



Sudden Unexpected Infant Deaths in Indiana



Indiana
Department
of
Health



SUDDEN UNEXPECTED INFANT DEATHS 2023 REPORT

INDIANA DEPARTMENT OF HEALTH DIVISION OF FATALITY REVIEW AND PREVENTION

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This report provides information about sleep-related infant deaths that occurred in Indiana in 2015 through 2019. These deaths, also called Sudden Unexpected Infant Deaths (SUIDs), typically occur in sleep environments and are largely preventable with consistent use of safe sleep practices. Data presented in this report are from the Statewide Child Fatality Review Committee, local Child Fatality Review teams, and local Fetal-Infant Mortality Review teams. Fatality review is a public health strategy based on a process of multidisciplinary collaboration to explain why deaths occur and identify strategies to prevent future deaths.

KEY FINDINGS

- There were 528 SUIDs in Indiana in 2015 through 2019.
- Non-Hispanic Black infants were overrepresented with 35% of the total deaths (n=187).
- 52% of deaths occurred while infants were sleeping in adult beds (n=276).
- Bedsharing with at least one adult accounted for 51% of total deaths (n=269).
- 12% of deaths occurred on couches, futons, or chairs (n=62).
- For 75% of the total deaths, a crib or bassinet was available in the home (n=394).
- For 189 SUIDs, the death occurred while the infant was napping (36%).
- Only 9% of the total number of deaths were known to have had a complete death investigation.
- The most commonly missing components of incomplete investigations were scene reenactments with or without a doll and complete x-rays.

Prevention strategies to prevent future sleep-related infant deaths include:

- Engaging Black families to increase our understanding of the barriers to following safe sleep practices.
- Ensuring all providers use consistent messaging that aligns with current American Academy of Pediatrics infant safe sleep guidelines.
- Promoting SUID prevention at the local level with Community Action Teams.
- Improving investigations and classifications of SUIDs by coroners, law enforcement, pathologists, and other death scene investigators.

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INTRODUCTION

The purpose of this report is to provide a summary of the sleep-related Sudden Unexpected Infant Deaths (SUIDs) that occurred in Indiana during 2015 through 2019. This report provides demographics, descriptions of the sleep environments, and an assessment of the investigations that were conducted. The information presented in this report provides a deeper understanding of the specific risk factors contributing to SUIDs in Indiana. Recommendations to reduce future deaths and improve how these deaths are investigated are also outlined.

BACKGROUND

Infant mortality is the death of an infant during the first 12 months of life and a key indicator of public health worldwide. Nationally, the leading causes of infant mortality are preterm birth, low birth weight, congenital anomalies, and SUIDs. SUIDs are further divided into three types: Accidental Suffocation and Strangulation in Bed (ASSB), sudden infant death syndrome (SIDS), and deaths due to unknown causes. Nationally, approximately 3,400 infants die each year due to SUID (CDC, National Center for Health Statistics, 2022). SUIDs typically occur in sleeping environments, and most of these deaths are preventable. Table 1 defines the three types of SUIDs.

Table 1. Three Types of SUIDs

1. Accidental Suffocation and Strangulation in Bed (ASSB)-cause of death that includes suffocation, strangulation, or positional asphyxia. These deaths occur in the sleep environment when unsafe sleep risk factors are present, and the infant's airway is obstructed, or normal breathing is hindered. These deaths must have a complete investigation.
 2. Sudden Infant Death Syndrome (SIDS)-cause of death when no unsafe sleep risk factors are present in the sleep environment, and there has been a complete investigation into the death.
 3. Unknown Causes-cause of death when there are unsafe sleep risk factors present but there has not been a complete investigation and/or there is not enough evidence to classify as ASSB.
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A comprehensive death scene investigation is often the only way to make a distinction between SIDS and ASSB as a cause of death. SIDS is a rare event, and the vast majority of SUIDs actually fall into the categories of ASSB or unknown because of risk factors in the infant’s sleep environment. SIDS is a diagnosis of exclusion, and the presence of risk factors means that ASSB as the true cause of death cannot be excluded. According to the CDC, a death can only be classified as SIDS after a thorough examination of the death scene, a review of the clinical history, and an autopsy fails to find an explanation for the death (CDC, National Center for Health Statistics, 2022). If there are risk factors present and there is an incomplete investigation, then the death should be classified as ASSB or unknown.

Improvements in how death scenes are investigated and documented have led to a better understanding of the circumstances of sleep environments, allowing pathologists, death scene investigators, and coroners to identify suffocation risk factors that likely contributed to deaths. ASSB encompasses several different mechanisms of death, including airway obstruction, overlay, positional asphyxia, strangulation, wedging, and rebreathing of carbon dioxide. Table 2 lists six different causes of ASSB.

1. Suffocation/Airway Obstruction	4. Strangulation
2. Overlay	5. Wedging
3. Positional Asphyxia	6. Rebreathing carbon dioxide

Nationally, suffocation by soft objects or bedding is the leading cause of explained SUIDs (Parks et al., 2021). In these deaths, blankets, pillows, stuffed toys, or other soft objects partially or fully obstruct the airway and prevent normal breathing while the infant sleeps. Infants have also died after their airways were obstructed by clothing, including sleepwear, bibs, and infant hats. Soft objects and bedding may be located away from the infant’s airway when first placed to sleep, but movement by the infant can cause objects to shift and result in obstruction of the mouth and/or nose. Figure 1 shows a doll reenactment of an infant with partial airway obstruction due to soft objects in the sleep environment.

Figure 1. Suffocation/Airway Obstruction – Doll Reenactment



Overlay is a specific cause of airway obstruction or chest compression that occurs when another person lies on top of a sleeping infant. This can happen when the other person, an adult or child, is asleep and rolls over onto the infant on the same sleeping surface. Obstruction can also occur when the other person moves during sleep and their legs or arms are placed over the infant's face or body. The weight of these limbs can block the nose or prevent the chest from expanding normally. Figure 2 shows a doll reenactment of a sleep environment with overlay.

Figure 2. Overlay - Doll Reenactment



While overlay requires another person sleeping next to the infant, both wedging and strangulation typically involve dangerous interactions with products. Infants can stop breathing when they become stuck in a gap between a bed mattress and the wall or when their heads become stuck between crib slats that are too far apart. Older infants are more likely to die by wedging (compared to suffocation from soft objects or positional asphyxia)

because they are more mobile and can roll or place themselves into locations where they become trapped. Strangulation deaths are often attributed to strings or cords that have been introduced into the sleeping environment. The infant becomes entangled in items such as strings that are attached to pacifiers, cords from window blinds, curtains, baby monitors or other devices, or from decorative mobiles that fall into the crib or are hung too low. Figure 3 shows a doll reenactment of a wedging event, and Figure 4 shows a doll reenactment of a sleep environment that includes a strangulation hazard from the cord of a baby monitor.

Figure 3. Wedging – Doll Reenactment



Figure 4. Strangulation with Baby Monitor Cord – Doll Reenactment



Positional asphyxia occurs when the infant's body is in a position that prevents normal breathing. In these cases, the airway is blocked, or the infant is in a position that prevents the chest from fully expanding. For example, infants who fall asleep in car seats or bouncer seats often end up in the chin to chest position with the neck hyperflexed forward, a position that inhibits normal breathing. Airway obstruction can occur in any direction,

including hyperextension of the neck, with the head tilting backwards. Most infants younger than four months of age do not yet have sufficient development of the neck muscles and are not able to move their relatively heavy heads to an appropriate angle. Figure 5 shows a doll reenactment of positional asphyxia.

Figure 5. Positional Asphyxia, Neck Hyperflexion in Crescent-Shaped Pillow – Doll Reenactment



Finally, the rebreathing of carbon dioxide occurs when an infant's airway is partially obstructed or when only a small space exists between the nose and an object. As the infant sleeps, exhaled carbon dioxide accumulates in the space, and the infant then re-breathes the exhalations, causing a drop in blood oxygen levels. This can occur if the infant's face is too close to a wall, soft object such as a blanket or pillow, or another person's body who is sleeping next to the infant. Figure 6 shows a doll reenactment of a sleep position that puts an infant at risk for rebreathing carbon dioxide.

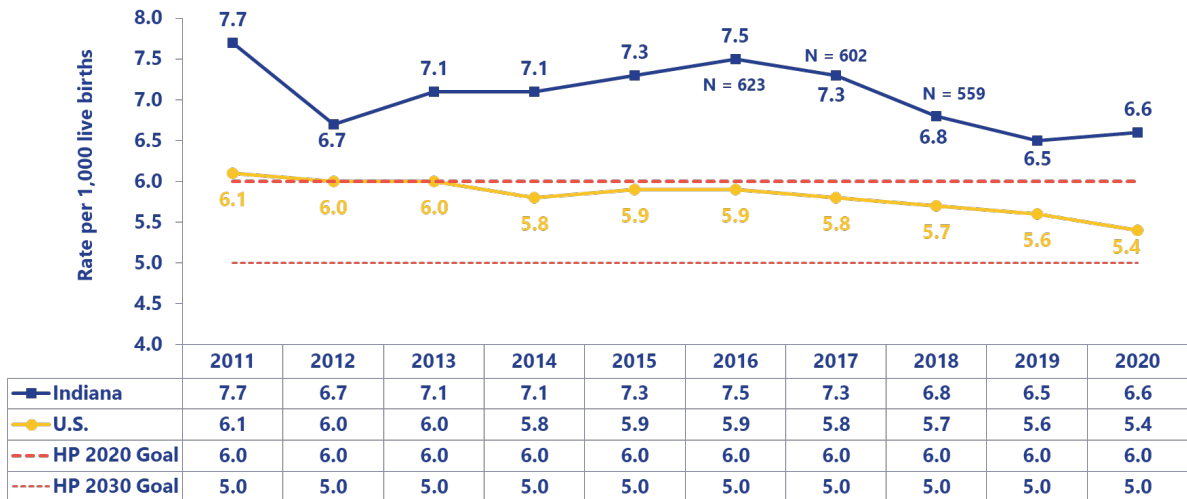
Figure 6. Rebreathing of Carbon Dioxide – Doll Reenactment



INFANT MORTALITY AND SUID IN INDIANA

The 2020 infant mortality rate in Indiana was 6.6 deaths per 1,000 live births, which was higher than the national rate of 5.4 deaths per 1,000 live births. Infant mortality rates in the state have been steadily decreasing since 2016 but increased slightly in 2020. Figure 7 shows infant mortality rates in Indiana from 2011 to 2020.

Figure 7. Infant Mortality Rates, Indiana, 2011-2020



Source: Indiana Department of Health, Maternal and Child Health Epidemiology Division [January 11, 2022]

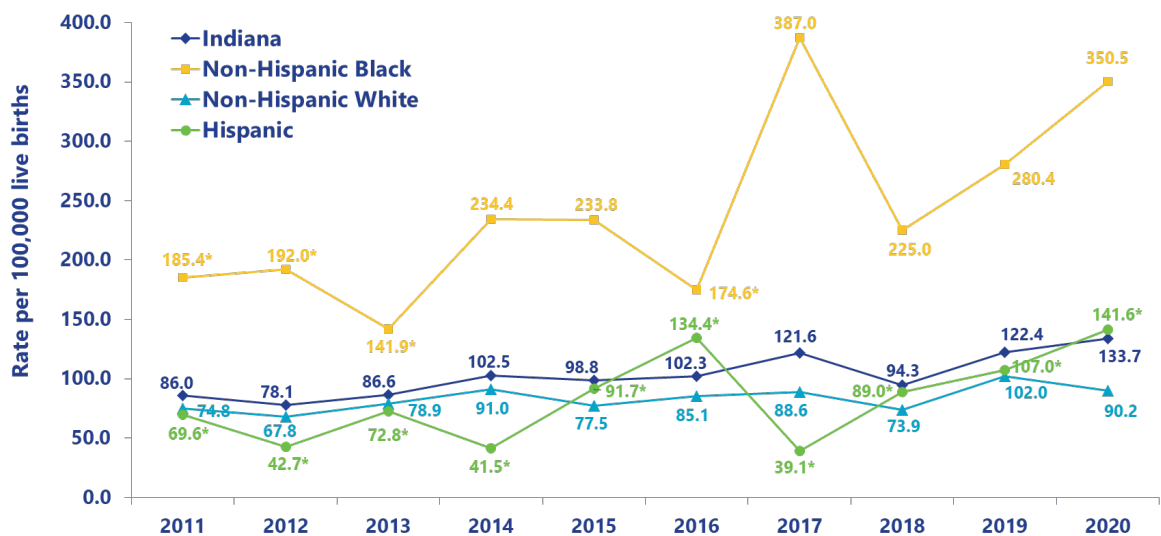
United States Original Source: Centers for Disease Control and Prevention National Center for Health Statistics

Indiana Original Source: Indiana Department of Health, Vital Records, ODA, Data Analysis Team

Although the overall infant mortality rate has been trending downward, the SUID rate in Indiana has shown the reverse pattern, with steady increases over time. The 2020 SUID rate in Indiana was 133.7 deaths per 100,000 live births, higher than the 2019 rate of 122.4 deaths per 100,000 live births and the 2019 national rate of 90.1 deaths per 100,000 live births (CDC, National Center for Health Statistics, 2020).

