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REPORT RELEASE

APRIL 7, 2014

Office of the Child Advocate and the State Child Fatality Review Panel Releases Public Health Alert: Unsafe Sleep Related Deaths are the Leading Cause of Preventable Deaths of Infants in Connecticut

The Office of the Child Advocate and the Connecticut Child Fatality Review Panel, co-chaired by Sarah Eagan, the State's Child Advocate, and Kirsten Bechtel, M.D., is releasing a Public Health Alert entitled: "Alert: Unsafe Sleep Related Deaths are the Leading Cause of Preventable Deaths of Infants in Connecticut."

This Alert is being issued to publicize that "the number of Connecticut infants who died between 2001 and 2013 where unsafe sleep conditions were present was almost three times the number of infants who died from child abuse."

After review of hundreds of individual infant death cases the report concludes: "infants in Connecticut are more likely to die from unsafe sleeping conditions than from child abuse, car accidents, choking, drowning, falls, or any other source of accidental injury."

In 2013, there were 23 infants who died with a finding of Sudden Unexpected Infant Death, Sudden Infant Death Syndrome or where the cause was identified as "undetermined." Of these 23 unexpected, unexplained deaths, 18 infants had risk factors associated with their sleep environment. These infants were, on average, 3 months old at the time of their death.

The most common unsafe sleep environments in Connecticut fatality cases included

1. Co-sleeping in an adult bed with parents or siblings
2. Sleeping in the car seat
3. Sleeping in a crib with blanket, pillows, or placed on their stomachs
4. Put to sleep with a bottle in an adult bed.

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Related risk factors for sudden infant death include parental mental health challenges, including depression, substance use, including alcohol and tobacco, obesity and parental isolation.

According to Sarah Eagan, Child Advocate for the State Of Connecticut and co-chair of the Child Fatality Review Panel, "while many of us have heard messages regarding safe sleep and 'back to sleep,' very few are aware how often infants in Connecticut die from unsafe sleep conditions. Barely a month goes by where our Child Fatality Panel doesn't review a tragic case of preventable infant death. We must shout this message from the rooftops."

Dr. Kirsten Bechtel, co-chair of the Fatality Review Panel, emphasized that "the multidisciplinary collaboration amongst the professionals on the CFRP has been critical to understanding factors that result in an infant's death during sleep. A similar collaboration is required to reduce the number of infants who die in unsafe sleep conditions in Connecticut."

Prevention recommendations in the Alert include:

1. Annual Child Fatality Hearing to publicly address CT child deaths and prevention strategies.
2. Screening for maternal depression in pediatric, Ob-Gyn, and primary care.
3. Expansion of evidence-based home visiting programs for parents and children that increase parental capacity and improve child well-being.
4. Uniform protocols for first responders for sudden unexplained infant death investigations.
5. Child Welfare case planning that includes emphasis on safe sleep practices for infants.

"Screening and home visiting, while always considered good policy and practice, are also infant fatality prevention strategies," said Eagan. "The sharing of information and provision of support can save lives."

The Office of the Child Advocate and the Child Fatality Review Panel will be publishing quarterly public health alerts regarding how children die in our state and how our public health systems and communities can prevent these tragedies in the future.

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THE OFFICE OF THE CHILD ADVOCATE AND THE CONNECTICUT CHILD FATALITY REVIEW PANEL

ALERT: UNSAFE SLEEP RELATED DEATHS ARE THE LEADING CAUSE OF PREVENTABLE DEATHS OF INFANTS IN CONNECTICUT

The number of Connecticut infants who died between 2001 and 2013 where unsafe sleep conditions were present was almost three times the number of infants who died from child abuse.

Each year infants die unnecessarily in Connecticut. This Public Health Alert outlines the tragedy of infant fatalities associated with unsafe sleep conditions and makes recommendations for prevention.

Infant Fatality Risk Factors

- Sleeping in adult beds with adults and other children
- Sleeping in beds with comforters, blankets and duvets
- Sleeping on couches or chairs when caregivers sleep holding them
- Sleeping in cribs with stuffed animals, blankets, toys and other items
- Overdressing/overheating baby
- Propping bottles

Research also confirms additional risk factors associated with sudden infant death.

