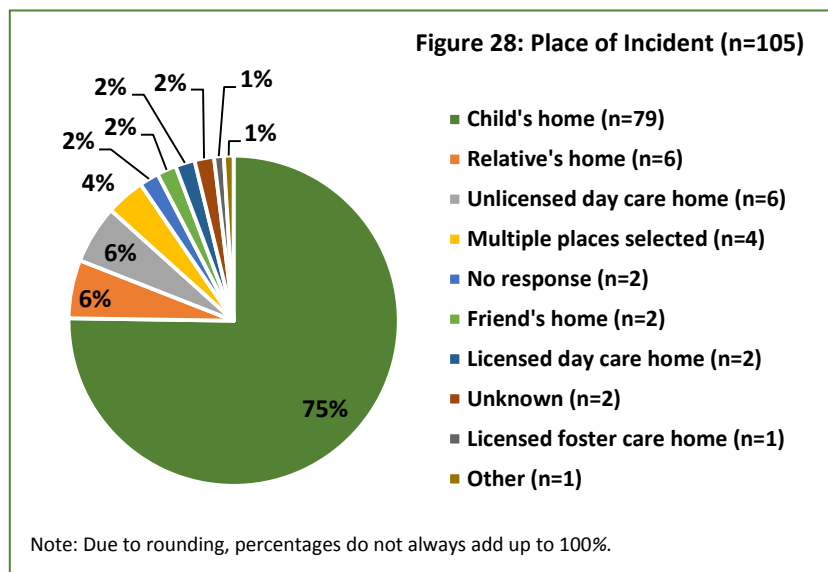
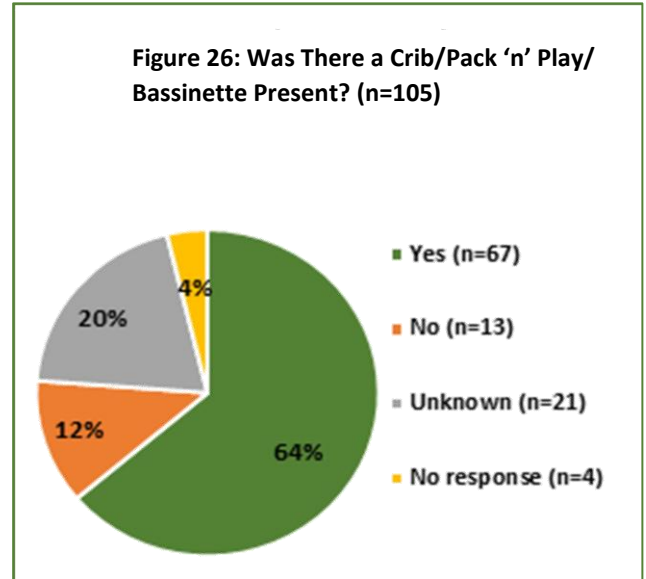
Other substances listed as being used by caregivers or supervisors were opiates and prescription drugs (n=7, 6.5%) followed by methamphetamine (n=6, 6%) (page 24, table 3).

Place of Incident

When we plan prevention to reduce SUID, we need to know where these deaths are occurring and details about the circumstances. Are they occurring at the family’s home? At a babysitter’s house? Did the infant have a crib or safe sleep surface, and if they did, were they being placed safely to sleep? Collecting this information helps inform prevention efforts, such as recommending infants are not placed to sleep on an adult bed or couch and that parents and caregivers share safe sleep recommendations with everyone, such as relatives or daycare homes, caring for their infant.

Out of 105 SUIDs, 64% (n=67) reported having a crib, bassinette or portable crib in the home for the child (figure 26). While the opportunity to ensure the infant was placed safely to sleep was present for these infants, half of the SUIDs (n=53) occurred in an adult bed, and 13% (n=14) occurred on a couch. Other unsafe sleep locations reported were a chair (n=2), a car seat (n=2) and the floor (n=1) (figure 27).

While a majority (75%, n=79) of the SUIDs occurred in the infant’s home, 6% (n=6) occurred in the home of a relative and 6% (n=6) occurred in an unlicensed daycare home (figure 28).



SUID Risk Factors

Other data points collected during SUID investigations and by local CFR teams during review can highlight the risk factors associated with the death and the need for or success of prevention activities. While the data reviewed was incomplete in many cases, some key findings should be noted.