Racial and ethnic disparities in SUID rates are also evident in Indiana. SUID rates per 100,000 live births for non-Hispanic Black infants were almost four times those of non-Hispanic White infants (350.5 and 90.2 respectively). SUID rates among Hispanic infants in Indiana (141.6 deaths per 100,000 live births) were also higher than rates for non-Hispanic White infants. Figure 8 shows SUIDs rates by race/ethnicity.

Figure 8. SUIDs Rates by Race/Ethnicity, Indiana, 2011-2020



SUIDS=W75, R95, R99

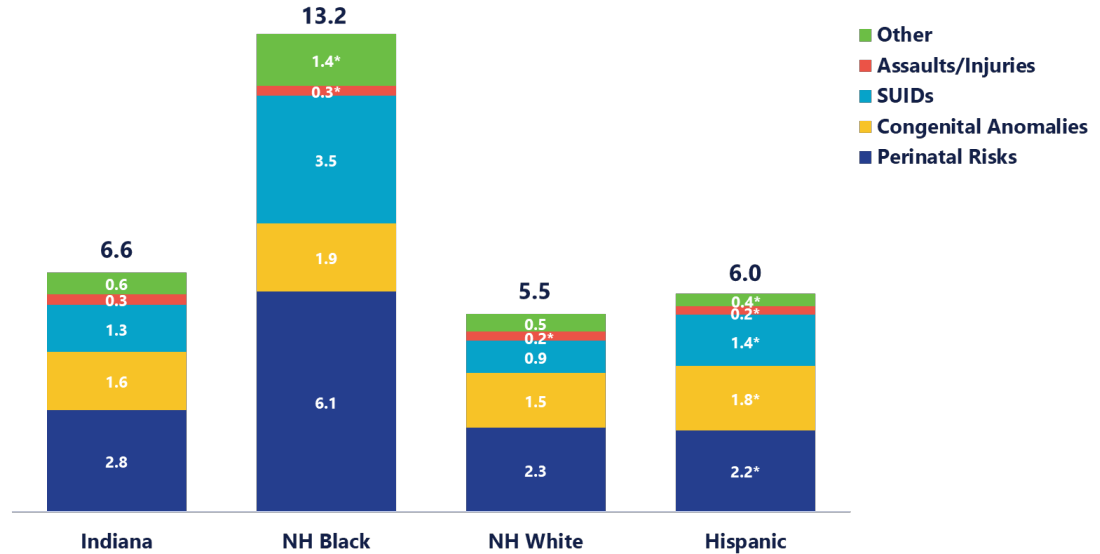
Source: Indiana Department of Health, Maternal and Child Health Epidemiology Division [October 28, 2021]

Indiana Original Source: Indiana Department of Health, Vital Records, ODA, Data Analysis Team

In 2020, SUIDs were the third leading cause of all infant deaths in Indiana, but for Black infants, SUIDs were the second leading cause death. National studies of SUIDs have shown similar patterns in SUID racial disparities. In fact, for Black infants in the U.S., the overall risk of SUID in the first year is greater than the risk of death due to motor vehicles, firearms, substance use, and suicide at any point in the first 19 years of life (Roehler, Batra, & Quinlan, 2019). Although other causes of injury-related death may get

more media attention and prevention resources, SUID remains the greatest risk of death for Black infants in America. Figure 9 shows the rates of the leading causes of infant death by race/ethnicity in Indiana.

Figure 9. Cause-Specific Infant Mortality Rates by Race/Ethnicity, Indiana, 2020



Source: Indiana Department of Health, Maternal and Child Health Epidemiology Division [October 26, 2021]

Indiana Original Source: Indiana Department of Health, Vital Records, ODA, Data Analysis Team

SUID PREVENTION

To prevent SIDS and reduce infant mortality, the American Academy of Pediatrics (AAP) in 1992 issued the recommendation that all infants should sleep on their backs or sides for every sleep. The United States National Institute of Child Health and Human Development (NICHD) began a national Back to Sleep campaign in 1994. This campaign focused primarily on educating caregivers to always place their infants on their backs for sleep. The recommendation for side sleeping was formally rescinded in 1996 after research showed that the side position was associated with a higher risk of death (AAP Task Force on Infant Positioning & SIDS, 1996).

In 2012, the NICHD prevention campaign expanded to address risk factors that encompassed all SUIDs (not just SIDS), specifically sleep-related suffocation and strangulation deaths (NICHD, National Institutes of Health, 2020). The 2012 materials included advice that babies should sleep in safety-approved cribs and without pillows,

blankets, or stuffed toys. As more has been learned through research, the AAP's list of recommendations has become more comprehensive over time, and the most recent version, released in 2022, advised parents to avoid exposing infants to first or secondhand smoke. Parents were also advised to breastfeed and to share a room but not the same sleeping surface with their babies (Moon & AAP Task Force, 2022).

The AAP recommendations are based on epidemiologic studies and are divided into levels using the Strength-of-Recommendation Taxonomy (SORT) for the assignment of letter grades to each recommendation. Level A means that there is good-quality patient-oriented evidence; level B means there is inconsistent or limited-quality patient-oriented evidence; and level C indicates that the recommendation is based on consensus, disease-oriented evidence, usual practice, expert opinion, or case series for studies of diagnosis, treatment, prevention, or screening. It is important to note that most infant safe sleep recommendations are based on generalizable research studies with high external validity and not on studies that draw conclusions based solely on sleep laboratory samples or studies that focus on cultures with sleep environments not comparable to those found in the U.S.

The AAP recommendations can be used by providers who work with families to guide conversations with parents and others who care for infants. It is important to avoid lecturing, stigmatizing, or shaming caregivers. The AAP encourages providers to have open and nonjudgmental conversations with families about the sleep practices used in their homes. Table 3 shows a summary of the current recommendations from the AAP regarding infant safe sleep.

Table 3. Summary and Strength Level of Current AAP Recommendations for Infant Safe Sleep

A-level recommendations

Back to sleep for every sleep.

Use a firm, flat, non-inclined sleep surface to reduce the risk of suffocation or wedging/entrapment.

Feeding of human milk is recommended because it is associated with a reduced risk of SIDS.

It is recommended that infants sleep in the parents' room, close to the parents' bed, but on a separate surface designed for infants, ideally for at least the first six months.

Keep soft objects, such as pillows, pillow-like toys, quilts, comforters, mattress toppers, fur-like materials, and loose bedding, such as blankets and nonfitted sheets, away from the infant's sleep area to reduce the risk of SIDS, suffocation, entrapment/wedging, and strangulation.

Offering a pacifier at naptime and bedtime is recommended to reduce the risk of SIDS.

Avoid smoke and nicotine exposure during pregnancy and after birth.

Avoid alcohol, marijuana, opioids, and illicit drug use during pregnancy and after birth.

Avoid overheating and head covering in infants.

It is recommended that pregnant people obtain regular prenatal care.

It is recommended that infants be immunized in accordance with guidelines from the AAP and CDC.

Do not use home cardiorespiratory monitors as a strategy to reduce the risk of SIDS.

Supervised, awake tummy time is recommended to facilitate development and to minimize the risk of positional plagiocephaly. Parents are encouraged to place the infant in tummy time while awake and supervised for short periods of time beginning soon after hospital discharge, increasing incrementally to at least 15 to 30 minutes total daily by age seven weeks.

It is advised that media and manufacturers follow safe sleep guidelines in their messaging and advertising to promote safe sleep practices as the social norm.

Continue the NICHD "Safe to Sleep" campaign, focusing on ways to reduce the risk of all sleep-related deaths. Pediatricians and other maternal and child health providers can serve as key promoters of the campaign messages.

B-level recommendations

Avoid the use of commercial devices that are inconsistent with safe sleep recommendations.

C-level recommendations

There is no evidence to recommend swaddling as a strategy to reduce the risk of SIDS.

Continue research and surveillance on the risk factors, causes, and pathophysiological mechanisms of sleep-related deaths, with the ultimate goal of eliminating these deaths entirely.

Source: Moon & AAP Task Force, 2022

FATALITY REVIEW IN INDIANA

DIVISION OF FATALITY REVIEW AND PREVENTION

Fatality Review (FR) is a collaborative public health process that helps explain why child deaths occur and identifies strategies to prevent future deaths. FR teams are multidisciplinary and conduct comprehensive, in-depth reviews of deaths and the circumstances and risk factors involved. Data presented in this report are from the Statewide Child Fatality Review (CFR) Committee, local CFR teams, and local Fetal-Infant Mortality Review (FIMR) teams. The Statewide CFR Committee reviews findings of local CFR teams and makes recommendations for prevention and improvements to state policies and practices.

In 2013, Indiana law, IC 16-49, went into effect, requiring CFR teams in each county, with coordination and support for these teams to be provided by the Indiana Department of Health (IDOH). IC 16-49 also required that a coordinator position be created under IDOH to help support local teams and the Statewide CFR Committee with Governor-appointed members. IC 16-49 was modified in 2022 to create an ordered list of professionals/agencies who may start local teams. The county prosecuting attorney in each county is required to establish a CFR team whose membership includes: the prosecuting attorney or their representative, the coroner/deputy coroner, a pathologist, a pediatrician or family practice physician, and local representatives from law enforcement, the local health department, DCS, emergency medical services, a school district within the region, first responders, the prosecuting attorney's office, and the mental-health community. If the prosecuting attorney is unable to establish the team, the responsibility then falls on the county coroner or deputy coroner. If the county coroner or deputy coroner is unable to establish the team, then the local health department or a local health or hospital corporation can create the team. If these agencies are unable to establish the team, then the Indiana Department of Child Services (DCS) local office must form the team. There are currently 67 CFR teams covering all 92 counties in Indiana.

The local CFR team is responsible for selecting members to serve on the team and determining whether to establish a county CFR team or enter into an agreement with another county or counties to form a regional CFR team. Local teams are required to review all deaths of children under the age of 18 that are sudden, unexpected, or unexplained, all deaths that are assessed by DCS, and all deaths that are determined to be the result of homicide, suicide, accident, or are undetermined. In July of each year, Local CFR teams submit reports with aggregate data collected from their reviews to the Statewide CFR Committee.

The FIMR Program at IDOH, described under IC 16-49-6, currently has 17 teams covering 36 counties in Indiana. FIMR is a multidisciplinary, multi-agency, community-based program that reviews fetal and infant deaths and develops recommendations and initiatives to

reduce these deaths. As with CFR, FIMR is a community-owned and action-oriented process to improve service systems and resources for women, infants, and families. Teams review deaths that occur during pregnancy and deaths that occur within the first 12 months following delivery. In addition to death reviews, maternal interviews are an important component of the FIMR process and give insight into mothers' experiences before and during pregnancy, and at the time of the infants' deaths. Interviews include descriptions of mothers' encounters with local service systems and provide information about social determinants of health.

Typically, FIMR teams consist of health care providers, social workers, mental health professionals, and local health department staff. Community Action Teams (CATs) act as the prevention arm of the FIMR process, and in Indiana, CATs have expanded to several local CFR teams as well. CATs include elected officials, community members, community leaders, health professionals, and representatives from the local health department, justice system, transportation, housing, and other leaders who can facilitate local-level system change. Case review data are used to identify issues and gaps in service systems that may contribute to fetal and infant deaths and may be used to augment community needs assessments and analyze root causes of infant health disparities. Actions taken based on recommendations from these case reviews are monitored over time. Maps of the current CFR, FIMR, and CATs can be found in Appendix A, B, and C.

SUID/SDY CASE REGISTRY

In 2012, the CDC began implementing the SUID/Sudden Death in the Young (SDY) Case Registry, a population-based surveillance system. Building upon the work of the National Center for Child Fatality Review and Prevention (NCFRP), the SUID/SDY Case Registry encourages existing multidisciplinary child death review programs to collect data on SUIDs. Currently in 22 states and jurisdictions, the SUID/SDY Case Registry provides a resource for understanding infant deaths by compiling comprehensive data surrounding the risk factors and circumstances associated with each death. 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.

FRP received funding in 2019 for its registry. The SUID/SDY 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 SUID/SDY Case Registry definitions state:

- 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 documented.
- For an autopsy to be considered complete, the following should be performed and documented:
 - Toxicology
 - Complete radiographs
 - Pathology (including histology, microbiology, and other pathology).

