INDIANA UNIVERSITY
1820–2020
FULFILLING the PROMISE

Indiana University School of Nursing

Racial Equity Considerations in Safe to Sleep Messaging: Learning from the Community

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Associate Professor

One baby dies every 14 hours

1-2 babies die everyday

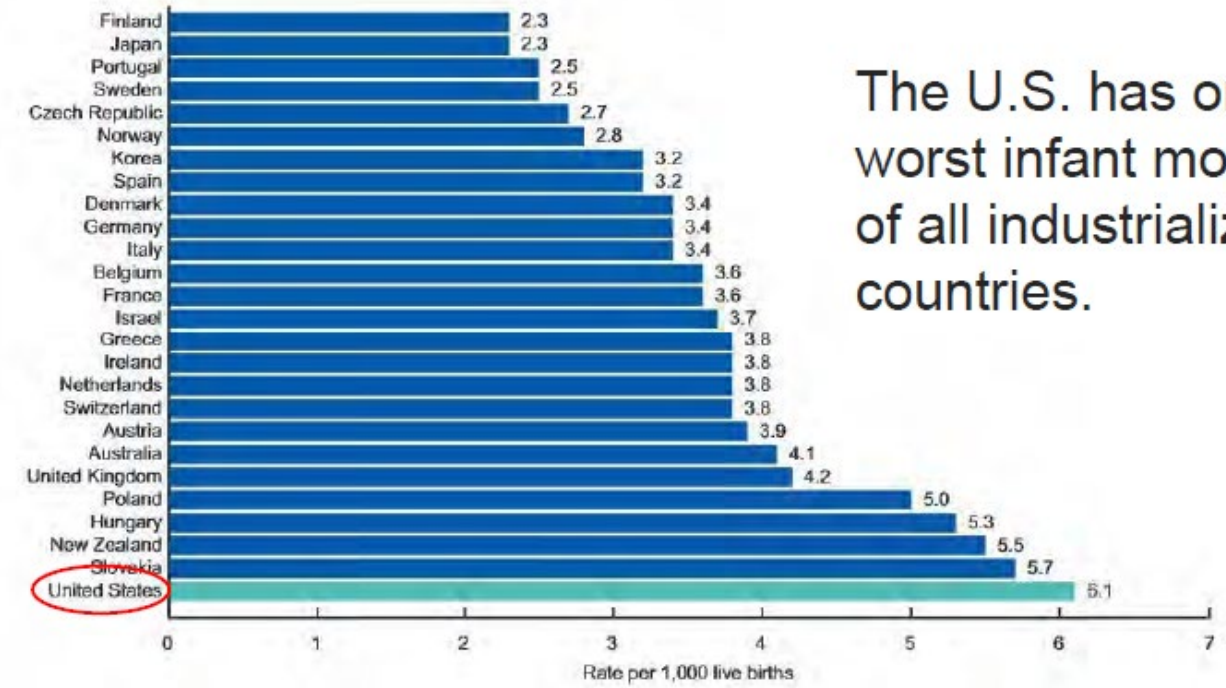
Infant Mortality

Death of infant before his/her 1st birthday

SECTION 1

Statistics

A National Disgrace



NOTES: Canada's 2010 data were not available from the Organisation for Economic Co-operation and Development (OECD) at the time of manuscript preparation. The 2009 infant mortality rate for Canada was 4.9. If the 2010 data for Canada had been available, the U.S. ranking may have changed. Deaths at all gestational ages are included, but countries may vary in completeness of reporting events at younger gestational ages.
SOURCES: CDC/NCHS, linked birth/infant death data set (U.S. data); and OECD 2014 (all other data). Data are available from: http://www.oecd.org.

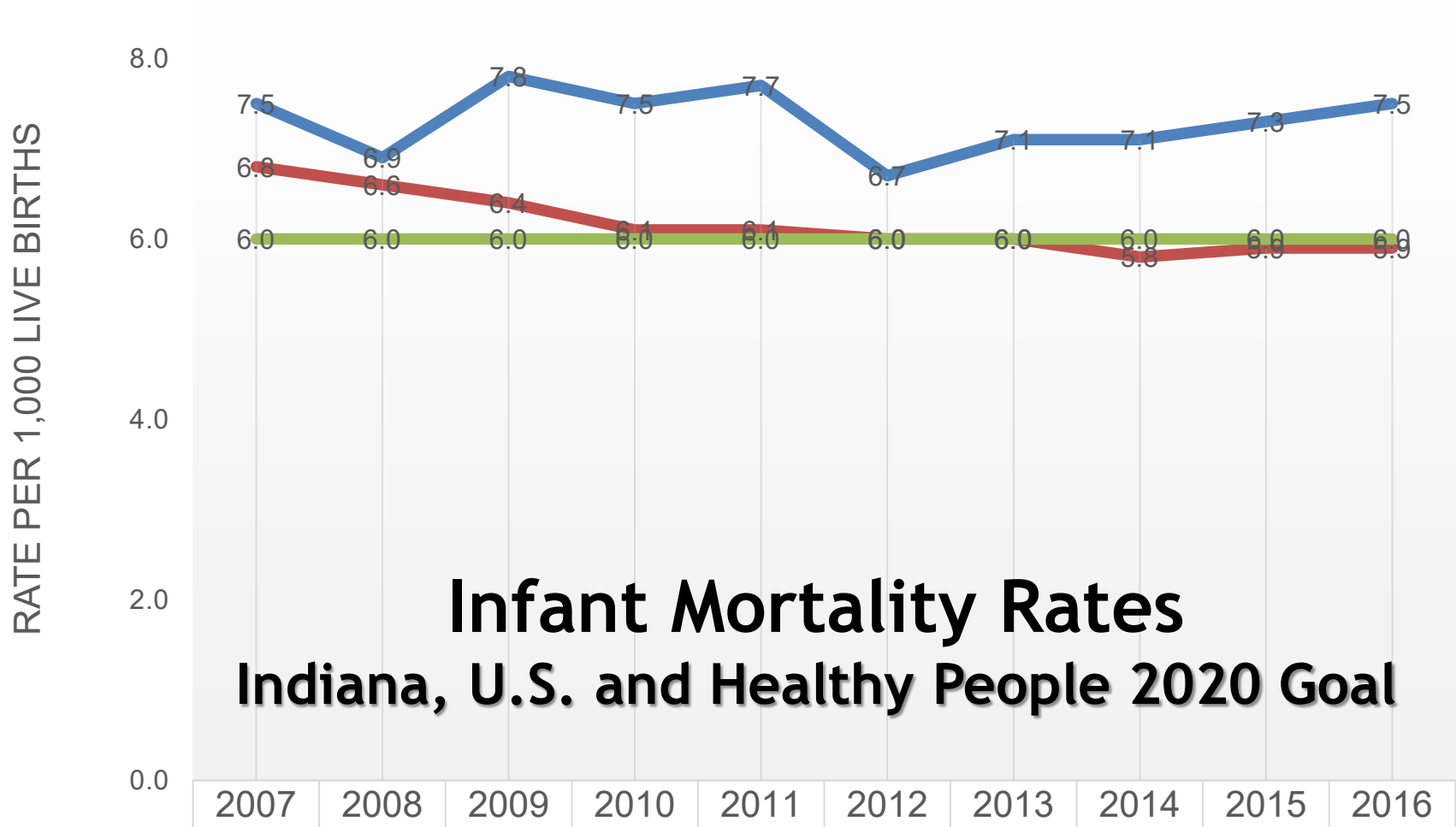
The U.S. has one of the worst infant mortality rates of all industrialized countries.

NICHQ

161	LEBANON	7.40	2017 EST.
162	KUWAIT	7.00	2017 EST.
163	RUSSIA	6.80	2017 EST.
164	CHILE	6.60	2017 EST.
165	SAINT PIERRE AND MIQUELON	6.50	2017 EST.
166	PUERTO RICO	6.40	2017 EST.
167	QATAR	6.20	2017 EST.
168	CAYMAN ISLANDS	5.90	2017 EST.
169	GIBRALTAR	5.90	2017 EST.
170	UNITED STATES	5.80	2017 EST.
171	SERBIA	5.80	2017 EST.
172	BOSNIA AND HERZEGOVINA	5.50	2017 EST.
173	FAROE ISLANDS	5.40	2017 EST.
174	NEW CALEDONIA	5.20	2017 EST.
175	LATVIA	5.20	2017 EST.
176	SLOVAKIA	5.10	2017 EST.

Central Intelligence Agency, The World Factbook, 2017

Source: Indiana State Department of Health, Maternal & Child Health Epidemiology Division [January 5, 2018] United States Original: Centers for Disease Control and Prevention National Center for Health Statistics Indiana Original Source: Indiana State Department of Health, PHPC, ERC, Data Analysis Team



	2007	2008	2009	2010	2011	2012	2013	2014	2015	2016
Indiana	7.5	6.9	7.8	7.5	7.7	6.7	7.1	7.1	7.3	7.5
U.S.	6.8	6.6	6.4	6.1	6.1	6.0	6.0	5.8	5.9	5.9
HP 2020 Goal	6.0	6.0	6.0	6.0	6.0	6.0	6.0	6.0	6.0	6.0

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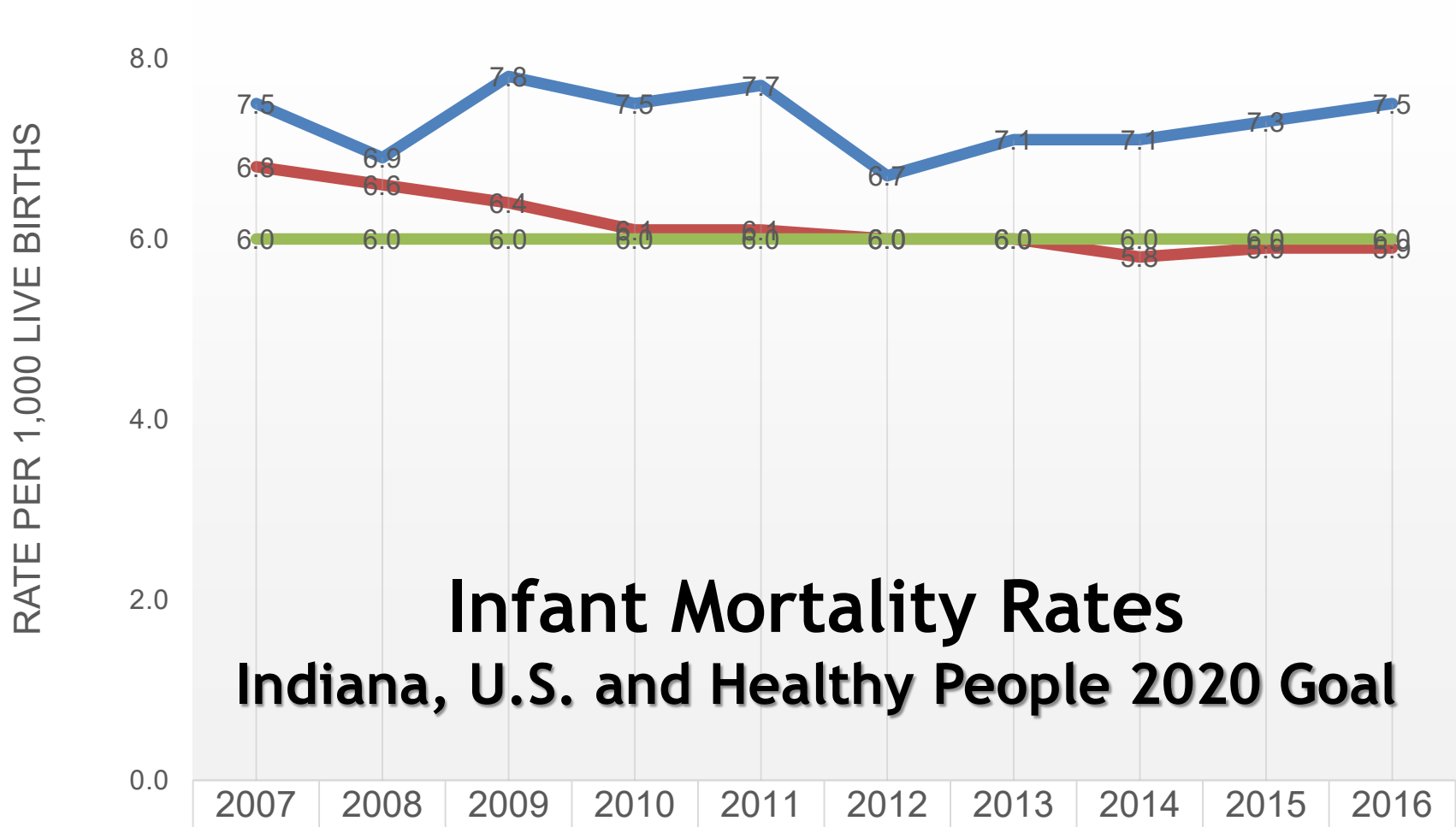

