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Way Beyond the ABCs: Preventing Sleep-Related Infant Death

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Cook County SUID Case Registry and Prevention

The SUID Case Registry for Cook County, IL, is funded by the CDC via Cooperative Agreement. The content presented is that of the investigators. They may not reflect the policies of the Department of Health and Human Services or the U.S. government.

The content of today's meeting regarding infant deaths can be difficult. The data we discuss represent families who have lost their infants to SUID and may evoke strong feelings or other distress.

Please prioritize your own wellbeing, even if you need to step away from the meeting.

Objectives

- Describe SUID epidemiology, risk and the role of **risk perception** in preventing SUID.
- Recognize systemic and individual **barriers to safe sleep** that lead to unsafe sleep practices.
- Develop **communication approaches** that respect, value and center families' circumstances and experiences.
- **Be inspired** to collaborate with healthcare, human services, community-based organizations and SUID prevention advocates to promote safe sleep during encounters with pregnant and parenting families.

My patient

7-week-old Hispanic male, breast and formula feeding

2 month check up visit, thriving and healthy, safe sleep discussed

Before work, Dad brought baby from crib to mom for breastfeeding.
After feeding, both fell asleep
Mom woke an hour later, baby unresponsive, blood from nose

Another patient of mine

3-month-old admitted to hospital for vomiting/dehydration

On second day in hospital, fontanelle started to bulge. Imaging showed cerebral edema or brain swelling

Mom revealed she had been sleeping with baby on couch, woke and found she had been laying on her baby

12 years later, saw mom and daughter in clinic. Daughter microcephalic, non-verbal and spastic. Mom aged more than the years.

Sudden Unexpected Infant Death

SUID

SIDS

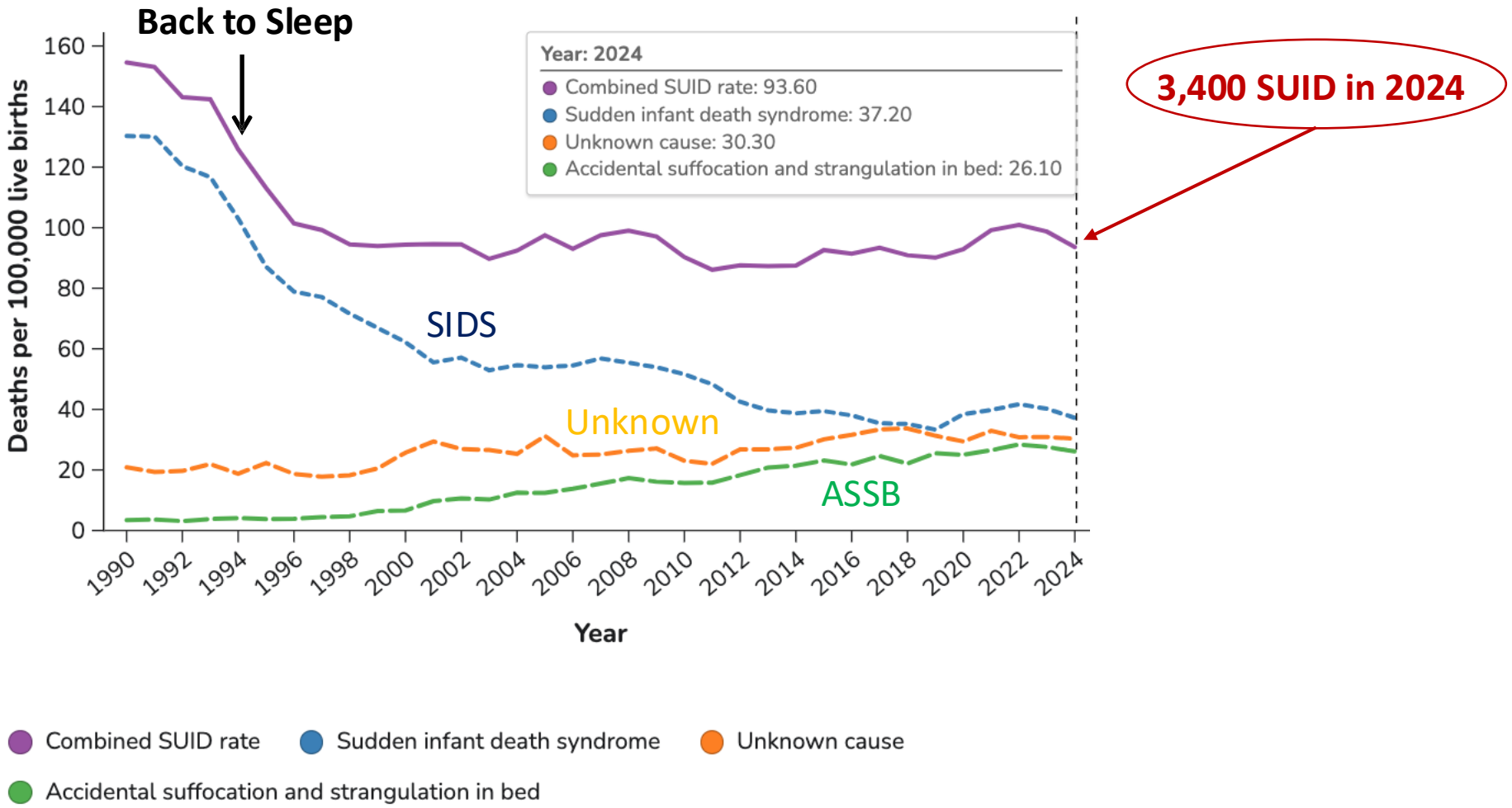
+

Unknown

+

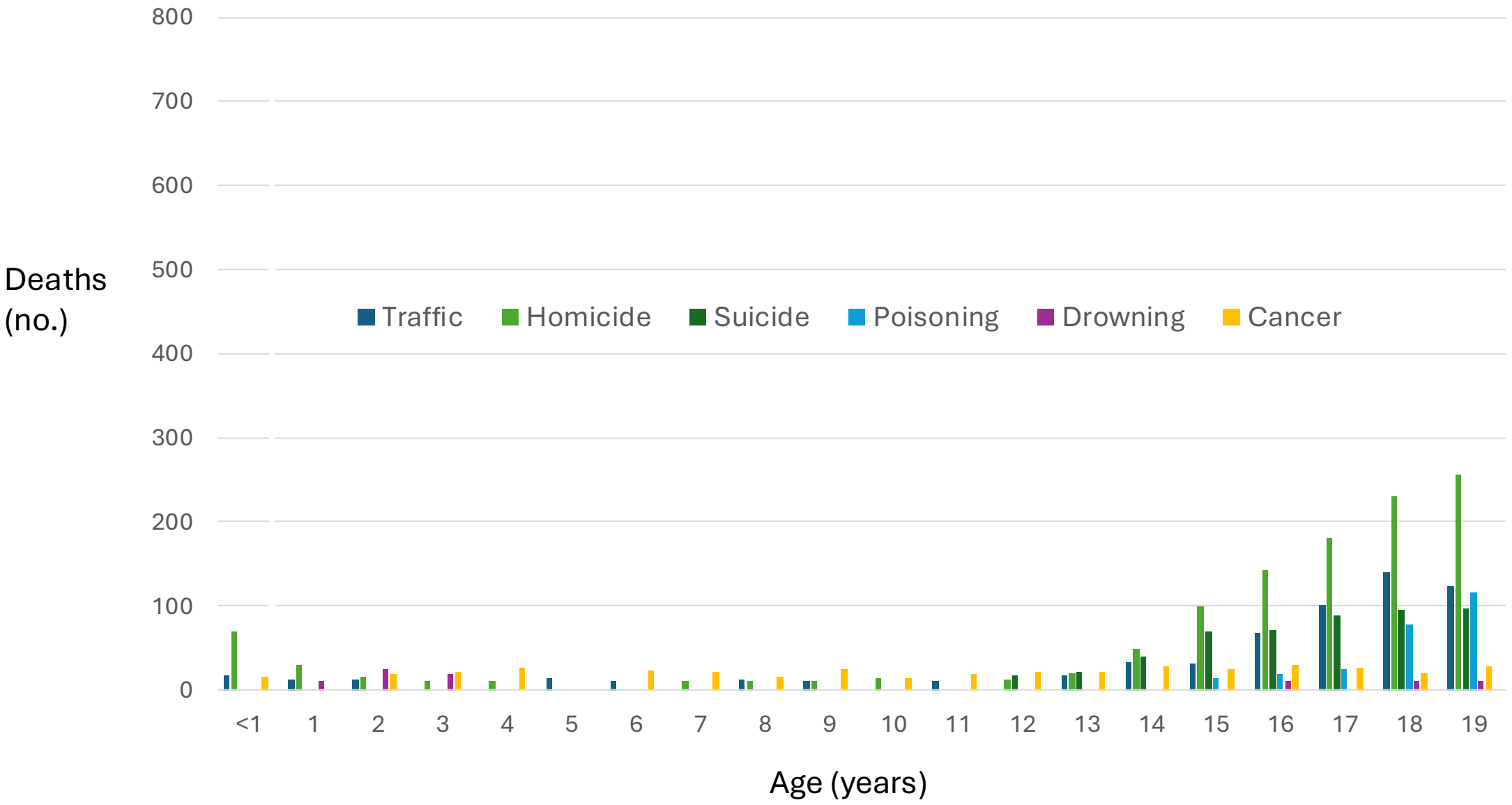
Accidental Suffocation

Trends in Sudden Unexpected Infant Death by Cause, 1990-2024



https://www.cdc.gov/sudden-infant-death/data-research/data/sids-deaths-by-cause.html

Deaths by Cause and Child Age—Illinois 2018-2023



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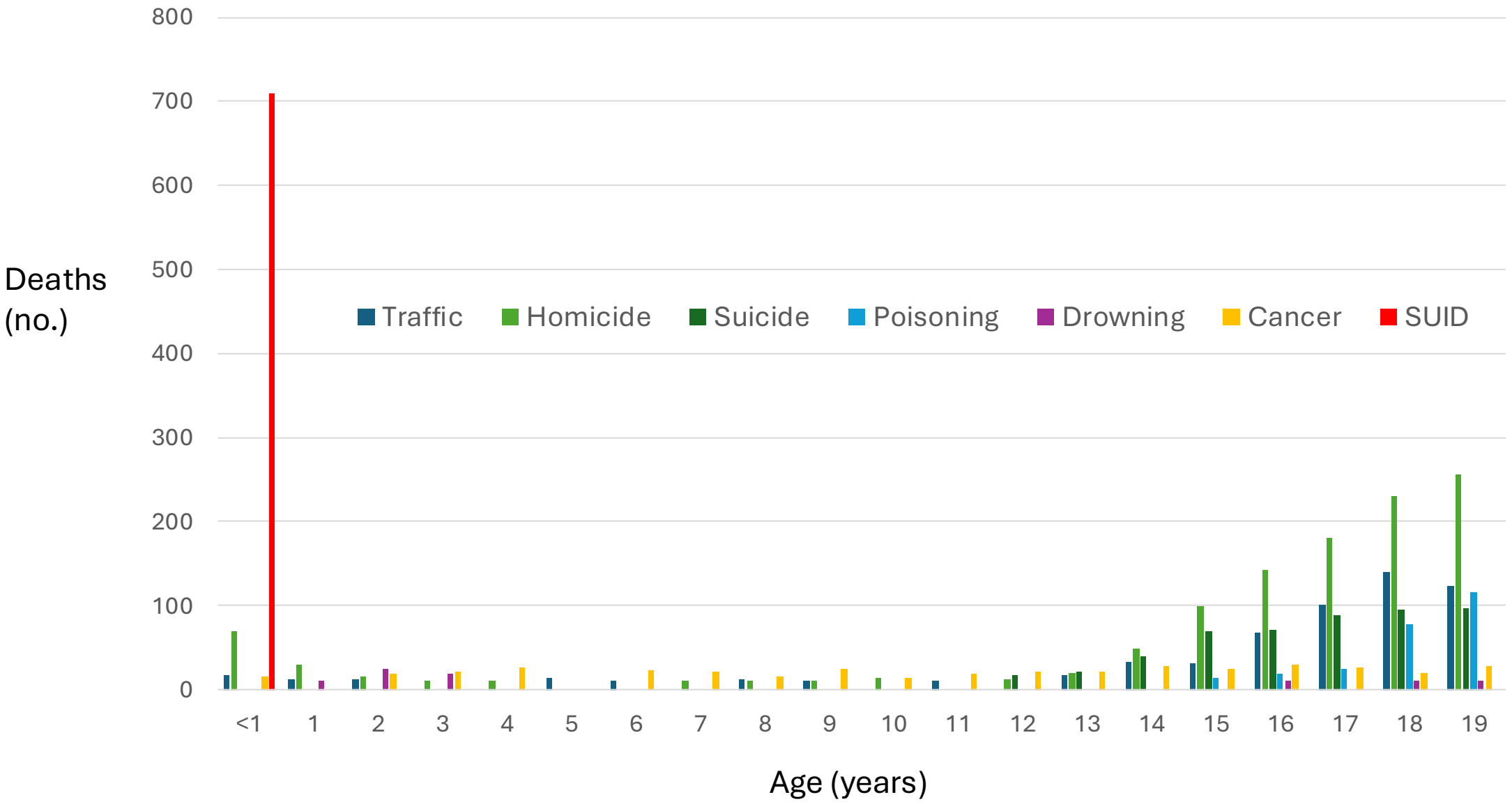


