SIDS Support and Bereavement Services

A Home Visit Guide for Ohio Department of Health Public Health Nursing Professionals

Ohio | Department of Health

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Infant soft sleep education, communityoutreachand/omilysupport.

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Introduction

The sudden, unexpected death of a child is both a medical and a psychological crisis for parents and their families. During this life-altering experience, public health professionals play a vital supportive role in the family bereavement process through counseling, comfort, and other support services. The purpose of this guide is to provide public health nursing professionals *operating in this supportive role* with best practices for conducting home visits with grieving families after a sudden, unexpected infant death (SUID). Through the home visiting model, outlined herein, public health nursing professionals will provide counseling and other appropriate, need-based services to families, in accordance with state law.[1]

The Baby 1st Network (formerly the SID Network of Ohio) serves as the state agent for the Ohio Department of Health (ODH) through the sudden infant death syndrome (SIDS) program to assure that parents are offered support and bereavement services and to assure that coroners and local health departments (LHDs) comply with respective state-mandated SIDS death procedures. The network also serves as a resource for national, state, and local SIDS organizations and the public around sleep-related infant deaths, infant safe sleep recommendations, and SIDS research, early intervention, and prevention. Community development of effective, sustainable strategies to address racial disparities in SUID, including SIDS, remains one of the central interests of the network.

Through continued partnerships with national, state, and local SUID/SIDS agencies, the network helps to reduce the incidence of preventable deaths, and, ultimately, the infant mortality rate (IMR) in Ohio. In partnership with ODH, the network developed this guide to assist public health nursing professionals in appropriately and effectively responding to infant deaths from sudden and unexpected causes, as required by law. The goal of this partnership is not only to provide immediate counseling and other services but also to educate families around SIDS risk reduction and prevention.

This guide outlines background information on SUID in Ohio, the ODH SIDS Program, support and bereavement services, and evidence-based SIDS risk reduction and prevention recommendations. In the circumstance of a sudden, unexpected loss of an infant, ODH and the network provide compassionate, culturally competent, and appropriate support services to families. Through this work, these agencies are committed to creating positive change by providing the tools necessary to empower and engage communities to keep infants safe.

Section 1: Understanding SUID in Ohio

1.1 Terms, Facts, and Data

Bereavement is the act of being deprived of something or someone, particularly a loved one who has died. Bereavement is often characterized by profound grief or sadness of a loss.

Child fatality review (CFR) is a comprehensive analysis of the circumstances and contributing factors of each child death in Ohio. The findings are intended to better inform interventions that help to reduce the incidence of child deaths, including SIDS and SUID.

Grief is the strong emotional response to a loss that can be overwhelming at times. It may be short- or long-term and vary in intensity from mild to intense. Symptoms of grief may manifest mentally and physically.

Infant death is the death of a live-born baby before their first birthday.

Infant mortality rate (IMR) is the number of infant deaths in a specific year divided by the number of live births within that same year, multiplied by 1,000.

Sleep-related deaths are those SUIDs from all causes, including SIDS, that occur while the infant is sleeping and in which the environment appears to play a role in the death. Sleep-related deaths are caused by SIDS, accidental suffocation, positional asphyxia, overlay, and undetermined causes. Deaths from specific medical causes are excluded from this category, even if the infant was sleeping when the death occurred.

Sudden infant death syndrome (SIDS), a subset of SUID, is a medical cause of death assigned to the sudden death of an infant – less than 1 year old – that remains unexplained after the performance of a complete postmortem investigation, including an autopsy, an examination of the death scene, and a review of the infant's health history. SIDS is a diagnosis of exclusion; therefore, all other reasonable causes must be ruled out, through these means, before a death is ruled SIDS. Diseases or conditions that have known markers or causes must also be ruled out.

Sudden, unexpected infant death (SUID) is any sudden and unexpected infant death, whether explained or unexplained, that occurs during infancy. After investigation, the cause of SUIDs may be attributed to accidental suffocation, positional asphyxia, overlay, entrapment, infection, ingestions, metabolic disorders, trauma, SIDS, or undetermined causes.

The distinction between SIDS and other SUIDs is challenging. Many of the risk factors for SIDS and, for example, asphyxia are similar. While it is not always possible to determine a specific cause for each SUID, those that are associated with infant sleeping environments occur all too often and, in many cases, are preventable. More than three infant deaths each week in Ohio are sleep related. To better understand the contributing factors for these deaths, the Ohio CFR boards in the state collect and analyze information and data about all causes of child death each year to inform intervention policies, procedures, and practice and to reduce preventable child deaths in the state.

There are approximately 3,500 SUID cases among infants less than 1 year of age in the United States annually. In 2018, the three commonly reported types of SUID – SIDS, unknown cause, and accidental suffocation and strangulation in bed (ASSB) – accounted for 1,300, 1,300, and 800 deaths, respectively.[2] In 2019, 929 infants died before their first birthdays in Ohio. In total, 147 of these deaths (16%) were attributed to SUID and 45% of these occurred among Black infants, which only account for 19% of the infant population in the state. About 50.0% of all SUIDs in the state were caused by ASSB, 36.0% by SIDS, and 12.9% by an undetermined cause. In 2019, the IMR for the state was 6.9 for all races. The rate for Asian/Pacific Islander infants was 4.4, the rate for white infants was 5.1, and the rate for Black infants was 14.3 – nearly three times higher than the rate for white infants.[3]

Recent aggregate reviews from the review boards, for the 2014 through 2018 period, provide a more comprehensive assessment of sleep-related deaths in the state over a five-year period. During this period, 693 sleep-related infant deaths account for 16% of all infant deaths (4,440). The review boards found that 72% of these deaths were preventable. About 53% (370) of the sleep-related deaths were among infants between 1 month and 3 months old. In approximately 51% of the 79 sleep-related infant deaths due to a medical cause, SIDS was the final ruling.

- Bed-sharing was reported at the time of the death in 371 cases reviewed, or 54%. Of these, infants most often shared a sleep surface with an adult only (68%), an adult and another child (15%), another child only (6%), or a pet (1%).
- Of the 308 reviews that indicated bed-sharing with an adult or adult and another child, 11% indicated that the supervisor was impaired at the time of the incident. Among them, 94% were impaired by alcohol, drugs, or a combination. **Note**: The reporting of supervisor impairment changed in version five of the CFR case reporting system; impairment by sleep was removed from the system. If sleep impairment was the only impairment type noted by the case review team, then supervisor impairment was changed from "yes" to "no."

- Forty reviews (11% of those indicating bed-sharing) indicated an adult fell asleep while feeding the infant, with 22 bottle-feeding, 16 breastfeeding, and two in which the nature of feeding is unknown.
- Infants were put to sleep on their backs in 53% of reviewed deaths and found on their backs in 33% of reviewed deaths.
- Of the 154 sleep-related infant deaths in which a crib or bassinet was indicated as the incident location, 90% (139) reported unsafe object(s) found in the sleep space. Among the 139 reviews indicating objects in the crib or bassinet, commonly found objects were thin blankets (73%), comforters or quilts (27%), and pillows (22%).
- Secondhand smoke exposure was reported for 240 (35%) of the infant sleep-related deaths.
- In 37% of sleep-related infant deaths, the cause of death was ruled *undetermined*.

All infants are at risk for SUID, but some infants seem especially vulnerable. More than 90% of sleep-related deaths occur before 6 months of age and about half occur before 3 months of age. In 2019, approximately 40% of the deaths occurred to Back infants, even though black infants represent only 15% of Ohio's infant population.[4]

1.2 Impact of Infant Deaths on Families

The sudden death of a seemingly healthy child is devastating for parents and creates a profound void. Parents and families may experience unbearable grief, doubts, guilt, unanswered questions, and even suspicion related to the suddenness and unexpectedness of a baby's death. The sense of loss changes the lives of families significantly.

1.3 State Law Governing SIDS Reporting and Services

SIDS legislation, House Bill 244, was passed in Ohio in November 1992, mandating autopsies for all sudden and unexpected deaths of children younger than 2 years of age and requiring LHDs to offer information, counseling, and other supportive services to affected families. CFR legislation, House Bill 448, was passed in July 2000, mandating multi-agency boards in each county to review the deaths of all children younger than the age of 18. Additional legislation passed in 2014 requires standardized death scene investigation of all SUID cases in which the cause is not immediately known. These investigations are intended to improve understanding of SUID risk factors and lead to development and implementation of effective prevention strategies. Current Ohio state law regulating SUID autopsy, reporting, investigating, and providing support services, Ohio Revised Code 313.121, as amended or revised, in its entirety, can be accessed online on

the Ohio Legislature Ohio Laws & Administrative Rules website or by accessing this link directly https://codes.ohio.gov/ohio-revised-code/section-313.121.[1]

1.4 Ohio Department of Health SIDS Program

Ohio Department of Health (2021): The Ohio Department of Health's SIDS Program is funded by the Maternal and Child Health Services Block Grant. The purpose of the program is to:

- Ensure compliance with the mandates of Ohio Revised Code 313.121, related to the reporting of SUIDs and the provision of support and bereavement services.
- Provide expert consultation on SIDS; serve as a liaison with national and local SIDS organizations; and act as a resource for current information on SIDS research and risk reduction.