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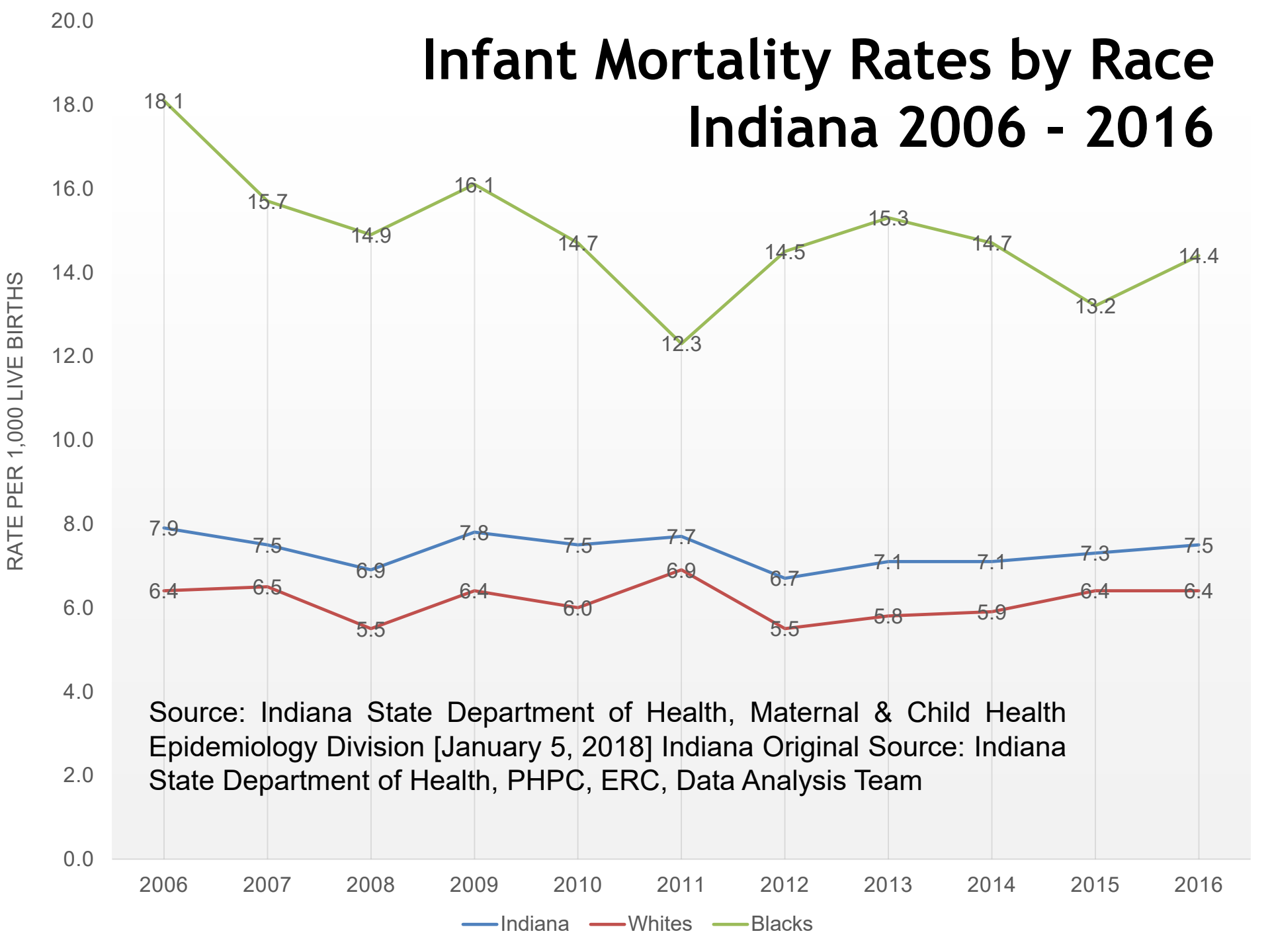
HP 2020 Goal	6.0	6.0	6.0	6.0	6.0	6.0	6.0	6.0	6.0	6.0

Infant Mortality Rates by Race
Indiana 2006 - 2016



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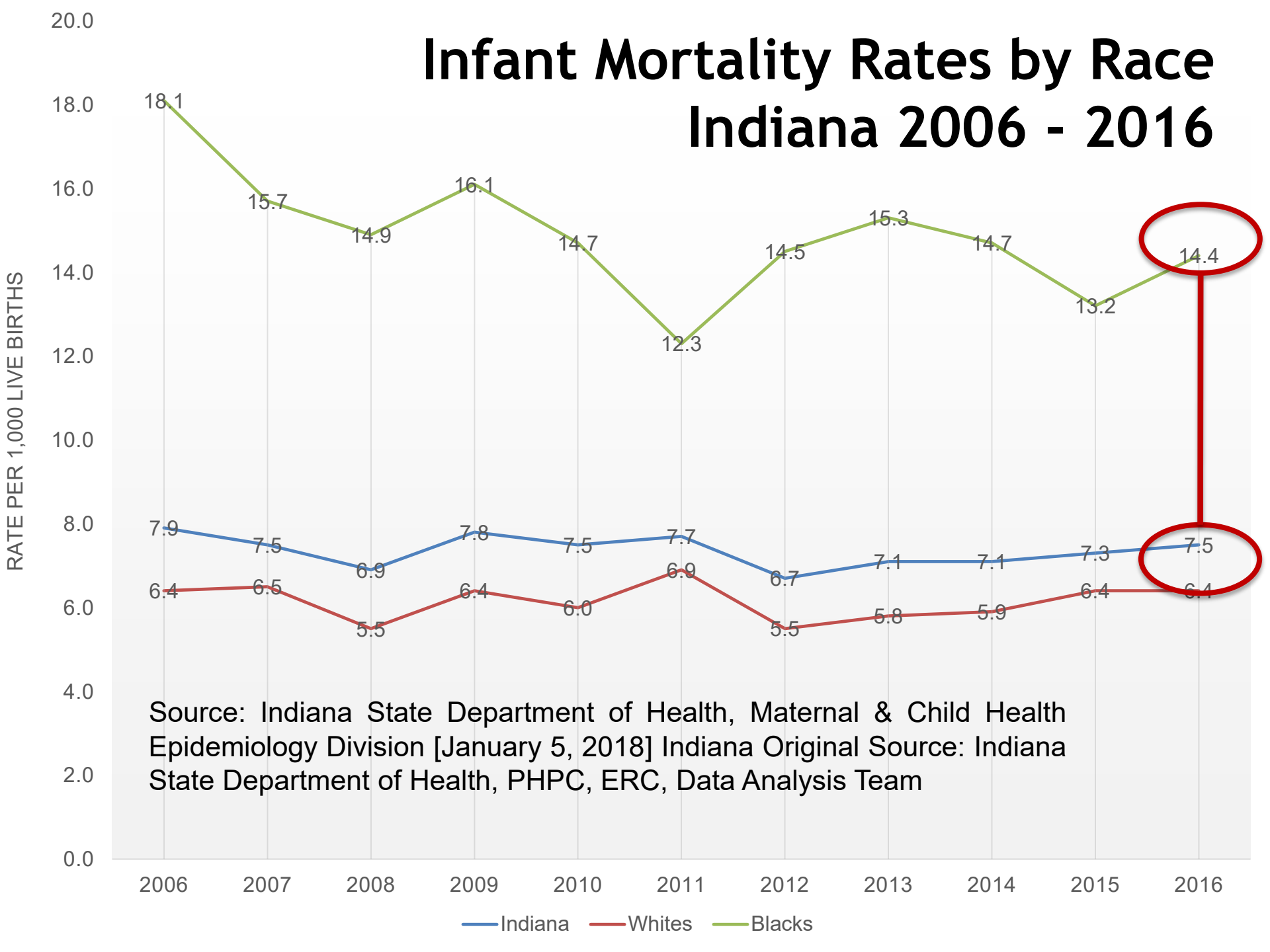
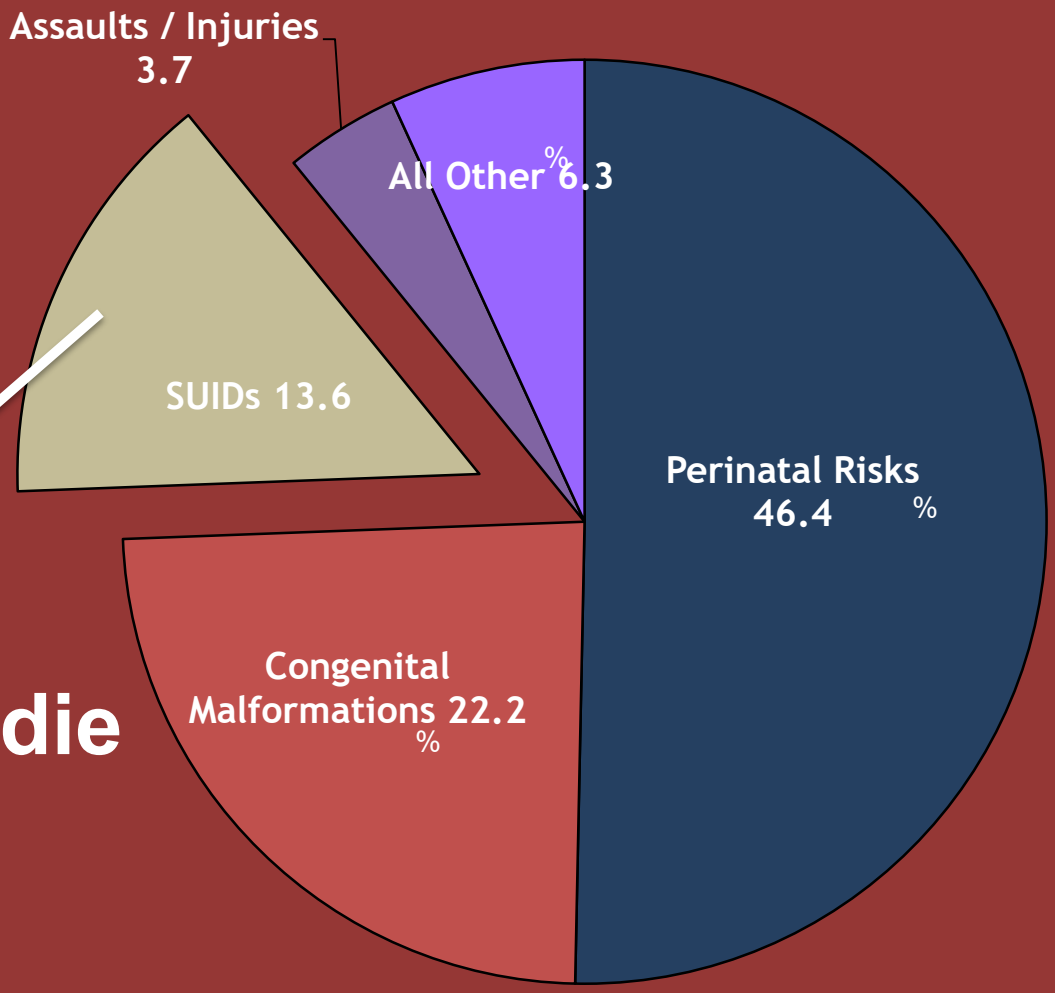