SUID in Illinois

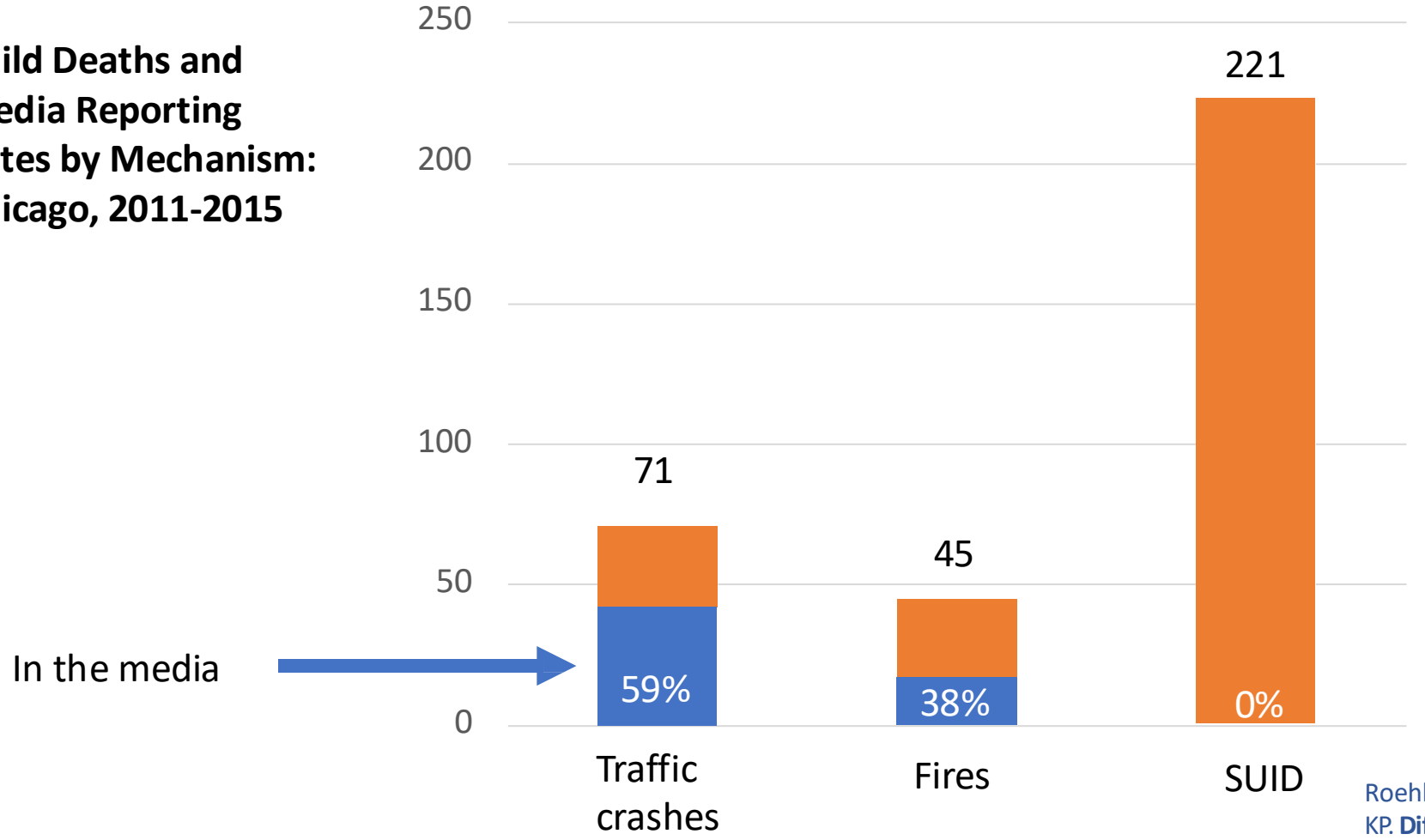
From 2018-2023, 710 SUID in Illinois

Average of 118 per year

One every 3 days

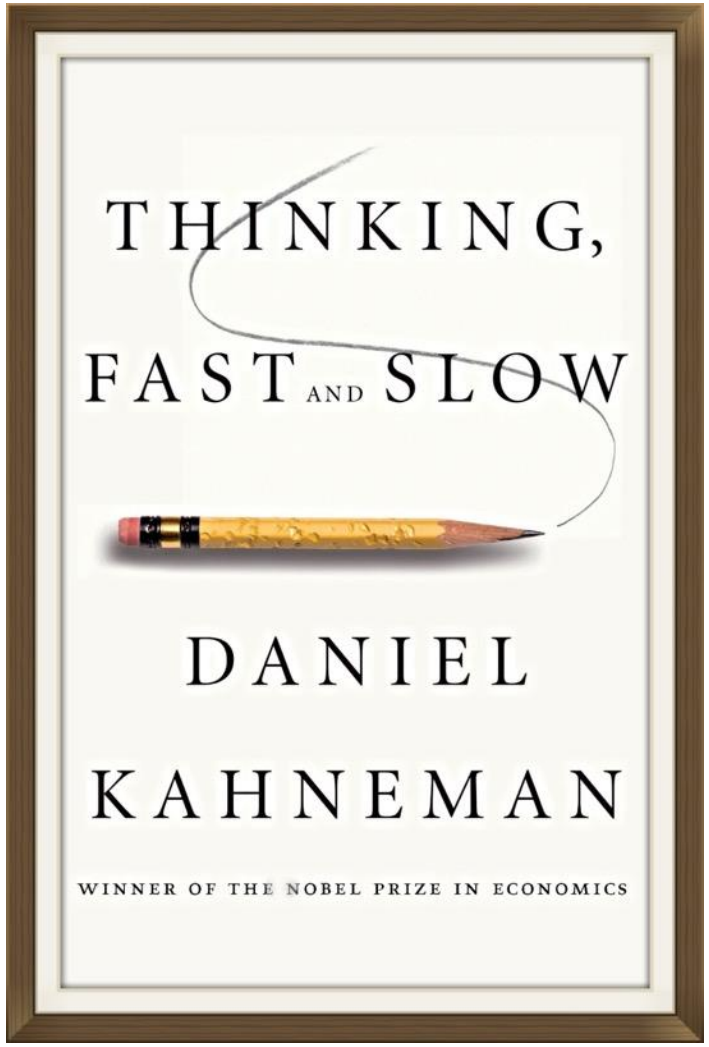
Media Reporting of SUID

Child Deaths and Media Reporting Rates by Mechanism: Chicago, 2011-2015



Roehler DR, Lowell GS, Silvestri JM, Eason EA, Quinlan KP. **Differential Media Reporting of Unintentional Child Deaths in Chicago**, 2011-2015. *Am J Public Health*. 2018 Oct;108(10):1318-1319.

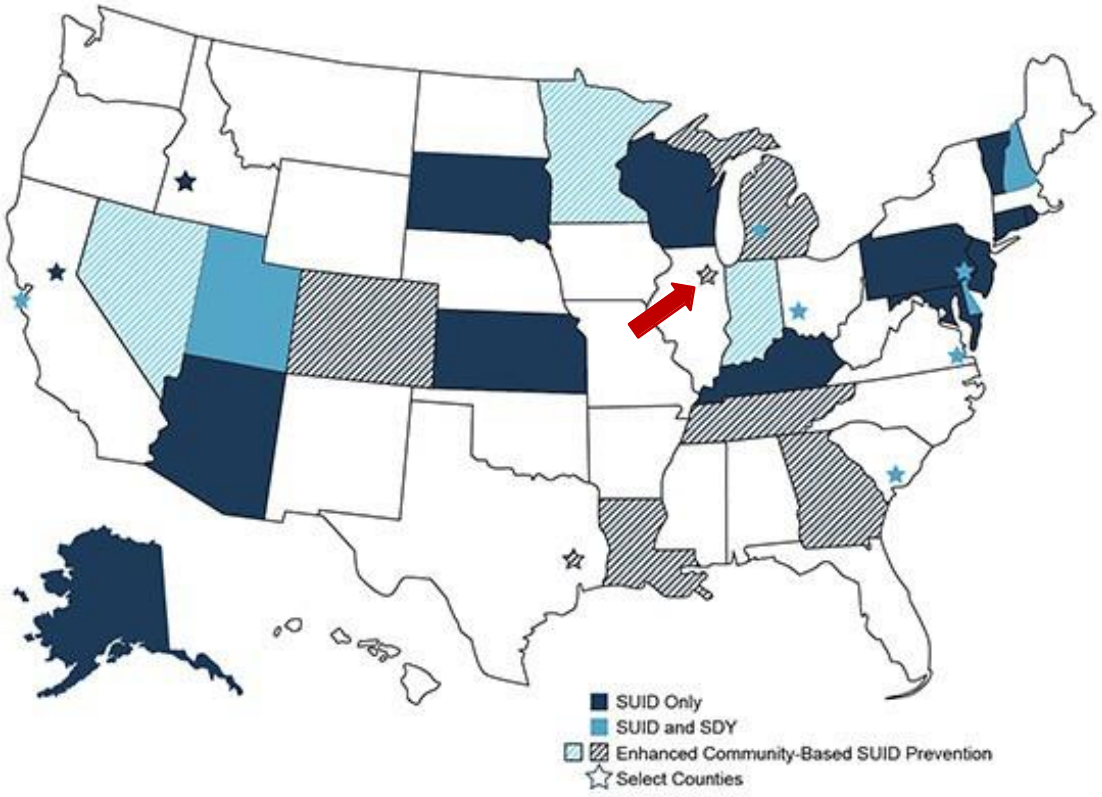
Availability heuristic



People judge frequency by "the ease with which instances come to mind"

What is the SUID Case Registry?