- Mental health challenges, including depression
- Substance use, including alcohol or drugs
- Smoking
- Obesity
- Parental isolation

Unsafe Sleep Fatalities: Case Examples from Connecticut, 2013

An 8 week-old baby boy was in the care of his maternal grandmother while his mother went out for the evening for the first time since his birth. The grandmother was sitting on the couch and fell asleep while holding him. When the mother returned home she found her mother asleep on the couch and her son face down on the couch in the space between the grandmother and the arm of the couch. He was blue and not breathing. He was rushed to the Emergency Department when he was pronounced dead.

A 7 week-old baby girl was placed to sleep on the side alongside her mother in the mother's bed. The infant was also swaddled in a heavy receiving blanket. Upon awakening the mother found her lying on her stomach (prone), cold, blue, and not breathing. She was declared dead by the paramedics who were called to the home. The mother had a history of opiate addiction for which she was treated with methadone. The baby had a crib that was used only for storing clothing and toys and not used for the infant to sleep. The family had a recently opened case with DCF.

What is an "unsafe sleep related" infant fatality?

Unsafe sleep related causes of infant death are linked to how or where a baby sleeps. Deaths may be due to blockages of the nose/mouth; entrapment/chest compression (when an infant gets trapped between two objects, such as a mattress and wall, and cannot breathe or overlying); or suffocation from a low oxygen/high carbon dioxide environment (under a blanket).

How often do infants in Connecticut die from unsafe sleeping conditions?

Infants in Connecticut are more likely to die from unsafe sleeping conditions than from child abuse, car accidents, choking, drowning, falls, or any other source of accidental injury.

2013 Infant Fatality by the Numbers

In 2013, there were 23 infants who died where the causes of death were SUID, SIDS, or "undetermined."[1] Of these 23 unexpected, unexplained deaths, 18 infants had risk factors associated with their sleep environment.

Sudden Unexplained or Undetermined Infant Deaths in 2013

- 17 Boys
- 6 Girls
- Average age of infants: 3 months
- In at least seven cases, the parent(s) had documented histories of substance

[1] When infants die unexpectedly, this is called "Sudden Unexpected Infant Death (SUID)." SUID includes all unexpected deaths: Deaths without a clear cause, such as SIDS, and deaths from a known cause, such as suffocation or other sleep-related causes. Sleep-related deaths are not SIDS. SIDS is term for the sudden death of an infant under 1 year of age that cannot be explained, even after a complete death scene investigation, autopsy, and review of the infant's health history.

2011 and 2012 Infant Fatality by the Numbers

In 2011 and 2012 there were 43 infants who died where the causes of death were SUID, SIDS, or "undetermined."[2]

There were 24 infant cases in 2011 and 19 infant cases in 2012.

30 were boys and 13 were girls.

Of these 43 unexpected, unexplained infant deaths, 31 infants had risk factors associated with their sleep environment.

Most common unsafe sleep environments in CT fatality cases

- Co-sleeping in an adult bed with parents or siblings
- Car seat
- In a crib with blanket, pillows, or placed on their stomachs
- Put to sleep with a bottle in an adult bed

Infant Fatalities in Connecticut over Time

The Office of the Child Advocate also conducted an evaluation 211 infant fatalities between 2002 and 2010 that were classified as due to SIDS, SUID, Undetermined or Accidental Asphyxia.

- 117 infant deaths were classified as SIDS, a finding that may not accurately account for unsafe sleep conditions present at the time of death.

- 77 infant deaths were classified as "undetermined," a finding often associated with "unsafe sleep" conditions.

- 17 infant deaths were classified as due to "asphyxia."[3]

We cannot say definitively how many of the 211 infants outlined above died from unsafe sleep conditions, but an OCA review of at least 140 of these deaths had findings associated with unsafe sleep environments including infants sleeping in bed with adults, in bed with other children, and in bed with adult pillows, toys, comforters, stuffed animals and other items.

Are "unsafe sleep" fatalities trending up or down in CT over the years?