Source: Indiana State Department of Health, Maternal & Child Health Epidemiology Division [January 5, 2018] Indiana Original Source: Indiana State Department of Health, PHPC, ERC, Data Analysis Team

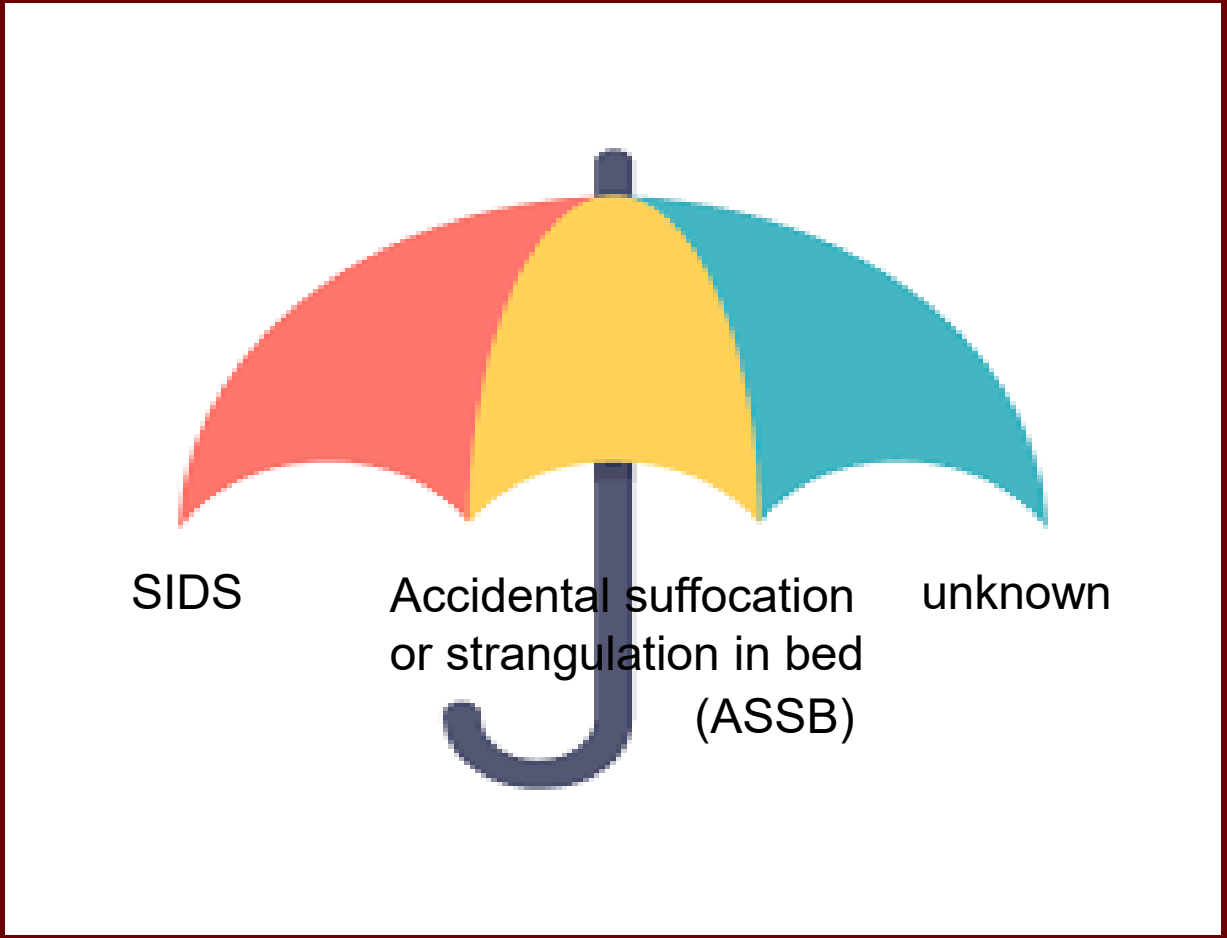
Indiana's Infant Mortality Causes

% Distribution of Infant Deaths IN 2016; N = 623

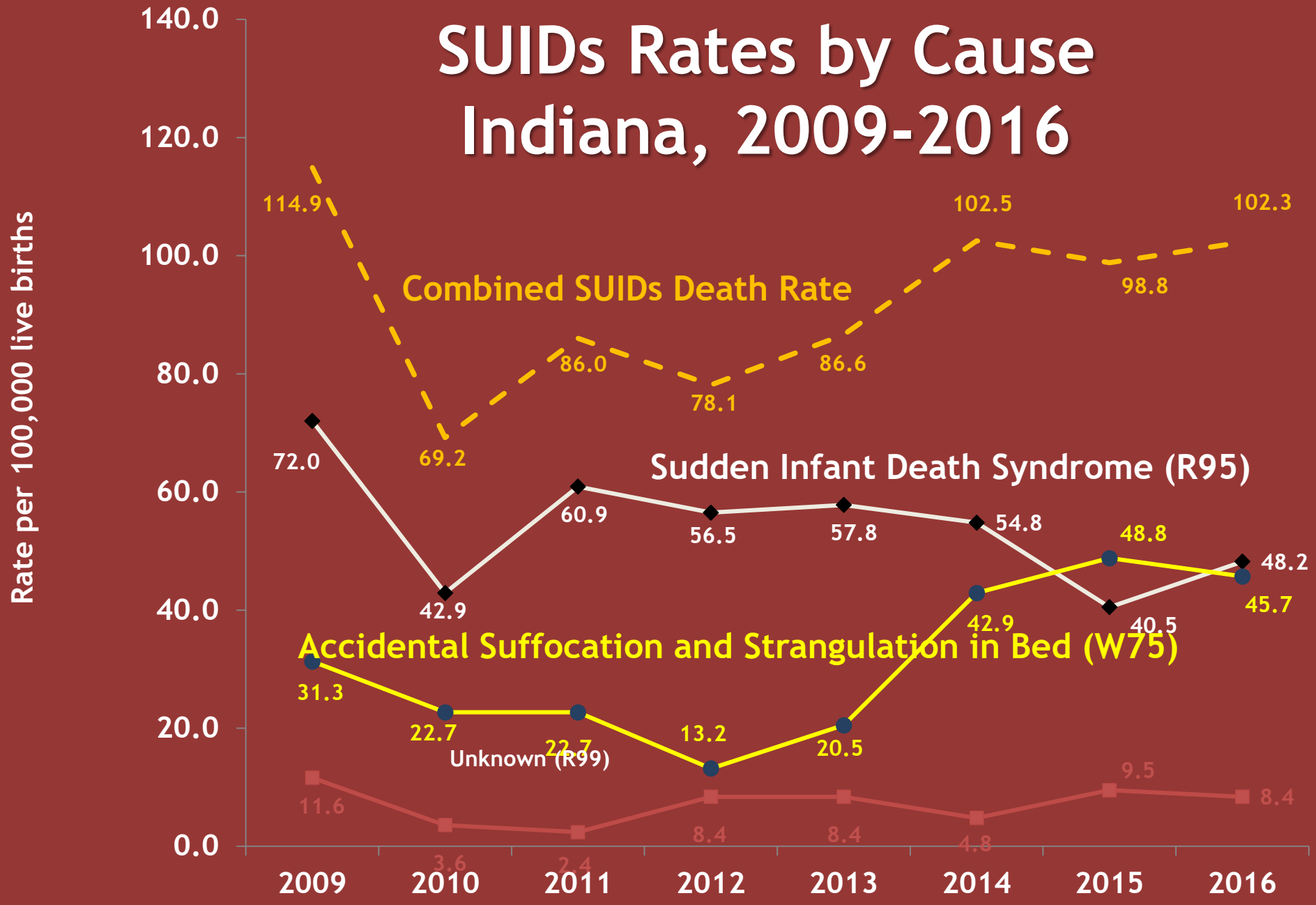


1 out of 8 babies who die

Sudden Unexpected Infant Death (SUID)



SUIDs Rates by Cause Indiana, 2009-2016



SUIDS = W75, R95, R99

Source: Indiana State Department of Health, Maternal & Child Epidemiology Division [January 5, 2018]