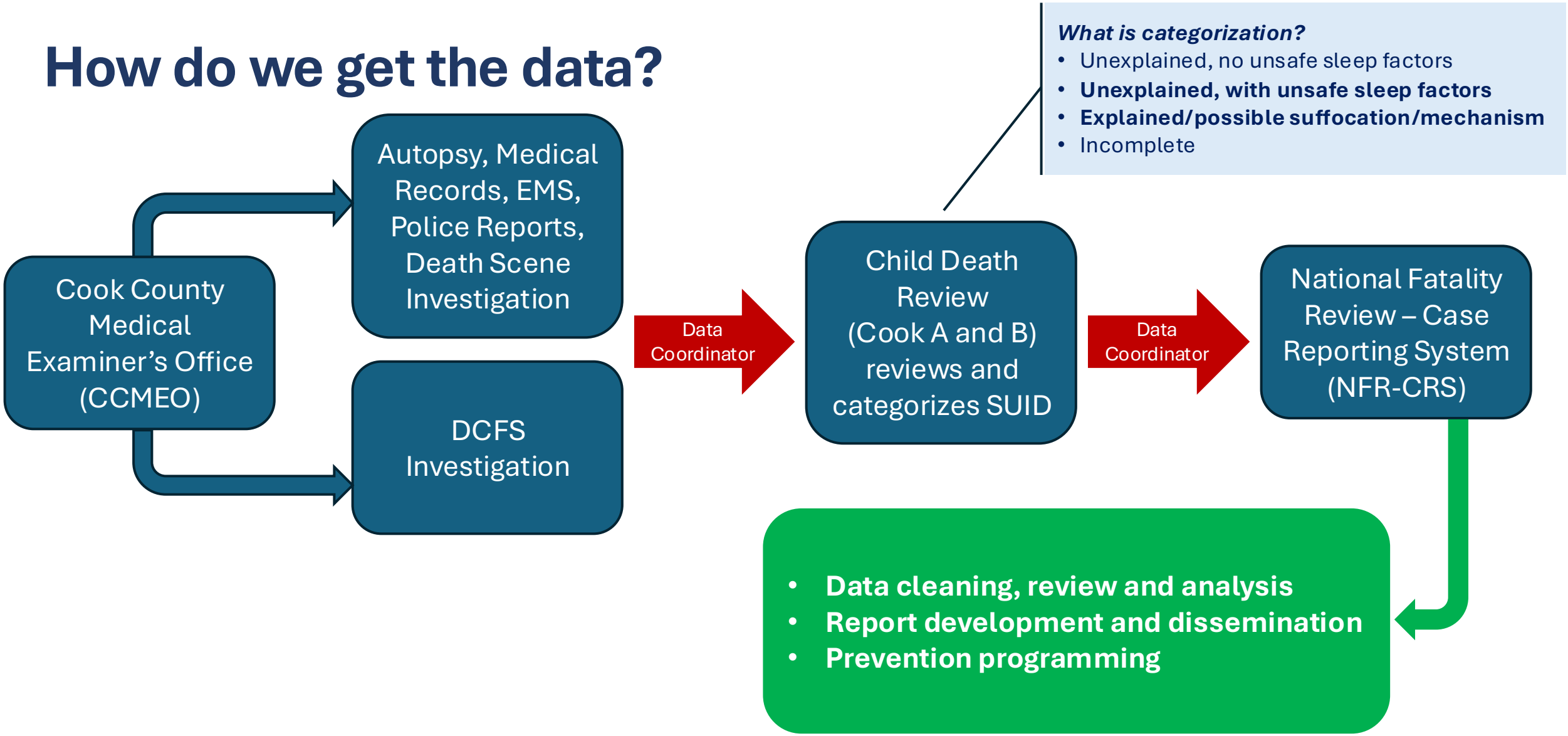
- CDC funds SUID surveillance in 32 states and jurisdictions, covering **40%** of SUID cases in the US.
- SUID-CR builds on **child death review** programs to bring together multidisciplinary information about the **circumstances surrounding SUID**.
- SUID Case Registry data **drives prevention**



Cook County's SUID Case Registry began in 2019

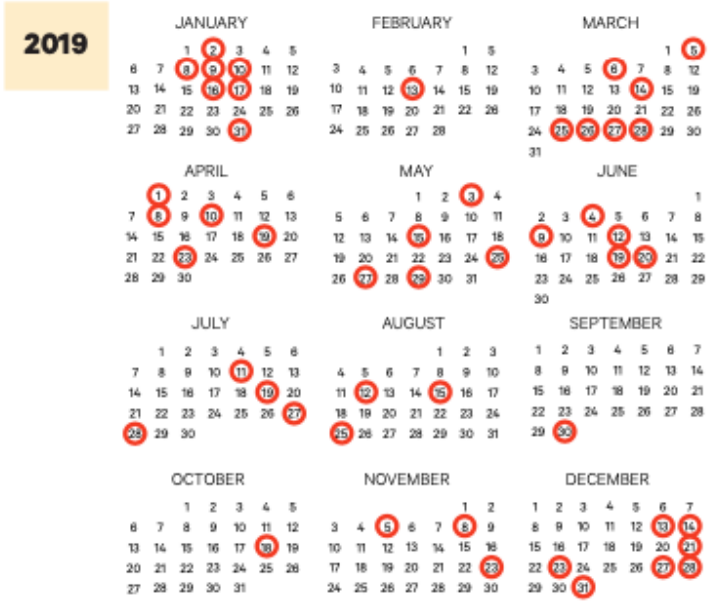
Description and map from: https://www.cdc.gov/sids/case-registry.htm

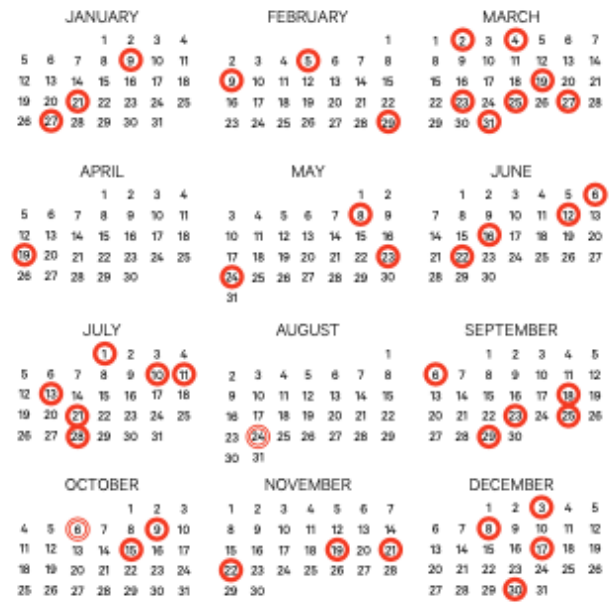
How do we get the data?

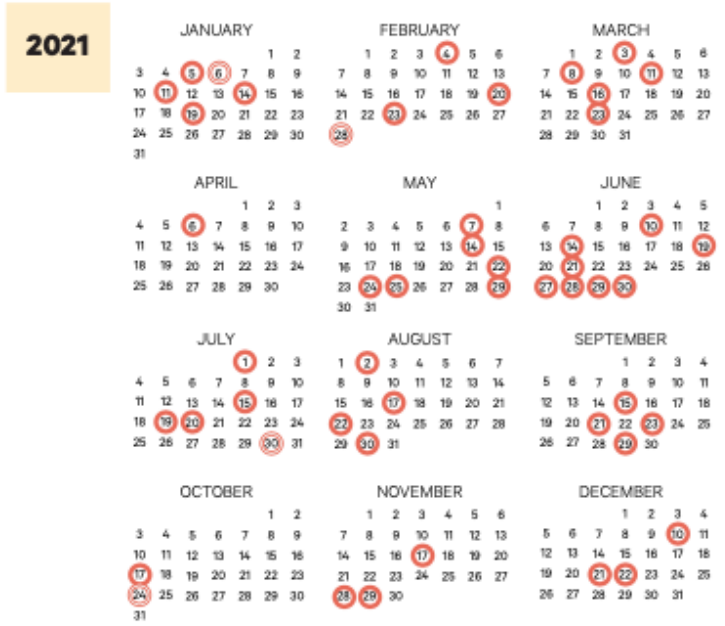


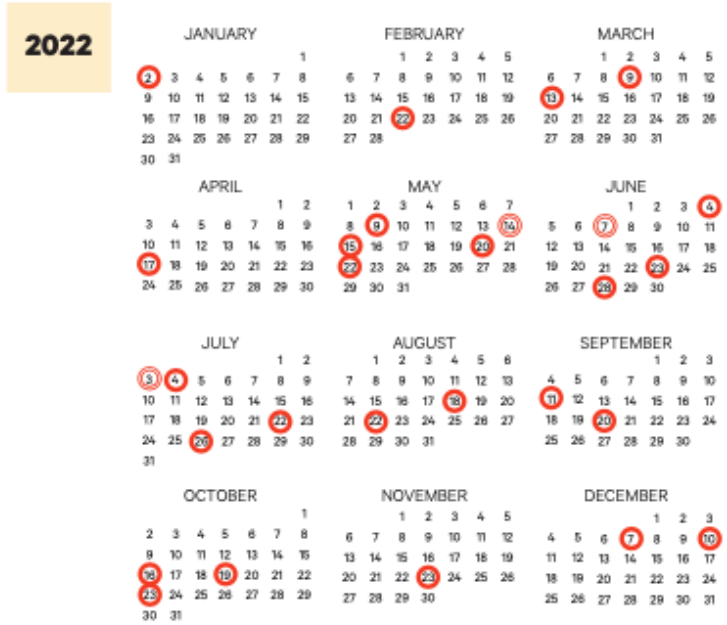
About once a week in Cook County, an infant dies while sleeping.

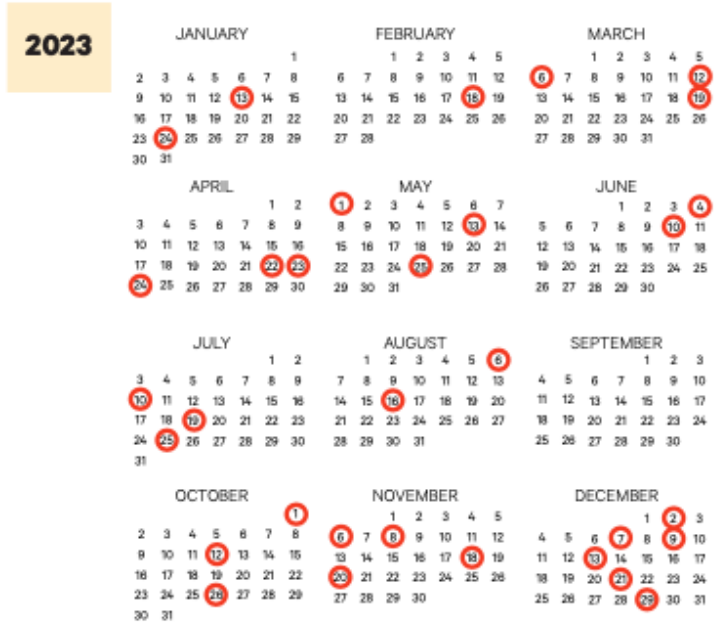
The **red** circles on the calendar represent the days that infants died suddenly and unexpectedly.