This is as difficult question to answer.
Overall the percentage of infant deaths classified as SIDS has shown a downward trend, but this has not translated into an overall decline in infant deaths. How we categorize findings regarding infant death has changed over time, and fewer infants are now determined to have died from SIDS. More infants are now categorized as having died from SUID--Sudden

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[2] See Note 3 infra.

[3] Over the last ten years, states are decreasing SIDS findings and increasing "undetermined" and "asphyxia" findings as fatality reviews and "scene" investigations become more thorough.

Unexplained Infant Death-- an umbrella term covering multiple infant death causes, including SIDS and suffocation.

It is Difficult to Always and Conclusively Determine Cause of Infant Death for Several Additional Reasons:

1. Inconsistent official use of "SIDS" to explain infant fatality. SIDS should only be an official "cause of death" when medical examination and scene investigation reveal no other potential causes or risk factors, such as abuse, unsafe sleep conditions or underlying medical issues. However, even today, SIDS may still be given as the "cause of death" even where there has been limited or no scene investigation, and limited police investigation.
2. Inconsistent investigations related to the scene of unexpected and unexplained infant fatalities result in lack of information that would be essential to understanding cause of death. Not every case is handled in the same way. Infants may be moved, scenes disrupted, certain information not obtained, e.g., toxicology screens of parent.
3. Lack of uniform training and protocols regarding examination and investigation of unexpected, unexplained child fatalities. Even different medical examiners approach "cause of death" investigations differently.

DCF'S Critical Role in Infant Death Prevention

Based on our review of 2013 data, many families who suffered a sudden infant death in Connecticut had been involved with the Department of Children and Families. There is further research to show that families under Child Protective Services' Supervision are 3 times more likely to have a Sudden Infant Death than those that are not.[4] This is likely due to related risk factors for sudden infant death such as mental health challenges and substance abuse.

Important 2014 Policy Development from DCF

Connecticut Department of Children and Families recently issued a new agency policy emphasizing the role that case workers will play in educating families about "safe sleep," and ensuring such expectations are part of families' case plans. This is a critical development given that DCF interfaces with thousands of parents of young children each year. Given the importance of this new policy in reducing child deaths, DCF should incorporate this policy into training and rigorously enforce compliance through spot checks of the records of all children under 1 year of age. [5]

RECOMMENDATIONS TO PREVENT UNSAFE SLEEP RELATED INFANT DEATH

RECOMMENDATIONS FOR LAWMAKERS

1. **Annual Child Fatality Report and Hearing.** Support efforts by the Office of the Child Advocate and the Child Fatality Review Panel to report annually to the Connecticut General

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[4] Putnam-Hornstein E. Schneiderman JU. Cleves MA. Magruder J. Krous HF. A Prospective Study of Sudden Infant Death after Reported Maltreatment. *Journal of Pediatrics. 164(1):142-8, 2014 Jan.*

[5] Connecticut Department of Children and Families, "Standards and Practice for Safe Sleep Environments: Assessing the Safety of an Infant's Sleep Environment," Practice Guide to be used in conjunction with DCF Policy 34-12-8 (2014).

Assembly the number of sleep-related deaths of infants. Legislation may consider the value of an annual hearing regarding fatalities, causes, trends, and prevention strategies.