The infant's sleeping position is a modifiable risk factor that can be addressed during prevention activities. Being placed on their stomach puts an infant at risk for SUID, and 34% (n=36) of the SUIDs in 2014 were found on their stomach (table 8). The back to sleep position, however, does not guarantee safety if the child is not put in a safe sleep environment. Of the 105 SUIDs reviewed, 26% (n=27) were found sleeping on their back (table 8) but in an unsafe environment.

Table 8: Infant Sleep Position

Table 8: The Sleeping Position the Child was Found in (n=105)		
Answers	# of Deaths	Percentage
On back	27	26%
On stomach	36	34%
On side	17	16%
Unknown	22	21%
No response	3	3%

In order to target prevention efforts, investigators must document the other modifiable risk factors involved. These modifiable risk factors include:

- Stomach and side sleeping positions
- Overheating
- Soft sleep surfaces
- Loose bedding
- Inappropriate sleep surfaces (such as sofa or water bed)
- Sharing the same sleep surface (such as bed)
- Maternal and second-hand smoke exposure and drug use

Of the infants lost to SUID in 2014, 46% (n=49) had a blanket/flat sheet and/or comforter in the sleeping area. A third (31%, n=33) had pillow(s) in their sleep environment, and 32% (n=3) were either wrapped or swaddled in a blanket. In 11% (n=11) of these deaths, the infant was sleeping with other children, and bumper pads were known to be present in 3% (n=3) of these SUIDs. Of the infants lost to SUID in 2014, 6% (n=6) were born drug exposed (table 9).

Table 9: SUID Risk Factors, per 2014 Case Data

Table 9: SUID Risk factors	Percentage (n=105)			
	No Response	Yes	No	Unknown
Child overheated	17%	2%	17%	64%
Child exposed to second-hand smoke	4%	18%	24%	54%
Child last placed to sleep with a +pacifier	6%	7%	40%	47%
Infant ever breastfed	2%	18%	33%	47%
Was death from problem with a consumer product?	1%	0	97%	2%
Illicit drugs - Infant born drug exposed	94%	6%	0	0
Alcohol use - Infant born with fetal alcohol effects or syndrome	100%	0	0	0
Child sleeping on same surface with other children	86%	11%	0	3%
Object(s) in sleeping area - Pillow	25%	31%	20%	24%
Object(s) in sleeping area - Cushion	28%	9%	35%	28%
Object(s) in sleeping area – Boppy or U-shaped pillow	31%	2%	39%	28%
Object(s) in sleeping area - Bumper pads	31%	3%	41%	25%
Child wrapped or swaddled in blanket	3%	32%	31%	34%
Object(s) in sleeping area - Clothing	30%	9%	29%	32%
Object(s) in sleeping area - Comforter	28%	25%	21%	26%
Object(s) in sleeping area - Thin blanket/flat sheet	15%	47%	19%	19%
Object(s) in sleeping area - Toy(s)	30%	6%	36%	28%

Note: Due to rounding, percentages do not always add up to 100%.

Key Recommendations

This retrospective review process targets all Sudden Unexpected Infant Deaths (SUIDs) and assesses the quality of investigative efforts as well as child fatality review processes and data collection involving infant death. SUIDs are mostly preventable. Timely access to useful data is crucial to design effective prevention measures for infants and their caregivers. The state CFR committee reviewed the quality of data being collected and reported by local authorities on death certificates, as well as that being entered by local CFR teams into the CDR- CRS. Even examining data for only one calendar year highlights the need for data quality training at the local and state level and provides a basis for recommendations aimed at reducing the incidence of SUID in Indiana.

Through comprehensive death scene investigation, consistent and accurate child death reviews and data collection, local CFR teams can offer well-informed, evidence-based and customized recommendations for more effective intervention plans.

Utilize SUIDI Protocol for all infant death scenes.

- ❖ All infant death investigators should utilize the SUIDI protocol, SUIDI Reporting Form and doll re-enactment at every infant death scene. All SUID investigations should be collaborative and multi-disciplinary to ensure the most accurate and complete data is collected.
- ❖ A Pre-Autopsy Conference should be a standardized best practice for all infant deaths. Coroners should require this step before finalizing death certificate data.
- ❖ Contributing factors to SUIDs should be carefully documented on all death certificates to improve the likelihood of accurate reporting of causes of death.