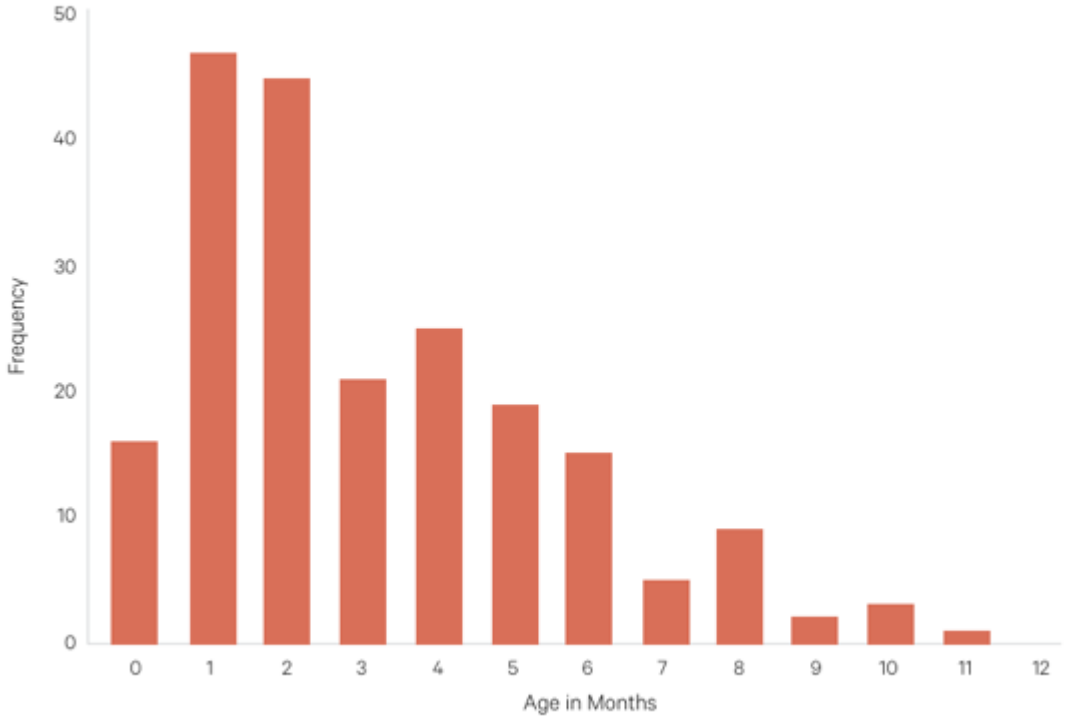
Cook County SUID: 2019-2023

Sleep-related: 208

Suffocation: 56

Undetermined: 152

Sleep-related SUID by Age (months)



The Sleep Environment

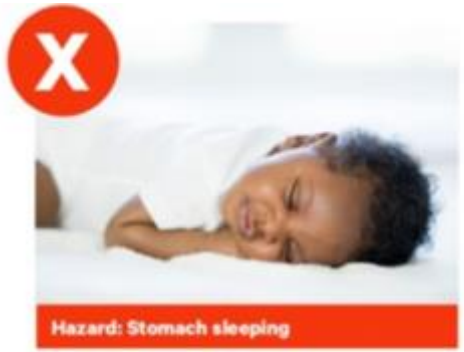
An infant sleeping safely is defined as:

- On their back
- In their own crib or bassinet
- With nothing in the crib or bassinet

Unsafe Sleep Factors Present: 99%

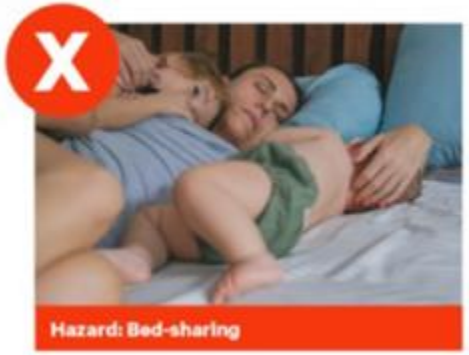
42%

Or **88** infants were found on their stomach or side in their sleep space.



66%

Or **135** infants were sleeping with another person(s).



84%

Or **175** infants were found in places not approved for infant sleep.

- 140 Adult Beds
- 18 Couch/Futon
- 4 Inclined products/3 Carseats
- 10 others

93%

Or **190** infants were found with soft bedding in their sleep space.

Unsafe Infant Products

Boppy Lounger

Snuggle Me

Yoocaa

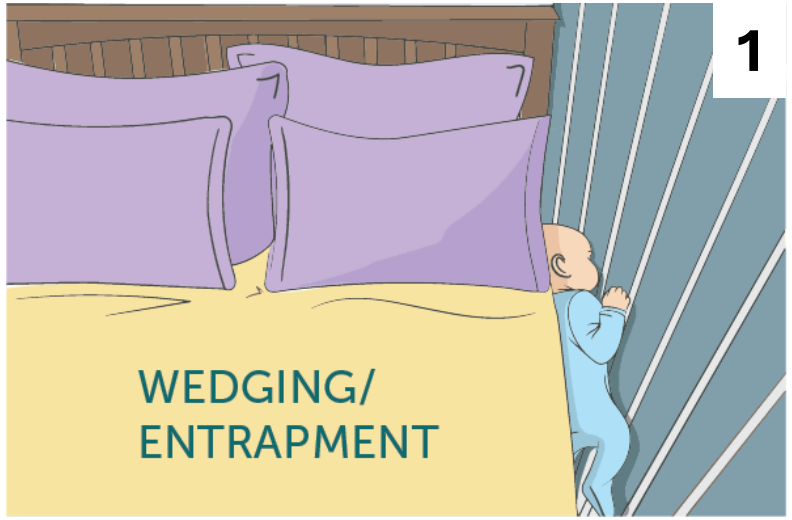
Dock A Tot

6 infant deaths occurred in "baby loungers"

Boppy Pillow

5 infant deaths occurred in boppy pillows when used for propping up infants for sleep*

Mechanisms of Suffocation (56)

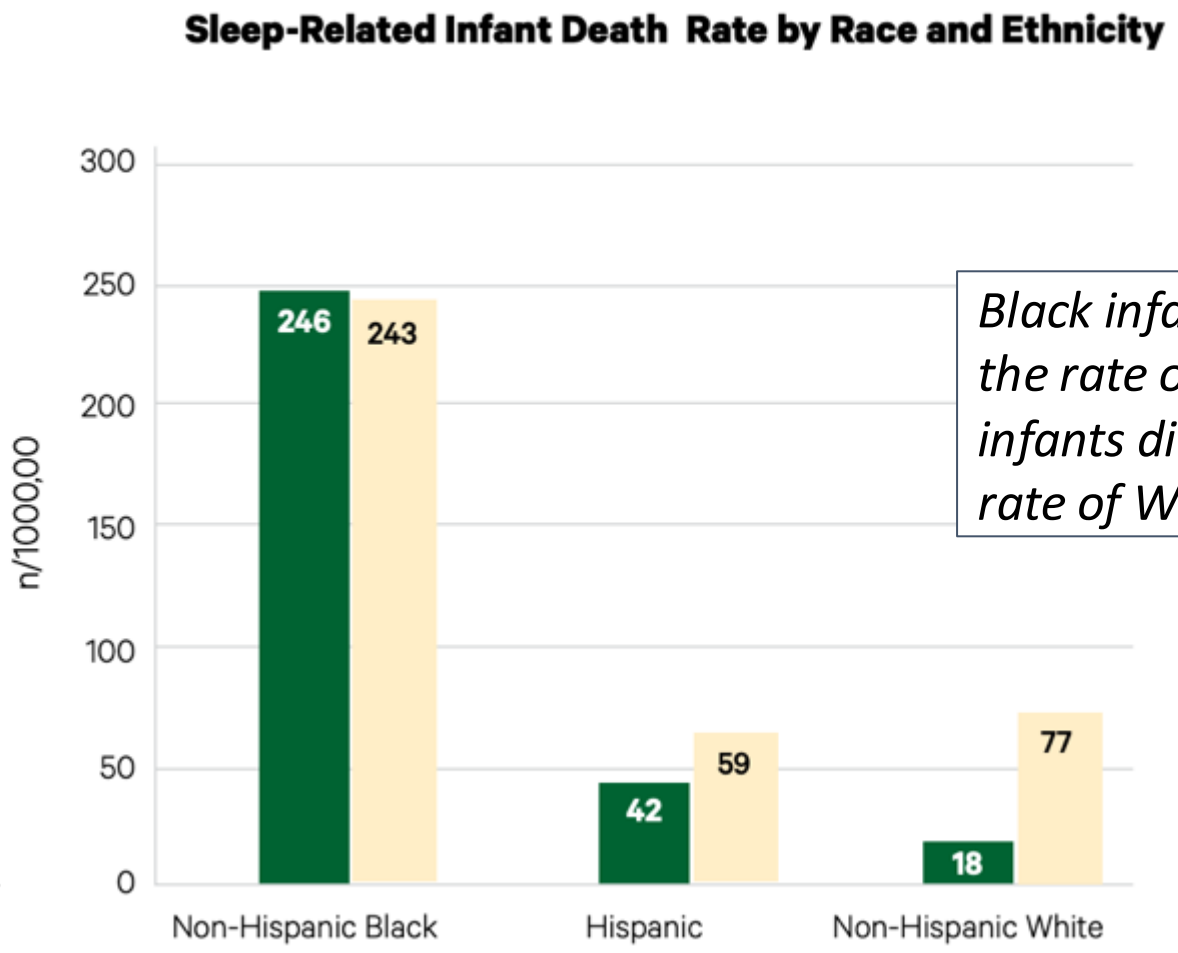


2 (soft bedding and overlay)

5 (soft bedding and wedging)

2 infants suffocated from **other mechanisms**

Race and Ethnicity



*Black infants died of SUID at **14 times** the rate of White infants, and Hispanic infants died of SUID at over **2 times** the rate of White infants.*

Cook County Rate

National Rate

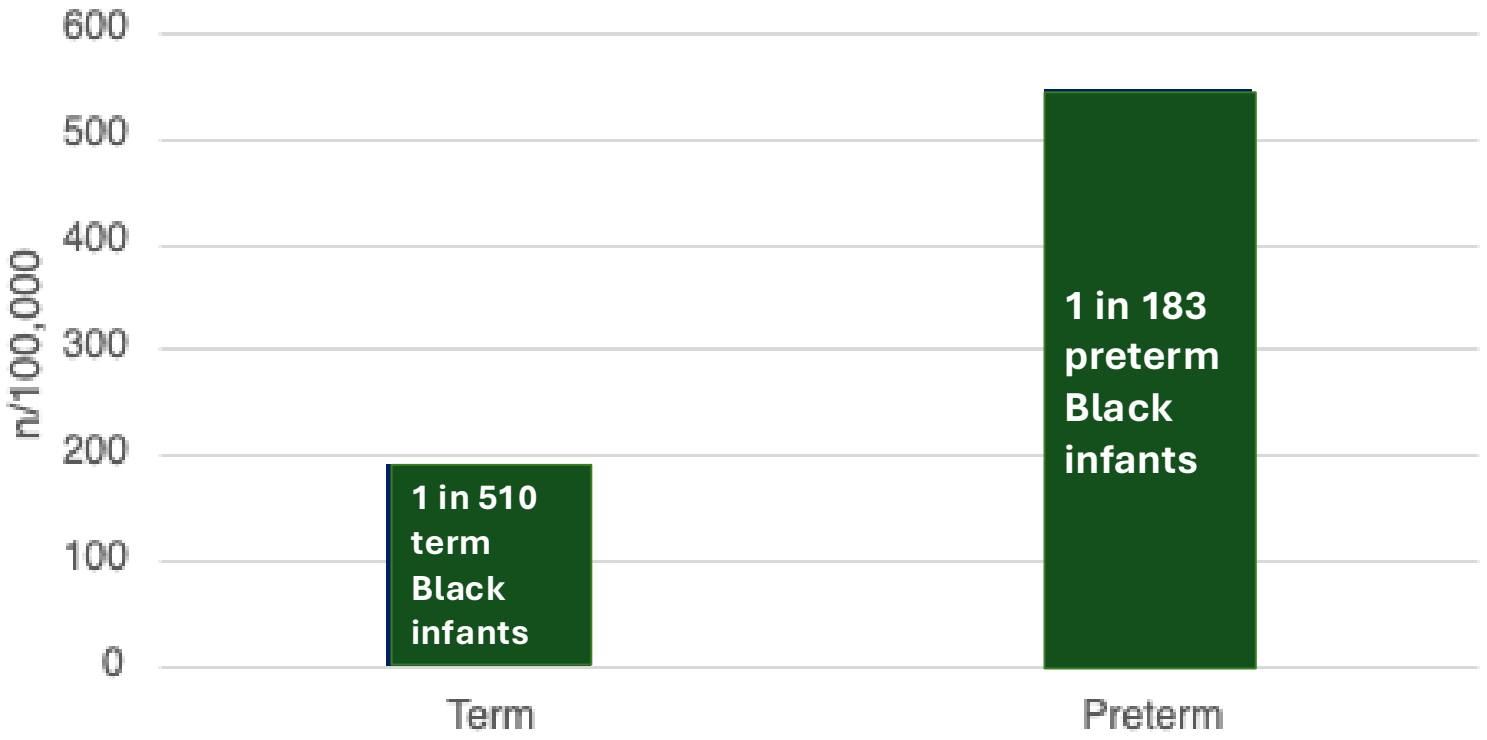
US Data from CDC WONDER, Multiple Cause of Death (final), 2019-2023, Queried 2.25.25