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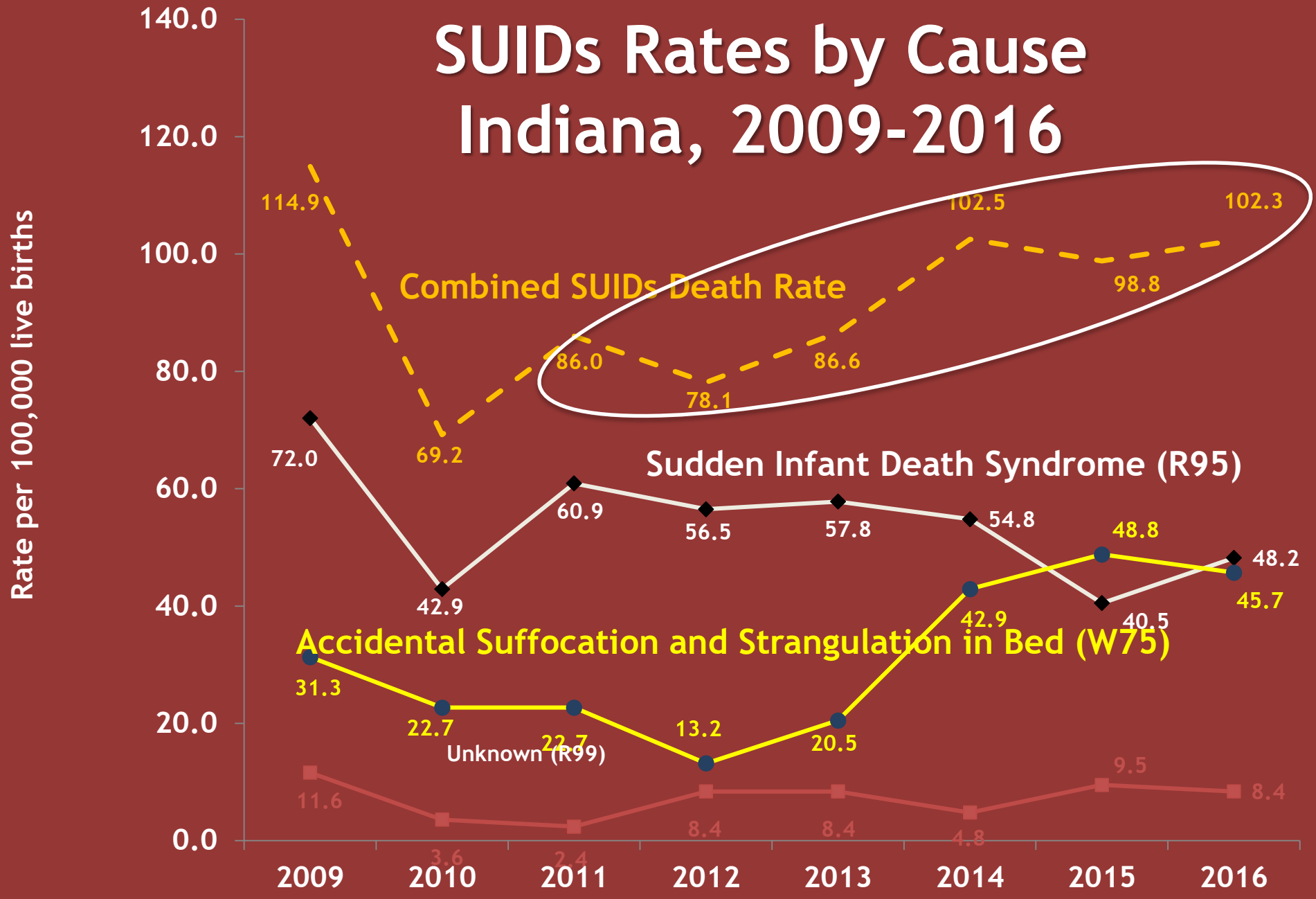

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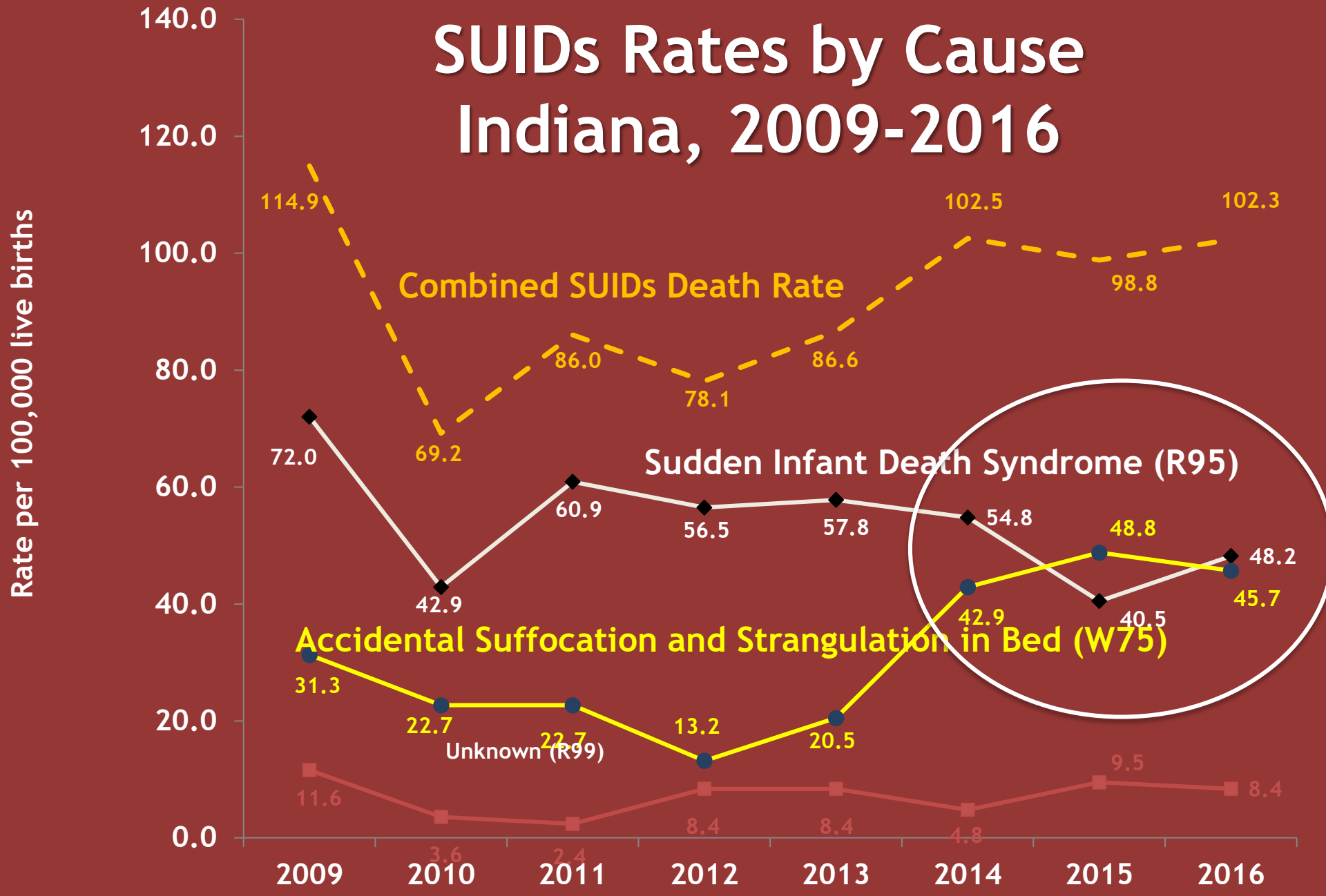

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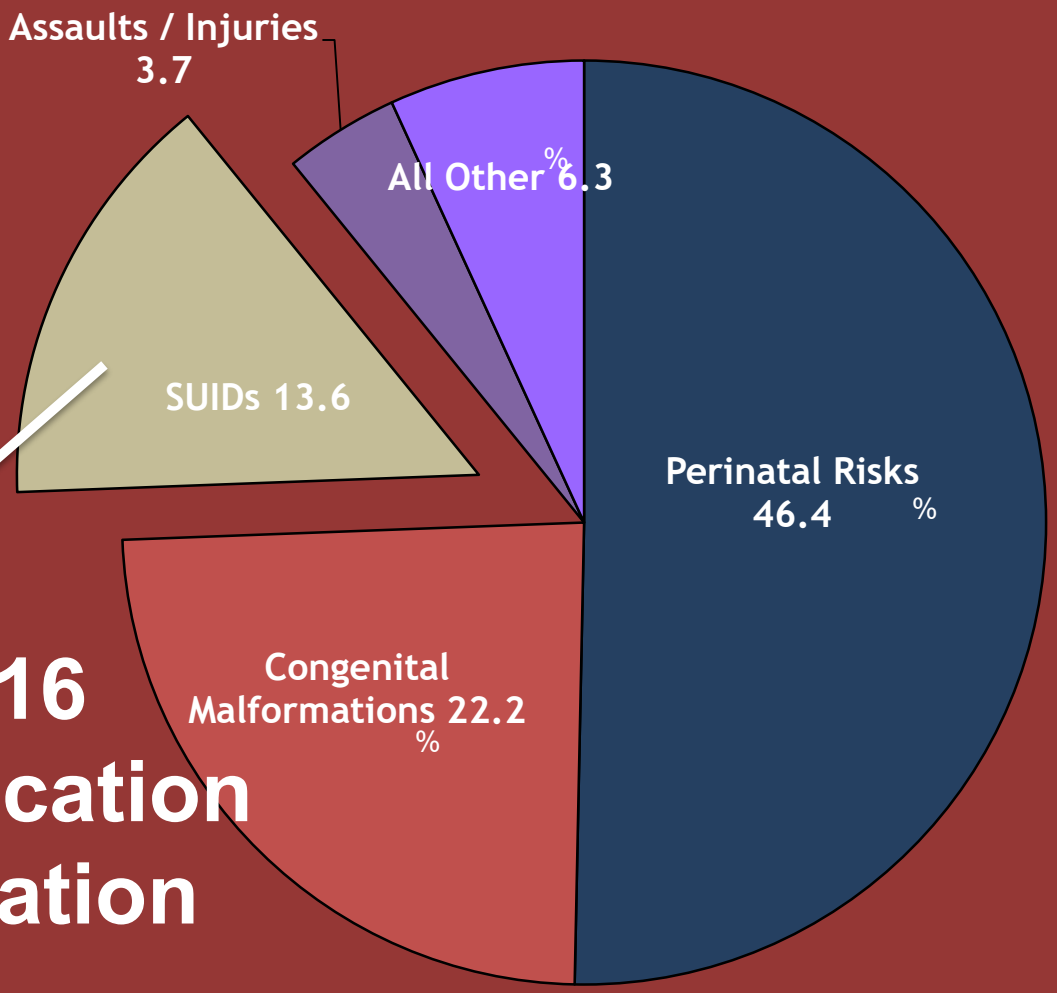
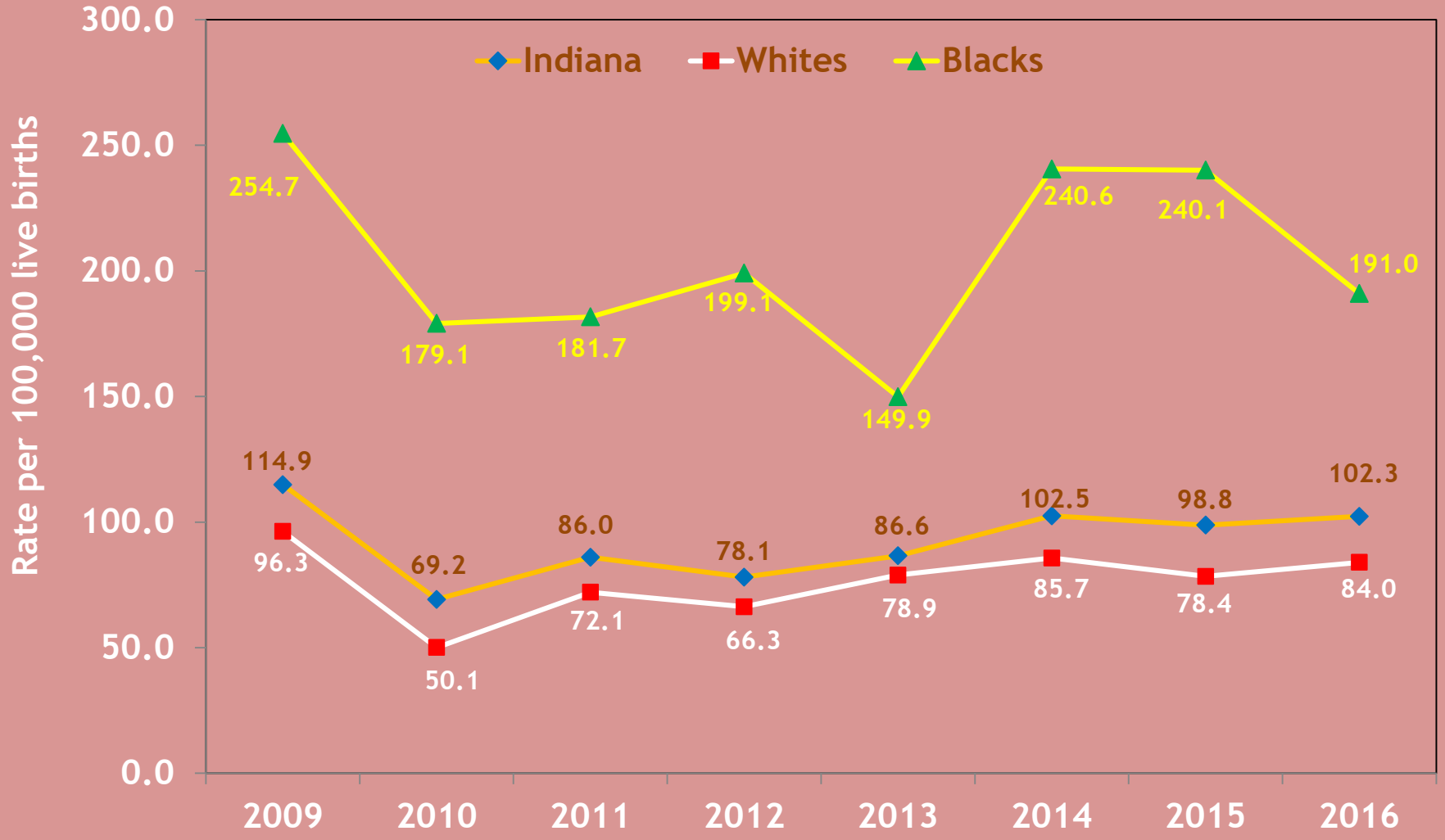