ODH works closely with the Baby 1st Network, the Ohio Coroner's Association, and LHDs to ensure appropriate service providers are alerted when there has been a sudden infant death in a community.[5]

Through relationships with national and state SIDS organizations and partners, including the network, the SIDS Alliance affiliates, chapters, support groups, LHDs, CFR boards, Ohio infant mortality reduction initiatives, and regional perinatal centers, ODH distributes educational and resource materials to the public and to professionals. ODH provides training sessions to nurses, first responders, social workers, day care providers, and others.

Section 2: SUID and SIDS Program Response

When an infant *in apparent good health* dies suddenly and unexpectedly, the parent or caregiver on the scene must call emergency services and the emergency medical team, first responders, will arrive immediately. The scene can become chaotic as the team moves swiftly to assess the baby and perform CPR and other lifesaving measures. The baby may be taken to the hospital emergency department where more life-saving techniques may be attempted. If the baby cannot be revived, the baby will be pronounced dead by a legally authorized individual. The coroner in the county where the infant died must be notified.

The coroner will assume responsibility for the infant's body, perform an autopsy, and conduct a death scene investigation as soon as possible via law enforcement and/or a coroner investigator. The coroner must notify the Baby 1st Network and ODH of the death within 72 hours. The coroner must also submit the Final Diagnosis of Infant Death Form to the network. The certificate of death and parent

notification of the cause of death are also completed by the coroner, who must participate in or designate an agency representative to the respective CFR board.

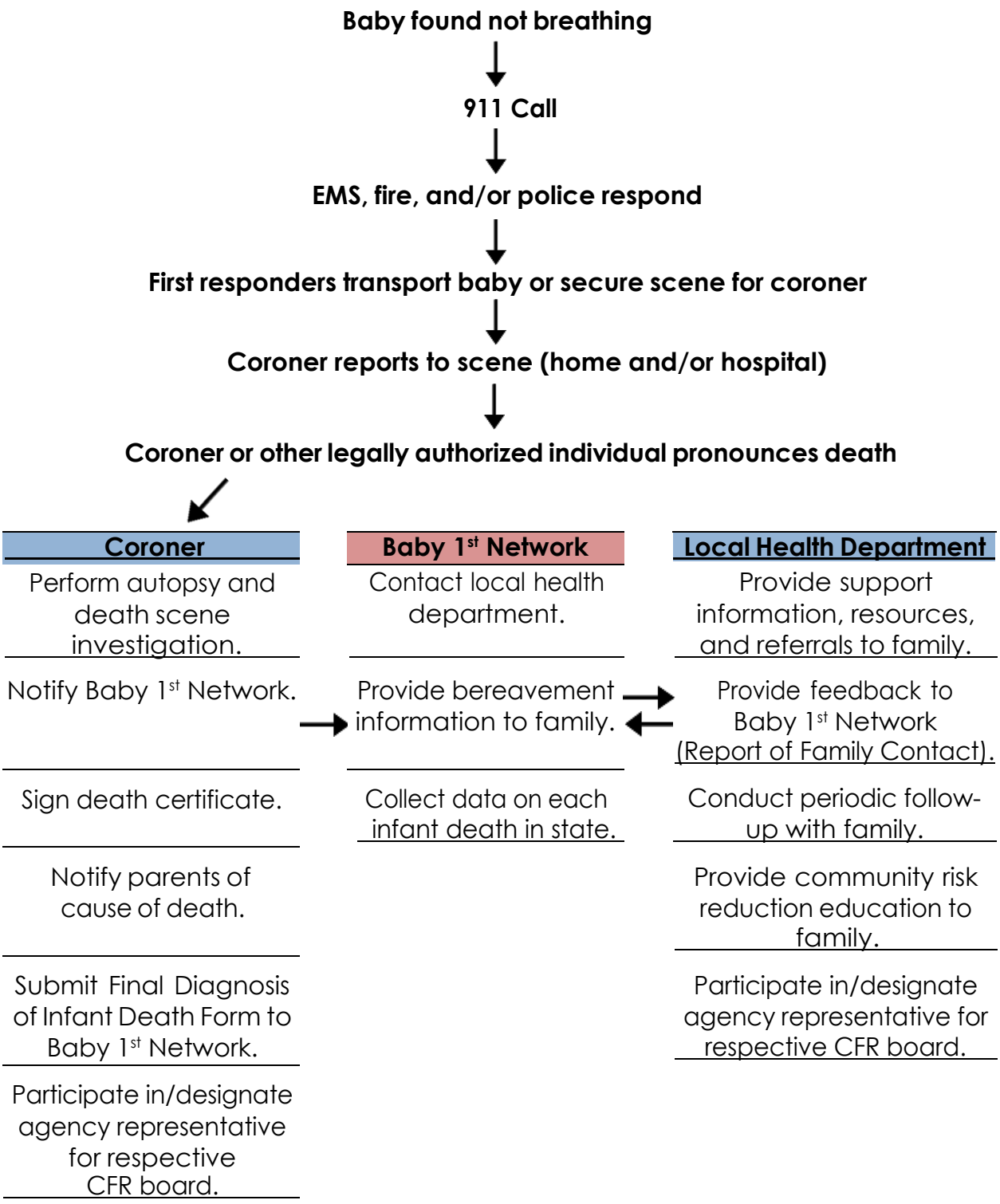
The network will notify the LHD within 10 days of the SUID and provide relevant bereavement information to the family. The network will coordinate with the LHD and the coroner to collect pertinent information and data. Data collected during this process is used to better inform federal, state, and local breastfeeding and safe sleep policies, procedures, and practice that impact infant mortality within the state and nationally. Based on findings from information and data, the network will engage communities in initiatives to reduce sleep-related infant deaths and support risk reduction and prevention efforts with available funding and up-to-date, relevant information and training.

The LHD – holding jurisdiction in the area of residence of the parent – provides bereavement information, resources, and need-based referrals to the family. The support services the LHD provides, include SIDS risk reduction education and periodic follow-up with the family. The LHD also provides feedback to the network and must submit the Ohio Department of Health Report of Family Contact Form to the network. (See Appendix A.) A designated representative from the LHD must also participate in the respective CFR board.

Each CFR board consists of designees from the county coroner, sheriff or police department, children services agency, public health services, mental health services, and a pediatrician or family practice physician. The board reviews all causes and circumstances of all child deaths to determine whether each death was preventable, identify risk factors, and develop effective prevention strategies. Since the review boards began collecting data in Ohio, the findings from reviews of sleep-related deaths have confirmed many of the risk factors identified in research: exposure to cigarette smoke; soft, fluffy bedding; infants sleeping on surfaces other than cribs; and bed sharing. Review boards make informed recommendations and seek new and continued partnerships to carry out safe sleep education and risk reduction initiatives in local communities. See Model of SUID Response in Figure 1.

Figure 1

Model of SUID Response



2.1 Coroner

Following immediate notification of a SUID – in which the infant was in apparent good health – the coroner in the respective county of death must:

A. **Perform an autopsy** on the infant, in accordance with rules adopted by the director of health.[6]

   1. If the coroner or court of jurisdiction finds that an autopsy is contrary to the religious beliefs of the parent of the infant, the coroner is not required to perform the autopsy.
   2. If the autopsy is not performed, the coroner must notify the respective LHD – holding jurisdiction in the area of residence of the parent.

B. **Complete and submit a copy of the Sudden Unexplained Infant Death Investigation Reporting Form** (SUIDI Reporting Form) or an alternative reporting form to the CFR board or regional CFR board, if the SUID is of an infant 1 year of age or younger at the time of death and the cause of death is not immediately obvious.

C. **Submit a copy of the SUIDI Reporting Form and coroner's report** to the respective review board.

D. **Assure that the completed reporting form and copies of completed reporting forms are not made available to the public, as they are not public records**.

E. **Provide verbal and written results,** whether preliminary or final, to the parents, state department of health, health district or department of jurisdiction, and child's attending physician, as required.[1]

All coroners within the state must notify the Baby 1st Network, of all SUIDs within 72 hours of the death using the Ohio Department of Health Notification of Infant Death Form. (See Appendix B.) Final Diagnosis of Infant Death Form must be submitted within 120 days. (See Appendix C.) The final diagnosis, which is based on autopsy findings, death scene investigation, and review of medical history, may take several weeks to determine. The coroner completes the Final Diagnosis of Infant Death Form after reviewing all the available information and ruling on the official cause of death.

2.2 Baby 1st Network

After receiving notification of a SUID from the coroner, the Baby 1st Network must:

A. **Identify appropriate bereavement resources** in the geographical area of the family. See Appendix D for the Bereavement Support and SUID/SIDS Risk Reduction Resources.

B. **Send a condolence letter and bereavement materials** to the family indicating that a public health nurse, social worker, or designee will contact the family by phone, in writing, or by home visit, as required by state law.

C. **Notify the appropriate LHD of jurisdiction** to ensure the LHD offers supportive services to the family.

D. **Coordinate with the coroner and LHD** to ensure all necessary information and data are reported and risk reduction education is provided.

Although the final cause of the death is not known when the initial Notification of Infant Death Form is received from the coroner, the network acts quickly to assure that sympathy and support are provided to grieving families as soon as possible.

2.3 Local Health Departments

After receiving notification of a SUID from the network, coroner, or other source, the respective local health department must:

A. **Offer the parent any counseling or other supportive services** it has available upon any of the following:

1. It learns through any source that an autopsy is being performed on a child under 2 years of age who died suddenly when in apparent good health.
2. It receives notice that the final result of an autopsy performed pursuant to Ohio law concluded that the child died of SIDS.
3. It is notified by the coroner that an autopsy was not performed.