Preterm SUID Among Black Infants

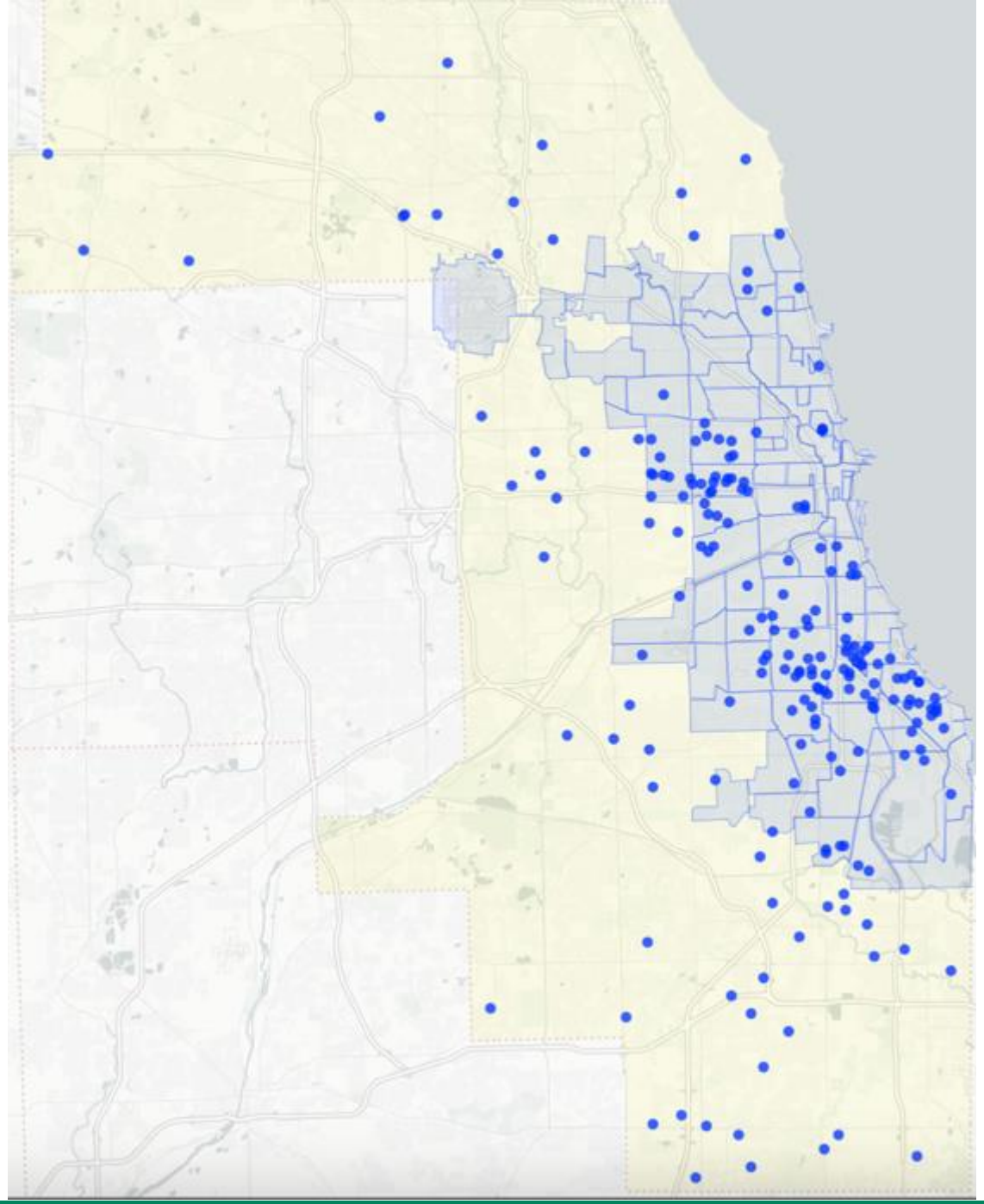
33%

of all SUID among Black infants had a history of **prematurity**

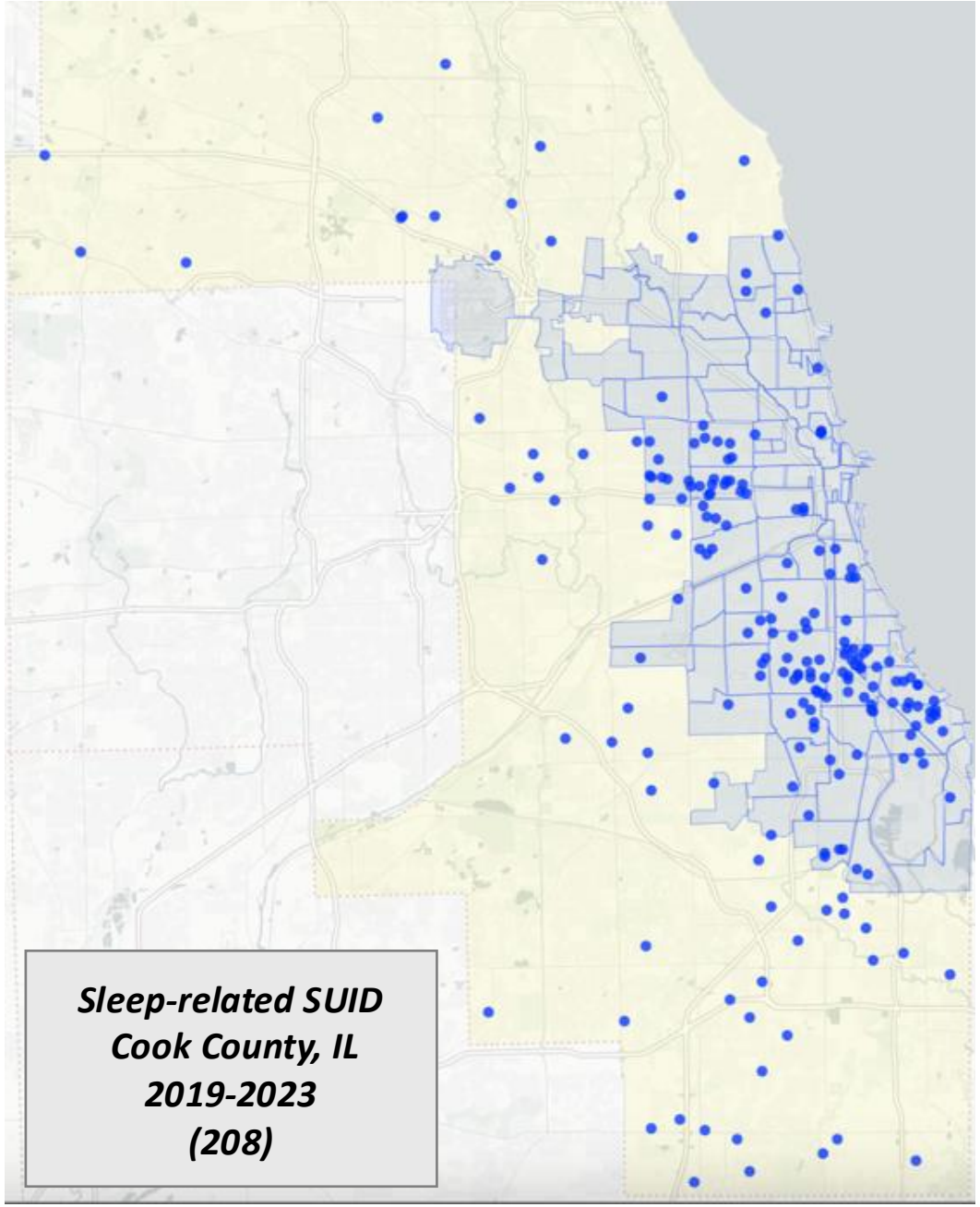
Term vs Preterm SUID Rate for Non-Hispanic Black Infants, Cook County, IL, 2019-2023

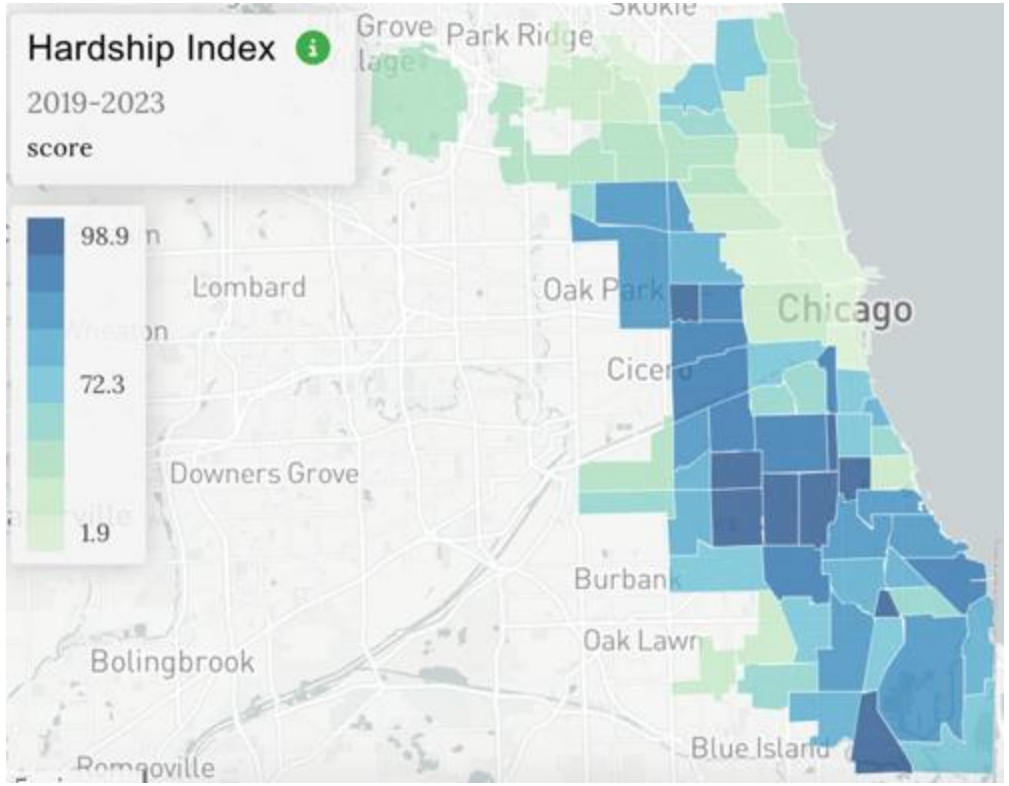


Sleep-related SUID
Cook County, IL
2019-2023
(208)



SUID and High Hardship





CHICAGO HEALTH ATLAS

The Hardship Index is a composite score reflecting hardship in the community (higher values indicate greater hardship). It incorporates unemployment, age dependency, education, per capita income, crowded housing, and poverty into a single score that allows comparison between geographies. It is highly correlated with other measures of economic hardship, such as labor force statistics, and with poor health outcomes.