Additional considerations:

- ❖ Emergency Medical Services (EMS) must be immediately summoned and all necessary life-preserving efforts taken.
- ❖ Law enforcement and DCS must be immediately called to the scene or to the hospital, if the child has already been transported.
- ❖ If a language barrier exists between investigators and witnesses, interpreters should be made available.
- ❖ All professionals on scene should exchange information, including observations and contact information. This is especially important for EMS and other first responders. They often have witnessed the most uncorrupted version of the scene.
- ❖ Contact and convene other professionals as appropriate, including coroner, prosecutors, special detectives, daycare licensing entities, tribal authorities, clergy, animal control, building inspectors, etc.
- ❖ The safety of any children remaining in the home must be secured.
- ❖ All investigation processes, observations and determinations must be thoroughly documented.

All Child Fatality Review teams should employ the SUID Case Registry Algorithm when reviewing SUIDs.

- ❖ Local CFR teams should utilize the SUID Case Registry algorithm to determine accuracy of cause and manner of death determinations in the deaths of all infants under 1 year.
- ❖ Local CFR teams should note incomplete investigations or inaccuracies of death certificate data and provide local recommendations and feedback to all agencies to encourage systemic improvements.
- ❖ Death certifiers and local CFR teams should ensure contributing factors to SUID are listed on all death certificates.
- ❖ Death certifiers and coroners should adopt the CDC definitions for types of SUID – SIDS, ASSB and unknown cause.

All Child Fatality Review teams should enter timely, accurate and complete data into the CDR-CRS.

- ❖ Local CFR teams must ensure data from all case reviews is entered accurately and in a timely manner.
- ❖ Local CFR teams must ensure that data entered from case reviews is complete and comprehensive. Circumstances and risk factors associated with the child's death are captured during the review process. This information is vital to inform prevention and is only available through child fatality review.
- ❖ Local CFR teams should report deaths involving consumer products (sleep positioners, "Boppy Pillows", etc.) to the Consumer Product Safety Commission (CPSC). The CPSC will often use CDR-CRS data to inform its work in reducing the risk of injury and death from products marketed for families with young children.
- ❖ Local CFR teams should be trained in both case review practices and data entry techniques. If possible, technical assistance and data quality verification should be offered to ensure timeliness and accuracy.

Prevention programming for infant health and safety should be evidence-based and follow AAP guidelines.

- ❖ Local CFR teams should use CDR-CRS data, in addition to other mortality and morbidity data, to implement evidence-based programs/activities specific to the risk factors, trends and circumstances identified in the community.
- ❖ All potential infant caregivers should be educated on safe sleep recommendations.
- ❖ Community leaders and health educators should identify multiple touchpoints for parent education and support during pregnancy and the infant's first year of life.

Conclusion

Child fatality review (CFR) remains the only source of data about risk factors and circumstances in infant and child death cases. Vital records data does not provide the rich information available only through complete child death reviews. Local CFR teams have unprecedented access to comprehensive detail about a child's history and the circumstances surrounding the death. This includes birth records, medical records, school records, coroner reports, reports from the Department of Child Services and child abuse history, law enforcement records and history of exposure to domestic or sexual violence, and autopsy results. Examination of these documents by a multi-disciplinary CFR team not only reveals opportunities for systems improvements and prevention efforts, but also offers an opportunity to verify and if necessary, correct the data entered into the death certificate.

Concern remains over the lack of standardized identification and classification protocol for cause and manner of death. For example, many positional asphyxia cases were classified as natural deaths on death certificates. All 92 Indiana counties need to strive to adopt a consistent process for cause and manner of death determination for infant deaths. By following SUIDI protocol, collaborating with all investigative agencies and establishing Pre-Autopsy Conferences with forensic pathologists as best practice, the number of SUIDs

misclassified or miscoded would significantly decrease. As infant death cases are reviewed, local CFR teams can provide evidence to community stakeholders toward process and systems improvements.

There are Indiana CFR teams which review very few SUIDs each year. It may seem like those efforts will not be impactful. However, when combined with results from the review of SUIDs across the entire state, which are then accumulated on a national level, the impact will be formidable. Geographic differences, such as those factors specific to rural or urban regions, will become apparent, for example.

Reducing the SUID rate in Indiana will require sustained efforts at the state and local level. This report will provide some valuable information to local CFR teams and death scene investigators. It can also be used by the ISDH CFR Division to craft training tools to improve the quality of data collected by the investigators, the completeness of documentation of data processed by the local teams, and the classification of the cause and manner of death. Improving the knowledge of factors surrounding SUID events and improving investigation practices will allow local CFR teams, researchers and program planners to create prevention strategies and interventions, and even seek funding toward ultimately reducing SUIDs and injury-related infant deaths.