B. **Offer the child's parent information about SIDS**, if a health district or department receives notice that the final result of an autopsy performed found that the child died of SIDS or that an autopsy was not performed but SIDS may have been the cause of death.[1]

A designated public health professional from the LHD should contact the family within 48 to 72 hours of notification of the SUID from the network.

Section 3: Support and Bereavement Services

3.1 Providing Services Through a Home Visiting Model

For many families, the home visit is a welcomed way for public health professionals to provide bereavement support. Providing information, in person and in a sensitive manner, explaining autopsy results, providing community resources, and offering guidance for surviving children can effectively address family needs and help alleviate guilt, pain, and suffering. Parents who receive home visits report that these visits have a positive impact on the grieving process. Please note that the purpose of the family contact is to provide support and not to investigate or interrogate the parents regarding the circumstances of the death.

3.2 The Role of the Home Visitor

The role of the home visitor – public health nursing professional – is to contact the family, identify immediate needs, establish supports (referrals), provide counseling and education, and follow up as needed and appropriate. The home visitor should be knowledgeable about SUID and SIDS, empathetic to the family, trained to listen and share information, and able to respond to the needs of the family and caregivers. Executing these skills effectively can positively influence the outcome for the family.

3.3 Planning a Home Visit

Assisting a family that has just lost a baby suddenly and unexpectedly can be a difficult task that may be easier with careful planning and preparation. The home visitor should pay special attention to the following key points:

A. **Review current SUID and SIDS information**. Explain the facts to parents or caregivers in a manner and language that is easy for them to understand. SUIDs (particularly sleep-related deaths including SIDS and other accidental deaths) are inherently met with incredible guilt and emotional pain as families live with the *what-ifs*. Providing this information is crucial in circumventing the guilt of a family that has lost a baby.

B. **Use listening and supportive skills.** Understand the special needs of families and assist them in verbalizing their fears and frustrations, which may cause uncomfortable emotions like crying and/or anger.

1. Expect these reactions and use them constructively.
2. Be aware that some emotional responses may differ from your cultural norms.
3. Contact a mental health professional and make a referral if necessary or by family request.
4. Act as quickly as possible to assist families in coping with their grief.

C. **Be knowledgeable of the grieving process**. Recognize and assess the difference between normal and abnormal reactions to grief.

1. Be aware of individual differences and sociocultural expressions of grief.
2. Assess your feelings of grief and separate them from those of the grieving family.

D. **Be knowledgeable of referral services**. Promptly and appropriately respond to the different types of problems the grieving families are experiencing.

1. Be familiar with community resources such as bereavement counselors and support groups, clergy, financial resources, and mental health professionals. The Baby 1st Network has a statewide database of local bereavement support groups and will assist with identifying appropriate referral services.
2. Bereavement services should focus on the parents, siblings, grandparents, and even child care providers.

3.4 Contacting the Family

The initial contact with the family is usually made as soon as possible by telephone. The public health professional should:

A. **Make the call as soon as possible but in consideration of any funeral and/or memorial service.**

1. Assure that you have all family information before placing the call: parent's names, address, child's name, etc.
2. Place the call in a quiet place where the necessary time can be devoted to the call.

    a. Follow the initial contact letter template when making initial contact with the family by phone. See Appendix E for the Initial Contact Letter to Family Template.
    b. If the family does not answer the phone, be sure to leave a voice message.

c. If unable to reach the family by phone after leaving a voice message, send a handwritten letter of sympathy and follow up with the family at a later date. See Appendix E for the Initial Contact Letter to Family Template.

B. **Explain to the family, at the beginning of the call, how you got their contact information and why you are contacting them**. *Always use the child's name*.

1. Follow this or similar script to initiate discussion of support services and scheduling a home visit:
   "My name is *[say your name]*. I am a public health nurse with the local health department. I have just received notification of your daughter/son [*say baby's name: for example, John's*] death. I am so sorry about your loss. I know that the death was sudden and unexpected. I hope that I can be of some assistance to you and your family by providing you with information and connection to supportive services to help you in the coming days and months. May I schedule a time to visit with you in the next few days?"
2. Be prepared for a family member or friend to answer the phone. They may be protective and may not let you speak with the parent(s). Keep in mind that grandparents, aunts, uncles, cousins, child care providers, co-workers, and the religious community are also grieving the loss of the child and it may be necessary to speak with them at that time. Ask how these family members/friends are coping as well.
3. Provide concise answers to questions the parents may ask about the preliminary diagnosis, community resources, and bereavement.
4. Assess any immediate needs or supports that the family indicates.
5. Encourage the family to allow a home visit, so you can provide more individualized information and assistance.

C. **Use the Baby 1st Network website**, www.baby1stnetwork.org, during the call for guidance. Access the Grieving Families tab and Seeking Support content.

D. **Allow the family time to process what is being said to them**. Quiet gaps in conversation are OK.

1. Expression of grief varies from family to family. A family's reaction to this initial contact and offer of support may also vary. While some families will accept the intervention early on, some families may be apprehensive and may become defensive, protective, mistrustful, or avoid future contact. The family may find it threatening to have a health

professional visit their home, if they are unfamiliar with the individual and in light of the recent death scene investigation.

2. These reactions may be based on a variety of environmental and cultural factors surrounding the issue of death and professional intervention. In many cases, not only are these families grieving the death of their child, but also, they may be defending themselves against societal biases. Anticipate this initial resistance and maintain an attitude of sympathy and understanding. Assure the family that you are not part of the investigation and will not interrogate them. Emphasize that your role is to provide information and support.

E. **Schedule a home visit**.

1. Explain the purpose of the home visit.
2. Secure the family's permission to visit their home on the agreed upon date and time.
3. Take the initiative in suggesting the date and time of the meeting when both parents and any other grieving family members are available at the home, if possible, as even minor decision-making is often difficult for families during this time.
4. If it is not possible to meet with each parent, inquire about the unavailable parent's need for information and support, and leave duplicate information packets.

Although a home visit with the family is the preferred method of contact, this may not be possible for every health department. When a home visit is not possible, contacting the family by phone call and sending a letter of sympathy that includes local supportive services is acceptable. The public health professional should follow up with the family periodically, and as appropriate.

3.5 Conducting a Home Visit

When conducting a home visit, the home visitor must:

A. **Plan at least one hour for the visit** after an acceptable time and location have been established by the family.

B. **Be on time** and do not appear rushed or distracted.

C. **Thank the family for allowing you to visit** and always refer to the child by name.

D. **Listen carefully** to stories about the child, feelings about the investigation, inaccurate information that needs to be addressed, and needed support services. The willingness of the health professional to listen as the family verbalizes their loss will help build a supportive relationship.

E. **Provide accurate and concise information**, in layperson's terms, about the preliminary diagnosis (if available and appropriate to discuss), peer support groups, grief process, SIDS, safe sleep, and other support services, as appropriate.

   1. Emphasize that the diagnosis may not yet have been confirmed by the coroner.
   2. Notify the parents that the autopsy report can be made available to them by request and how to submit the request. Advise them to review the autopsy with the child's physician and/or with the coroner or designee.
   3. Provide *written* grief materials to the family, as needed. Keep in mind that families may not have access to the Internet.

F. **Make referrals to appropriate community resources**. Provide a packet with written information about SIDS/SUID and local support services, so parents can review information as they feel comfortable.

   1. If there are local bereavement support services for children in the area, it is a good idea to include the contact information for these resources.
   2. Offer information about volunteer SUID parents who are available to speak with families. A complete list is available through the Baby 1st Network.
   3. Provide your contact information to the family before ending the visit.

G. **Schedule a second visit** to discuss support options and to follow up with the family if the parents are not ready to discuss or use information on local support resources during the initial home visit.

H. **Complete and submit a copy of the Report of Family Contact Form** to the Baby 1st Network within 45 days of final home visit. Retain the original form at the LHD. Mail, email, or fax one copy of the form to:

   Baby 1st Network
   P.O. Box 403
   Toledo, OH 43697-0403
   Email: forms@baby1stnetwork.org
   Fax: 330-929-0593

l. **Provide a summary of the visit** and any other requested information to the appropriate CFR board, as required by state law.

If you encounter issues or have concerns regarding obstacles that the family is encountering, see Appendix F for the Common Issues, Concerns, and Practical Solutions for Home Visiting Guide.

3.6 Facilitating Effective, Supportive Conversation with Grieving Families

Grieving is the process that begins when an individual experiences a life-changing event. The feelings of grief can be extremely intense and long-lasting. Parents experience more intense, complex, long-term, and significant fluctuations of grief after the loss of a child, when compared with grief associated with other types of loss.[7] Navigating through grief in a healthy manner, requires support and careful completion of certain tasks: accept the reality of the loss of a child, allow themselves to experience the emotions/pain of grief (behavioral, emotional, and physical), adjust to a new environment from which the child is absent and understanding how this absence impacts their lives, and identify an enduring connection with the child to reflect on as they move forward with their lives.[8]

Supportive intervention by health professionals, as well as family and friends, can help grieving individuals negotiate these tasks. Please note that the individual grief process is unique to the individual. Allow parents and families to grieve in the manner that is appropriate for them. Culture, religion, and personal history impact the way someone expresses grief. To facilitate effective, supportive conversation with families, understanding what grief looks like and helping to work through these experiences is important. See Table 1 Common Expressions of Grief.