27%

of SUID occurred among infants with a history of **prematurity**

27%

of SUID occurred among infants with a history of **low birth weight or very low birth weight.**

32%

of SUID occurred among infants with a history of a **NICU stay**

18%

of SUID occurred among infants with a history of **prenatal or household smoking.**

18%

of SUID occurred among families with a history of **domestic violence.**

29%

of SUID occurred among families with a history of a **substance use.**

30%

of SUID occurred among infants of mothers with a history of **justice-involvement.**

49%

of SUID occurred among infants of fathers with a history of **justice-involvement.**

14%

of SUID occurred among infants with both mothers and fathers with a history of a **justice-involvement.**

SUID During Temporary Stays

16%

of SUID occurred when infants were **temporarily staying somewhere else***

	Usual Home (174)	Temporary Stay (34)
Peak Age	1-2-months	4-months
Non-Hispanic Black infants	121 (70%)	32 (94%)
Maternal Age <25 years*	65 (37%)	19 (56%)
Supervisor: Mother	125 (72%)	14 (41%)
Supervisor: Non-parent relative	9/171 (5%)	9/26 (35%)
No crib available	42/146 (29%)	17/29 (59%)

Characteristics of SUID that occurred while an infant was temporarily staying with others

**Data from 208 sleep-related SUID, 2019-2023*

All statistically significant differences ($p<0.05$)

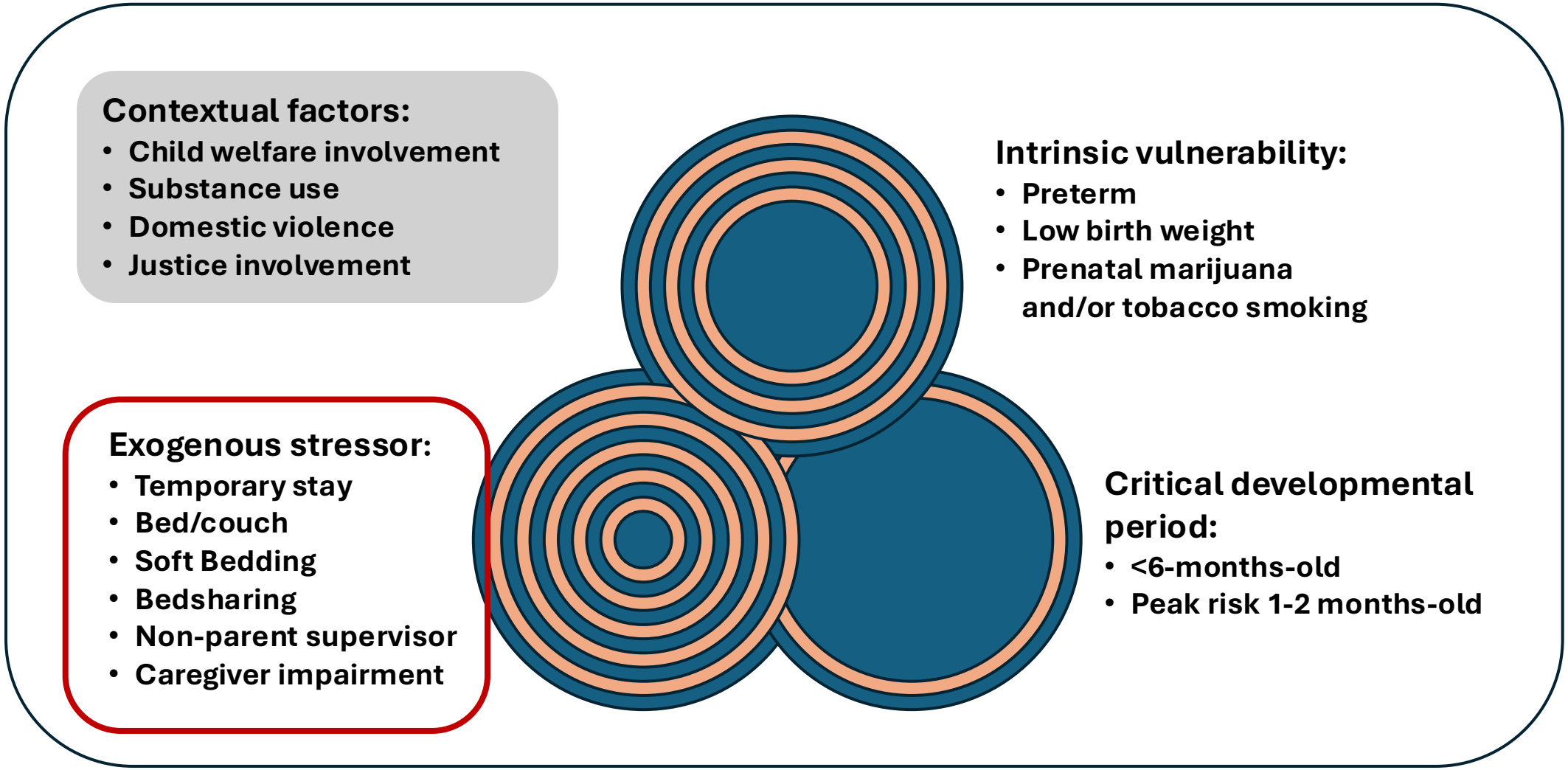
Sensitivity Warning: Case Sharing

The next slides show doll scene reenactments, and not the real baby.

These photos may evoke difficult feelings.

Please step away if needed.

Please do not take screenshots out of respect for our families.



Triple Risk Model demonstrating layered risk and underlying contextual factors for sleep-related infant death

Towards Prevention

Safe Sleep is life-saving.

We have known the ABCs of safe sleep for a long time.

How do we address what gets in the way of safe sleep?

Community Partnership Approaches to Safe Sleep: CPASS Chicago

RUSH UNIVERSITY Children's Hospital

CHICAGO birthworks co.

FAMILY FOCUS

P.T. MAN
Proviso Township Ministerial Alliance Network
"Committed to Community Transformation

Follow us on Instagram at cpasschicago

Barriers to Safe Sleep: Family Experiences in Chicago

Physical Environment

Lack of space
- Can't fit crib
- Using crib for storage
- Choosing crib for toddler sleep

Sharing with other families
- Having to live by others' rules

Lack of heat
- Keep baby close to keep warm

Bugs/Rodents
- Keep baby close to keep safe

Staying with others/Change in environment
- No arrangements made for safe sleep
- Fathers/others may not have cribs with them when baby stays overnight

Safety

Neighborhood violence/Domestic violence
- Feels safer if baby is right next to parent
- If something happens, baby is close

Shelter living
- Fear baby will be taken
- Cribs unavailable in some shelters

What matters

Getting to school/work in the morning
- Shift work
- Reliance on tired caregiver

Rewarding/satisfying to have baby close

Bonding

Better sleep (on stomach)

Education

Mothers typically "know" the ABCs

Fathers/others may not be present during education in hospital/clinic

SIDS is something that just happens (cannot prevent)

Non-urgency of the problem

Experience/Expectations

Nothing happened with other babies (who were in "unsafe" sleep)

SIDS – is something that just happens (cannot prevent)

Non-urgency of the problem

We collected our experiences with families that inform our lens when holding conversations about SUID and Safe Sleep with parents. ***Listening and letting families lead centers our approach.***

*I thought it was very informative. I **didn't know this was common within our community** amongst my demographic*

*Being a first time mom when the lady said "you would never think it'll happen to you until it does" it stuck out to me. **Preparation is key**! Having a crib for my baby is the safest option*

Scan to watch our safe sleep video

*I feel as though the safe sleep video is extremely helpful because **I'm able to hear the point of view from a parent who has lost her child** due to unsafe sleeping. This video has now alerted me on what not to do with my baby and how I can avoid unsafe sleeping.*

*I feel that's good to know I am a new mother and that's something I needed to understand that baby sleeps in own crib **I have lost a nephew** due to SIDS*

*The video was very helpful im a first time mom and **actually planned on sleeping with my baby** in my bed but now that I see the video I see that its not safe helped me a lot to understand the danger of sleeping with my baby thank you*

*As a first time mom, I am very concerned with keeping my child safe. **To realize that black infants have a higher rate of dying by sleeping with adults is eye opening**. This has opened my eyes to how important it is to have my child sleep in her own bed when she arrives.*

*It kinda made me sad and cry a little bit , mainly because **I never knew** some of the things they were saying! And unfortunately my daughter sleeps with me! Now it has me a little scared and worried*

*This video is very informative, growing up babies slept with family members, **I wanna break that cycle**, I want my baby to have a baby bed for **safety most of all***

Scan to watch our safe sleep video

*Parent reflections**

**selected from 170 responses*

"[He] was born not breathing properly. . .And he was addicted to Tramadol. . . showing massive withdrawal. He was shaking, wasn't breathing, he was really upset. I was one of those people who was "He will not be in my bed", I was very adamant of that. I thought I knew what I wanted to do, but I think as my anxiety grew, it seemed to get way worse. . . I brought him in [to my bed]. . . I just done it; I didn't give anyone else an option. At that point ***I was extremely anxious about being away from him****. I think it was first for a nap. . . and it just progressed." (Charlie, 36, 3 children).*

Barrett S, Barlow J, Cann H, Pease A, Shiells K, Woodman J, et al. (2024) Parental decision making about safer sleep practices: A qualitative study of the perspectives of families with additional health and social care needs. PLoS ONE 19(3): e0298383. https://doi.org/10.1371/ journal.pone.0298383

I ended up having to stay with my mum because I was panicking, obviously, cot death—people got it drilled into my head, "You can't do this, you can't do that" so it was scaring me. I couldn't cope being a new mother. It was hard. ***I felt like I had no one to help me.*** *The resentment towards my daughter was just getting worse. So that's when I just decided what happens if I share a bed with her? So, I just tested it out. I got a lot more sleep and she got a lot more sleep and we just felt better the next day. It got to the point where she had to actually sleep in my bed so I can feel her breathe. I felt better. I felt more safe and less anxious because she was there right next to me.* (Ellie, 19, 1 child).

Barrett S, Barlow J, Cann H, Pease A, Shiells K, Woodman J, et al. (2024) Parental decision making about safer sleep practices: A qualitative study of the perspectives of families with additional health and social care needs. PLoS ONE 19(3): e0298383. https://doi.org/10.1371/ journal.pone.0298383

Conversation starters

~~Is your baby sleeping in their own crib, on their back, with nothing in the crib?~~

Where does your baby sleep at night? **How about for naps?**

Does your baby ever end up in bed with you? **Tell me more about that.**

How did you sleep with your other babies? **What's different now?**

Does your baby ever spend the night somewhere else?
Do they have a place for your baby to sleep?

