Ethical Issues in Infant Mortality: A Study in Disparities

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Disclosures

• I have no financial disclosures.
Objectives

• Recognize Indiana’s high infant mortality rate and the existing black-white disparity
• Understand how structural racism and implicit bias may play a role in disparities in infant mortality rates
• Gain knowledge of programs working to reduce disparities in infant mortality and promote equity in Indiana
One of these babies is more likely to die before his first birthday.
What is infant mortality?

• The death of a baby before his or her first birthday

• Infant Mortality Rate: number of infant deaths per 1000 live births
Causes of Infant Mortality

• Premature birth (less than 37 weeks gestation)
• Low birthweight (less than 2500 grams – 5 ½ pounds)
• Congenital malformations (birth defects)
• Sudden unexpected infant death (sleep related deaths - accidental suffocation/strangulation in bed, SIDS)
• Injuries/Assaults
US Infant Mortality
<table>
<thead>
<tr>
<th>Country</th>
<th>Infant Mortality Rate</th>
</tr>
</thead>
<tbody>
<tr>
<td>Finland</td>
<td>2.3</td>
</tr>
<tr>
<td>Japan</td>
<td>2.3</td>
</tr>
<tr>
<td>Portugal</td>
<td>2.5</td>
</tr>
<tr>
<td>Sweden</td>
<td>2.5</td>
</tr>
<tr>
<td>Czech Republic</td>
<td>2.7</td>
</tr>
<tr>
<td>Norway</td>
<td>2.8</td>
</tr>
<tr>
<td>Korea</td>
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</tr>
<tr>
<td>Spain</td>
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</tr>
<tr>
<td>Denmark</td>
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<tr>
<td>Germany</td>
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<td>Italy</td>
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<tr>
<td>Belgium</td>
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<td>France</td>
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<tr>
<td>Israel</td>
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<tr>
<td>Greece</td>
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</tr>
<tr>
<td>Ireland</td>
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<tr>
<td>Netherlands</td>
<td>3.8</td>
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<tr>
<td>Switzerland</td>
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</tr>
<tr>
<td>Austria</td>
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<td>Australia</td>
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<tr>
<td>United Kingdom</td>
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<td>Canada</td>
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<tr>
<td>Poland</td>
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<tr>
<td>Hungary</td>
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<tr>
<td>New Zealand</td>
<td>5.5</td>
</tr>
<tr>
<td>Slovakia</td>
<td>5.7</td>
</tr>
<tr>
<td>United States</td>
<td>6.1</td>
</tr>
</tbody>
</table>
Figure 1. Infant mortality rates, by race and Hispanic origin of mother: United States, 2005–2014

1Includes persons of Hispanic and non-Hispanic origin.
Figure 1. Infant mortality rates, by state: United States, 2013–2015

†Significantly different from the U.S. rate.
Figure 3. Infant mortality rates for infants of non-Hispanic black women, by state: United States, 2013–2015

†Significantly different from the U.S. rate.
The black infant mortality rate has been more than double the white infant mortality rate for decades.
The black infant mortality rate in 2015 just reached the level of the white infant mortality rate in the 1980s.
Implementing new programs to help more babies celebrate their first birthdays, regardless of their zip codes.
In 2017, 602 babies in Indiana died.
Infant Mortality Rates
Indiana, U.S. and Healthy People 2020 Goal
2007 - 2017

<table>
<thead>
<tr>
<th>Year</th>
<th>Indiana</th>
<th>U.S.</th>
<th>HP 2020 Goal</th>
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</thead>
<tbody>
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<tr>
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<tr>
<td>2017</td>
<td>7.3</td>
<td>5.8</td>
<td>6.0</td>
</tr>
</tbody>
</table>

Source: Indiana State Department of Health, Maternal & Child Health Epidemiology Division [November 1, 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
**Infant Mortality Distribution by Cause**

**Indiana, 2017**

**% Distribution of Infant Deaths**  
N = 602

- **Perinatal Risks**: 47.3%
- **SUIDs**: 16.6%
- **Congenital Malformations**: 18.1%
- **Assaults / Injuries**: 4%
- **All Other**: 14.0%

**Cause Specific Mortality Rates**  
*Per 1,000 Live Births*

- **Perinatal Risks**: 3.5
- **SUIDs**: 1.3
- **Congenital Malformations**: 1.2
- **Assaults / Injuries**: 0.3
- **All Other**: 1.0