2. **Support Pediatric Counseling Regarding Safe Sleep.** Ensure reimbursement for primary care providers for the time spent counseling families regarding a safe sleep environment for infants. Analogous reforms were implemented in other states such as Washington for oral primary care.[i]
3. **Increase Screening for Maternal Depression.** Given the link in the national data between mental health challenges and "unsafe sleep" fatalities, it is critical that Medicaid and commercial carriers support screening for maternal depression and increased access to in-home supports for high need mothers. Although Connecticut has not done consistent, in-depth investigations into the parental profiles of parents who suffer an infant loss as described in this paper, our recent data does confirm a number of the infants who died had parents with documented histories of substance abuse and involvement with the Department of Children and Families.
4. **Connect Home Visitation and Clinical Home-based Services to Pediatrics.** Home visitation is an evidence-based service for increasing caregiver capacity and improving child well-being. Home visiting programs provide essential support and education to new parents. Home Visitation Services, including dyadic and clinical home-based services, should be brought to scale as critical parts of our health care for maternal/child wellbeing. All pediatric primary care providers should have direct connection to and collaborative relationship with home visitation programs for families.
5. **Mandate "safe sleep" guidance by health care providers.** Devise legislation, similar to New York and Maryland efforts regarding Shaken Baby Syndrome that mandates anticipatory guidance for provision of a safe infant sleep environment is delivered by health care providers to caregivers at newborn hospital discharge.[ii]
6. **Ensure Uniform Law Enforcement and First Responder Protocols for Sudden Unexplained Infant Death Investigations.** Police and first responders should respond to child deaths as they would to any crime scene. Many departments follow the Centers for Disease Control Protocol for Sudden Unexplained Infant Death Investigations (SUIDI). Efforts should be made to ensure that police departments and first responders have adequate resources to implement SUIDI training and ensure uniform protocols for investigation. Washington State created guidelines for first responders that can serve as a model for Connecticut.
7. **Ensure Uniform Protocols for the Office of the Medical Examiner Regarding Sudden Unexplained Infant Death Investigations.** Some investigators conduct thorough scene investigations and collaborate with police in reenactments which have led to greater understanding of the causes of Sudden Unexplained Infant Deaths. Medical examiners should adopt standard protocols for SUID investigations and adopt standard language to identify causes of infant death. Examiners within the Connecticut office still varyingly classify infant deaths as SIDS, SUID or Unexplained without clear distinction between terms. This makes tracking infant death causation and creating public health responses much more difficult.
8. **Address Sale of Unsafe Infant Bedding and Positioners.** Regulate the sale and advertising of bedding for infant cribs or cradles, and infant co-sleepers so that any devices that are marketed meet Consumer Protection Safety Commission guidelines for safety.[iii] Maryland, for example, banned baby bumpers and positioners, devices that may be promoted as preventing SIDS.

RECOMMENDATIONS FOR DCF, IN-HOME SERVICE PROVIDERS, AND CHILDCARE PROVIDERS

1. **Quality Engagement and Assessment.** Case planning must include skilled engagement and information sharing regarding safe sleep practices, infant needs, resources for caregiver support and risk factors for infant death.
2. **Outreach and Education.** Organization of outreach programs and drives, and utilization of educational materials like brochures, leaflets and DVDs. This should include tailoring of safe sleep messages to specific communities and using trusted figures in the community to advocate these practices. Materials are available already from*: **www.ct.gov/dph/safetosleep and http://www.nichd.nih.gov/SIDS and 1-800-505 CRIB (2742).***
3. **Collaboration with Best Practice Centers.** Collaborations may be done with Sudden Infant and Child Death (SICD) Resource Center, which provides outreach and education on the subject of safe sleep practices and is available to provide free on-site training to local districts and other child welfare agencies.
4. **Ongoing monitoring and engagement regarding safe sleep.** Monitoring sleep conditions in home as well as institutional settings, such as hospital inpatient units, childcare providers, day care centers, foster homes.
5. **Address barriers to safe sleep.** Explore with parents any barriers or challenges to ensuring a safe sleep environment they may be experiencing and assist in identifying and accessing needed resources. Document all activities.

RECOMMENDATIONS FOR OB-GYNS, PEDIATRICIANS AND HOSPITALS

1. **Engagement, assessment, and education.** There should be a discussion on safe sleep practices, particularly with parents of infants who fall in high risk categories: low birth weight/ premature infants, those from socioeconomically disadvantaged backgrounds, or with parents who smoke, drink or are substance abusers. Screening for possible risk factors and exploration of actual parenting practices are necessary components of prevention.
2. **Address concerns/misperceptions.** Practitioners should aim to not only inform caregivers about sleep safe practice guidelines, but also address any concerns about infant sleep that they may have. Commonly held misconceptions include the "stomach" or "side" sleep position being more comfortable for the infant and reducing chances of regurgitation and choking.
3. **Address unsafe bedding and positioners directly.** Use of baby blankets, quilts or bedding sets advertised as 'infant friendly/ safe', baby positioners and bumpers and devices marketed to reduce SIDS should be strongly discouraged.
4. **Modeling Best Practices.** Parents are more likely to follow care practices when they see nursery staff consistently model this behavior in the hospital. Safe sleep practices can be modeled during postpartum care in hospitals as well as out-of-hospital birth settings, such as birthing centers.
5. **Collaboration with Best Practice Centers.** The use of safe sleep resources like Continuing Education Program on Sudden Infant Death Syndrome (SIDS) Risk Reduction by NICHD should be used to provide information and tools needed to communicate and model SIDS risk reduction messages effectively and quickly.