1 out of 16 dies of suffocation or strangulation

SUIDs Rates by Race
Indiana, 2009-2016



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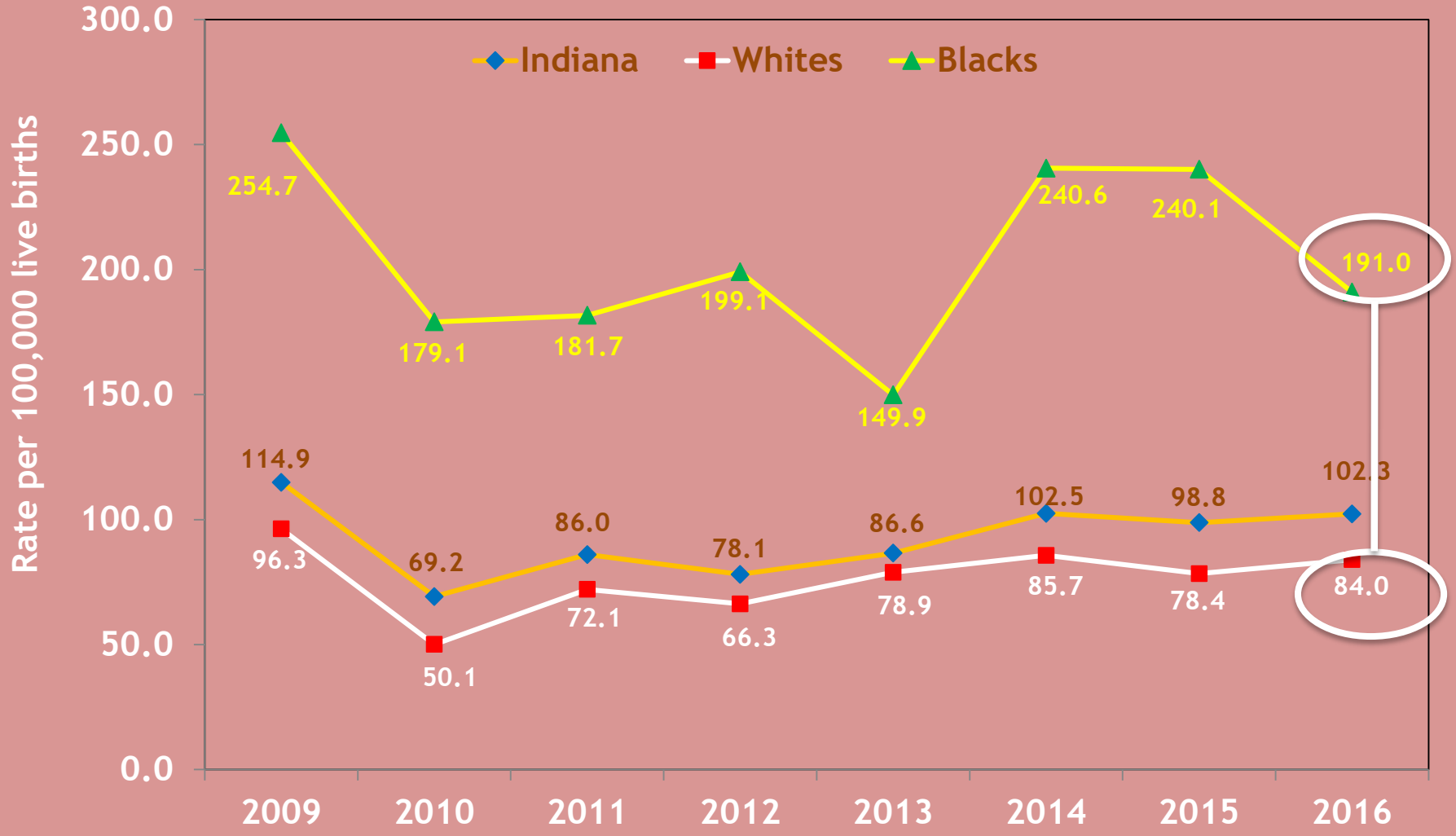

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Research 1: When Baby Stops Breathing

Qualitative AIMS

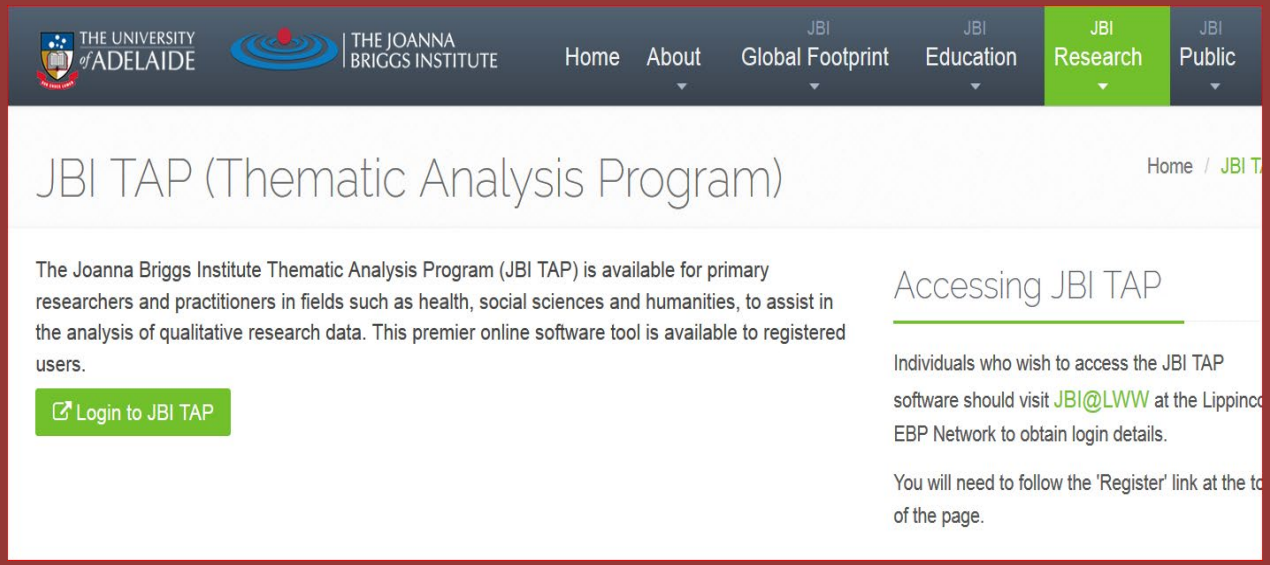
- Maternal FIMR interview data from central Indiana were extracted in order to examine the phenomena.
  - Indiana has a higher than average risk for infant death therefore case exploration provided a rich data source
- The purpose of our research study was to describe the parents' experiences when death of an infant occurs suddenly and unexpectedly.

Methods

- Phenomenology seeks to understand the context of lived experiences
- 17 SUID Infant Mortality Reviews
- Maternal narratives
- Convenience sample
- The Thematic Analysis Program (TAP) from the Joanna Briggs Institute (JBI), available through OVID Tools
- IRB was determined exempt – de-identified

Thematic Analysis Program -TAP

- Computer-based tool
- Meta-aggregation emanates from a pragmatic tradition
- Theme is linked to an informed action or behavior directing clinicians



Meta-aggregation

- Phase 1 extracting data narrations provided illustrations.
- Phase 2 placed similar illustrations into categories with similarity of meaning.
- Phase 3, a meta-aggregation with themes and concepts provided syntheses to inform professional practice
- Saturation: no new concepts rose from data
- Credibility check consisting of data validation and thematic dependability insured rigor
- Limitations

Findings

- A total of 79 illustrations were identified from maternal narrations
- Nine Categories were formulated from the illustrations
- Through meta-aggregation, three themes were synthesized


Emotional Shock
911...Help me!!
Checking my story
I was in shock that my baby died
We feel like we're to blame
Not where s/he's supposed to sleep
Naming the cause of death increases my guilt
It was our fault
Working toward moving on
I can't talk about it
One step forward
Support helps get me through

1st Theme: Extreme Emotional Shock

- Three Categories
  - 911…help me!
  - Checking on my story
  - I was in shock that my baby died

Extreme Emotional Shock!

- “I called 911 and they talked me through CPR, but I knew he was already dead. He was so limp. . . My husband was running through the house just screaming, so I knew I had to hold myself together.”
- “After the death of my baby, I stopped working. A lot of police and homicide detectives were coming around . . . .”
- Some mothers could not remember anything that happened from that day; others remembered minute details.

2nd Theme: We Feel Like We're to Blame

- Three Categories
  - Not where s/he's supposed to sleep
  - Naming the cause of death increases my guilt
  - It was our fault

We feel like we're to blame

- I had a crib for him that I put him in during the day, but he didn't rest well in it. He slept better sleeping with me.
- Mothers felt that comments on the death certificate and autopsy notes were guilt inducing: positional asphyxia, respiratory failure due to compression asphyxia, unsafe sleep position
- "I remember the policeman took me in his car to the hospital . . . he was asking me questions, and then he called the officer at the house that was with my husband and they talked and they said our stories matched."