Improving data collection and documentation during infant death scene investigations is essential to help coroners accurately report the cause of death. To ensure valid and reliable data, which are necessary to support research and prevention efforts, standardized techniques and data collection at infant death scenes and consistent classifications of cause-of-death on death certificates are crucial. Inaccurate reporting and inconsistent practices of classifying infant deaths prohibit the ability to (1) monitor trends in SUIDs, (2) conduct research to identify risk factors, (3) design interventions to prevent deaths, and (4) evaluate prevention programs. Appendix D shows the complete SUID/SDY Case Registry Algorithm. Table 4 shows the definitions and criteria used to assign cases to SUID/SDY Case Registry categories.

Table 4. Definitions and Criteria for Assigning Cases to SUID/SDY Case Registry Categories

Category	Criteria that must be met
Unexplained: no autopsy or death scene investigation	<ol style="list-style-type: none"> 1. Death is unexplained. 2. No death scene investigation or post-mortem examination information reported.
Unexplained: incomplete case information	<ol style="list-style-type: none"> 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 one of three 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	<ol style="list-style-type: none"> 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. <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>
Unexplained: unsafe sleep factors	<ol style="list-style-type: none"> 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 bassinette, 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 (e.g., pillow, egg crate foam, sleeping bag, or couch), witnessed overlay, entrapment, or wedging.

	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: possible suffocation with unsafe sleep factors	<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 (e.g., 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 (e.g., otherwise healthy 11-month-old infant found face down on pillow).</p>
Explained: suffocation with unsafe sleep factors	<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 (e.g., 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 medical conditions^c were not present at postmortem examination.</p>

^a Complete 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 three 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.

^b Safe 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.

^c An example of a concerning medical condition is an infant who has fever, vomiting, and lethargy in the 72 hours before death.

Source: Shapiro-Mendoza et al., 2014

LEGISLATIVE EFFORTS TO IMPROVE THE INVESTIGATION OF SUIDS

Governor Eric Holcomb announced the 2022 Next Level Agenda for the state of Indiana in January 2022. The agenda includes expanding data collection surrounding SUIDs to better understand the root causes of these deaths. The improved data collection will be used to develop effective programming and services. Inclusion of SUIDs in a statewide agenda demonstrates the strong support for improving how SUIDs are investigated in the state.

Please click on this link to learn more about the 2022 Next Level Agenda:

<https://www.in.gov/gov/next-level-agenda/2022-next-level-agenda/>.

House Enrolled Act 1169

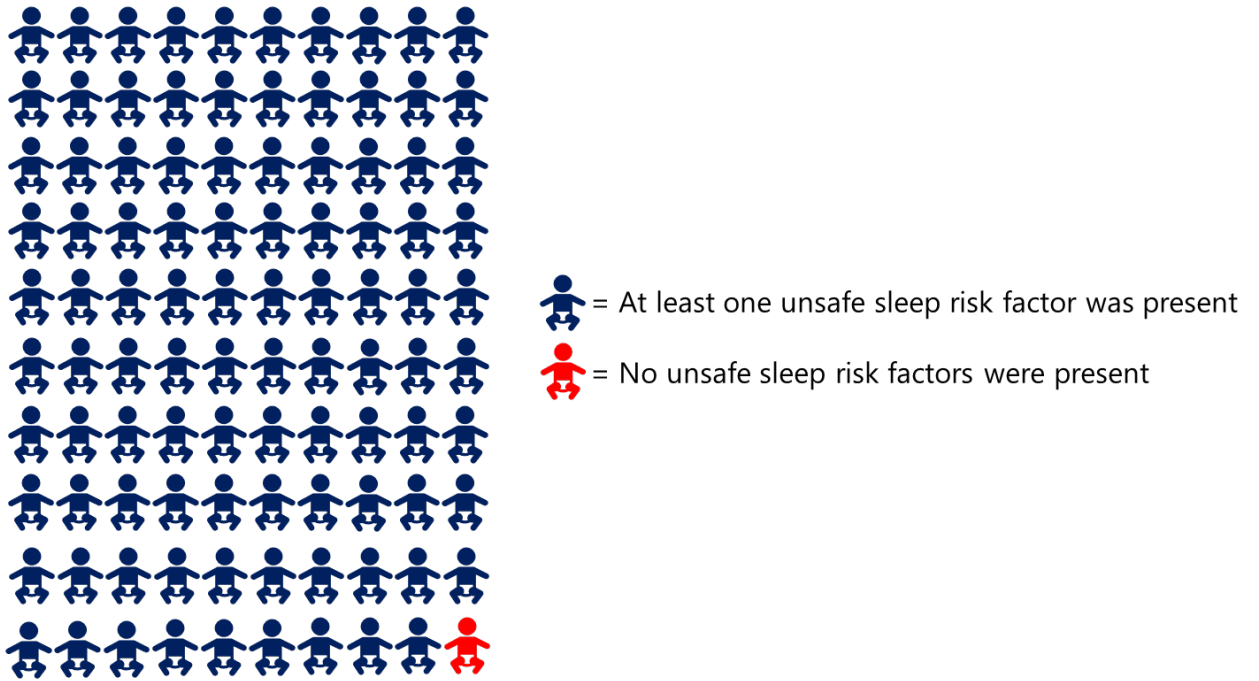
In addition to the 2022 Next Level Agenda, new legislation was passed in 2022 to establish consistent standards for SUID investigations. House Enrolled Act 1169 took effect July 1, 2022, and it aligns Indiana's process for investigating SUIDs with the best practices developed by the CDC. This alignment will ensure that coroner investigations into deaths among infants and children who die suddenly and unexpectedly are handled consistently across the state and will include imaging, pathology, and toxicology.

METHODS

To determine cases for this report, all death certificates were compiled for infants 12 months of age and younger with the official ICD-10 Codes of R95, R99, and W75. Next, ICD-10 Codes that are often incorrectly applied to SUIDs (e.g., W76-W80, Y20) were added. Then, we searched the remaining death certificates for any mention of unsafe sleep or sudden respiratory-related death in any section. Finally, each case from this list was examined in the Child Death Review-Case Reporting System (CDR-CRS) to determine if it was truly a SUID. DCS assesses all SUIDs, and those reports were also examined to generate a list of cases for each year. This left us with a final number of deaths that met the definition of SUID. Using the information collected in the CDR-CRS, supplemented with death certificate information, this report presents data on demographics, risk factors, and investigation quality.

A more accurate count of SUID cases is created using CFR and DCS data, compared to other types of public health data. For example, vital records reported 444 SUIDs between 2015 and 2019 using ICD-10 Codes of R95, R99, and W75. This is 84 fewer SUIDs than were identified for this report. Vital records reported 230 SIDS cases during this time period (IDOH Office of Data Analytics, 2022). However, only nine percent of the total deaths identified for this report had a complete investigation (n=47). Of these deaths, only three, or 1%, occurred in safe sleep environments (no unsafe sleep risk factors present). For 99% of the deaths presented in this report, at least one unsafe risk factor was present (n=525). Therefore, the true number of SIDS cases during 2015-2019 is only three (out of a total of 528 deaths). Figure 10 shows the percentage of deaths that occurred in unsafe sleep environments. Each image of an infant represents one percent of the total deaths that occurred in 2015 through 2019.

Figure 10. Percentage of Deaths that Occurred in Unsafe or Safe Sleep Environments, Indiana, 2015-2019



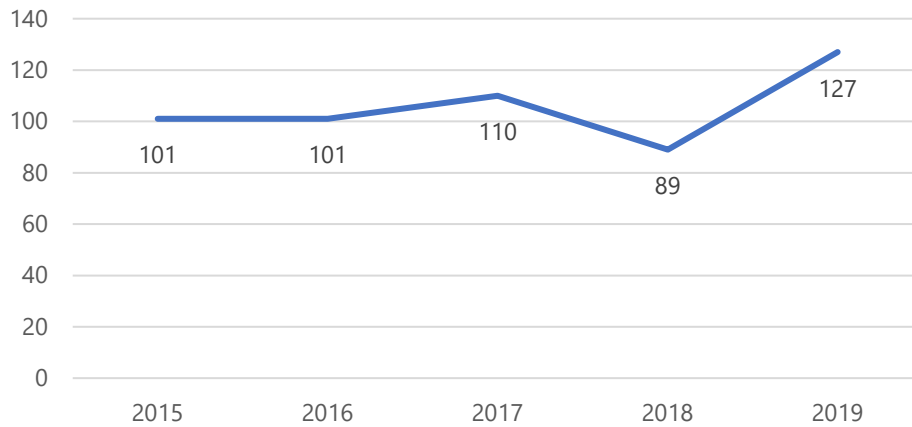
Each infant represents one percentage point of the total number of deaths.

RESULTS

INFANT AND MATERNAL DEMOGRAPHICS

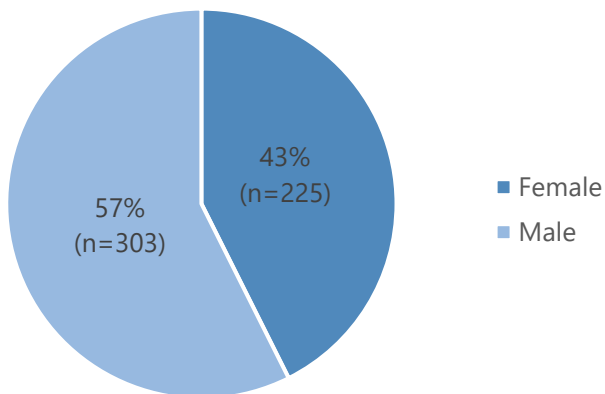
Between 2015 and 2019, there were 528 SUIDs in Indiana. 2019 had the highest number of SUIDs with 127 deaths, while 2018 had the fewest number with 89 deaths. Figure 11 shows the number of SUIDs in Indiana for each of the five years.

Figure 11. SUIDs by Year of Death, Indiana, 2015-2019 (n=528)

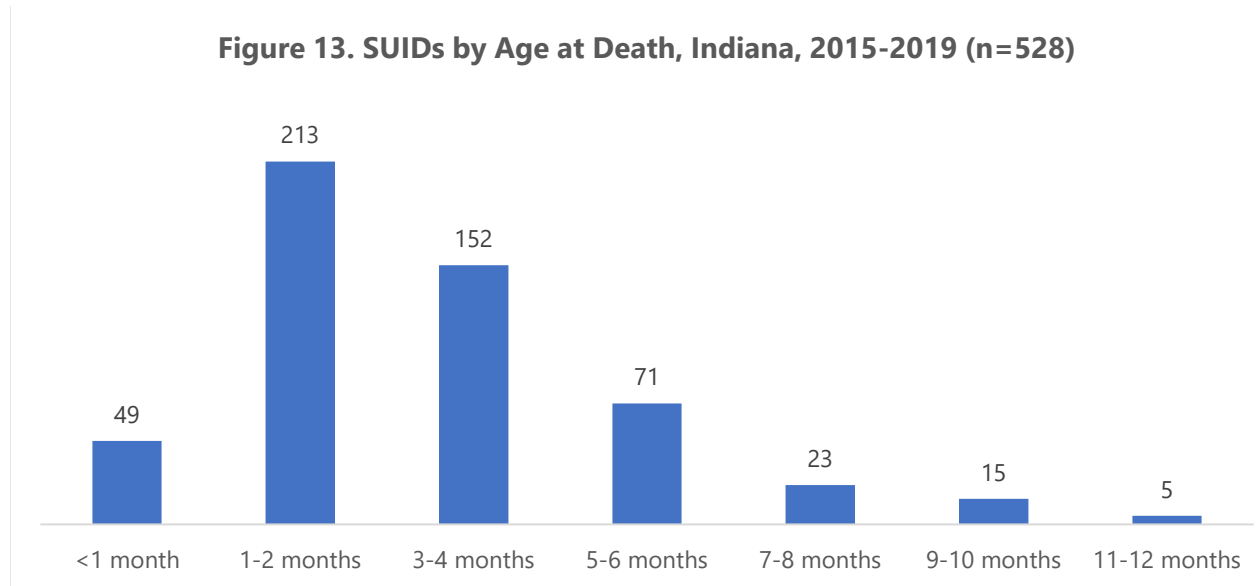


Fifty-seven percent of deaths were of male infants (n=303), and 43% were female infants (n=225). Figure 12 shows SUIDs by sex. This breakdown is identical to what occurred in 2014 (57% males and 43% females), published in a previous report by IDOH.