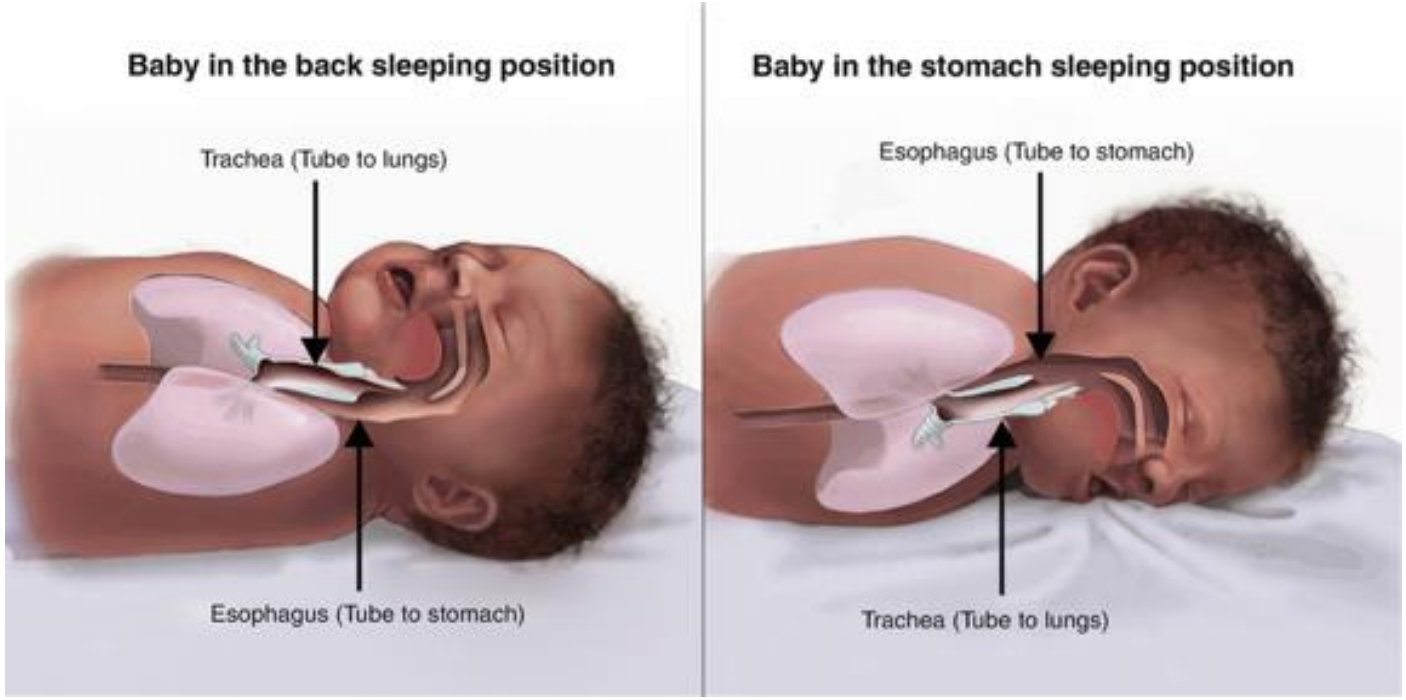
Where does your baby sleep when they're sick?
They're already having a hard time breathing, it can be even harder in bed with you.

At this age, babies can roll into a pillow or another person, but may not be able to roll back out.
It's just so easy for a little baby to suffocate.

Counsel to prevent ***suffocation***

Preventing Suffocation:

Airway Risks in Side or Stomach Positions



- ***Back sleeping does not increase the risk of choking.***
- *On their backs, refluxed/regurgitated fluid must work against gravity to be aspirated.*
- *On their stomachs, refluxed/regurgitated fluid will pool at the opening of the trachea, and more easily be aspirated.*

Preventing Suffocation:
Airway Risks in Inclined Sleep

Illustration by Chris Philpot for Consumer Reports

Inclined Sleep among Cook County infant deaths

87/247 (35%)

were placed on an incline
when put to sleep

Adult pillows
(40, 46%)

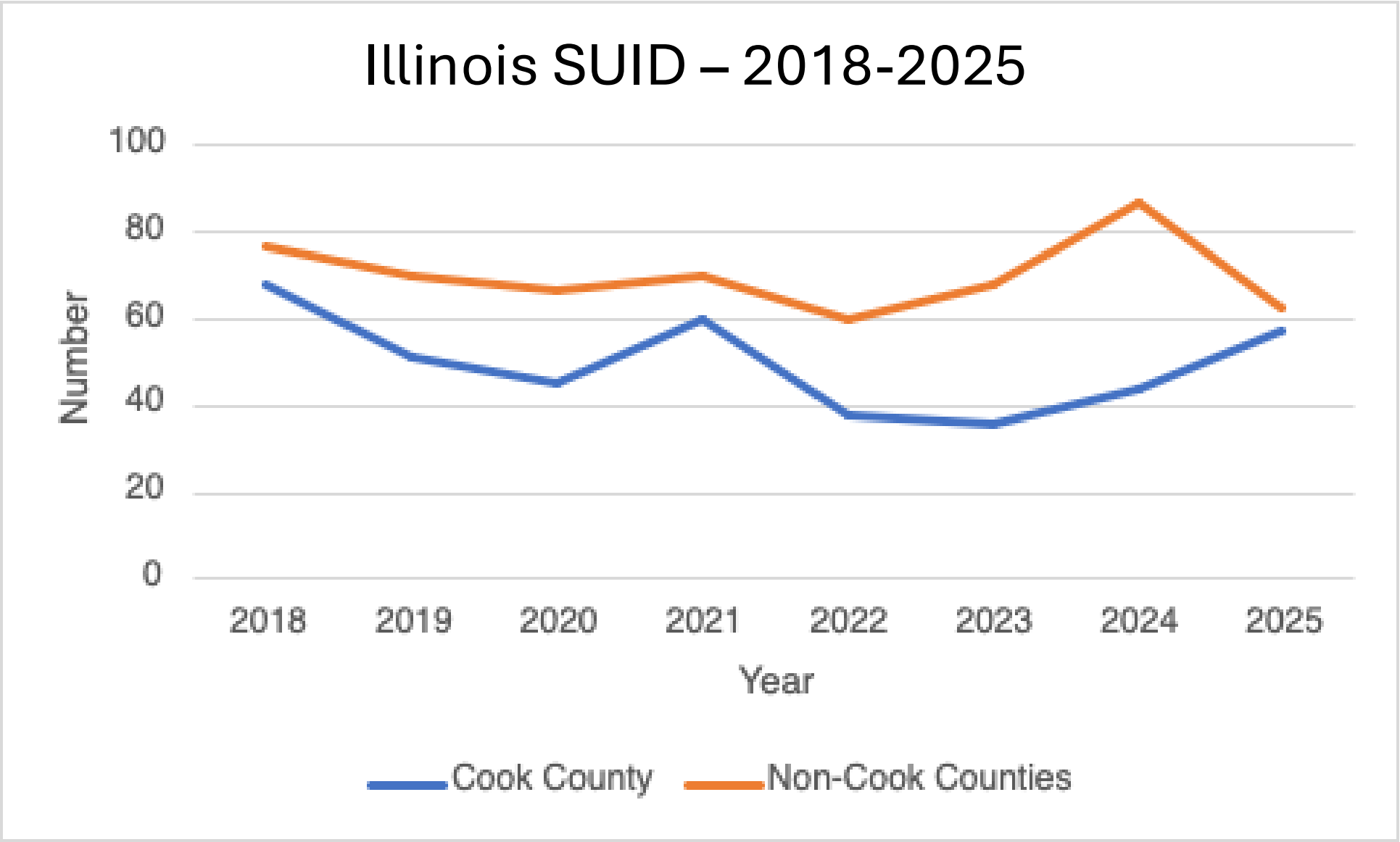
Arm/chest
(20, 23%)

Pillow product
(15, 17%)

Inclined product
(11, 13%)