3rd Theme: Working Toward Moving On

- Three Categories
  - I can't talk about it
  - One step forward
  - Support helps get me through

Working toward moving on

- “I think I do want to talk to somebody at some point about all of this, but I’m not ready.”
- I am pregnant now. I thought it was too soon to get pregnant. The baby’s father thought it was too soon to get pregnant. We are happy, but are scared, too.
- I was offered keepsake items of my baby, and I was given information on burial arrangements for my baby. I was offered information on support groups.

Discussion

- Losing a child is a catastrophic and life-changing event
- Parent can experience profound loss and physical pain
- Parents may be unable to function for long periods of time
- Grief may continue for a significant length of time

Safe to Sleep

- Of the 17 narratives reviewed, none of the infants was in a safe sleep environment at the time of death
- Safe to Sleep information is part of the discharge information given to all post partum mothers, but not all mothers “hear” or follow the information
- Information may be in conflict with cultural values of parents

Resolution of Grief

- Not every parent is able to resolve the grief on their own
- Most hospitals have pastoral care, social workers, support groups
- Internet support groups are popular
- Mental health professionals and medication are sometimes indicated

Implications for Practice

- Every family will grieve differently. Bereavement nurses should be able to identify normal grief and when it goes beyond normal, and what support resources are available
- Support services should be tailored to the family's culture and beliefs
- An in depth knowledge of the community is necessary to provide tailored solutions for each family

Limitations

- A variety of FIMR data collection forms are currently in use
- Accuracy of data
- Maternal interviews
- Qualitative study

Future Areas of Research

- Standardized National FIMR data collection forms
- How does SES affect SUID risk?
- What, when, and how is the best way to educate families about SUID risks?
- How do we tailor education to vulnerable populations?

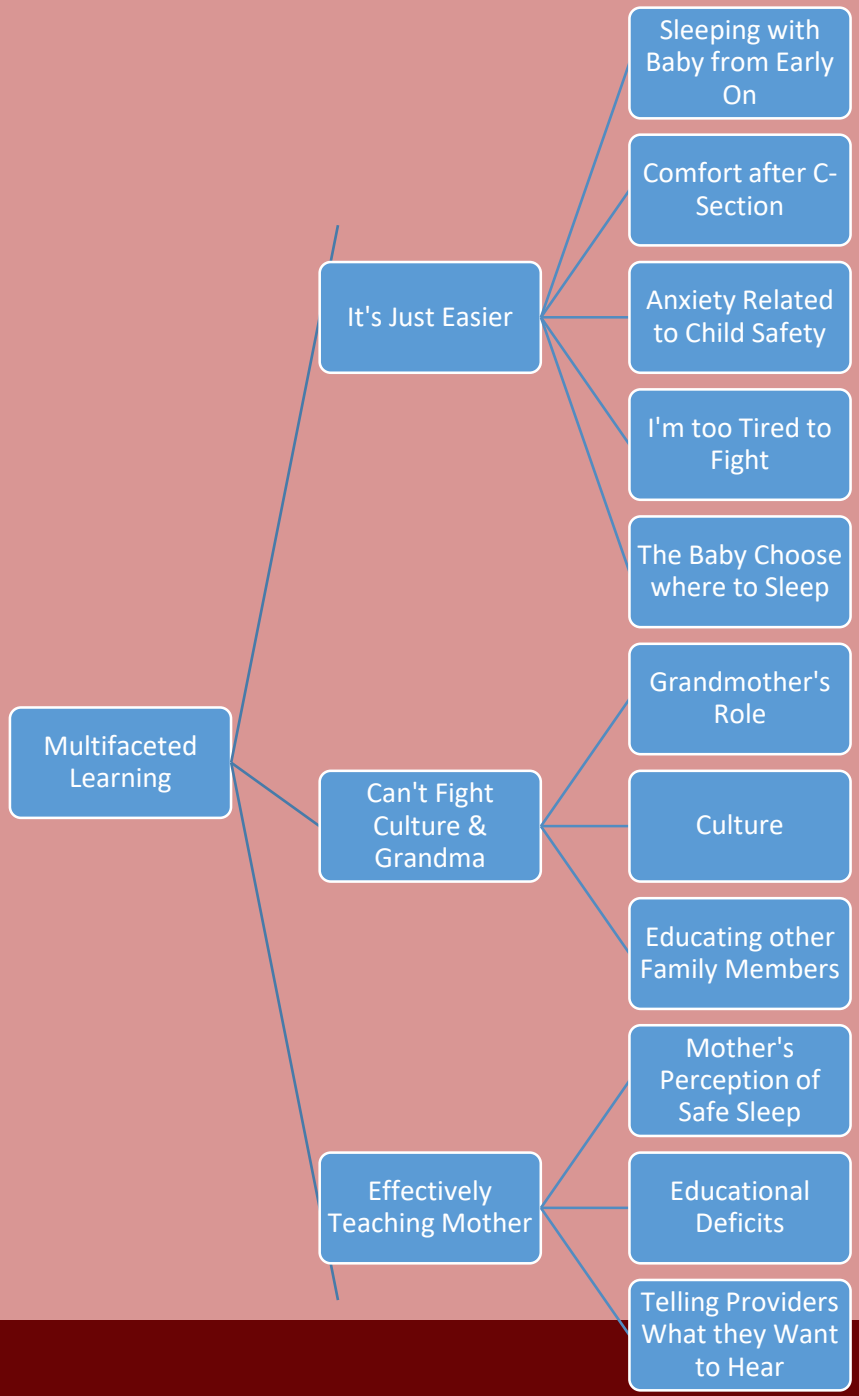
Research 2: Racial Equity considerations in safe sleep messaging

Racial Equity

- This project done in collaboration with Nurse Family Partnership
- This project was supported by the Indiana Clinical and Translational Sciences Institute, funded in part by grant # TR001107 from the National Institutes of Health, National Center for Advancing Translational Sciences.
- The purpose was to identify why African American new mothers do not tend to follow the Safe Sleep recommendations
- Held focus groups of African American new mothers
- We used ethnography in order to find shared patterns of beliefs and behaviors

Results

1. Identified 14 concepts
2. Formulated them into three categories
   - It's just easier
   - Can't fight culture and Grandma
   - Effectively teaching mother
3. Identified the shared value of
   - Multifacited Learning


Multifaceted Learning
It's Just Easier
Sleeping with Baby from Early On
Comfort after C-Section
Anxiety Related to Child Safety
I'm too Tired to Fight
The Baby Choose where to Sleep
Can't Fight Culture & Grandma
Grandmother's Role
Culture
Educating other Family Members
Effectively Teaching Mother
Mother's Perception of Safe Sleep
Educational Deficits
Telling Providers What they Want to Hear

It’s just easier

- ” You don’t get any sleep, when you put your baby on its back, I have to stay up with the baby, she’s crying, I’m crying. Where do you draw the line?”
- “The baby doesn’t like sleeping on the hard pack-n-play, so he sleeps with me.”
- “Baby loves her room, but doesn’t want to be in her bed.”

Can’t fight culture and Grandma

- “My culture has the baby sleep with us, my mom helped me a lot with my first daughter, but she insisted that the baby should sleep with me and on her tummy.”
- “My mother called it ‘New mommy stuff,’ (following safe sleep guidelines) that’s not for me.”
- Another new mother described how her mother kept trying to put decorative things into the crib because the crib “looks like a little baby prison.”
- “grandma shuts me down and says she knows everything.”
- Every time I try to tell my mother about putting the baby to sleep on her back, she talks about what she did when I was little, or what her mother did, etc., etc. You need to be talking to the grandmothers! There are generational differences!

Effectively teaching mother

- Many cultures, including the African American community can hold a fatalistic view of infant mortality. They believe that if an infant dies, it is an act of God or God's Will and cannot be prevented.
- "most women know about safe sleep, but they don't listen. What keeps them from following? 'This is my baby. I can do what I want.' It's about beliefs. I know what is best for my baby."
- For first time moms, you believe everything and try to follow everything, but with each subsequent child, you know it won't work, so you don't try. When she slept on her belly, she slept for hours, but on her back, she was fussy all night. The postpartum depression kicks in because of lack of sleep. If you don't get any sleep, you are cranky to everyone else. You don't get any sleep, when you put your baby on its back, I have to stay up with the baby. She's crying, I'm crying. Where do you draw the line?

How would moms change the message?

1. “There cannot be one blanket class because of culture. Have young African American people in the message. Throughout the first year of the baby’s life you should have them keep getting the message—not just in the hospital.”
2. Have more details, not just a pamphlet
3. Make sure you tell everyone: parents, mother, father, grandparents, everyone
4. Stress the statistics about the higher incidence among African American infants
5. Have a person give the message, not just a video
6. Dads frequently watch infants, so they need to be educated
7. People who look like me telling what happened to them
8. They need to give examples—real people giving real life examples

Multifacited Learning

Teaching African American mothers about the Safe to Sleep® recommendations is much more than just education. It is multifaceted and should be more than a “one and done” session. The Safe to Sleep® recommendations should be discussed at every appointment with every family member. Providers should explain why these recommendations are especially important for African American families due to the staggering infant mortality statistics among African Americans. Providers and nurses should provide anticipatory guidance, providing strategies to assist mothers with common problems that they may face when trying to get their infants to learn to sleep alone on their backs.

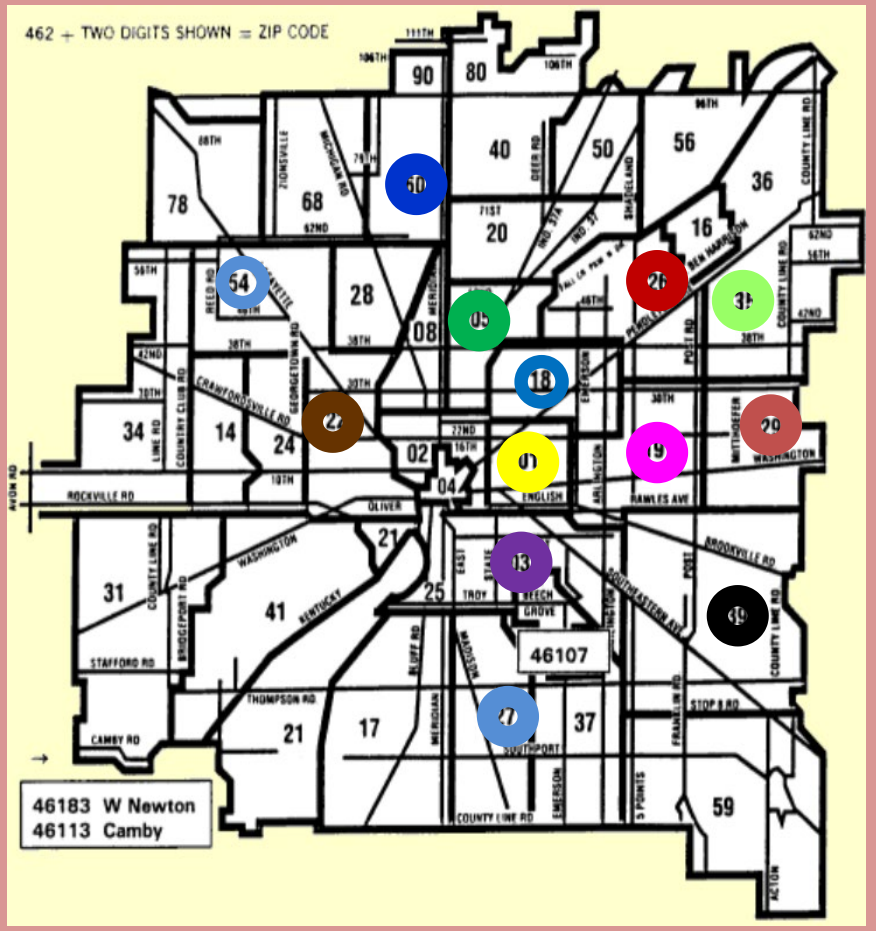
Research 3: Grassroots Maternal-Child Health Leadership