Figure 12. SUIDs by Sex, Indiana, 2015-2019 (n=528)

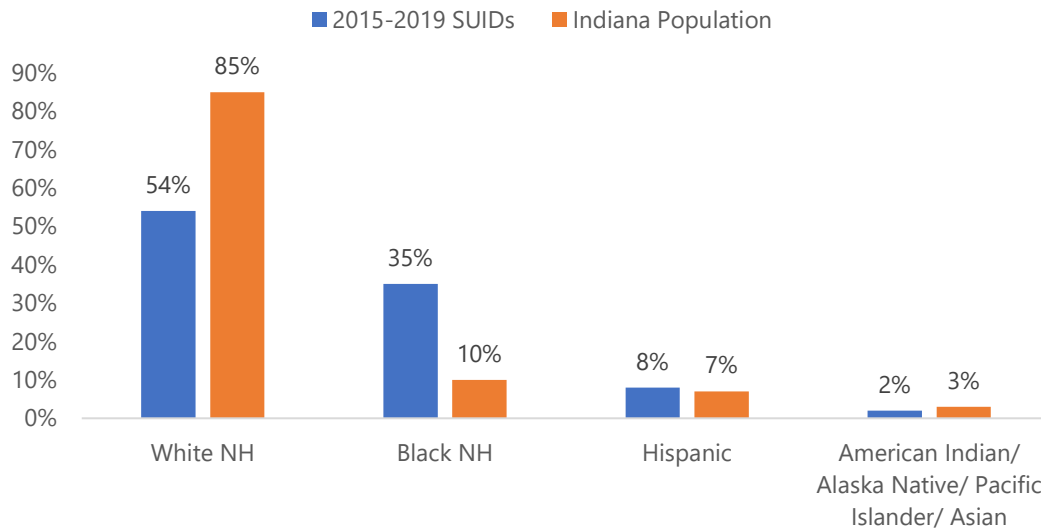


Ninety-two percent of SUIDs were among infants younger than six months of age (n=485). The largest percentage of deaths were among infants one to two months of age (n=213, 40%), followed by infants three to four months of age (n=152, 29%). Infants 11 to 12 months of age had the smallest percentage of deaths. For 27 cases, the infant who died was a twin (5%). Figure 13 shows SUIDs by age at death.



Non-Hispanic White infants were represented in 54% of the total deaths (n=285) and 85% of the total population in the state. Non-Hispanic Black infants were overrepresented with 35% of the total deaths (n=187), while only 10% of Indiana residents identify as non-Hispanic Black. Eight percent of deaths were among Hispanic infants (n=41), and 2% of deaths were among Asians, Indigenous Americans, and Pacific Islanders (n=10). For five deaths, race and ethnicity of the infants were unknown. Figure 14 shows SUIDs by race and ethnicity.

**Figure 14. SUIDs by Race/Ethnicity, Indiana, 2015-2019
(n=528)**



Eighty-two counties had at least one SUID between 2015 and 2019 (infant’s county of residence). There were 24 counties that had more than five deaths during the total five-year period. Marion County and Lake County had the highest numbers of deaths (n=94 and n=48, respectively). These two counties accounted for 27% of the total number of deaths. Table 5 shows the ten counties with the highest SUID counts in 2015 through 2019.

Table 5. Counties with Highest Numbers of SUIDs, Indiana, 2015-2019

County	Number
Marion	94
Lake	48
Allen	25
St. Joseph	25
Elkhart	24
Delaware	16
Tippecanoe	16
Clark	14
Vanderburgh	13
Vigo	11

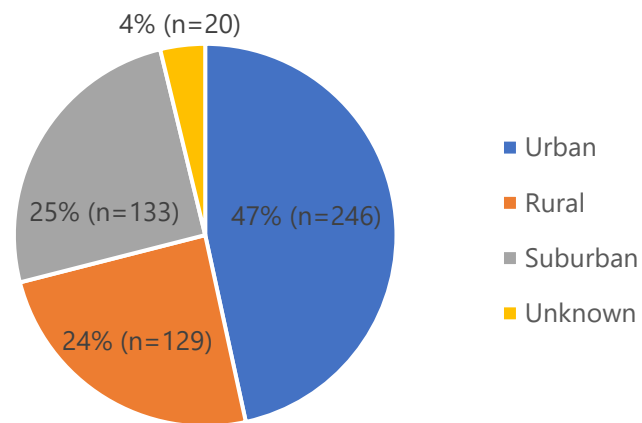
Table 6 shows the counties with the highest rates of SUIDs. Rates using counts less than 20 should be interpreted with caution because small numbers create rates that are unstable.

Table 6. Counties with Highest Rates of SUIDs, Indiana, 2015-2019

County	Rate per 10,000 live births
Delaware	28.5
Clark	19.4
Vigo	18.0
Lake	16.8
Elkhart	15.4
St. Joseph	14.3
Tippecanoe	14.3
La Porte	14.1
Marion	13.3
Vanderburgh	11.9

For 47% of SUIDs, the deaths occurred in urban areas (n=246), and 25% occurred in suburban areas (n=133). Twenty-four percent occurred in rural communities (n=129), and for 20 deaths, the type of area was unknown. For this variable, urban is defined as a large city or densely populated area, and suburban is defined as a residential district located on the outskirts of a city. A rural area is a community with low population densities and can include agricultural and recreational land. Figure 15 shows infant residence by type of area.

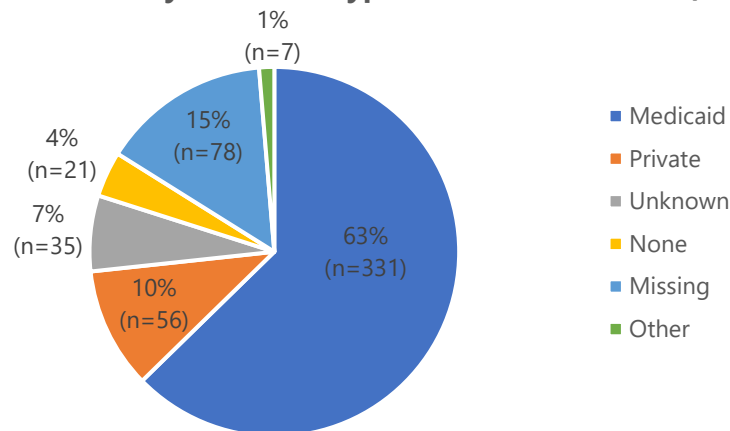
Figure 15. Type of Area Where Death Occurred, Indiana, 2015-2019 (n=528)



Most of the infants had Medicaid listed on their insurance on their death certificates (n=331, 63%). Medicaid is a health care program that assists low-income families or individuals in paying for long-term medical and custodial care costs. Medicaid is a joint program, funded primarily by the federal government and run at the state level, where coverage may vary.

Ten percent of infants who died had private insurance (n=56). Private health insurance refers to health insurance plans marketed by the private health insurance industry, as opposed to government-run insurance programs. Twenty-one infants had no medical insurance at time of incident (4%). For 78 cases, information on insurance type was missing. Figure 16 shows SUIDs by infant’s insurance type at time of death.

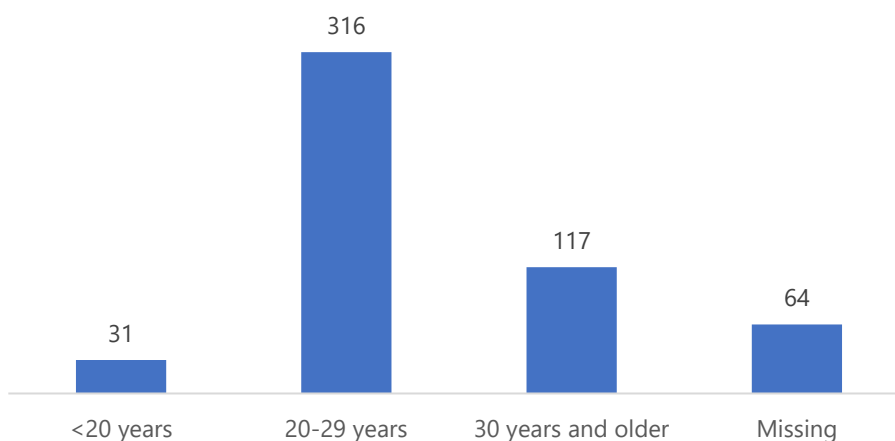
Figure 16. SUIDs by Insurance Type, Indiana, 2015-2019 (n=528)



Forty-two percent of infants had been seen by a healthcare provider within the past two months prior to the death (n=222). This variable refers to the last time the infant had contact with a health care provider of any kind, including in the emergency room, primary care setting, urgent care, or a specialist’s office. Twenty percent of infants who died due to SUID had a Neonatal Intensive Care Unit (NICU) stay of more than one day (n=106).

Six percent of SUIDs occurred among mothers who were younger than 20 years at the time of the infant’s death (n=31). The largest percentage of SUIDs were among mothers who were between 20 and 29 years of age at the time of the infant’s death (n=316, 60%). Twenty-two percent of deaths occurred among mothers who were older than 30 years (n=117). For 64 SUIDs, the mother’s age was unknown. Figure 17 shows mother’s age at the time of death.

Figure 17. Mother's Age at Time of Death, Indiana, 2015-2019 (n=528)



A prenatal visit (as stated on birth certificate or medical records) is defined as pregnancy-related medical care delivered by a doctor, nurse, or other health professional with the goal of monitoring the pregnancy, providing education, and increasing the likelihood of positive maternal/infant outcomes. It is recommended that first prenatal care appointments are made as soon as possible because early prenatal care can identify high-risk pregnancies that may require a higher level of care. Preterm and low birth weight infants are known to be at a higher risk for SUID.

Eighty-one percent of the mothers of infants who died due to SUID had prenatal care (n=430). Four percent did not have any prenatal care (n=21), and for 77 deaths, prenatal care information was unknown or left blank on the case review form (15%). Seventy-nine mothers were known to have attended a post-partum visit within the first three weeks after the infant was born (15%).

The AAP recommends breastfeeding to reduce SUIDs that are attributed to SIDS. Unless contraindicated, mothers should breastfeed exclusively (or feed with expressed milk) and avoid offering any formula or other nonhuman milk-based supplements for at least six months after delivery. The protective effect of breastfeeding increases with exclusivity, but any breastfeeding has been shown to be more protective against SIDS than no breastfeeding. Although nearly all the SUIDs in Indiana during 2015 to 2019 had unsafe sleep factors and could not be classified as SIDS, breastfeeding is still an important strategy to ensure the short- and long-term health of mothers and infants. Forty-three percent of the infants who died due to SUID had never been breastfed (n=227), while 191 infants had been breastfed at some point in time prior to their deaths (36%). For 110 deaths, breastfeeding history was unknown or left blank on the case review form (21%). This

variable in the CDR-CRS refers to breastfeeding for any duration of time, as long as there is some reported indication that the infant received breast milk, either expressed or at the breast.

Eleven percent of infants were placed to sleep with pacifiers (n=59). The AAP recommends that caregivers offer infants a pacifier at nap time and bedtime to help reduce the risk of SUID. Only after breastfeeding has been successfully established should an infant be given a pacifier, typically around three to four weeks of age.

SUBSTANCE USE FACTORS

Thirteen percent of infants were born drug exposed (n=69). To determine this variable, review teams can consider maternal history, clinical presentation of the newborn, and laboratory testing of the mother and/or infant. Twenty-one infants were born with Neonatal Abstinence Syndrome (NAS) (4%), meaning that these infants exhibited drug withdrawal syndrome, including observable clinical symptoms that typically appear within 48 to 72 hours after birth.

More than a third of mothers had a history of substance use during pregnancy prior to the infant's death (n=189, 36%). A similar percentage of mothers were not known to have used substances while pregnant (n=196, 37%). For 27% of mothers, information regarding substance use during pregnancy was unknown or left blank on the case review form (n=143). For this variable, substance use includes any over-the-counter medications, prescription drugs, illicit drugs, mood-altering substances, homeopathic remedies, or supplements that were not prenatal vitamins.

Almost a quarter of mothers of infants who died smoked tobacco products in the three months prior to their pregnancies (n=125, 24%). Twenty-five percent of mothers were known to have smoked at any time during their pregnancies (n=132).