Majority of inclined sleep deaths

Heavy prevention focus, studies, recalls

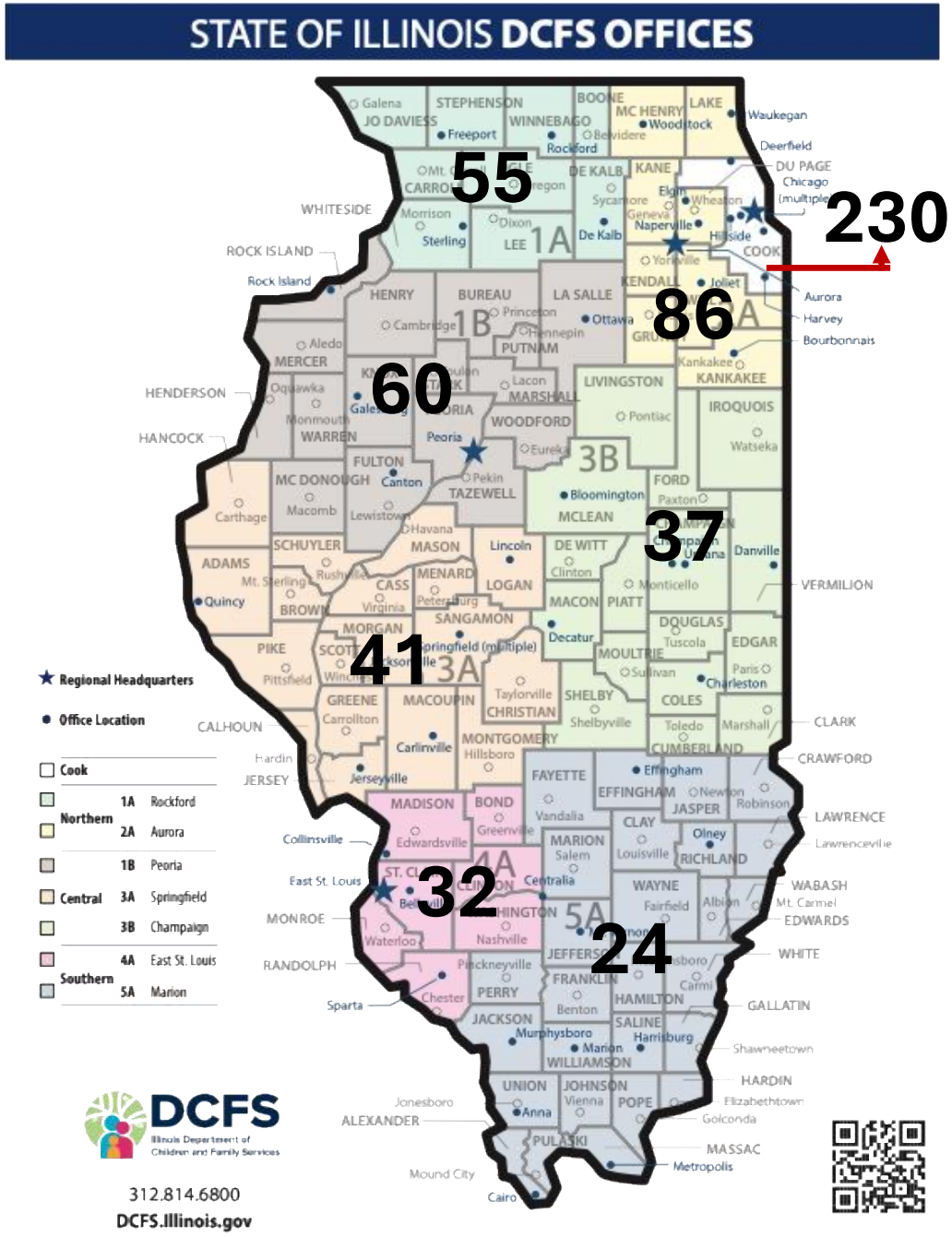


Average

70

50

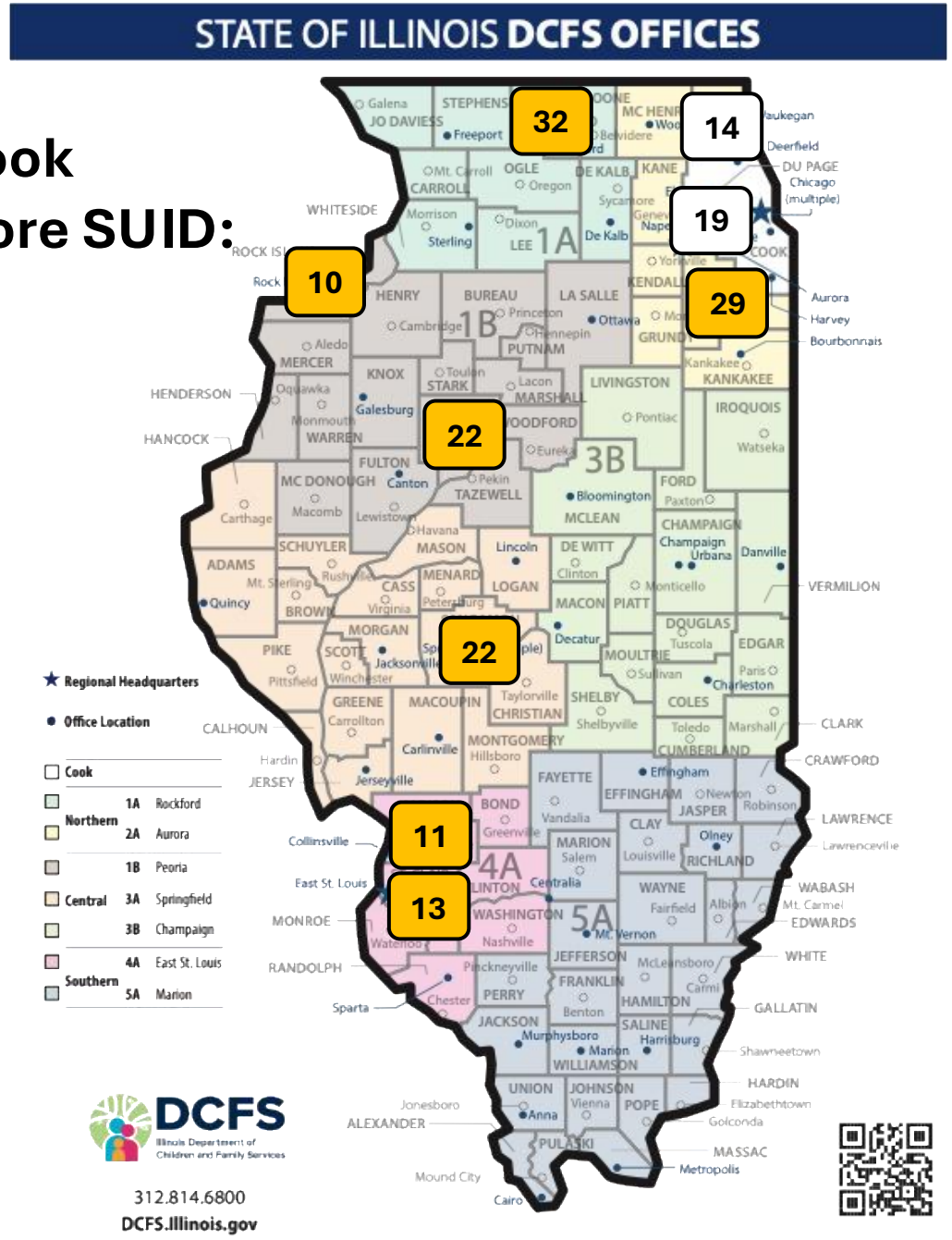
SUID Among IL Counties by CDRT region: 2019-2023



Total SUID*: 565

Data from CDC WONDER, Multiple Cause of Death (final), ICD-10 codes W75, R95, R99

SUID Among IL non-Cook Counties with 10 or more SUID: 2019-2023



n Indicates rate higher than Cook County (75/100,000)

	County	SUID	SUID Rate (n/100,000)
*	Winnebago	32	194
	Will	29	83
*	Peoria	22	204
*	Sangamon	22	213
	DuPage	19	39
	Lake	14	42
	St Clair	13	96
	Madison	11	82
	Rock Island	10	129

Data from CDC WONDER, Multiple Cause of Death (final), ICD-10 codes W75, R95, R99

DCFS investigation of Cook County SUID

Cook County SUID	2023 (34)	2025 (47*)
Not Taken for Investigation	4 (12%)	31 (66%)
Investigated	30 (88%)	16 (33%)
Indicated	4 (12%)	1 (2%)

*42 of 53 SUID reviewed to date

How does SUID prevention intersect with the work of CACI?

Resources

Safe Sleep Video

Charlie's Kids

Pep talks

Animated videos

Is a Baby Product Product Safe?

Go to SaferProducts.gov:

SaferProducts.gov is where the public can file and read complaints about thousands of types of consumer products.

Report unsafe products
Your report will let CPSC and other Americans know you found a dangerous product.
REPORT NOW

Search for unsafe products
Protect your family and search to see if a product is unsafe before you buy.
Enter a product name here...
SEARCH NOW

Business registration and product reports
Business owners only – register to report unsafe products, receive notifications, and respond to unsafe product reports.
REGISTER/RESPOND

Enter product name: e.g. "yoocaa"

Find consumer issues and recalls

And report unsafe products too!

SaferProducts.gov
Report. Search. Protect.

Report | Search | Business | About | FAQs

All Types | yoocaa | SEARCH

Advanced Search +

Print | Export

Sort By: Relevance | Show: Summary | Results per page: 10

Consumer reported 3 MOM was put down to sleep in co-sleeper pillow, later he was found deceased,...
Incident Report | 12/18/2023 | 20231116-DE3B6-2147343983

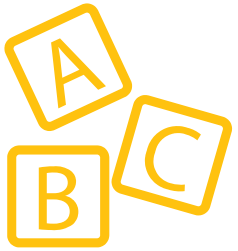
Incident Description: My son was put down to sleep in the co-sleeper pillow made by yooca and sold by Amazon. I purchased the pillow in April of 2021, and on July 18th, 2021 my son was found deceased, entrapped between my bed and the wall as a result of getting out of this co-sleeper at just 3 months old. Court documents ruled that his death was due to "unsafe sleep" from use of this co-sleeper.

It is reported that a 4-month-old baby has been found dead in the baby lounger due to...
Incident Report | 4/19/2023 | 20230314-FFAF4-2147348751
Incident Description: A 4-months-old baby has been found dead in one these loungers due to Asphyxiation.

Yoocaa Baby Loungers Recalled Due to Suffocation Risk and Fall and Entrapment Hazards; Fails to...
Recall | 11/2/2023
Recall Description: This recall involves baby loungers made of a cloth cover with a foam sleeping pad and padded bumper. The baby loungers were advertised as "baby lounger" and "baby nest" and were sold in different printed fabrics and colors, including animal, blue star, cloud, feather, flower, forest, leaf, pink star, polar bear and zoo. "SLEEPING SET" is printed on a tag sewn on the interior of the cover. The recall applies to products purchased on or after June 23, 2022, and consumers should review their...

Unsafe Infant Sleep Products

Follow the ABCs of Safe Sleep in all Sleep Situations



Baby is Alone and has their own separate sleep space from adults and children.
Baby is placed to sleep on their Back.
Baby sleeps in a Crib, play yard or bassinet that meets the federal safety standard.

Avoid the Following Unsafe Products for Sleep

Crib Bumpers

Crib bumpers can pose suffocation, strangulation, and choking hazards. A baby's face can get pressed against the bumper or wedged between the bumper and the crib side or mattress.

Inclined Sleep Products

Inclined sleep products are often marketed for sleep, but present suffocation risks due to potential chin-to-chest positioning that restricts airways. Infants can also roll in the product and become entrapped.

Sleep Positioners/ Loungers

Sleep Positioners have been known to suffocate children when they roll into them. Loungers, like the one shown, violate the CPSC's Infant Sleep Products Rule.

Remove all soft bedding from your baby's sleep area.
This includes pillows, blankets, stuffed animals, and toys. ALONE is SAFE.

Kids In Danger | www.kidsindanger.org

Infant Sleep Product Recalls and Warnings

Inclined Sleep Products

1. Fisher-Price Rock 'n Play Sleeper
2. Dorel Inclined Sleepers
3. Summer Infant SwaddleMe By Your Bed Sleeper
4. Graco Little Lounger Rocking Seat
5. Kids II Rocking Sleeper
6. Evenflo Pillo Portable Napper
7. Fisher-Price Ultra-Lite Day & Night
8. Delta Incline Sleeper with Adjustable Feeding Position for Newborns
9. Kolcraft Inclined Sleep Accessory in Cuddle 'n Care and Preferred Position 2-in-1 Bassinets & Incline Sleepers
10. Graco Inclined Sleeper Accessory in Pack 'n Play Play Yard Models
11. Fisher-Price 4-in-1 Rock 'n Glide Soother and 2-in-1 Soothe 'n Play Glider
12. Peg Perego Inclined Sleeper Bassinets
13. Nap Nanny

Sleep Positioners/Loungers

1. Dockatot Deluxe+
2. Yoocaa Baby Loungers
3. Boppy Newborn Loungers
4. Momaid Infant Loungers
5. Gorsetle US Infant Loungers
6. La-La-Me Infant Loungers
7. Miracle Baby Loungers
8. "Baby Lounger" Sold by Poetint002 on Amazon

Other Sleep Products

1. Meiling Hou Crib Bumpers
2. CaTeam Canvas Baby Hammock
3. Girasol Rainbow Love Woven Wrap Sling Carriers
4. CCATTO Baby Tents
5. Sling Carriers Sold as Biayxms, Brottfor, Carolily Finery, Gotydi, Musuos, N\C, Topboutique, and Vera Natura
6. "5-in-1 Rocker Bassinets" sold at Walmart
7. Karriw Crib Bumpers

Check all products that you use for sleep against the CPSC website for more recent recalls and warnings.

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Jan. 2024

Hazardous infant products: **Inclined sleepers**

Hazardous infant products: **Baby Loungers**

Boppy Lounger

Snuggle Me lounger

Yoocaa lounger

Dock A Tot

6 infant deaths occurred in these products in Cook County from 2019-2023

Hazardous infant products: **Nursing Pillows**

Boppy Pillow

September 2024

- CPSC approved a new federal mandatory standard to improve the safety of nursing pillows to protect babies from injury and death.

- CPSC reported **154 infant deaths** and 64 injuries between 2010 and 2022 associated with nursing pillows, with most occurring among infants **younger than three months old**.

- Majority of these deaths involved the nursing pillow being used for **propping up an infant to sleep** on an adult bed or mattress, in a crib or portable playpen, or on a couch.

5 infant deaths occurred in these products in Cook County from 2019-2023

Hazardous infant products: **Weighted sleep sacks**

Dreamland

Nested Bean

CPSC has linked weighted sleep products to at least 2 infant deaths

Hats and Bonnets

No hats needed after discharge from the hospital – may cause overheating, suffocation

Safe Sleep Checklist

Use this checklist to help keep babies in your shelter sleeping in safe environments.

ALONE	☐	Does the baby have their own, separate sleep space?	☐	If the parent had twins or multiples, is each baby sleeping separately?
BACK	☐	Is the baby sleeping on their back?		
CRIB	☐	Is the baby in an approved crib or bassinet?	☐	If the Snuggle Nest bassinet is being used, is it on the cot alone?
NO SOFT BEDDING	☐	No blankets, toys, stuffed animals, pillows, or any item other than a pacifier in the baby's sleep space.		

Illinois
Safe Sleep
Support

To order IL Safe Sleep Support materials
email **DHS.BMCHEDF@illinois.gov**

This happens in our state
every 3 days.

Counsel to prevent ***suffocation***

Cook County SUID Case Registry and Prevention

Find us at

rush.edu/suid

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