Table 1

Common Expressions of Grief

Feelings	Physical Sensations	Thought Patterns	Behaviors
• Anger.	• Breathlessness.	• Confusion.	• Absent-minded behaviors.
• Anxiety.	• Dry mouth.	• Disbelief.	• Appetite disturbances.
• Fatigue.	• Hollowness in the stomach.	• Hallucinations (auditory or visual).	• Avoidance of reminders of deceased.
• Guilt.	• Lack of energy.	• Pre-occupation with death or deceased.	• Crying.
• Helplessness.	• Oversensitivity to noise.	• Sense of presence; arms ache to hold infant.	• Dreams of the deceased.
• Loneliness.	• Sense of depersonalization.		• Restlessness.
• Sadness.	• Tightness in the chest.		• Searching or calling out.
• Shock.	• Tightness in the throat.		• Sighing.
	• Weakness in muscles.		• Sleep disturbances.
			• Social withdrawal.
			• Treasuring objects that belonged to the infant.
			• Visiting places or carrying objects of the deceased.

The home visitor should:

- ☑ **Listen** quietly and allow families to express their feelings and tell their story without passing judgment.
- ☑ **Refer** to the child by name and ask about their special endearing qualities.
- ☑ **Offer** your condolences and ask about the funeral or memorial service.
- ☑ **Ask** about other family members and include significant others in your home visit.
- ☑ **Give** special attention to siblings. They are hurting and confused. Their parents may be incapable of being supportive at this time. Consider a social service consult for a sibling in crisis.
- ☑ **Reassure** parents that they did everything they could, that the medical care their child received was the best, or whatever else you know to be true or positive about the care given to their child.
- ☑ **Encourage** parents to talk freely about their feelings and to be honest about what kind of help they really want from others.
- ☑ **Encourage** family members to be patient with their own grieving processes.
- ☑ **Answer** their questions and refer them to the appropriate local support/counseling providers.
- ☑ **Call** the parents after your initial visit and let them know you are thinking about them.
- ☑ **Provide** them with a note or phone call on special occasions: birthday, death anniversary, and holidays, for example.
- ☑ **Respect** that every ethnic and cultural group has unique expressions of grief.

The home visitor must assure the following:

- ⊗ **Do not** ask a series of questions without a break or use clichés like "I know how you feel," "At least you have other children," or "You can always have another baby."
- ⊗ **Do not** pass judgment.
- ⊗ **Do not** answer a question if you do not know the answer.
- ⊗ **Do not** give legal or medical advice.
- ⊗ **Do not** make comments that suggest the care given to the child was inadequate.
- ⊗ **Do not** assume that their grieving is over in a few weeks or months. They may need ongoing support for at least a year.
- ⊗ **Do not** try to find something positive, such as a moral lesson or closer family ties, because of the child's death. The family will come to this realization on their own, if or when it occurs.
- ⊗ **Do not exclude the other parent or caregivers.** Include mothers, fathers, children, grandparents, significant others.
- ⊗ **Do not** assume you know what the family needs. Every individual has different needs and desires. *Be sure the kindness you plan is acceptable*.

The home visitor should assess the needs of each parent without regard to the family's living situation prior to the infant's death. See Appendix G: Questions to Facilitate Effective, Supportive Conversation With Families. Although both parents did not reside in the home with the child, for example, the home visitor should assess the needs of both parents and provide support. Be sensitive to individual needs and responses.

3.7 Special Considerations for Grieving Families

Occasionally, a family member will experience a severe reaction, which will require professional mental health intervention. Assess the parents, family members, and any day care workers (if the death occurred while the child was in their care) for severe expressions of grief, including the following, which require urgent intervention:

- Auditory and visual hallucinations.
- Hostile or aggressive behavior.
- Inability to return to a daily routine several months following the death.
- Marked increase in the use of alcohol, drugs, or tobacco.
- Parental neglect or extreme overprotection of other children.
- Suicidal ideations.

The home visitor should review the local crisis intervention plan before the home visit and be prepared to facilitate referrals.

3.8 Following Up With Families

Immediately after an infant death, a family often has a strong support network of family members, neighbors, co-workers, friends, community and religious affiliations. Informal support systems often break down within a couple months as friends and relatives move on with their lives, which is why it is important to offer to follow up with the parents at a later date. The home visitor should continue to provide reminders throughout the first year that supportive services are available at any time. These reminders may be in the form of letters, cards, or telephone calls. The anniversary of the child's death and the child's first birthday may be especially difficult times for the family and they may appreciate contact.

Section 4: SIDS Risk Reduction and Prevention

The primary goal of this guide is to prepare health professionals to provide bereavement support to families after the sudden, unexpected death of their infant. However, public health professionals are in a unique position to reduce the risk of these tragedies by sharing the latest research and recommendations with

clients and the community. This section provides information and resources to support risk reduction activities.

4.1 National, State, and Local Interventions

National Interventions

The Sudden Infant Death Act of 1974 was passed as Public Health Law 93-270. The law recognized SIDS as a significant public health issue and provided funding for research and for the establishment of information and counseling programs in all 50 states. Since then, significant efforts to promote infant safe sleep and to reduce the risk of SIDS have continued:

- During the late 1980s, growing public and legislative concern developed about the impact of SIDS on parents, caregivers, medical emergency services personnel, and first responders.
- The American Academy of Pediatrics (AAP) recommended in 1992 that babies be placed on their backs or sides to sleep.
- In 2000, the *Healthy People 2010* national health promotion and disease prevention initiative established SIDS goals and objectives: reduce deaths from SIDS and increase the percentage of healthy full-term infants who are put down to sleep on their backs.
- In 2004, scientists proposed a new definition of SIDS that incorporates more recent knowledge of the epidemiologic and pathologic features.
- In 2005, the AAP no longer recognized side sleeping as a safe alternative to back sleeping and promoted a safe sleeping environment and the use of pacifiers at sleep time.
- In 2011, the AAP revised and expanded its recommendations for a safe infant sleep environment and acknowledged the difficulties in diagnosing SUIDs and the similarity between risk factors for SIDS and for suffocation.
- In October of 2016, the AAP advised that risk factors for SIDS and sleep-related infant deaths are similar. The AAP focused on safe sleep environments that reduce the risk of all sleep-related infant deaths including SIDS: infants sleeping on a bare, separate surface, such as a crib or bassinet, with a tight-fitting sheet and never sleeping with soft bedding, including crib bumpers, blankets, pillows, and soft toys. The AAP also recommended breastfeeding and that infants share their parents' bedroom, in a separate bed, for at least the first six months and, optimally, for the first year of life.

State Interventions

The Ohio Department of Health SIDS Program was developed to ensure compliance with the mandates of the state law related to the reporting of sudden and unexpected infant deaths and the provision of support and bereavement services. (See Section 1.4.) ODH has implemented an infant safe sleep policy, which can be adapted and endorsed by LHDs. Accurate, consistent, culturally appropriate education materials are made available at any client contact point, such as perinatal, well-baby, and immunization clinics, as well as WIC, Help Me Grow, and Vital Statistics.

Local Interventions

Public health professionals are in an ideal position to have a positive impact on reducing the risk of SIDS and other sleep-related infant deaths by both community and individual interventions. By mobilizing community partnerships, the public health professional can identify influential stakeholders and increase their awareness of SIDS and the risk factors that will also impact the rate of other sleep-related deaths. Public health professionals can facilitate partnerships among groups not typically considered health-related, such as faith-based organizations, to expand outreach for risk reduction messages and support groups. Health education and health promotion program partnerships with schools, faith communities, work sites, childcare providers and others can target the risk reduction messages to vulnerable populations. Through individual encounters, the health professional can inform, educate, and empower clients about SUID and risk reduction methods.

The Baby 1st Network provides technical assistance and material resources to help in community and individual intervention programs, including:

- Infant Safe Sleep awareness campaigns.
- Participation in healthy baby fairs.
- Community outreach forums for organizations, clubs, and churches.
- Training workshops for health professionals, child care workers, and first responders.
- Training forums for community leaders on promoting safe sleep within their communities.
- Mini-grant funding opportunities for neighborhoods and community groups to conduct outreach projects to reduce the rate of SIDS and sleep-related infant deaths.
- Baby 1st Network online newsletter.
- Website – www.baby1stnetwork.org and real time updates via Facebook and Twitter.

Community health forums have been held in many Ohio cities where maternal and child health disparities are the greatest to build partnerships with key stakeholders and community leaders, educating and empowering them to share the risk reduction and infant safe sleep messages throughout their communities. Opportunities to provide infant safe sleep and SIDS risk reduction messages should be incorporated into the regular workflow of the LHD. See Appendix H for Safe to Sleep Campaign Materials Order Form to order safe sleep education materials.