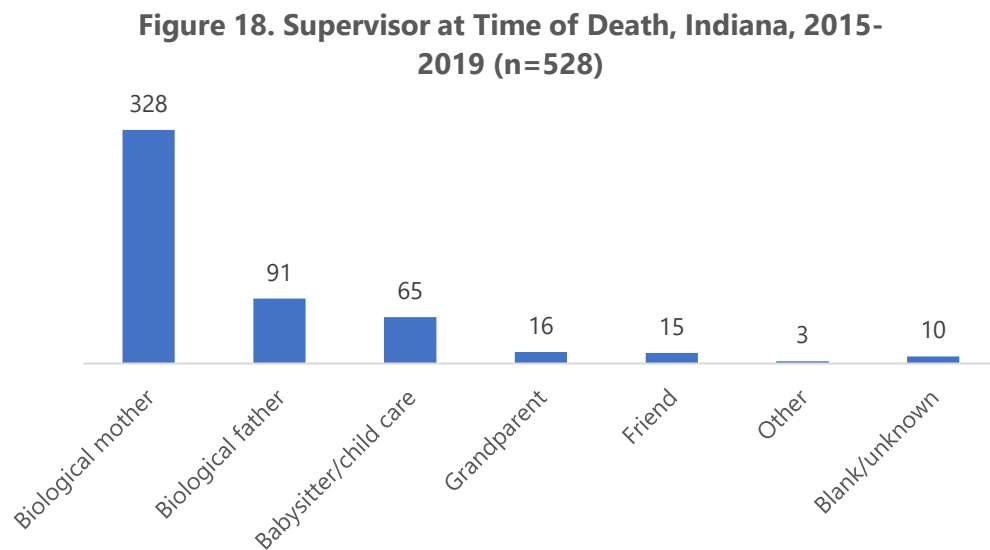
MALTREATMENT HISTORY

Seventeen percent of infants who died had a known history of involvement with DCS (n=88). This variable refers to both abuse and/or neglect with a referral or substantiation from DCS or documentation from autopsy, law enforcement reports, or medical records. This variable also includes referrals that were made but not necessarily substantiated. Nine percent of infants who died had open cases with DCS at the time of their deaths (n=48). For 410 SUID cases, DCS action was taken as a result of the infant's death (78%). The highest level of action taken by DCS for 62% of the cases was that the report was unsubstantiated

(n=328). For 14% of cases, the report was substantiated (n=74). Less than one percent had the report screened out (n=3).

SUPERVISOR INFORMATION

For the majority of SUIDs, the biological mother was supervising the infant at the time of death (n=328, 62%). Biological fathers were supervising for 91 of the deaths (17%). For 12% of the deaths, the infant was supervised by a babysitter or childcare worker (n=65). Grandparents (n=16) and friends (n=15) accounted for three percent of deaths each. For 10 deaths, the supervisor was unknown or left blank on the case review form. Figure 18 shows type of supervisor at time of infant's death.



Most of the supervisors were not known to have been impaired at the time of the infant's death (n=351, 66%). Ninety-one supervisors were impaired at the time of the infant's death (17%). For 86 cases, information regarding supervisor impairment was unknown or left blank on the case review form (16%).

Among the 17% of supervisors who were impaired in some way at the time of the infant's death, 59 were drug impaired (20 of these were in 2019 alone), 25 were impaired by alcohol, 10 were distracted, and one was listed as absent. According to the National Center for Child Death Review, this variable is interpreted broadly and includes being distracted or absent. Drug impaired refers to being under the influence of any intoxicating compound or combination of intoxicating compounds to a degree that impairs a person's ability to

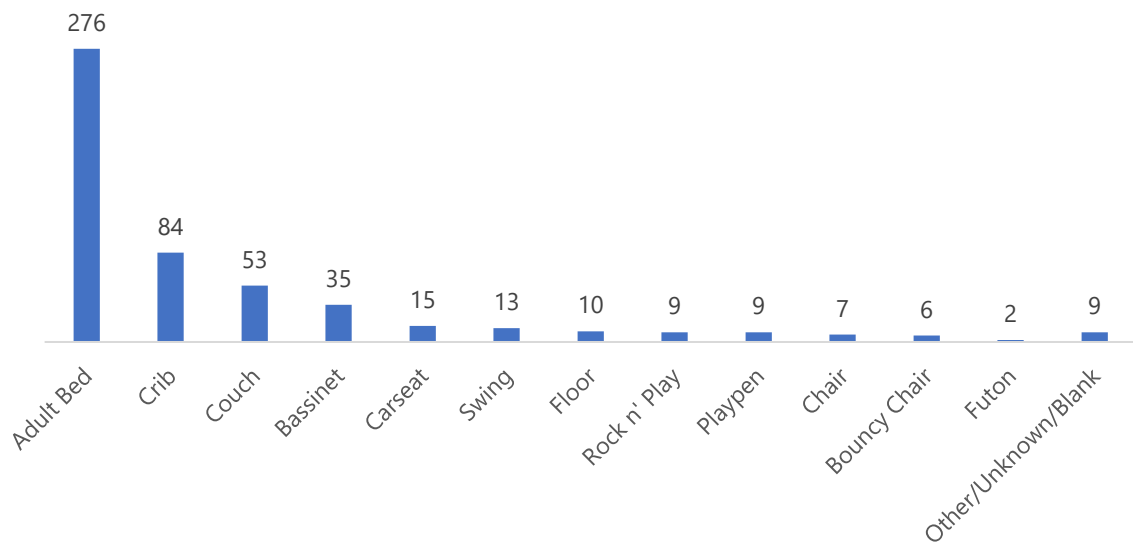
supervise a child. Alcohol impaired refers to being under the influence of alcohol to a degree that impairs a person’s ability to supervise a child. Absent means that the supervisor was not present at time of the infant’s death. These categories are not mutually exclusive.

SLEEP ENVIRONMENT FACTORS

Eighty percent of SUIDs occurred at the children’s homes (n=423). Eleven percent occurred at a relative’s or friend’s home (n=59). Four percent of deaths occurred at unlicensed childcare or babysitter’s homes (n=23), and 2% occurred at licensed childcare homes or centers (n=10).

For just over half of the infants who died due to SUIDs, the deaths occurred in adult beds (n=276, 52%). Twenty-two percent of total deaths occurred in cribs or bassinets (n=119). Twelve percent of deaths occurred on couches, futons, or chairs (n=62). Five percent of deaths occurred in swings, rock n plays, or bouncy chairs (n=29), and three percent occurred in car seats (n=15). For 75% of the total deaths, a crib or bassinet was available in the home (n=394). This number includes cases where the infant was placed in a crib or bassinet to sleep. Figure 19 show SUIDs by sleep location.

Figure 19. SUIDs by Sleep Location, Indiana, 2015-2019 (n=528)



Sixty-eight percent of infants who died were sleeping in the same rooms as their caregivers or supervisors at the time of death (n=357). Infants were not sleeping in the same room for 29% of the deaths (n=152). For 189 SUIDs, the death occurred while the infant was napping

(36%). To identify these deaths, we used the time of death or time of injury from the death certificates and included any that occurred between 10 am and 6 pm.

Seventy percent of total deaths occurred among infants who were usually placed on their backs to sleep (n=372). For 13% of deaths, the infants were usually placed on their stomachs or sides to sleep (n=68). Sixty-six percent of total SUIDs occurred among infants who were placed on their backs to sleep at the time of death (n=347). More than a quarter of deaths were among infants who were placed to sleep on their stomachs or sides (n=136, 26%). For 45 SUIDs, the infant initial sleep position was unknown or was blank on the case review form (9%). Forty-five percent of SUIDs occurred among infants who were found on their stomachs or sides (n=240), and 43% of deaths were among infants who were found on their backs at the time of death (n=228). Table 7 shows usual, placed, and found sleep positions.

Table 7. Infant Sleep Position: Usual Placement, Placed on Day of Death, and Found on Day of Death, Indiana, 2015-2019

Position	Usual		Placed		Found	
	#	%	#	%	#	%
On back	372	70%	347	66%	228	43%
On stomach	51	10%	86	16%	180	34%
On side	17	3%	50	9%	60	11%
Unknown	39	7%	22	4%	23	4%
Blank	49	9%	23	4%	37	7%
	528		528		528	
<i>Percentages may not add up to 100% because of rounding.</i>						

Bedsharing with at least one adult accounted for 51% of total deaths (n=269). For 72 deaths, the adult was sharing a sleep surface because they were feeding the infant (14% of total deaths). Thirty-five deaths occurred when the infant was breastfeeding, and 30 deaths occurred when the infant was bottle feeding. The feeding method was unknown to the review teams for seven deaths. For 104 deaths, the adult was sharing a sleep surface because they were trying to soothe the infant (20% of total deaths). In 64 cases, the infant was sleeping next to at least one other child (12% of total deaths). The age of the child was documented for 45 children, and of those cases, 71% were children five years of age or younger (n=32).

Soft objects in the sleep environment are a known risk factor for SUIDs. More than 200 deaths occurred with a thin blanket or flat sheet (41%, n=217). This does not include fitted sheets that were on a mattress underneath the infant. Thirty-eight percent of deaths had a comforter or quilt in the sleep environment (n=203). Twenty percent of infants were wrapped or swaddled in blankets at the time of death (n=108).

At least one pillow was present for 40% of the deaths (n=212), and nursing or crescent-shaped pillows were present for 7% of deaths (n=36). For the crescent-shaped pillows, 16 of the total 36 cases occurred in 2019 alone. Cushions, typically associated with deaths that occur on couches, were present for 49 deaths (9%). Three sleeping environments included bumper pads, and 15 sleeping environments had at least one toy.

Sixty infants were known to be sleeping in a new environment when they died (11%). Almost a quarter of the SUIDs for this time period was among infants who had been exposed to secondhand smoke (23%, n=120). Of the 120 infants known to have been exposed to secondhand smoke, 57% were exposed frequently (n=68), and 18% were exposed occasionally (n=22). For 5% of the 120 infants, the frequency of exposure was unknown (n=6). Table 8 shows a summary of SUID risk factors present for the total number of deaths.

Table 8. Unsafe Sleep Risk Factors Present for SUIDs, Indiana, 2015-2019 (n=528)

	Percentage of Total			
	Yes	No	Blank	Unknown
Bedsharing with at least one adult	51%	44%	4%	1%
Not sleeping in a crib or bassinet	23%	76%	1%	1%
Bedsharing with at least one child	12%	80%	7%	1%
Infant in new sleep environment	11%	84%	3%	1%
Infant exposed to secondhand smoke	23%	39%	26%	12%
Infant overheated	2%	70%	18%	9%
Infant swaddled in blanket*	20%	69%	6%	5%
Object(s) in sleep environment – Thin blanket or flat sheet	41%	43%	12%	4%
Object(s) in sleep environment - Comforter	38%	49%	10%	2%
Object(s) in sleeping environment - Pillow	40%	47%	10%	3%
Object(s) in sleep environment - Nursing or crescent-shaped pillow	7%	80%	10%	2%
Object(s) in sleep environment - Cushion	9%	77%	11%	3%
Object(s) in sleep environment - Toys	3%	84%	11%	2%
Object(s) in sleep environment - Clothing	6%	79%	12%	3%
Object(s) in sleep environment - Bumper pads	1%	88%	2%	10%

Percentages may not add up to 100% because of rounding.

- *When done correctly, swaddling is not necessarily an unsafe practice, but there is no evidence to recommend swaddling as a strategy to reduce the risk of SUID. Please see the latest guidelines from AAP for more information regarding the safety of swaddling (Moon & AAP Task Force, 2022).*

SUID INVESTIGATIONS

To accurately identify SUIDs, there must be a complete investigation, which should include at least the following:

- Death scene investigation
- Autopsy
- Scene reenactment with or without a doll
- SUID Investigation reporting form
- Toxicology
- Complete x-rays

With death scene investigations and scene reenactments, investigators are able to document any unsafe sleep risk factors that may have contributed to the death. The autopsy, toxicology, and complete x-rays are part of the process of ruling out other causes of death. DCS should be immediately notified of all potential SUIDs so that child welfare assessments can be completed.

Autopsies were performed for 98% of total deaths (n=519). Of those, 92% were performed by a Forensic Pathologist or General Pathologist (n=478). For 90% of SUIDs, a death scene investigation was completed (n=475). For 16 deaths, a scene investigation was not completed (3%), and for 37 deaths, scene investigation was blank or unknown to review teams (6%). For 22% of SUIDs, a scene reenactment with a doll was completed as part of the investigation, and for 39% of SUIDs, a scene reenactment without a doll was completed as part of the investigation. Ninety-two percent of investigations included toxicology reports (n=485). For half of the deaths, complete x-rays were included in the death investigation (50%, n=265), and for 57% of the deaths, a SUID Investigation reporting form was completed as part of the investigation (n=301). Table 9 shows the completion of each component of a SUID investigation.

Table 9. SUID Investigation Components, Indiana, 2015-2019

	Percentage of Total Deaths			
	Yes	No	Blank	Unknown
Components of a complete investigation				
Death scene investigation	90%	3%	6%	<1%
Autopsy	98%	<1%	1%	0%
Scene reenactment with doll	22%	42%	31%	5%
Scene reenactment without doll	39%	34%	22%	5%
SUID Investigation reporting form	57%	18%	22%	3%
Toxicology	92%	3%	4%	1%
Complete x-rays	50%	31%	14%	4%
Additional components				
Reliable witness account	55%	13%	32%	<1%
Single x-ray	18%	59%	17%	6%
Multiple x-rays	17%	60%	17%	6%
Other imaging (CT, MRI, brain scan)	7%	66%	18%	9%
Examination of gross appearance	91%	0%	9%	<1%
Gross examination of organs	89%	<1%	9%	1%
Cultures for infectious disease	30%	47%	16%	7%
Metabolic screen	12%	60%	17%	11%
Microscopic/histologic examination	70%	11%	13%	7%
Vitreous fluid test	31%	45%	16%	8%
Genetic test	3%	70%	17%	11%
<i>Percentages may not add up to 100% because of rounding.</i>				

Only 9% of the total number of deaths during 2015 through 2019 were known to have had a complete investigation. The percentages of complete investigations improved each year, and more than doubled between 2018 and 2019. The most commonly missing components of incomplete investigations were scene reenactments with or without a doll and complete x-rays (as shown in Table 9). FRP is committed to improving the quality of SUID investigations in Indiana, and we will continue to collaborate with coroners, DCS staff, law

enforcement personnel, and other first responders to provide training and resources. Table 10 shows the number of complete investigations by year.