29 worst zip cods for infant mortality

	Zip Codes	County	Live Births 2011-2015	Infant Deaths 2011-2015	IMR 2012-2016	White[a]	Black[a]	Hispanic[a]	Asian[a]
3	46201	Marion	2,909	32	11	57%	24%	14%	0%
4	46203	Marion	3,319	37	11.2	72%	14%	11%	0%
5	46205	Marion	2,404	28	11.7	42%	49%	4%	2%
6	46218	Marion	2,498	33	13.2	20%	73%	6%	0%
7	46219	Marion	2,449	24	9.8	66%	21%	10%	1%
8	46222	Marion	3,171	29	9.1	31%	40%	25%	1%
9	46226	Marion	3,488	49	14.1	41%	59%	13%	0%
10	46227	Marion	5,165	36	7	71%	7%	7%	12%
11	46229	Marion	1,997	27	13.5	44%	45%	7%	1%
12	46235	Marion	3,187	29	9.1	27%	57%	13%	0%
13	46239	Marion	2,042	20	9.8	75%	12%	7%	3%
14	46254	Marion	3,621	26	7.2	21%	54%	18%	3%
15	46260	Marion	2,607	21	8.1	50%	29%	14%	3%
16	46350	LaPorte	2,530	25	9.9	88%	2%	9%	1%
17	46312	Lake	2479	41	16.5	7%	36%	57%	0%
18	46324	Lake	1,478	21	14.2	44%	22%	31%	0%
19	46360	LaPorte	2,950	23	7.8	68%	22%	5%	1%
20	46514	Elkhart	2,747	22	8	78%	5%	12%	2%
21	46516	Elkhart	3,004	26	8.7	62%	16%	18%	1%
22	46805	Allen	1,765	20	11.3	76%	10%	6%	4%
23	46806	Allen	2372	34	14.3	24%	43%	25%	4%
24	46902	Howard	2,118	20	9.4	84%	8%	3%	3%
25	46953	Grant	1392	20	14.4	77%	14%	6%	1%
26	47130	Clark	2,974	29	9.8	76%	14%	5%	1%
27	47201	Bartholomew	3,193	31	9.7	81%	2%	7%	8%
28	47302	Delaware	1,858	24	12.9	85%	11%	1%	0%
29	47374	Wayne	2,750	28	10.2	85%	7%	4%	1%
30	47905	Tippecanoe	3,216	25	7.8	81%	5%	10%	1%
31	47909	Tippecanoe	3,279	27	8.2	79%	7%	11%	1%

13/29 (45%) highest risk zip codes are in Marion County

	5 year data 2011-2015 Births and Infant Mortality				
zip code	births	deaths	IMR	avg births/yr	avg deaths / year
46226	3488	49	14.1	698	10
46229	1997	27	13.5	399	5
46218	2498	33	13.2	500	7
46205	2404	28	11.7	481	6
46203	3319	37	11.2	664	7
46201	2909	32	11	582	6
46219	2,449	24	9.8	490	5
46239	2,042	20	9.8	408	4
46222	3,171	29	9.1	634	6
46235	3,187	29	9.1	637	6
46260	2,607	21	8.1	521	4
46254	3,621	26	7.2	724	5
46227	5,165	36	7	1033	7



GMCHL

Background: It is time to complement the work of our health care providers with a concerted statewide, community-centered approach to build infrastructures and systems that address social-economic-environmental factors that contribute to poor birth outcomes. The complexity of system issues that contribute to poor birth outcomes requires an interprofessional team, comprised of community and academic partners to develop feasible, affordable and implementable solution strategies.

Hypothesis: Community capacity building improves MCH-related social-political factors of communities with poor birth outcomes.

Interprofessional teams

Community teams

Guiding Framework

Socio-Ecological Framework

Features of grassroots leadership

1) Grassroots leaders have **different motivations and needs** than those of traditional leaders.

2) Investing in grassroots leadership development leads to **increased community well-being and encourages long-term problem-solving**.

3) The best results are achieved by using a triple focus on **the individual leaders**, the involved **organization**, and the **community or issue of concern**.

4) Grassroots leaders **encourage funders and support organizations** to take actions that support the efforts of grassroots leadership.

Curriculum

- Partner with communities to identify leaders
- Implement training, curriculum elements include:
    - Principles of Leadership Development
    - Community Health Promotion
    - Infant Mortality Causes and Prevention
    - Promoting Health Equity
    - Media Development
    - Policy Advocacy and Development
- Teach narrative storytelling
- Mentor GMCHL in their community development work

Train and Mentor Grassroots MCH Leaders

Social, Economic, Environmental, Political Change

Community Characteristics Support Healthy Birth Outcomes

Some first year outcomes

- GMCHL advocated to two state representatives for pregnancy accommodations in workplace, and to expand grandparents' rights.
- GMCHL taught social determinants of maternal and child health to maternal and child health division of Indiana State Department of Health
- One GMCHL is first ever community representative on the Indiana March of Dimes MCH Committee
- Three GMCHL now participate in the Marion County Fetal-Infant Mortality Review Community Action Team
- One GMCHL presented at Black Breastfeeding Symposium
- One GMCHL now employed as breastfeeding advocate for WIC
- One GMCHL now employed as domestic violence reduction consultant for local county hospital
- One GMCHL now employed as member of Indiana University Public Policy Institute
- Three GMCHL providing consultation to member of US House of Representative regarding bill to address infant and maternal mortality.

We are YouTube stars!

1. https://youtu.be/vHLZMzFLxv8
2. https://youtu.be/5a5-rymyTRY
3. http://www.youtube.com/watch?v=owcSnuXIH5A

Safe Sleep Recommendations

PRACTICES TO REDUCE INFANT MORTALITY

- Improve overall health for women of child-bearing age
- Promote early & adequate prenatal care
- Decrease early elective deliveries before 39 weeks
- Decrease prenatal smoking & substance abuse
- Increase breastfeeding duration & exclusivity
- Support birth spacing & interconception wellness
- Promote the ABC's of safe sleep: place baby to sleep *a*lone, on his or her *b*ack, in a *c*rib

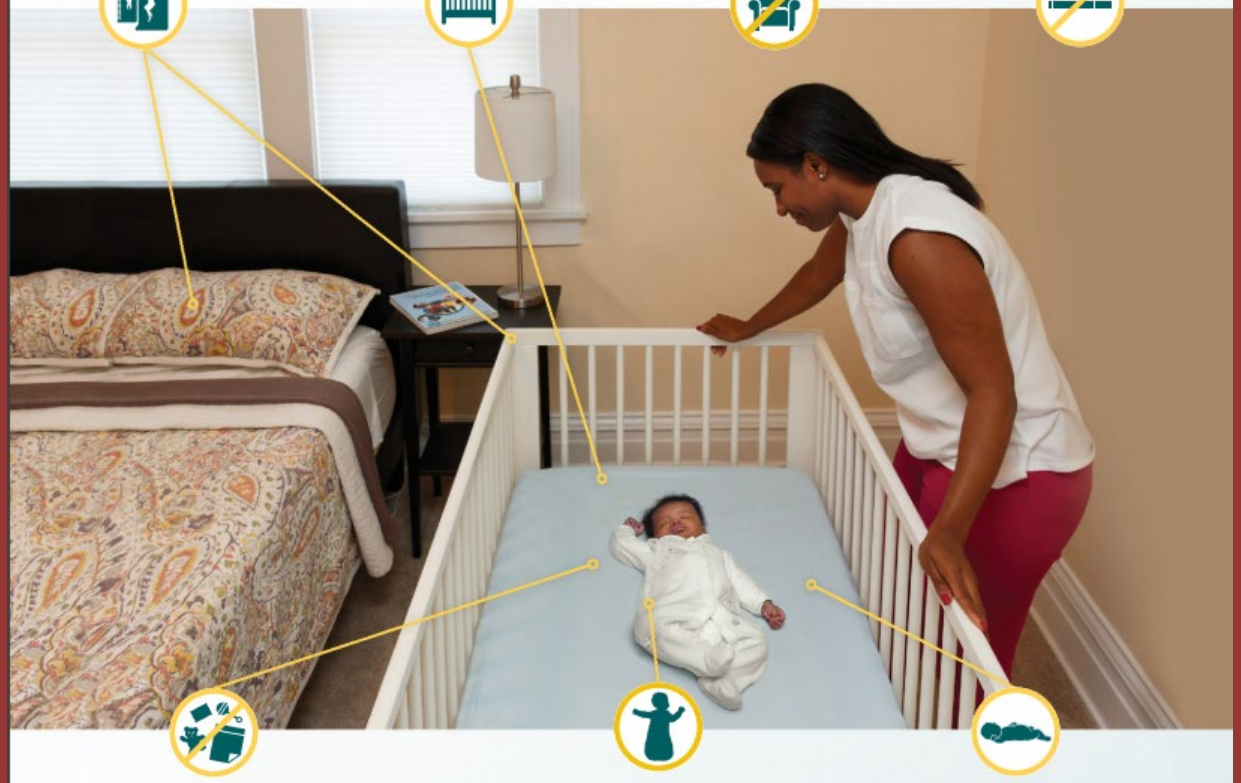
The image below shows a safe infant sleep environment.

Baby's sleep area is in the same room, next to where parents sleep.

Use a firm and flat sleep surface, such as a mattress in a safety-approved crib*, covered by a fitted sheet.

Baby should not sleep in an adult bed, on a couch, or on a chair alone, with you, or with anyone else.

Do not smoke or let anyone else smoke around your baby.