6. **Value of Anticipatory Guidance.** Hospitals should consider practice policies that encourage the delivery of anticipatory guidance for providing a safe infant sleep environment to caregivers of infants whenever they are encountered within the hospital (e.g. well infant visits, sick visits, Emergency Department visits, subspecialty care visits).
7. **Encourage Breastfeeding:** Breastfeeding, especially during the first 6 months, has been shown to reduce the incidence of Sudden Infant Death by as much as half, as long as safe sleep practices are followed after. Pacifier use is also encouraged and may have a protective effect after the infant has been weaned off breastfeeding.

SAFE SLEEP GUIDELINES FOR PARENTS

Back To Sleep Position

- Studies have consistently demonstrated that the practice of placing infants on their back to sleep is linked with significantly decreased rates of infant deaths, as opposed to those placed to sleep on their stomachs or sides.
- The infant should be placed on his/her back during every nap time, in every setting- at home, in childcare, or during travelling.
- Placing infants who usually sleep on their backs to sleep on the stomach is a high risk factor for sudden infant death.
- Infants who are able to roll themselves on their stomach, usually after 5 months of age, need not be repositioned during sleep.

Safe Sleep Environment

- The safest place for an infant to sleep is a hard surface such as a crib or bassinet that complies with the Consumer Product Safety Commission recommendations. Places like couches, sofas, car seats and adult beds are unsafe sleep environments for infants, and may increase chances of suffocation and entrapment.
- The sleeping surface should be covered with only a firm mattress and fitted sheets. Other extraneous items like soft bedding, pillows, blankets or comforters increase the risk of strangulation, suffocation and overheating and should not be placed in the crib. Infant positioners and bumpers are also sleep hazards and should also not be used.
- The infant should ideally be put to sleep in fitted sleepwear at a comfortable temperature.

Room-sharing but not bed- sharing

- Room- sharing, or placing an infant's cradle or bassinet in the same room as the care giver has shown to be linked with lower rates of Sudden Infant Death, especially during the first 6 months of the infant's life.
- Sharing a sleeping surface has, on the other hand, been consistently demonstrated to increase the risk of suffocation and entrapment. The risk significantly increases when the caregiver has consumed alcohol, is sedated, or excessively tired.

Breastfeeding

Breastfeed your baby for as long as possible, preferably for the first year of life. After breastfeeding your baby, **put your baby down on his/her back in a crib or bassinet with a fitted sheet, without toys, blankets or pillows**. Keep the baby's crib or bassinet right next to your bed, so you can see and hear your baby and be able to respond to his/her needs.

Smoking and Usage of Alcohol, Drugs or Tobacco Products

- Maternal smoking and exposure to tobacco smoke is a very important risk factor that has been shown to play a role in almost a third of sudden infant deaths, with risk increasing exponentially with increasing levels and frequency of exposure.

Remember to talk to other caregivers about safe sleep priorities!!

- Communicate with anyone who will be taking care of the child: babysitters, grandparents, siblings, child care providers, boyfriends, and other caregivers.

Support provided by Yale University Masters in Public Health Student, Ankeeta Shula.

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[i] http://www.innovations.ahrq.gov/content.aspx?id=3793
[ii] http://www.ncsl.org/research/human-services/shaken-baby-syndrome-prevention-legislation.aspx.; see also https://www.medstarhealth.org/Pages/Services/Pediatrics/MedStar-Franklin/Pediatric-Community-Services-and-Events-at-MedStar-Franklin-Square.aspx#Sleep (outlining Franklin Square Hospital in Baltimore Maryland's affidavit program for both safe sleep and Shaken Baby Syndrome).
[iii] http://www.cpsc.gov/en/Newsroom/News-Releases/2014/New-Infant-Bedside-Sleeper-Standard-Approved/