Table 10. Complete Investigations by Year, Indiana, 2015-2019 (n=528)

	#	% (of that year)
2015	4	4%
2016	6	6%
2017	8	7%
2018	6	7%
2019	23	18%
Total	47	

PREVENTING FUTURE SUIDS IN INDIANA

IDOH FRP develops and supports CATs throughout the state, and FRP Community Coordinators provide ongoing technical assistance to new and existing teams. IDOH also provides funding for local prevention activities, when available, and disseminates data regarding risk factors and trends. IDOH will continue to provide safe sleep resources to teams and other community partners, when funding is available. These resources include portable cribs, infant sleep sacks, and printed materials. In addition to these activities, additional actions are recommended to prevent SUIDs in Indiana.

1. Engage Black Families

There are several additional actions that can be taken to prevent SUIDs in Indiana. The most important is engaging Black families. Non-Hispanic Black infants are dying at a rate that is nearly four times higher than Non-Hispanic White infants, and solutions to address this disparity are long overdue. There are limitations to a one-size-fits-all policy toward prevention, and it may not be prudent to keep doing what has been done for many years and expecting different results. Reducing deaths due to unsafe sleep practices is ultimately about facilitating the adoption of safe behaviors by individuals, families, and communities. Although some excellent research has been published on sleep practices among Black families in Indiana (see Ayers *et al.*, 2015; Stiffler *et al.*, 2018; & Stiffler *et al.*, 2020), additional funded research opportunities are needed to identify and address caregivers' beliefs and behaviors. Effective prevention requires an understanding of social and cultural

factors associated with parental choices around sleep practices, including factors related to social determinants of health and structural racism. We need to listen to Black families. Findings from community-led, community-driven research can be used to develop, implement, and evaluate new, targeted infant safe sleep initiatives that are culturally relevant to the populations at highest risk. This research is a crucial first step in the process of reducing the disparities in Indiana’s SUID rates.

2. Ensure all providers use consistent messaging that aligns with current AAP guidelines

Hospitalized infants should be kept predominantly in the supine position, unless contraindicated, and all infants should be acclimated to supine sleeping before being discharged. All Pediatric Intensive Care Unit (PICU) and NICU personnel should consistently endorse and model safe sleeping practices from the time of admission until discharge. Physicians who specialize in pediatrics, family medicine, or obstetrics/gynecology should also provide consistent messaging to families that complies with current AAP guidelines. Service providers throughout the state, including lactation consultants, doulas, midwives, Special Supplemental Nutrition Program for Women, Infants, and Children (WIC) personnel, DCS Family Case Managers, and appropriate state and local health department staff, should educate families on the safest way for their infants to sleep—alone, on their backs, and in cribs. Agencies should examine their existing safe sleep training materials to ensure that the content includes deaths caused by ASSB and guidelines to reduce the risk of these deaths from occurring. Materials that only discuss SIDS should be revised to focus on ASSB. This applies to all internal trainings for staff and education that is provided to families and caregivers. Please contact safesleep@isdh.in.gov if you would like assistance with updating materials.

3. Promote prevention at the local level

SUID is a complex public health issue, and prevention requires a multi-faceted response and the promotion of best practices within communities. Community Action is an innovative strategy that builds on existing strengths in communities while addressing the needs of at-risk populations. Previous research has shown that Community Action is an effective, sustainable strategy to promote public health and reduce health disparities (Hennessey *et al.*, 2005; Backer & Guerra, 2011; Johnson *et al.*, 2017).

Support is needed for existing CATs in Indiana, and local communities are seeking champions to lead new county or regional teams. Support can come in many forms, including funding, resources, cooperation, promotion, and collaboration. Please contact safesleep@isdh.in.gov or visit safesleep.health.in.gov to learn more about Community Action in Indiana.

Any SUID prevention initiatives should be evidence-based and follow current 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 their communities.

4. Improve investigation, classification, and fatality team reviews of SUIDs

One barrier that affects the quality of fatality reviews is lack of records. Prior to a review, teams request records from hospitals, DCS, coroners, law enforcement, mental health service providers, and others. Teams are able to conduct timely reviews only when agencies comply with these records requests promptly. Often, team coordinators must make multiple requests for the same records, which creates additional delays. Some agencies never respond to records requests at all. Teams continue to struggle to access records from Emergency Medical Services (EMS) providers and agencies that serve women and infants. It is recommended that all agencies and hospitals provide review teams with records within five business days of the initial request. Please contact safesleep@isdh.in.gov with questions about the legal obligation to respond to records requests.

SUID investigations should be collaborative and multidisciplinary to ensure the most accurate and complete data are collected. All infant death investigators should use the SUID Investigation Protocol and the SUID Investigation reporting form. Pre-autopsy conferences should be a standardized best practice for all infant deaths, and coroners should require this step before finalizing death certificate data. DCS should ensure that scene photos and doll reenactments are completed (by DCS, law enforcement, or the coroner) for every case and documented based on the SUID/SDY Case Registry Algorithm. With complete death scene investigations and accurate data collection, local CFR and FIMR teams can offer well-informed, evidence-based, and customized recommendations to inform effective interventions.

Additional considerations:

- EMS must be immediately called to conduct all necessary life-preserving efforts.
- 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.
- The safety of any children remaining in the home must be secured.

- Bereavement services should be offered to families and documented as part of the investigation. Please see the IDOH FRP Bereavement Guide for additional information at: <https://www.in.gov/health/cfr/files/Bereavement-guide-Final.pdf>.

Local FR teams should document incomplete investigations and inaccuracies of death certificate data and provide local recommendations and feedback to all agencies to encourage system improvements. Local FR teams should utilize the SUID/SDY Case Registry Algorithm and enter complete data into the CDR-CRS.

CONCLUSION

FR data continues to be the most detailed, comprehensive source of information about risk factors and circumstances for fetal, infant, and child deaths. This report identifies areas for improvement regarding review team processes and death investigations. Local FR teams can conduct effective reviews only when agencies and hospitals comply with records requests in a timely manner. Another area for improvement is with SUID investigations. During this reporting period, only 9% of SUIDs had all the components of a complete investigation. Efforts are currently underway to improve investigations and provide training to coroners and other investigators. In Indiana, the Governor and Legislature have also shown their support for improved investigations with the passing of HEA 1169. Data from more accurate investigations will lead to effective prevention initiatives throughout the state.

Most importantly, this report provides specific information on the sleep environments where infants died. The data show that in Indiana, the greatest barriers to safe sleep are bedsharing with adults and infants sleeping in adult beds, rather than alone in cribs or bassinets. We continue to lose too many babies who are placed to sleep on couches. Hundreds of babies died in sleep environments that included blankets, crescent-shaped nursing pillows, and other soft objects. Almost 200 infants died during daytime naps. Targeted, culturally proficient strategies are needed to change unsafe sleep practices. Caregivers need to receive consistent, evidence-based safe sleep messaging from all service and medical providers.

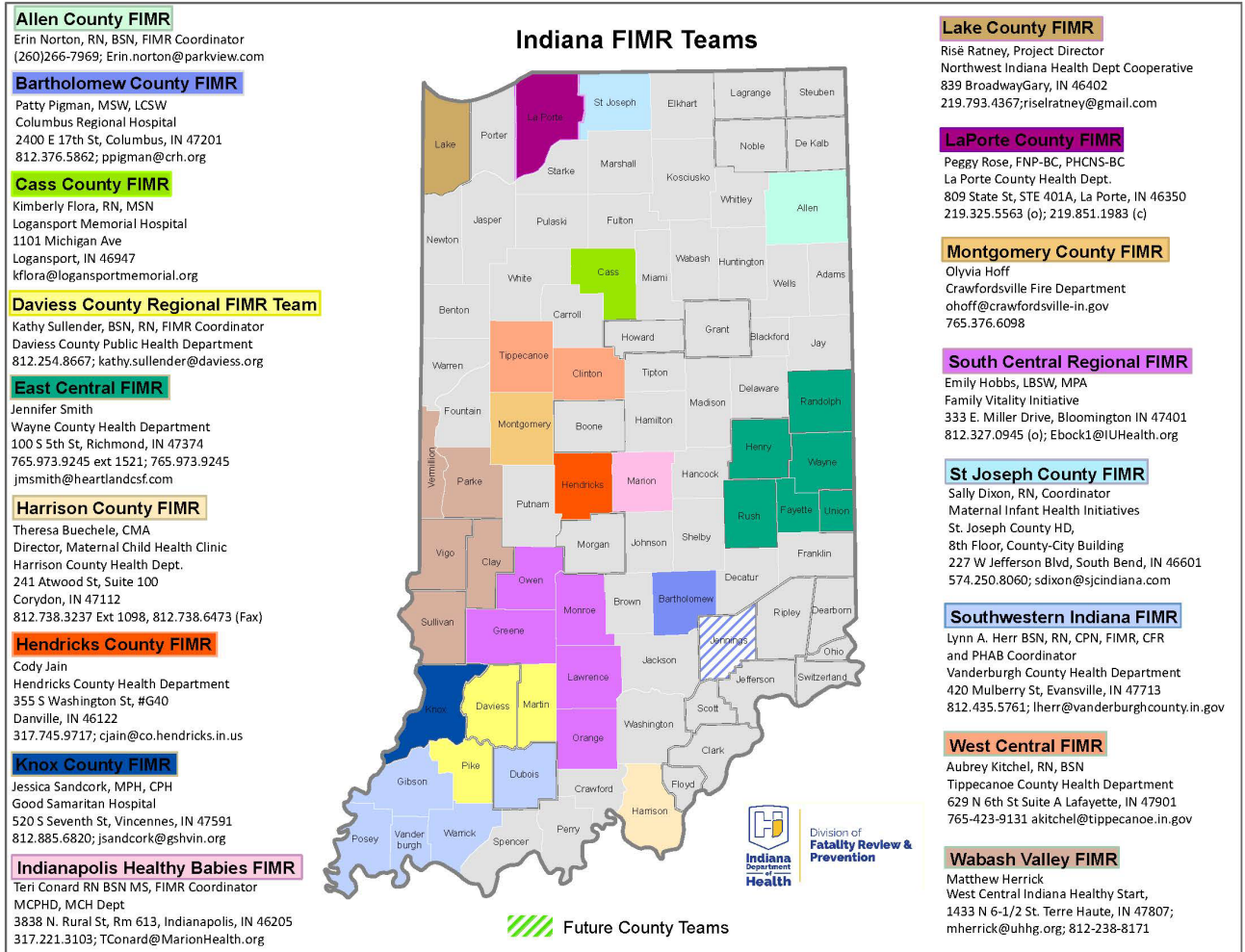
Support is needed for research and engagement with the most at-risk populations and for the prevention work of local CATs. Participatory action and community-engaged research can generate a better understanding of the decisions caregivers make regarding their infants' sleep environments and will allow for the development of effective education, training, and messaging that addresses caregivers' concerns. Reducing the SUID rate in

Indiana will require sustained efforts at the state and local levels. There are hundreds of dedicated professionals in each of Indiana's counties who work tirelessly to prevent infants from dying. Working together with families, we can prevent sleep-related infant deaths in Indiana.