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Resources and Appendices

Appendix 1

Indiana Statewide Child Fatality Review Committee Members

Chair and Pediatrician: Roberta A. Hibbard, MD <i>Professor of Pediatrics, Chief, Section of Child Protection Programs IU School of Medicine</i>	Local Health Department Representative: Craig Moorman, MD <i>Local Health Officer Johnson County Health Department</i>	Ad Hoc Members: Kelly Cunningham, MPH <i>Child Fatality Specialist Indiana State Department of Health</i>
State Child Fatality Review Program Coordinator: Gretchen Martin, MSW <i>Indiana State Department of Health</i>	Forensic Pathologist Representative: John Cavanaugh, MD <i>Marion County Coroner's Office</i>	Kathy Detweiler, RN <i>Breastfeeding/Perinatal Coordinator Indiana State Department of Health</i>
Law Enforcement Representative: Major Robert Herr <i>Bedford Police Department</i>	Child Abuse Prevention Representative: Nicholas T. Miller, MSW, LSW <i>General Manager Ireland Home-Based Services</i>	Marsha French <i>State Coordinator Safe Kids Indiana</i>
Prosecuting Attorney Representative: Todd Meyer <i>Boone County Prosecutor</i>	Epidemiologist Jodi L. Hackworth, MPH, CSTR <i>Trauma Epidemiologist Research Coordinator Riley Hospital for Children at IU Health</i>	Fausta Houzanme, MPH <i>Maternal Mortality Review Coordinator Indiana State Department of Health</i>
Department of Education Representative: Jolene Bracale, MSN, RN <i>Program Coordinator for Student Health Services</i>	Emergency Medical Services Provider Representative: Charles E. Ford <i>Chief of Administration Indianapolis EMS</i>	Catherine Huber, MD <i>IU School of Medicine</i>
Coroner or Deputy Coroner Representative: Alfarena Ballew <i>Chief Deputy Coroner Marion County Coroner's Office</i>	Representative of the Department of Child Services Ombudsman: Alfreda Singleton-Smith <i>DCS Ombudsman</i>	Rachel Kenny, MPH <i>INVDRS Epidemiologist Indiana State Department of Health</i>
Department of Child Services Representative: Ellis Dumas <i>Deputy Director Lake County Office</i>	Mental Health Provider Representative: Angela Comsa, LCSW <i>Clinical Director, Children & Family Services, Regional Mental Health</i>	Sandy Runkle <i>Director of Programs Prevent Child Abuse Indiana</i>
		Holly Wood <i>Safe Sleep Coordinator Indiana State Department of Health</i>

Appendix 2

Collaboration, Preservation, Observation and Documentation (C-POD) Guidelines

Collaboration

Infant death scenes are often chaotic, highly emotional and stressful for both the families and the responding professionals. SUIDI protocol emphasizes these events are “crime scenes without a crime.” Witnesses and family members must be approached with care and compassion, but investigations must still be thorough. Furthermore, scenes and evidence must be preserved and documented.

By establishing in advance who will be responsible for each key step in the SUIDI process, the most accurate, sensitive and standardized work can be done. The interviews must be conducted in such a way that the necessary information is gathered, but the family does not feel interrogated. The ability to interview witnesses is a skill all successful infant death investigators must attempt to master. While such interviews are difficult for any investigator, the interviewer must be prepared to ask non-accusatory questions sensitive to the grief and emotions of family members and witnesses.

The tone established at the beginning of the interview will have a direct impact on the cooperation the interviewee is willing to offer. Very general lead-in questions can get the interview started successfully and avoid back-tracking due to a poor first impression. Utilizing standard data collection tools, such as the SUIDI Reporting Form, is best-practice for collecting data during interviews. Collaborative approaches to SUIDI will lead investigative teams to more easily identify the most qualified interviewers based on the situation and circumstances.

Preservation

Preservation recommendations focus on maintaining an infant death scene as it was when the child was discovered, until all necessary evidence is seized, documented and/or circumstances are demonstrated or reconstructed. Often this is the job of law enforcement, but DCS, EMS and coroners will also have access to details imperative to an accurate cause of death determination. Scene management includes:

- Striving first to preserve life with all necessary medical aid;
- Disturbing the scene as little as possible;
- Collecting, preserving and documenting all evidence;
- Limiting contamination;
- Securing scene(s), understanding there are often multiple scenes to consider;
- Identifying witnesses and interviewing on video, if possible;
- Taking photos/video at scene of injury and at hospital if child was transported; and
- Recording detailed observations as soon as possible.