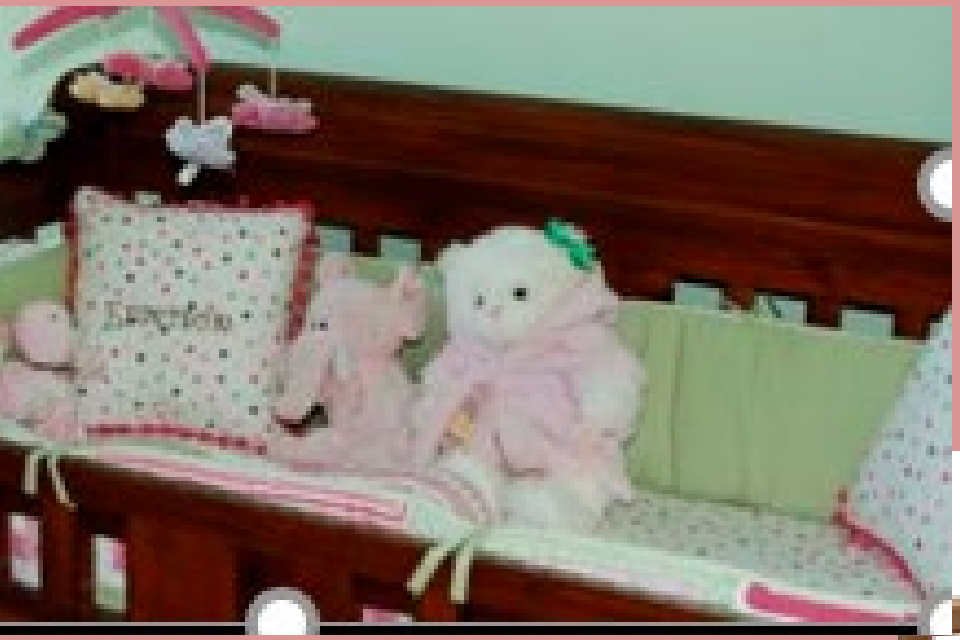
Do not put pillows, blankets, sheepskins, or crib bumpers anywhere in your baby's sleep area.

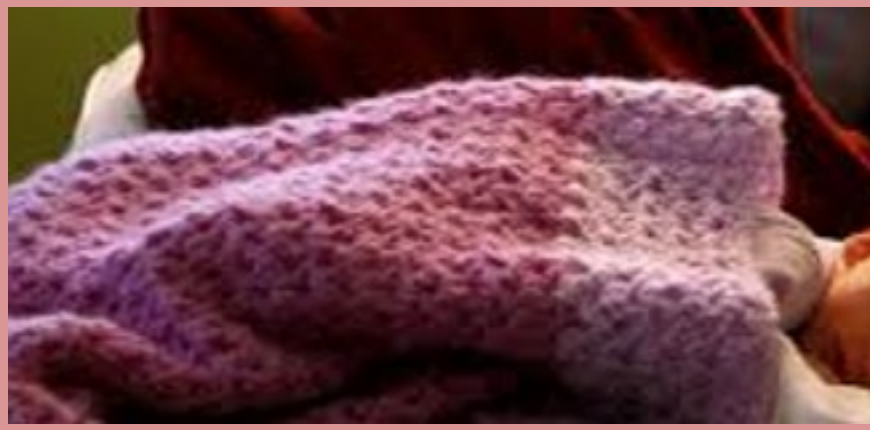
Keep soft objects, toys, and loose bedding out of your baby's sleep area. Make sure nothing covers the baby's head.

Dress your baby in sleep clothing, such as a wearable blanket. Do not use a loose blanket, and do not overbundle.

Always place your baby on his or her back to sleep, for naps and at night.

CDC.gov





The A B C's of Safe Sleep

A Alone

Not with other people, pillows, blankets, or stuffed animals.

B on my Back

Not on the stomach or side.

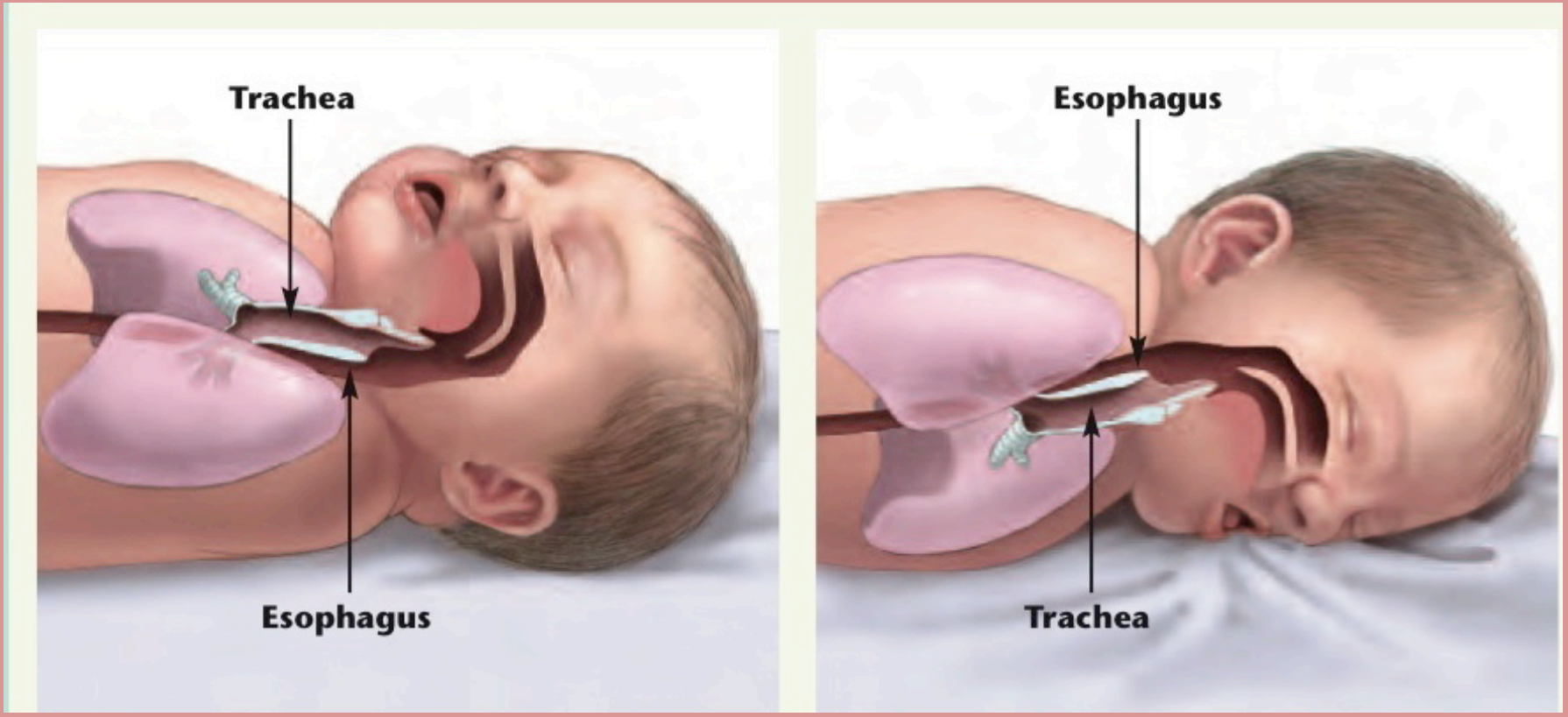
C in my Crib

Not on an adult bed, sofa, cushion, or other soft surface.

Don’t let products fool you! Is this safe?

- It has not been tested for safety
- It keeps the baby from being flat on her back
- It is not a firm surface
- Baby can move her face over and become entrapped and suffocate

Remember the anatomy!



A-level recommendations

- Back to sleep for every sleep.
- Use a firm sleep surface.
- Breastfeeding is recommended.
- Room-sharing with the infant on a separate sleep surface is recommended.
- Keep soft objects and loose bedding away from the infant's sleep area.
- Consider offering a pacifier at naptime and bedtime.
- Avoid smoke exposure during pregnancy and after birth.
- Avoid alcohol and illicit drug use during pregnancy and after birth.
- Avoid overheating.
- Pregnant women should seek and obtain regular prenatal care.
- Infants should be immunized in accordance with AAP and CDC recommendations.
- Do not use home cardiorespiratory monitors as a strategy to reduce the risk of SIDS.
- Health care providers, staff in newborn nurseries and NICUs, and child care providers should endorse and model the SIDS risk-reduction recommendations from birth.
- Media and manufacturers should follow safe sleep guidelines in their messaging and advertising.
- Continue the "Safe to Sleep" campaign, focusing on ways to reduce the risk of all sleep-related infant deaths, including SIDS, suffocation, and other unintentional deaths. Pediatricians and other primary care providers should actively participate in this campaign.

B-level recommendations

- Avoid the use of commercial devices that are inconsistent with safe sleep recommendations.
- Supervised, awake tummy time is recommended to facilitate development and to minimize development of positional plagiocephaly.

C-level recommendations

- Continue research and surveillance on the risk factors, causes, and pathophysiologic mechanisms of SIDS and other sleep-related infant deaths, with the ultimate goal of eliminating these deaths entirely.
- There is no evidence to recommend swaddling as a strategy to reduce the risk of SIDS.

The following levels are based on the Strength-of-Recommendation Taxonomy (SORT) for the assignment of letter grades to each of its recommendations (A, B, or C).[2] Level A: There is good-quality patient-oriented evidence. Level B: There is inconsistent or limited-quality patient-oriented evidence. Level C: The recommendation is based on consensus, disease-oriented evidence, usual practice, expert opinion, or case series for studies of diagnosis, treatment, prevention, or screening. Note: "patient-oriented evidence" measures outcomes that matter to patients: morbidity, mortality, symptom improvement, cost reduction, and quality of life; "disease-oriented evidence" measures immediate, physiologic, or surrogate end points that may or may not reflect improvements in patient outcomes (eg, blood pressure, blood chemistry, physiologic function, pathologic findings). CDC, Centers for Disease Control and Prevention.

Summary of Talking Points

- Too many babies are dying in Indiana
- African American babies die at two to three times that of white babies.
- The most preventable cause is unsafe sleep.
- Babies need to sleep A, B, C –Alone, on their Back and in a Crib (bassinet, Pack N' Play)
  - Do NOT cover with blankets, do NOT put toys or other things with baby;
  - Have baby next to you in crib, bassinet, Pack N' Play, NOT in bed or couch with you
  - Safe sleep every sleep – day or night

American Academy of Pediatrics (2016)

More First Birthdays!

NICHQ

Articles

1. **Stiffler, D.,** Cullen, D., Stephenson, E., Luna, G. & Hartman, T. (2016). When baby stops breathing: Analysis of mothers' interviews. *Clinical Nursing Research, 25*(3), 310-324. doi:10.1177/1054773815619580

2. Cullen, D., Oberle, M., Elomba, C., Luna, G. & ***Stiffler, D.** (2016). Illustrations of unexpected infant sleep deaths. *Journal of Forensic Nursing 12*(3), 141-146. doi: 10.1097/JFN.0000000000000120

3. Cullen, D., Vodde, C. R., Williams, K. J., Luna, G. & ***Stiffler, D.** (2016). Infant co-bedding: Practices and teaching strategies. *Journal for Specialists in Pediatric Nursing, 21* (2), 54-63. Article first published online: 5 April 2016. doi:10.1111/jspn.12140

4. **Stiffler, D.,** Birch, N., Campbell, H., & Cullen, D. (2017). A synthesis of coping experiences after infant death. *Holistic Nursing Practice, 31*(2). doi:10.1097/HNP.00000000000199

5. **Stiffler, D.,** Ayres, B., Fauvergue, C. & Cullen, D. (2018). Sudden infant death and sleep practices in the Black community. *Journal for Specialists in Pediatric Nursing, 23*(2). doi: 10.1111/jspn.12213

6. ***Stiffler, D.,** Mukasa Matemachani, S., Crane, L. (Accepted). Racial equity considerations in safe to sleep messaging: Learning from the community. *Journal of Specialists in Pediatric Nursing.*