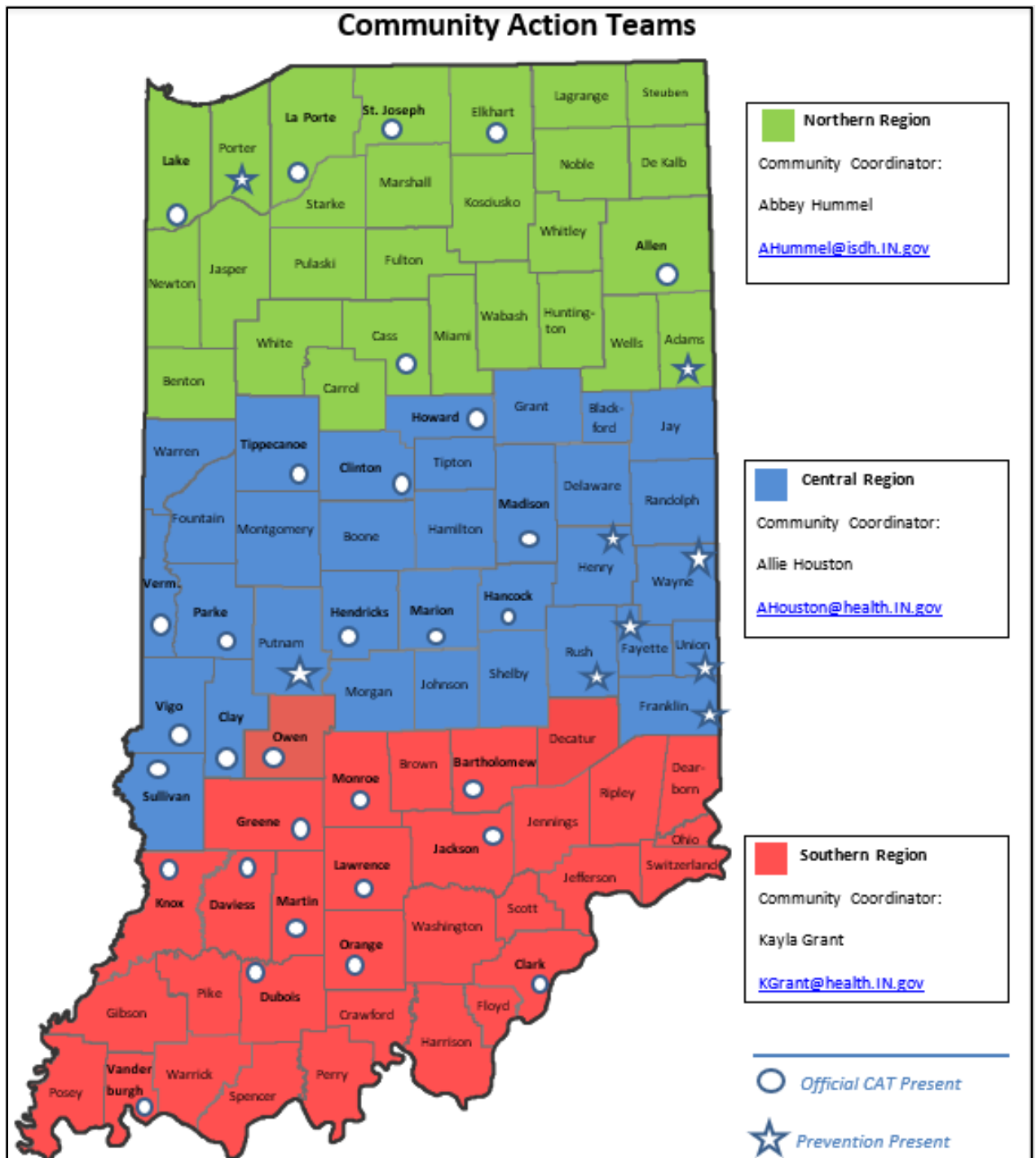
APPENDIX A-MAP OF CFR TEAMS



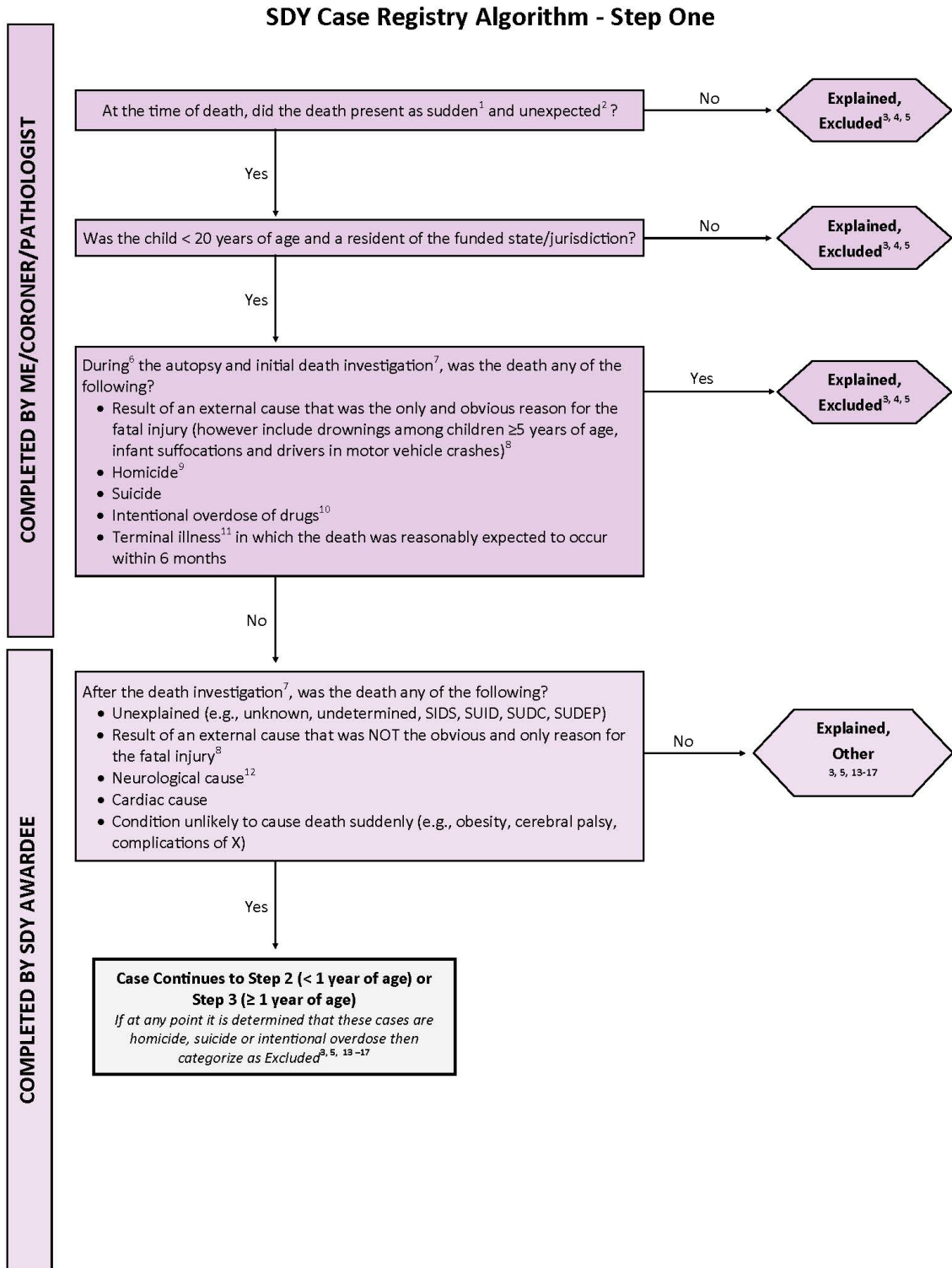
APPENDIX B-MAP OF FIMR TEAMS



APPENDIX C-MAP OF COMMUNITY ACTION TEAMS

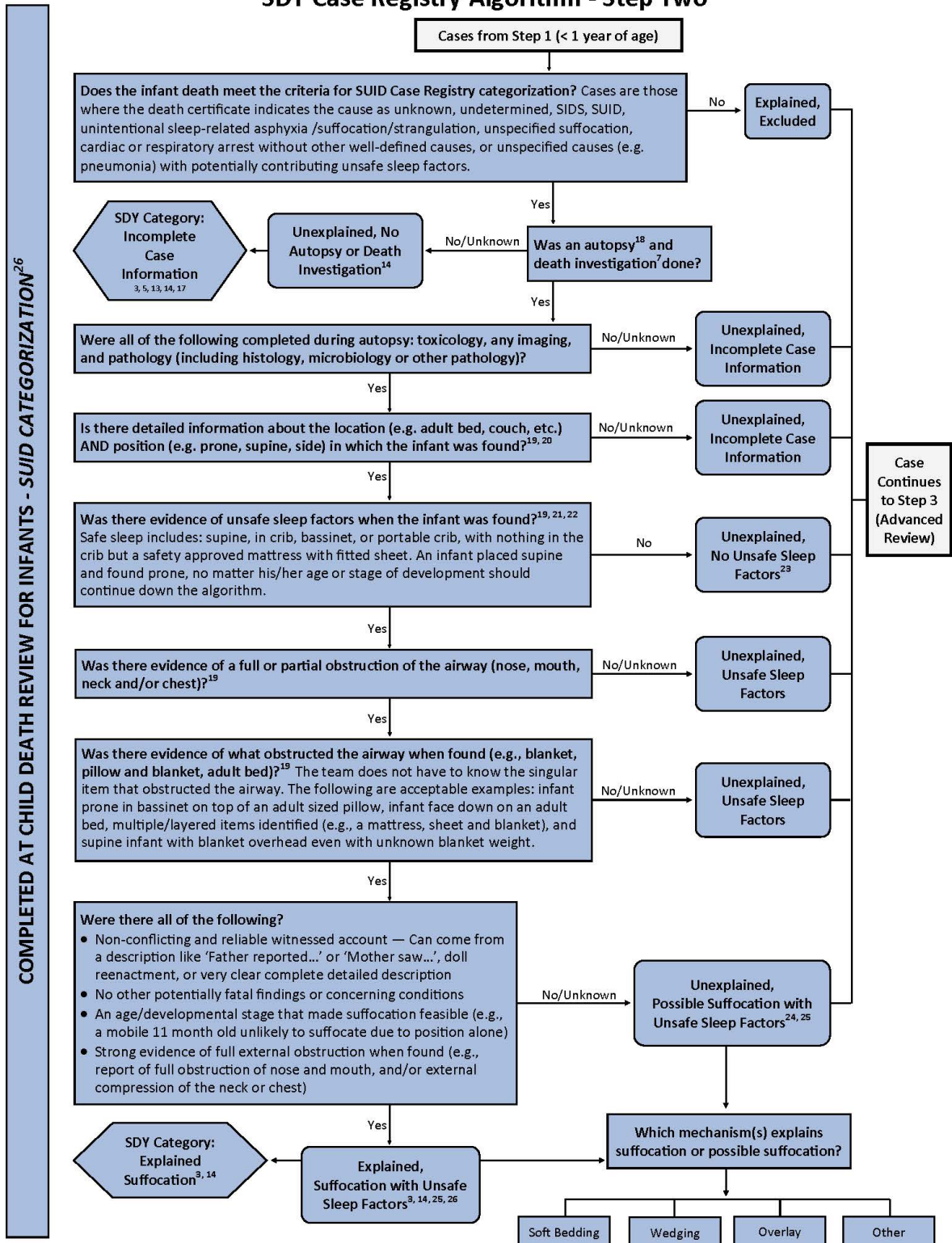


APPENDIX D-SUID/SDY ALGORITHM



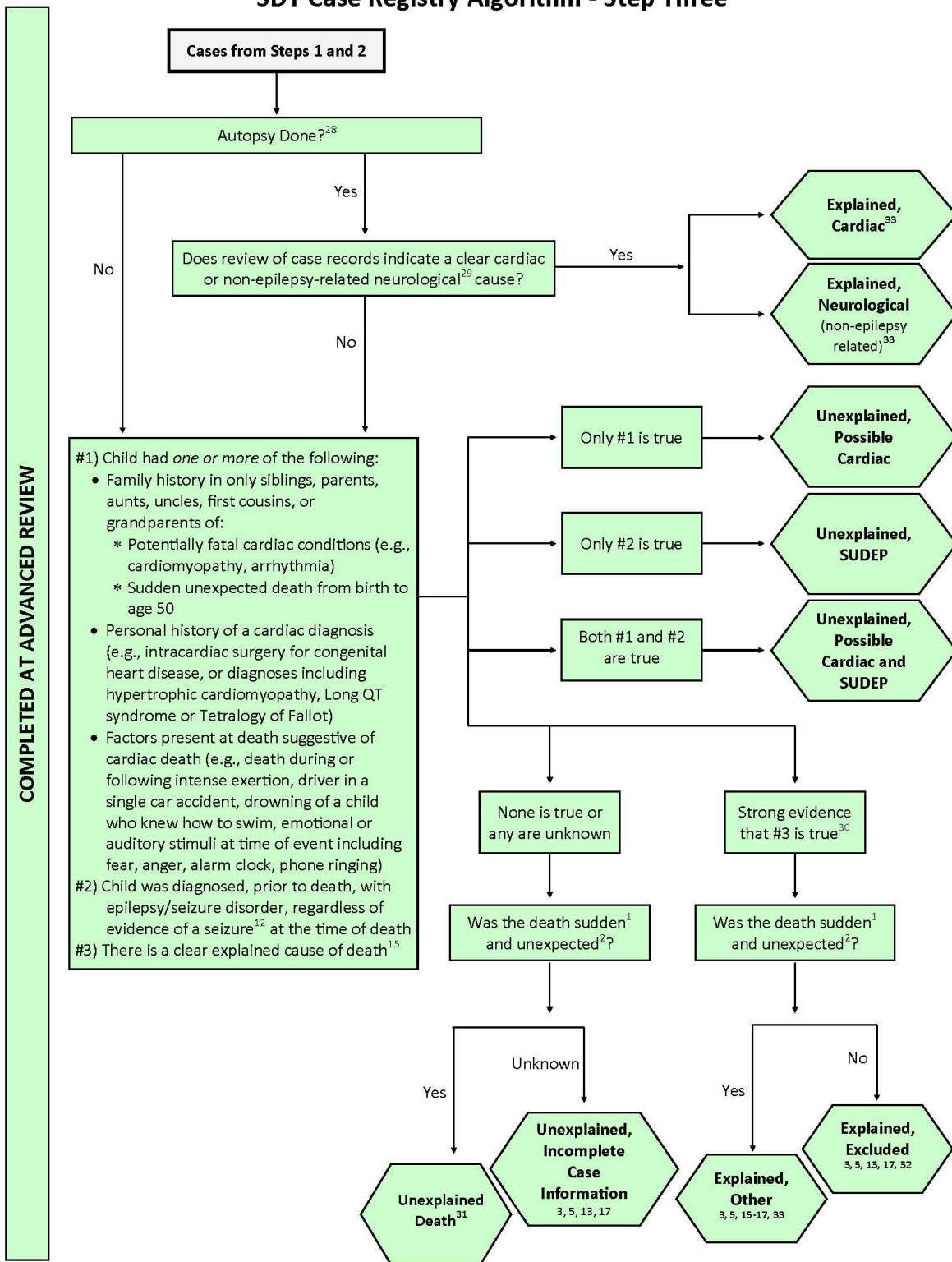
Last updated December 2021 (v8.3)