Observation

In order to collect the most detailed and accurate case information, all investigators must be aware and conscious of everything within the environment. This includes Information such as:

- Location where the child was placed to sleep, where the child was last known alive and where the child was found;
- Details such as body position (on stomach, on back, etc.), paying specific attention to head and neck orientation on the sleep surface;
- The presence of any possible suffocation hazards in the sleeping area or near the nose or mouth;
- Details about the scene such as any delays in assistance, who rendered aid, what was moved, presence of siblings, presence of animals, presence and number of sleep environments;
- Details about both the outdoor and indoor environments--objects in scene possibly involved in injury, who else was in the sleeping environment with child, ambient temperatures, presence of water, clothing items, bedding, etc.; and
- The manner and mood of witnesses, excited utterances, and who had access to the sleeping child.

Documentation

Documentation is crucial. All observations and details about the scene and witnesses should be immediately recorded. While assigning at least one investigator to the task of documenting infant death scene information is important, the combined details from all parties present at any and all scenes is critical to creating the most accurate picture of what caused the infant's injuries. These reports, coupled with medical records from both the infant and mother, will aid investigators in hypothesizing a probable cause of death to present to pathologists (Toth & Guttman, 2008).

Photographic documentation of the death scene should also include a doll re-enactment with the caregiver(s) who placed the child in the sleep environment (Placer), the caregiver(s) who found the child in distress (Finder) and the last caregiver to hear/see the infant alive (Last Known Alive). Each of these witnesses should be asked to utilize a SUIDI doll to demonstrate to investigators the body, head and neck positions of the infant as well as the position of any environmental factors that may have contributed to the death. These re-enactments should be photographed from multiple angles and clearly labeled for the pathologist to review prior to the autopsy.

The documentation collected at the scene should be presented to the pathologist during a pre-autopsy conference. The pre-autopsy conference is a meeting of investigators, prosecutors and the forensic pathologist and should take place prior to the autopsy. It provides an opportunity for all members of the investigative team to share information collected at the scene and conduct a thorough records review. Not only does it give the pathologist a description of the

circumstances surrounding the infant death and alert him/her to possible suspicious circumstances, but it makes him/her aware of evidence on or in the infant's body for which they should be searching.

Autopsies conducted for infant deaths should not rely solely on gross examination (IC 36-2-14-6.3). The autopsy should always include complete X-rays of the body. A complete skeletal series is the gold standard; however, in jurisdictions where this is not an option for financial or technical reasons, a single film would show documentation of gross findings. In Indiana, an autopsy on any child less than three years of age who dies suddenly, unexpectedly or whose death is unexplained must be done by a forensic pathologist (IC 36-2-14-6.7). Toxicology, histology, microbiology and other pathology, including genetic and metabolic testing, should also be conducted.

Appendix 3

“The SUIDI Top 25”

- Case Information
- Asphyxia
- Sharing sleep surfaces
- Change in sleep conditions
- Hyperthermia/hypothermia
- Environmental hazards (CO, chemicals, etc)
- Unsafe sleeping condition
- Diet
- Recent hospitalizations
- Previous medical diagnosis
- History of acute life threatening events
- History of medical care without diagnosis
- Recent fall or other injury
- History of religious, cultural, or ethnic remedies
- Cause of death due to natural causes other than SIDS
- Prior sibling deaths
- Previous encounters with police or social service agencies
- Request for tissue or organ donation
- Objection to autopsy
- Pre-terminal resuscitative treatment
- Death due to trauma (injury), poisoning, or intoxication
- Suspicious circumstances
- Other alerts for pathologist’s attention
- Description of circumstances (what happened?)
- Pathologist Information (name/agency/phone)

Appendix 4

International
Disease, 10th Revision

Code	Definition
R95	Sudden Infant Death Syndrome
R99	Ill-defined and unknown cause of mortality
W75	Accidental Suffocation and Strangulation in Bed
W81	Confined to or trapped in a low-oxygen environment
W83	Other threats to breathing
W84	Unspecified threat to breathing
Y20	Hanging, strangulation and suffocation, undetermined intent