4.2 The Importance of Hospital Nurses and Community Health Educators

Staff in newborn nurseries and neonatal intensive care units, primary care providers, and other healthcare professionals, as well as child care providers are uniquely situated to educate parents about safe sleep practices and risks for SIDS from the time a baby is born. Hospital staff should receive continuing education on infant safe sleep and breastfeeding recommendations. Nurse health educators and other staff should play an active role in hospital policy development that impacts the education and support services mothers and families receive around safe sleep and breastfeeding. Hospital nurses, community health educators, healthcare providers, child care providers, and other community partners will need to work collaboratively to provide education and to promote safe sleep practices.[11]

4.3 Recommendations for Infant Safe Sleep and SIDS Risk Reduction

Research into the cause of SIDS led to the development of the Triple-Risk Model. The model describes the possible interaction of the environment, the age of the infant, and underlying abnormalities and illustrates that SIDS is more likely to occur when certain environmental stressors impact a vulnerable infant at a critical point in development. The Triple-Risk Model illustrates how SIDS results from the impact of certain conditions on an infant such as vulnerability, critical development stage, and outside stressors:

- **Vulnerability**: An undetected genetic, developmental, or anatomical defect may predispose an infant for SIDS. For example, there may be an underlying abnormality or defect in the brain that controls respiration, heart rate, or cardiac function.
- **Critical developmental stage**: The peak incidence of SIDS is between 2 to 4 months of age with ninety percent occurring before 6 months of age. During this time, dramatic changes in the infant's growth and development are occurring, including changes in metabolism, sleep state organization, and cardiorespiratory controls. The brain nearly doubles in size during these

months. These rapid changes may produce instability in the vulnerable infant.

- **Outside stressors:** All infants are exposed to a variety of environmental stressors, such as exposure to second-hand smoke, overheating, rebreathing of carbon dioxide, and simple colds and viruses. Normal, healthy infants can cope with these stressors with nonfatal results. Though, the vulnerable infant at a critical developmental stage is not able to overcome the challenge of the external stressor and a sudden unexpected death results.

The Triple Risk Model requires that three elements must be present for SIDS to occur:

1. The baby's vulnerability is undetected.
2. The infant is in a critical developmental period that can temporarily destabilize their body systems.
3. The infant is exposed to one or more outside stressors that he or she cannot overcome because of the first two factors.[9]

SIDS is unlikely to occur, according to the theory, if caregivers can remove one or more factors. Therefore, removing external stressors, such as placing an infant to sleep on the back instead of on the stomach, can reduce the risk of SIDS. In addition, common risk factors associated with SUID and SIDS are important to understand.

SUID victims share three major epidemiological characteristics. The infants appear healthy prior to death. There is sometimes a slight cold or stuffy nose, but there is usually no history of significant respiratory illness. The infants die during sleep. The death occurs silently, with no warning. The infants are most often between the ages of 1 month and 1 year. Ninety percent of the deaths occur before 6 months of age, the majority between 2 and 4 months.

Other common characteristics are called risk factors because they seem to put a baby at higher risk of SUID. These are not the causes of SUID. Risk factors can be categorized as infant, maternal, and environment.[10] Some factors cannot be modified, such as race and sex. Other factors can be modified, such as improving the sleep environment, to give the infant the best chance for survival. See Table 2 for an outline of risk factors of SIDS in each category.

Table 2

Risk Factors of SIDS

Infant Risk Factors	Maternal Risk Factors	Environmental Risk Factors
• Being 4 months of age or younger.	• Being 20 years of age or younger.	• Bed sharing with adults, children, or pets.
• Being born with a low birth weight.	• Inadequate prenatal care.	• Exposure to cigarette smoke during pregnancy or after birth in the house, vehicle, or other areas.
• Having a family history of SIDS (family members or siblings who have died of SIDS).	• Smoking cigarettes.	• Overheating by warm room temperature or excessive clothing and bundling.
• Race – nonwhite.	• Using drugs and/or alcohol.	• Soft sleep surfaces such as couches, recliners, chairs, air mattresses, and adult mattresses.
• Residing with a smoker.		• Soft bedding, including loose sheets, fluffy blankets, pillows, sheepskins, bumper pads, and waterbeds.
• Sex – male.		• Stomach or side-lying position for sleep.
		• Stuffed toys, extra clothing, wedges, and other objects in the crib.

Note. Risk factors identified by National Institute of Child and Human Development.[10]

The distinction between various causes of sleep-related deaths is challenging and many of the risk factors for SIDS and suffocation are strikingly similar. To reduce modifiable risk factors associated with sleep-related infant death, including SIDS, suffocation, other unintentional deaths, the American Academy of Pediatrics

(AAP) expanded its SIDS prevention recommendations to include safe sleep, which has evolved from the *Back to Sleep* to the *Safe to Sleep* campaign. The new recommendations are supported by scientific research and are the basis for the ODH infant safe sleep policy and safe sleep campaign.[11]

Always place infants wholly on the back to sleep for every sleep, nap time, and night time. While most new mothers acknowledge having received the *Safe to Sleep* message, many still place their babies on their stomach for sleep, citing cultural influences, advice from relatives, and a perception that the baby sleeps better on their stomach. Babies who sleep on their stomach have a five times greater risk of dying from SUID. Infants accustomed to sleeping on their backs appear to be particularly vulnerable to SUID when they are placed on their stomachs for sleep the first time. This situation can occur when a back-sleeping baby is left with a caregiver who is unfamiliar with the "Safe to Sleep" message. Babies who are put on their tummies to sleep but are accustomed to sleeping on their backs have a seven to eight times greater risk of dying from SUID. Once an infant can turn from their back to front (supine to prone) and from front to back (prone to supine), place the infant to sleep on their back, but allow the infant to sleep in the position he or she assumes.

Avoid alcohol and illicit drug use during pregnancy and after birth. There is an increased risk of SUID with prenatal and postnatal exposure to alcohol or illicit drug use. Mothers should not use illicit drugs during pregnancy or after the baby is born. Mothers should also avoid using alcohol during pregnancy or when caring for the baby after the baby is born.

Avoid commercial devices marketed to reduce the risk of SIDS. None have been proven safe or effective. Commercial devices such as wedges, positioners, special mattresses, or other types of sleeping products should be avoided. There is no evidence that these devices or products protect against SUID or that they are safe. Home monitors that check the infant's breathing and/or heart rate are not advised as a way to prevent SIDS and should be used only under a physician's advice.

Avoid overheating. Research into the causes of SIDS has focused on microscopic brain abnormalities that affect the development and control of breathing, blood pressure, temperature regulation and sleep and arousal reflexes. Overheating may hinder the development of the autonomic nervous system and its ability to regulate many of the responses necessary to maintain life. Do not let the infant get too hot or cover the infant's head when sleeping. The area where the infant sleeps should be well-ventilated and at a temperature that is comfortable for a lightly-clothed adult. An infant is too hot if they are sweaty or their chest is hot to the touch. Infants should be dressed in no more than one layer more than an adult is wearing.

Breastfeed. Recent research shows that breastfeeding reduces the risk of SIDS and this effect is stronger when breastfeeding is exclusive. The health advantages of breastfeeding include support of the immune system are well documented. The recommendation to encourage the initiation and continuation of breastfeeding throughout the first year of life should be included with other SIDS risk reduction messages to both reduce the risk of SIDS and for its many other infant and maternal health benefits.

Do not smoke during pregnancy. Avoid infant's exposure to secondhand smoke. Ohio CFR reports that infants were exposed to smoke either in utero or after birth in 43% of sleep-related deaths. There should be no smoking near pregnant women or infants. No one should ever smoke around an infant, especially in the same room, car, or room where an infant sleeps. Strategies to help parents eliminate smoking can improve the health of the whole family.

Do not use home cardiorespiratory monitors as a strategy to reduce the risk of SIDS. The use of cardiorespiratory monitors has not been documented to decrease the incidence of SIDS. These devices are sometimes prescribed for use at home to detect apnea or bradycardia and, when pulse oximetry is used, decreases in oxyhemoglobin saturation for infants at risk of these conditions. In addition, routine in-hospital cardiorespiratory monitoring before discharge from the hospital has not been shown to detect infants at risk of SIDS. There are no data that other commercial devices that are designed to monitor infant vital signs reduce the risk of SIDS.

Infants should be immunized in accordance with AAP and Centers for Disease Control and Prevention (CDC) recommendations. There is no evidence that there is a causal relationship between immunizations and SUID, while there is some evidence suggesting that immunizations might protect against SIDS. It is also important that infants have regular well-child checkups.

Keep soft objects and loose bedding out of the crib. The crib should be free of soft, fluffy materials such as bumper pads, sheepskins, comforters, blankets, pillows, and stuffed animals. Sleep sacks or blanket sleepers can be used to eliminate the need for additional loose blankets. Educating parents about the dangers of soft, fluffy bedding is a challenge with the marketing of elaborate crib sets and nursery décor displayed in stores and online.

Offer a pacifier at naptime and bedtime. The reduced risk of SIDS associated with pacifier use during sleep has been demonstrated in numerous research studies. Pacifier introduction should be delayed until approximately 1 month of age when breastfeeding has been firmly established. Do not attach a pacifier by a string

around the infant's neck or to their clothing or other object. Once the infant is asleep, do not reinsert the pacifier.

Pregnant women should receive regular prenatal care. The risk of SUID increases with decreasing birth weight and decreasing gestational age. Mothers who receive early and adequate prenatal care have the best chance for having a healthy infant.

Provide supervised *tummy time* when infants are awake. Tummy time promotes motor development and facilitates development of upper body muscles needed to reach important developmental milestones such as rolling over, sitting up, and crawling. It also minimizes the risk of plagiocephaly (flat head).

Room-share without bed sharing. Ohio CFR reports that 55% of sleep-related deaths occurred to infants sharing a sleep surface with another person. The infant's crib should be in the parent's bedroom, close to the parent's bed for at least the first six months. Infants can be brought into bed for feeding or comforting but should be returned to their own crib, immediately, when they fall asleep and/or when the parent is ready to sleep.