SDY Case Registry Algorithm - Step Two



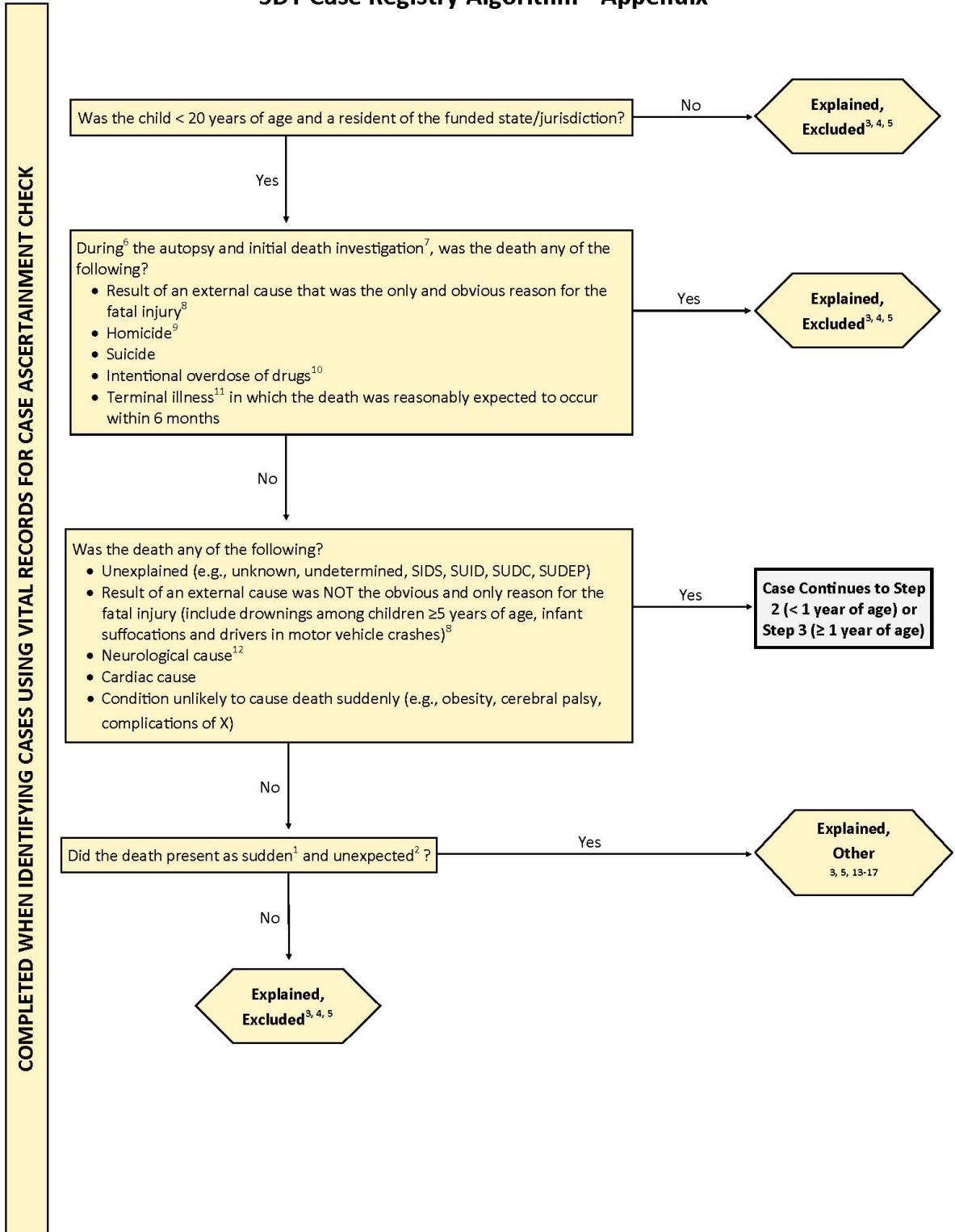
Last updated December 2021 (v8.3)

SDY Case Registry Algorithm - Step Three



Last updated December 2021 (v8.3)

SDY Case Registry Algorithm - Appendix



Last updated December 2021 (v8.3)

Footnotes

1. Sudden = Death within 24 hours of first symptom, or death in the initial hospitalization after resuscitation from a cardiac event.
2. Unexpected = Death of someone who was believed to be in good health, or have a stable chronic condition or acute illness that would not be expected to cause death.
3. No consent necessary, but if consent was obtained send it and the sample in.
4. Answer no to N1.
5. Retain all data entered.
6. This includes the initial autopsy results and death investigation; do not wait for the toxicology results.
7. Death investigation = Any agency obtaining information about the circumstances of the death; this does not need to include a visit to the scene.
8. Cases in which the underlying cause of the fatal event (e.g., drowning among children ≥ 5 years, infant suffocation, drivers in motor vehicle crashes, etc.) may be cardiac or neurological in origin should not be considered the 'result of an external cause that was the obvious and only reason for the fatal injury' and should continue to Step 2 or 3. Drownings among children < 5 years should be excluded.

Motor vehicle crashes can be categorized as Explained Other on Step 1 at the discretion of the SDY staff only when information is known for the checklist below and the information points to a true accident. Each point must be thoroughly documented in the narrative.

 - Circumstances of the crash including road conditions (e.g., dry, icy), time of day and speed
 - Condition of the driver including if they were distracted, sleep deprived, intoxicated, upset, an inexperienced at driving, or feeling sick in the day/hours leading up to the event
 - Medical history of the driver including if they had any history of fainting, seizures, arrhythmia or heart palpitations
 - Family medical history of the driver including young sudden death (< 50 years old), irregular heart rhythms, unexplained fainting, motor vehicle crashes or drowning
9. Homicide = Intention to kill, not by official manner of death or if charges were filed (e.g., this excludes accidental unsafe sleep cases where charges were filed against the parents).
10. Intentional overdoses should be excluded however accidental overdoses, medical treatment mishaps and adverse medication effects should be included.
11. Terminal Illness = Diagnosis prior to death that is incurable and irreversible.
12. Exclude status epilepticus - categorize status epilepticus as Explained Other, no Advanced Review necessary.
13. Answer yes to N1.
14. No Advanced Review necessary.
15. Excludes infant suffocation cases; includes status epilepticus at the time of death.
16. Explained Other needs to be one definable cause, not "Complications of...". If the cause cannot be identified specifically and supported by autopsy evidence then it is not an explained cause of death and should be categorized as Unexplained Infant Death/SUID or Unexplained Child Death.
17. Enter at a minimum the data elements of age, sex, cause of death and category in the Case Reporting System.
18. Autopsy must include an internal exam.
19. When there is conflict:
 - Use the expertise of your multi-disciplinary team and ALL of the evidence to figure out what really happened.
 - If there is enough evidence for the team to resolve the conflict, then document the team's decision in the narrative and continue down the algorithm.
 - If the evidence does not reveal a clear resolution, then document the sustaining conflict and treat it as an unknown.
20. Consideration of lividity may be useful in verifying position, but lack of information on lividity does not make the case incomplete. Lividity that indicates supine positioning could be from flipping the infant after death and should be considered cautiously.
21. Answer no, if the infant was not sleeping.
22. Infant put in car seat...
 - To sleep, should continue down the algorithm
 - To travel, not sleep, with soft objects or loose bedding, should continue down the algorithm
 - To travel, not sleep, with no soft objects or loose bedding, should be categorized as Unexplained, No Unsafe Sleep Factors

Footnotes

23. Includes infants who were witnessed going unresponsive.
24. Includes infants whose airways were obstructed by a Consumer Product Safety Commission approved mattress used as recommended in a crib, portable crib, or bassinet.
25. Needs to be assigned at least one mechanism using the following definitions (the following are examples, not a comprehensive list):
- **Soft bedding:** when an infant's airway is obstructed by a blanket, sheet, pillow, couch or recliner cushions, or other soft objects of loose bedding that are part of the immediate sleep environment.
 - ⇒ Nose and/or mouth obstructed at the intersection of soft bedding (e.g., where a pillow and mattress meet, where the back and seat of a couch meet)
 - **Wedging:** when an infant's airway is obstructed as a result of being stuck or trapped between inanimate objects.
 - ⇒ Wedged with face clear (e.g., in gap, face above mattress), chest/neck obstruction only
 - **Overlay:** when a person rolls on top of or against an infant obstructing the infant's airway.
 - ⇒ Overlay with face clear (obstructed chest/neck only)
 - ⇒ Face into person with or without chest/neck obstruction
 - ⇒ Infant pinned between person and couch, facing person
 - ⇒ *Note: Surface sharing only is not enough evidence for overlay. An overlay needs to be witnessed (e.g., someone waking up on top of an infant, or someone seeing someone else on top of an infant).*
 - **Other:** when an infant's airway is obstructed by something in the sleep environment other than soft bedding, overlay or wedging like a plastic bag.
 - ⇒ *Note: Other should not be selected for unsafe sleep factors like prone positioning or impaired caregivers.*
 - **Multiple mechanisms:**
 - ⇒ **Wedging and Soft Bedding**
 - * Wedged with face into soft bedding (mattress, pillow, blankets), nose and mouth obstructed
 - * Wrapped/entangled in blankets and wedged
 - ⇒ **Overlay and Soft Bedding**
 - * Overlay with nose/mouth obstructed by soft bedding (mattress, pillow, blankets)
 - * Infant pinned between person and couch, facing couch
26. Examples include:
- A 1-month-old infant found face down in a pillow with her nose and mouth fully obstructed.
 - A 2-month-old infant found with her head and face wedged between the cushions at the back of the sofa.
 - A 4-month-old infant found lifeless in a twin bed with his head and body underneath his mother.
27. Reference: Shapiro-Mendoza CK, Camperlengo L, Ludvigsen R, et al. Classification system for the Sudden Unexpected Infant Death Case Registry and its application. *Pediatrics*. 2014;134:e210-e219.
28. If extensive testing was performed during the same hospitalization as the death and identifies a cause of death, the Advanced Review Team can decide to answer "yes" to this question, even if an autopsy was not performed. Justification and explanation of why the Advanced Review Team made their decision needs to be documented in the Case Reporting System in the *Notes from Advanced Review Meeting*.
29. Includes first seizure at time of death with neurological process that could have independently led to death found on autopsy (e.g., large subarachnoid hemorrhage, meningitis, or encephalitis).
30. If Explained Other is selected, and #1 or #2 are also present, please document, in the Case Reporting System in the *Notes from Advanced Review Meeting*, the evidence supporting your choice of Explained Other over the other categories.
31. Includes all Sudden Unexpected Infant Death (SUID) cases including those the Advanced Review Team deems to be suffocation.
32. The combination of yes to N1 and the category of Excluded should only be used when a case looked like it was sudden and unexpected until the experts at the Advanced Review Team uncovered that it was not.
33. If a case is assigned an explained SDY category by a full Advanced Review Team (including clinicians and a forensic pathologist), the SUID category should be Explained, Excluded. If a forensic pathologist is not present at the Advanced Review meeting, one should be consulted. Document this change in the Case Reporting System and communicate with CDR.

Shape indicates
SUID category

Shape
indicates SDY
category

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