Classification of
Code Definitions

Source: World Health Organization, 2016

Appendix 5

Definitions and Criteria for Assigning Cases to SUID Case Registry Categories

Category	Criteria That Must Be Met
Unexplained: no autopsy or death scene investigation	1. Death is unexplained.
	2. No death scene investigation or post-mortem examination information reported.
Unexplained: incomplete case information	1. Death is unexplained.
	2. Incomplete death scene investigation or autopsy information reported (including reports pending further investigation).
	3. Lack of detailed information about where and how the body was found OR 1 of 3 tests: (1) toxicology, (2) radiograph, and (3) pathology was not performed and documented. Pathology can include histology, microbiology, or other pathology such as genetic testing, but not solely gross examination.
Unexplained: no unsafe sleep factors	1. Death is unexplained after complete case investigation. ^a
	2. Death may or may not occur during sleep. For those deaths that occur during sleep, the sleeping environment is free of unsafe sleep factors ^b or other suffocation or strangulation hazards.
	Note: case may or may not have other potentially fatal findings, concerning conditions, ^c or competing cause of death, but how these factors contribute to death is uncertain.
Unexplained: unsafe sleep factors	1. Death is unexplained after complete case investigation. ^a
	2. Found in an unsafe sleep environment, but the role of the unsafe sleep environment in causing or contributing to the death is uncertain. Examples of unsafe sleep factors are soft objects or loose bedding (e.g., pillow, blanket), not in a crib, portable crib or bassinet, shared sleep surface, found non-supine.
	3. No factors that might indicate suffocation were present. No evidence of face pressed into or obstructed by soft bedding (eg, pillow, egg crate foam, sleeping bag, or couch), witnessed overlay, entrapment, or wedging.

Category	Criteria That Must Be Met
	<p>Note: case may or may not have other potentially fatal findings, concerning conditions,^c or competing cause of death, but how these factors contribute to death is uncertain.</p>
<p>Unexplained: possible suffocation with unsafe sleep factors</p>	<p>1. Death is unexplained after complete case investigation.^a</p> <p>2. Scene investigation provides evidence of suffocation or asphyxiation caused by an external airway obstruction. Examples include overlay, entrapment or wedging, or face pressed into and airway fully occluded by soft bedding (eg, pillow, egg crate foam, cushion, sleeping bag, or couch).</p> <p>3. Event was not witnessed or there was a conflicting account of full external obstruction of both nose and mouth, or external compression of the neck or chest.</p> <p>AND/OR</p> <p>Potentially fatal findings or concerning medical conditions^c were present at postmortem examination.</p> <p>AND/OR</p> <p>Although there was strong evidence of suffocation, suffocation does not seem probable given the infant's age and likely stage of development (eg, otherwise healthy 11-month-old infant found face down on pillow).</p>
<p>Explained: suffocation with unsafe sleep factors</p>	<p>1. Death is explained after complete case investigation.^a</p> <p>2. Scene investigation provides sufficient evidence of suffocation or asphyxiation caused by an external airway obstruction. Examples include witnessed overlay, entrapment or wedging, or face pressed into and airway fully occluded by soft bedding (eg, pillow, egg crate foam, cushion, sleeping bag, or couch). Suffocation must be probable given the infant's age and likely stage of development.</p> <p>3. Evidence of full, external obstruction of both nose and mouth or external compression of the neck or chest.</p> <p>4. Event was reliably witnessed and there were no conflicting accounts of full external obstruction of both nose and mouth or external compression of the neck or chest.</p> <p>5. Potentially fatal findings or concerning^c medical conditions were not present at postmortem examination.</p>

Category	Criteria That Must Be Met
	<p>^aComplete case investigation is defined by the components of the death scene investigation and autopsy that were documented in the case report. For death scene investigation, detailed information about where and how the body was found was available. For autopsy, all 3 tests were performed and documented: (1) toxicology, (2) radiograph, and (3) pathology. Pathology can include histology, microbiology, or other pathology such as genetic testing, but not solely gross examination.</p> <p>^bSafe sleep environment: supine position on a firm sleep surface including a crib, bassinet, portable crib, or pack-and-play. Sleep surface is free of soft objects, loose bedding, bumper pads, or any objects that could increase the risk for entrapment, suffocation, or strangulation out of the crib. Intentionally placing an infant to sleep in a car seat is considered unsafe. We derived these criteria from the 2011 AAP recommendations for a safe infant sleeping environment.</p> <p>^cAn example of a concerning medical condition is an infant who has fever, vomiting, and lethargy in the 72 h before death.</p>

Source: Shapiro-Mendoza et al., 2014