Use a firm sleep surface for infants. Infants should be placed to sleep on a firm crib mattress, that maintains its shape, covered by a fitted sheet. A crib, bassinet, or portable crib/play yard that meets the current Consumer Product Safety Commission standards is recommended. Chairs, sofas, adult beds, waterbeds, and futons are particularly dangerous for infants and should not be used as a sleep surfaces for infants. Car safety seats, infant seats, bouncers and swings should not be used as regular sleep places. If an infant falls asleep anyplace that is not a safe sleep environment, the infant should be moved to a firm, safety-approved sleep surface immediately. When using sling carriers, caution must be used to ensure that the infant's head is up and above the fabric, the face is visible, and the nose and mouth are not obstructed.

These AAP recommendations encourage health policy makers, researchers, and professionals to endorse and model the safe sleep practices; continue research and surveillance; adhere to safe sleep guidelines in media and manufacturing advertising; and expand the *Back to Sleep* campaign for parents, grandparents, and all other caregivers with major focus on the safe sleep environment.[11]

Conclusion

The Baby 1st Network understands the importance of building trust in communities in an effort to improve birth outcomes. We also recognize the importance of providing compassionate and supportive bereavement services to families who have suffered the devastating loss of an infant. Our mission reflects our determination to become a leading resource for infant safe sleep information and training, and a valued collaborator in community efforts to reduce infant mortality.

Recognizing the importance of partnerships, the Baby 1st Network will strive to collaborate with the public and private sector, institutions of higher learning, faith-based and civic organizations, and to community-based associations in both rural and urban areas. Through these collaborative efforts and the implementation of SIDS risk reduction activities, the goal is to increase awareness regarding infant safe sleep practices and to help reduce the number of infants who die suddenly and unexpectedly from sleep-related causes.

For more information, please contact:

The Baby 1st Network
P.O. Box 403
Toledo, OH 43697-0403
Phone: 330-929-9911
Fax: 330-929-0593
www.baby1stnetwork.org

Appendix A: Ohio Department of Health Report of Family Contact Form

The Report of Family Contact Form can be downloaded from the ODH website at www.odh.ohio.gov or obtained directly from the Baby 1st Network. The purpose of the form is to document contact with the family in response to a referral from the network. Fill in all sections as completely as possible from information learned from the death certificate and from the interaction with the family. Use the form to document the discussion, not as the focus of the discussion.

Ohio Department of Health • Sudden Infant Death Program

Report of Family Contact

Date Referral Received:_____

Infant's name			Date of birth	Date of death
Last	First			
Gender ☐ Male ☐ Female	Ethnicity ☐ Hispanic ☐ Non-Hispanic		Race ☐ White ☐ Black ☐ Asian ☐ Other_____	
Mother's Name				
Last	First		Phone	
Address		City		Zip
Father's Name				
Last	First		Phone	
Address ☐ Same as Mother		City		Zip
Other Family				
Last	First		Relationship	Phone
Address ☐ Same as Mother		City		Zip

Family Contact Record				
Date	Type of Contact			Next Steps
	☐ Mail	☐ Phone	☐ Visit	
	☐ Mail	☐ Phone	☐ Visit	
	☐ Mail	☐ Phone	☐ Visit	
	☐ Mail	☐ Phone	☐ Visit	

Information Provided to Family

Referrals Made for Family

Family Notes/Comments (Use back of form if needed)

Please record the following information only if it is learned through conversation with the family. Your role is to assist with bereavement, not to investigate the death.

Location at time of death ☐ Crib/bassinet ☐ Playpen ☐ Adult Bed ☐ Couch/Chair ☐ Infant Seat ☐ Other _____

Infant placed to sleep ☐ On Back ☐ On Stomach ☐ On Side ☐ Other _____

Infant sharing sleep surface with ☐ Adults ☐ Children ☐ Blankets ☐ Pillows ☐ Other _____

Report Completed By			
Name		Agency	
Address		City	Zip
Phone	Cell		County

For guidance in contacting families or completing report, refer to Guide for the SID Home Visit at www.odh.ohio.gov or call (330) 929-9911.
Return completed report to: Baby 1st Network, P.O. Box 403, Toledo, Ohio 43697-0403. Or Fax (330) 929-0593

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Appendix B: Ohio Department of Health Notification of Infant Death Form

The Notification of Death Form is completed by the coroner and submitted to the Baby 1st Network within 72 hours of an infant's death. The purpose of the form is to document infant deaths.

Ohio Department of Health
Notification of Infant Death

Infant's Name Last First Middle	Date of Birth	Date of Death

Gender	Age	Hispanic Ethnicity	Race (Check all that apply)
☐ Male ☐ Female ☐ Unknown		☐ Yes ☐ No	☐ White ☐ Black / African American ☐ American Indian / Alaskan Native ☐ Hawaiian Native / Pacific Islander ☐ Asian ☐ Unknown ☐ Other _____

County of Death	County of Residence	County of Autopsy

Father's Name Last First Middle	Area Code and Phone Number	Age

Residence Street Address	City	State	Zip

Mother's Name Last First Middle	Area Code and Phone Number	Age

Residence Street Address	City	State	Zip

The **Preliminary** diagnosis of this death is:

- ☐ SIDS
- ☐ Unintentional Injury / Accident
  - ☐ Asphyxia
  - ☐ Other Unintentional Injury
- ☐ Inflicted Injury / Homicide
- ☐ Undetermined (Natural)
- ☐ Undetermined (Not Natural)
- ☐ Undiagnosed Disease / Natural
- ☐ Other (Please Explain)

☐ Circumstances dictate that **NO** contact with the family should be made until final diagnosis

Form Completed by: _____

Area Code and Phone Number: _____

County: _____

Please send this report to:
Baby 1st Network
P.O. Box 403
Toledo, OH 43697-0403
Or Fax (330) 929-0593

If you have questions regarding this form, please call Dr. Stacy Scott at (330) 929-9911

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Appendix C: Ohio Department of Health Final Diagnosis of Infant Death Form

The Final Diagnosis of Infant Death Form is completed by the coroner and submitted to the Baby 1st Network within 120 days of an infant's death. The purpose of the form is to document infant deaths.

Ohio Department of Health

Final Diagnosis of Infant Death

Infant's Name Last	First	Middle	Date of Birth	Date of Death

Gender	Age	Hispanic Ethnicity	Race (Check all that apply)
□ Male □ Female □ Unknown		□ Yes □ No	□ White □ Black / African American □ American Indian / Alaskan Native □ Hawaiian Native / Pacific Islander □ Asian □ Unknown □ Other _____

County of Death	County of Residence	County of Autopsy

Parents' Name	Address	City	State	Zip

Final Diagnosis

Part I. Enter the diseases, injuries or complications that caused the death. Do not enter the mode of dying, such as cardiac or respiratory arrest, shock or heart failure. List only one cause on each line. Type or print in permanent black ink.

	Cause of Death	Approximate Interval between Onset and Death
Immediate Cause (Final disease or condition resulting in death)	A.	
Sequentially list conditions, if any, leading to the immediate cause	B.	
	C.	
Enter underlying cause last (Disease or injury that initiated events resulting in death)	D.	

Part II. Please list other significant conditions contributing to death but not resulting in the underlying cause given in Part I.

Was an autopsy performed? □ Yes □ No

Were autopsy findings available prior to completion of cause of death? □ Yes □ No

Manner of death: □ Natural □ Accident □ Homicide □ Could not be determined

Comments:

Form Completed by: _____

Area Code and Phone Number: _____

County: _____

Please send this report to:
Baby 1st Network
P.O. Box 403
Toledo, OH 43697-0403
Or Fax (330) 929-0593

If you have questions regarding this form, please call Dr. Stacy Scott at (330) 929-9911

HEA 7722 – Revised 07/18

Appendix D: Bereavement Support and SUID/SIDS Risk Reduction Resources

Helpful Online Resources
Bereavement Support Resources for Families

Baby 1st Network – www.baby1stnetwork.org
Provides general information about SIDS/SUID, risk reduction, infant safe sleep practices, SUID statistics, grief support for families, a memorial page for babies who have died, and resources for both professionals and community members. In addition, parents can be connected with support contacts located throughout the state.

Empty Cradle – www.emptycradle.org/
Empty Cradle is a nonprofit organization that provides support to families who have experienced the loss of a baby due to miscarriage, stillbirth, infant death or SIDS.

First Candle – www://firstcandle.org
First Candle is a leading national nonprofit organization dedicated to safe pregnancies and the survival of babies through the first years of life. Current priorities are to eliminate stillbirth, sudden infant death syndrome (SIDS) and other sudden unexpected infant deaths (SUID) with programs of research, education and advocacy. They also provide compassionate grief support to those affected by the death of a baby through a dedicated crisis hotline at 800-221-7437.

Share Pregnancy and Infant Loss, Inc. – https://nationalshare.org/
Learn ways to care for yourself as you travel the journey of grief after the death of your precious baby. Watch personal testimonials, read heartfelt stories, and find ritual planning examples.

Support for Parents, Grandparents, and Siblings –
https://www.missfoundation.org/grieving/
MISS Foundation – parents, grandparents, sibling support services.

Bereavement Support Resources for Health Professionals

The American Academy of Bereavement – www.thebereavementacademy.com
The American Academy of Bereavement is a national association devoted to the education, preparation, and advancement of bereavement specialists. The association provides members with educational opportunities and research and addresses issues relevant to the field of thanatology (the study of dying).

Association for Death Education and Counseling – www.adec.org
A multi-disciplinary professional organization dedicated to promoting excellence in death education, bereavement counseling, and care of the dying. Current information in the field of thanatology and counseling and links to special interest topics on grief and bereavement.

Centering and Grief Digest Magazine – www.centering.org
Centering is a nonprofit organization dedicated to providing education and resources for the bereaved. Centering was founded in 1978 by Joy and Dr. Marvin Johnson. The organization also works to develop needed books and caring workshops on grief for adults and children.

Australian Centre for Grief and Bereavement – www.grief.org.au
An independent, nonprofit opened in 1996 and based in Melbourne, Australia, the Centre for Grief and Bereavement offers links to education programs, individual counseling, a journal called "Grief Matters," a bereavement support directory, and grief support information.

First Candle – www.firstcandle.org
First Candle is a leading national nonprofit organization dedicated to safe pregnancies and the survival of babies through the first years of life. Current priorities are to eliminate Stillbirth, Sudden Infant Death Syndrome (SIDS) and other Sudden Unexpected Infant Deaths (SUID) with programs of research, education and advocacy. They also provide compassionate grief support to those affected by the death of a baby through a dedicated crisis hotline at 800.221.7437.

Grief Watch – www.griefwatch.com
Information on how to help those who experience a loss.

General Information on Grieving

Baby 1st Network – http://www.baby1stnetwork.org
Provides general information on SIDS risk reduction and infant safe sleep practices specific to professionals, statistics, grief information for parents and caregivers, and a memorial page for babies who have died.

Bereavement Magazine: A Journal of Hope and Healing – www.bereavementmag.com
Designed to be "a support group in print," Bereavement Magazine includes articles, stories, and poetry. Readers have full access to archived issues at its website, as well as access to some material only available online.

First Candle – www.firstcandle.org
Includes risk reduction information for expectant parents as well as coping and bereavement information and resources for families who have suffered a SIDS/SUID related death. Advocacy opportunities and information for child care providers are also available.

The Compassionate Friends – www.compassionatefriends.org
The Compassionate Friends is a national nonprofit, self-help support organization that offers friendship and understanding to bereaved parents, grandparents, and siblings. The mission of The Compassionate Friends is to assist families toward the positive resolution of grief following the death of a child of any age and to provide information to help others be supportive.

The Dougy Center: The National Grief Center for Children and Families – www.dougy.org
This center based in Portland, Oregon, offers support services to children, teens, and adult caregivers grieving a death. The site has information about training, books, videos, and training manuals for those interested in constructing grief programs in their own communities.

General Information on Sudden Unexpected Infant Death

American Academy of Pediatrics – www.aap.org
AAP's site includes general information on children's health with a section on SIDS prevention included. Information on ongoing research and advocacy related to SIDS is listed.

Healthy Child Care – www.healthychildcare.org/
Healthy Child Care is a collaborative effort of health professionals and child care providers to improve the early education, health, and safety of children in out-of-home child care.

Healthy People 2030 – www.healthypeople.gov
Healthy People provides science-based, 10-year objectives to improve the health of the nation.

National Action Partnership to Promote Safe Sleep Improvement and Innovation Network (NAPPSS-IIN) – https://www.nichq.org/project/national-action-partnership-promote-safe-sleep-improvement-and-innovation-network-nappss
NAPPSS-IIN is an initiative to make infant safe sleep and breastfeeding the national norm by aligning stakeholders to test safety bundles in multiple care settings to improve the likelihood that infant caregivers and families receive consistent, evidence-based instruction about safe sleep and breastfeeding.

National Center for Education in Maternal and Child Health – www.ncemch.org
Offers a large library of maternal and child related literature, including information on SIDS. This site offers access to national maternal and child health databases.

National Institute of Child Health and Human Development – http://www.nichd.nih.gov
This Institute provides general information on child health. Resources for SUID/SIDS and infant safe sleep are available for order, and information pertaining to these topics can be found here.

National SUID/SIDS Resource Center – www.sidscenter.org/
Offers SUID/SIDS and cultural competency information and lists periodicals on bereavement.

Ohio Department of Health – https://odh.ohio.gov/wps/portal/gov/odh/know-our-programs/Sudden-Infant-Death-Syndrome/Sudden-Infant-Death-Syndrome
Provides information on infant safe sleep practices. Safe sleep facts, partners, resources, and family stories. The main website, www.odh.ohio.gov, has information regarding health-related programs offered in Ohio. Health statistics and vital statistics related to births and deaths in Ohio and other statewide surveys are also available through the information warehouse.

U.S. Consumer Product Safety Commission – www.cpsc.gov
The site provides a wide variety of consumer product safety information, including product recalls and information on infant safe sleep.

Appendix E: Initial Contact Letter to Family Template

Initial Contact Letter to Family Template

This template can be used to make initial contact with a family when you have learned through any source that their baby died suddenly and unexpectedly. Use your agency letterhead and personalize it so it does not seem like a form letter.

Date

Parent(s) Name
Address
City, State, Zip

Dear (Name of Parent(s)),
I am writing to you on behalf of the (name of health department) to express my deepest sympathy and concern on the recent death of your son/daughter (baby's name). I have been notified that (name of baby) died suddenly and unexpectedly. This must be an extremely difficult time for you and your family members.

I would like to offer you my support and help. I am available to help you search out the answers to your many questions. I would like to put you in touch with other parents (or child care providers, etc.) who have lost their baby as well. It can be very comforting to talk to other people who have gone through the same experience you are going through now.

The Baby 1st Network may have already contacted you. They will be sending you grief- related literature and offering referrals to supportive agencies. With hope, this information will better assist you in your grieving process. I will be calling you soon to arrange an appointment to visit you. In the meantime, please feel free to call me at (phone number) if you would like more information or have questions.

Sincerely,

(Your name)

Appendix F: Issues, Concerns, and Practical Solutions for Home Visiting

Common Issues, Concerns, and Practical Solutions for Home Visiting

Issues	Concerns	Practical Solutions
Another nurse is working with family on other issues.	Family may be more comfortable with a familiar face.	Contact other nurse, coordinate services, and make joint visits.
Parents are divorced, separated, not together, or having relationship issues.	May not be able to visit and assist them together.	Set up separate appointments, or have a second nurse on case to maintain confidentiality.
		Notify Baby 1st Network to send each parent a SID informational packet.
		Focus on each individual's grieving needs.
Family refuses visit.	Family may be in crisis and not receiving support.	If willing, link the family to local support group.
		Provide information by phone. Send or deliver a packet of information.
Discover other mental or health issues during interview.	Nurse may not be experienced/qualified to assess/address issue.	Refer to appropriate program or health professional.
Family cannot be located.	Family may be in crisis without support.	The local coroner's office or Baby 1st Network may have recent family contact information.
Death occurs in child care/foster care.	Two families in crisis.	Provide services, education, and information to both families.
	Two nurses may be involved with the case.	Contact other nurse, coordinate services, and make joint visits.
	Family may be in one county and child care provider in another.	Contact Baby 1st Network.
	Are there issues between the family and the child care provider?	Provide education and support for both.
		Visit the child care provider when other children in their care will not distract from your visit.
		Know the phone numbers of local agencies; set up communication and coordination with professionals already assisting the family.
Parent(s) lack resources for the funeral or other expenses connected with the death.	Money worries may interfere with them benefiting from visit.	Social services may provide funds for low-income families.
	Family may need to be prepared that donated services will only cover costs for basic services.	Check with local funeral homes for possible programs for low-income families.
		Contact Baby 1st Network for assistance with organizations that may offer financial support. Other options are local churches, service clubs, and crisis programs.

Appendix G: Facilitating Effective, Supportive Conversation With Families

Questions to Facilitate Effective, Supportive Conversation With Families

How did the baby seem to you the week or so before their death?
Refer to the baby by name. Allow the parent to share memories of the baby in happy times. This question may also bring forth a history of respiratory or other minor illness. There may be guilt feelings if the infant was not taken to the doctor. If a doctor treated the child, the parents may blame the doctor for what they feel is inadequate treatment. The nurse or social worker should take this opportunity to reassure the family that it is very unlikely that a minor illness contributed to or caused the death of the infant.

Can you tell me about what happened to the baby?
Let the parent freely recount the last time the baby was seen alive and when the baby was found unresponsive. Ask for details to clarify, but avoid an interrogative tone. In telling their story, parents may express feelings of guilt about not using a crib, propping the bottle, not having checked often enough, putting the baby on its tummy, finding the baby with covers over their head, etc. Reassurance must be given that babies usually can tolerate all of these risks and we are not always aware of which babies cannot.

Had you heard of sudden infant death before?
This will give the nurse/social worker an idea of how much information is needed. The response also may provide the nurse with clues as to how much misinformation the family has received and from what sources.

Does your partner understand what happened to the baby?
This may bring out differences in adjustment or the problem of one partner blaming another. Individuals often express themselves differently, and communication problems may develop. Men and women often deal with grief differently.

Do your relatives and friends understand sudden infant death? Who is providing the most support? Who, if anyone, is most difficult to talk to about the death?
This will provide a picture of how much help is available from those who are close to the family. Those who care most for the family often make disturbing comments out of ignorance. If these can be dealt with and accurate information passed on to the offenders, much family turmoil will be avoided. An understanding and informed extended family could be of great help.

Have you experienced other tragedies in your life prior to the death of your baby? Were there any deaths among your family or friends that were sudden and unexpected?
Discussion of their previous experiences with crises can provide information that may be helpful in determining how the family copes in a stressful situation.

Questions the Family Might Ask

Why did my baby die?
The final cause of death will likely not be determined before the health professional contacts the family. Autopsies and death scene investigations are the best tools for determining the cause of SUIDs. After investigation, the cause of death may be attributed to accidental suffocation, a previously undiagnosed infection or metabolic disorders, SIDS, or other undetermined causes.

What causes sudden, unexpected infant deaths?
Much promising research currently is being done in the areas of immunology, infection, and neurology and in the mechanisms that regulate the heart and respiration. Researchers are particularly interested in possible abnormalities in the ability of babies to regulate breathing during periods of sleep. We are also gaining a greater understanding of the risks of suffocation in the sleeping environment.

I didn't think this happened to families like mine!
Sudden, unexpected infant deaths occur to all races, all income levels, and in all geographic regions. It is true that the rates of SUID are higher in African-American infants compared with white infants. Research shows that some risk factors are more common among low-income families, such as lack of safe sleep space and exposure to smoking.

Do these deaths always occur at night?
The majority of SUIDs occur at night or at naptime when the baby is sleeping. However, there are reports of these deaths occurring at other times when the baby is awake.

Do these deaths always occur during sleep?
The majority of sudden, unexpected infant deaths occur unobserved while the baby is sleeping.

Are all infants found on their tummies?
The risk of sudden, unexpected death is greater for infants placed to sleep on their sides and tummies, but infants have died in all positions. Because of the normal movements before the death occurred and muscle spasms that immediately follow death, infants are frequently found in a different position than when they were put down to sleep.

What causes blotches on the infant's face when found face down?
Gravity causes blood to pool after death, causing discolored blotches. Bruise-like marks or pale blanched areas of skin may occur where the body was in contact with the bed surface.

What causes blood around the baby's nose and mouth?
This is found frequently and results from drainage of fluid from the lungs, which occurs as a result of post-death muscle relaxation. Tiny pinpoint hemorrhages occur in the lungs, and these can discolor the lung fluid that drains out after death. The baby may also have vomit about the face as the stomach contents are pushed upward by muscle relaxation after death. The vomit and fluid from the lungs are the result of the death, not the cause of the death.

Could he/she have cried and I not heard him/her?
It is unlikely that the baby cried out before the death. Sudden, unexpected infant deaths have occurred in many families where parents were sleeping in the same room with their infants. Some parents have been holding their sleeping infant when the death occurred.

Did my baby suffer?
Evidence indicates that sudden, unexpected infant deaths occur quickly, with no sound and with no struggle. Infants appear to fall asleep, then just stop breathing. In some cases, infants have been found in unusual positions or with bedclothes in disarray. This occurrence is attributed to normal muscle spasms, which occur in the baby following death, rather than due to a struggle.

Why was an autopsy and death scene investigation done?
Ohio law requires autopsies for all children younger than 2 years and death scene investigations for all children younger than 1 year. Everyone, especially parents, want to understand how and why the infant died. An autopsy and death scene investigation are the best tools we have for determining the cause of sudden, unexpected infant deaths. Parents whose babies have died suddenly and unexpectedly have reported that receiving autopsy results as to how their child died was one of the most effective therapeutic measures they received in coping with their loss.

What about having another baby? Can this happen again? How long should we wait?
It has been known for sudden, unexpected infant death to happen more than once in a family, but those cases are extremely rare. Current research shows that the risk of sudden, infant death occurring in a family a second time is no greater than it was the first time. The risk is less than one per 1,000 live births in Ohio. The family should not be discouraged from having another baby. They should only do so when they feel they are ready and provided their physician feels there are no

contraindications. Birth intervals of at least 18 months reduce the risk of low birth weight, preterm birth, and babies being small for gestational age, placental abruption, and other poor birth outcomes and maternal morbidities. The Baby 1st Network (330-929-9911) has more information available to families on this topic.

How will I survive raising another child?
For those parents who do have another baby, there is a tendency to be overprotective. However, it is unrealistic and physically and emotionally draining to attempt to keep a 24-hour vigil over the new baby. There will be many uneasy moments, but parents need to relax and concentrate on developing a new relationship with this baby. Usually, after the new baby passes the age of the baby who died, parents will become much less anxious and will be able to settle into a comfortable routine. Talking to another SIDS parent who has had a subsequent child may be helpful and supportive. The Baby 1st Network (330-929-9911) has more information available to families on this topic.

Do you know of other parents whose baby died in this way? Can you help me locate a parent who would be willing to talk with me?
The Baby 1st Network may be contacted for this service. This organization exists primarily to assist bereaved families and to help increase the awareness of SIDS and SUID among public and professional groups. The network has regional bereavement support contacts who are parents who have lost their babies to SIDS/SUID and are willing to talk to families one-on-one. These parents know firsthand what families are going through and can relate on a personal level to the feelings they are experiencing. Any parent or professional can reach out to the network at any time for contact information and phone numbers. This information is also included in the bereavement letter each family will receive from the network. In addition, there are many other organizations that offer support to families experiencing a sudden infant death, and the network has an updated resource listing of these support groups for all regions of the state. The Baby 1st Network can help in making referrals for those families who might be interested in participation in any of these groups.

Appendix H: Safe to Sleep Campaign Materials Order Form

Safe to Sleep Campaign Materials Order Form

Safe to Sleep® Campaign Materials Order Form

MATERIALS FOR ALL CAREGIVERS		-	QTY
***Safe Sleep for Your Baby: Reduce the Risk of Sudden Infant Death Syndrome (SIDS) and Other Sleep-Related Causes of Infant Death* Brochure** Explains SIDS and describes ways to reduce the risk of SIDS and other sleep-related causes of infant death.	 0481 0482 0484 0485	General Outreach *0481* African American Outreach *0483* American Indian/Alaska Native Outreach *0484* En Español *0485*	
***What does a safe sleep environment look like?* Single Sheet** Shows a safe sleep environment and lists ways to reduce the risk of SIDS and other sleep-related causes of infant death. (In sets of 25 sheets)		English *0482* En Español *0486*	
***Safe Sleep for Your Baby* Door Hanger** Designed to hang on a doorknob, shows a safe sleep environment and lists ways to reduce the risk of SIDS and other sleep-related causes of infant death.		General Outreach *0494* African American Outreach *0495* Online Only En Español *0496* Online Only	
***Safe Sleep for Your Grandbaby* Brochure** Explains how grandparents can reduce the risk of SIDS and other sleep-related causes of infant death when caring for their grandchildren.		English *0497* En Español *0498*	
***Safe Sleep for Your Baby* DVD** Explains SIDS risks and ways to reduce the risk of SIDS and other sleep-related causes of infant death. English and Spanish subtitles. Running time 9:55.		English *0487* En Español *0506*	
***Honor the Past, Learn for the Future: Reduce the Risk of SIDS in Native Communities* Flyer** Lists ways to reduce the risk of SIDS and other sleep-related causes of infant death among American Indian/Alaska Native babies.		*0434*	
Safe to Sleep® Campaign Materials Order Form		*0327*	

MATERIALS FOR HEALTH CARE PROVIDERS, EDUCATORS, AND COMMUNITY HEALTH WORKERS	-	QTY
***Continuing Education (CE) Program on SIDS Risk Reduction: Curriculum for Nurses* (Workbook and Handouts - Online Only)** Approved for 1.1 CE credit hours, offers communication strategies for nurses on SIDS, SIDS risks, and risk-reduction recommendations. *Available at http://www.nichd.nih.gov/cbt/sids/nursececourse/Welcome.aspx.*	-	-
***SIDS Risk Reduction: A Continuing Education (CE) Activity for Pharmacists* (Online Only)** Approved for 0.125 CE units, explains how pharmacists can communicate safe sleep messages to caregivers. *Available at http://www.nichd.nih.gov/cbt/sids/pharmacistcecourse/Welcome.aspx.*	-	-
***Sudden Infant Death Syndrome (SIDS) and Other Sleep-Related Causes of Infant Death: Questions and Answers for Health Care Providers* (Booklet)** Answers to common questions about sleep position, sleep environment, and Sudden Infant Death Syndrome (SIDS) for health care providers.	*0524*	*Limit 25*
***Healthy Native Babies Project Facilitator Packet* (Facilitator's Guide, Cards, Chart, Flipchart)** For leading training sessions for those who work with parents and caregivers in American Indian/Alaska Native communities. Includes training modules and materials for leading 2-hour or 1-day sessions.	*0457*	*Limit 1*
***Healthy Native Babies Project Workbook Packet* (Workbook, Handouts, and Toolkit Disk)** For conducting outreach in American Indian/Alaska Native communities. Toolkit creates custom outreach materials that incorporate Tribal and regional photos, languages, and graphic elements.	*0435*	*Limit 1*

TO ORDER MATERIALS, CONTACT US:

Phone: 1-800-505-CRIB (2742)
Fax: 1-866-760-5947
TTY: 1-888-320-6942
Mail: P.O. Box 3006, Rockville, MD 20847
Email: NICHDInformationResourceCenter@mail.nih.gov
Website: http://safetosleep.nichd.nih.gov

Name/Title			
Organization/Business			
Street Address			
City, State, ZIP		❒ Residential Address ❒ Business Address	
Telephone		**Email***	

**Optional: If you want confirmation that your order has been placed.*

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December 2015

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