*Note: Cause specific mortality rates may not exactly equal the overall infant mortality rate due to rounding.  
Source: Indiana State Department of Health, Maternal & Child Health Epidemiology Division [January 3, 2019]  
Indiana Original Source: Indiana State Department of Health, PHPC, ERC, Data Analysis Team*
Infant Mortality Rates
County Level, All Races
2013 - 2017

**HIGHEST** Infant Mortality Rates in Indiana

- Jay, 13.2
- Grant, 9.2
- Shelby, 9.2
- Cass, 9.1
- St. Joseph, 8.7
- Clark, 8.5

Counties that have **REACHED HP2020 Goal**

- Hamilton, 4.9
- Johnson, 5.0
- Porter, 5.3
- Hendricks, 5.8

*Unstable counties may have a rate higher or lower than state rate. These counties are suppressed due to numerator <20*

**Source:** Indiana State Department of Health Division of Maternal and Child Health
**Created:** November 15, 2018
**Data Source:** Indiana State Department of Health Epidemiology Resource Center Data Analysts
## Infant Mortality Rates by Race
### Indiana
#### 2010 - 2017

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<thead>
<tr>
<th>Year</th>
<th>Indiana</th>
<th>Whites</th>
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<td>2017</td>
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<td>5.9</td>
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</tbody>
</table>

Note: Hispanic ethnicity can be of any race
Source: Indiana State Department of Health, Maternal & Child Health Epidemiology Division [January 22, 2019]
Indiana Original Source: Indiana State Department of Health, PHPC, ERC, Data Analysis Team

Increasing disparity
## Infant Mortality Rates by Zip Code

<table>
<thead>
<tr>
<th>Zip Code</th>
<th>County</th>
<th>Births</th>
<th>Deaths</th>
<th>Infant Mortality Rate (IMR)</th>
<th>White IMR</th>
<th>Black IMR</th>
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<td>46404</td>
<td>Lake</td>
<td>1,093</td>
<td>22</td>
<td>20.1 **</td>
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<td>46312</td>
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<tr>
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<tr>
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<tr>
<td>46218</td>
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<td>14.5 18.7*</td>
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<tr>
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<tr>
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</tr>
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</table>

*Numerator less than 20, the rate is unstable.

**Rate has been suppressed due to five or fewer outcomes.
Causes of Infant Mortality by Race
Indiana 2017

Source: Indiana State Department of Health, Maternal & Child Health Epidemiology Division [November 1, 2018]
Indiana Original Source: Indiana State Department of Health, PHPC, ERC, Data Analysis Team
% Low Birthweight Births (<2,500 grams)
Indiana, by Race
2010 - 2017

Source: Indiana State Department of Health, Maternal & Child Health Epidemiology Division [January 3, 2019]
Indiana Original Source: Indiana State Department of Health, PHPC, ERC, Data Analysis Team
% Preterm Births (Obstetric Estimate)  
< 37 weeks gestation  
Indiana, by Race 2010 - 2017

Source: Indiana State Department of Health, Maternal & Child Health Epidemiology Division [November 1, 2018]  
Indiana Original Source: Indiana State Department of Health, PHPC, ERC, Data Analysis Team
Why is the black infant mortality rate higher than the white infant mortality rate?

Is it genetic?
Race and Low Birthweight Deliveries

US born white mothers  US born black mothers  African born black mothers
FIGURE 2—Birthweight distributions of 3 Illinois subpopulations.
Is this difference sustained across generations?

- In non-immigrant populations, birthweight tends to rise in each subsequent generation
Is this difference sustained across generations?

- Grandchildren of European immigrants
- Grandchildren of African and Caribbean immigrants
What drives disparities between white and black infant mortality rates?

• It is not “race” or genetic predisposition.
• So what is it?
Factors associated with Infant Mortality

- Smoking
- Poor/limited prenatal care
- Poor maternal health status
  - Obesity
  - Pre-existing chronic health conditions
  - Depression/anxiety
  - Substance use
- Short interpregnancy interval
- Unsafe sleep practices
What drives disparities between white and black infant mortality rates?

• Conventional risk factors have a more pronounced negative effect on black infant outcomes.

• “Protective factors” for pregnant women do not provide the same benefits for black women.
Socioeconomic Status

- Women from lower SES backgrounds are more likely to have a preterm birth.
  - Diminished access to quality health care, food, housing
  - Increased poverty-related stressors
Socioeconomic Status

- Low SES
  - White mothers – 7.7% low birthweight
  - Black mothers – 10.9% low birthweight
Improvement in Socioeconomic Status and birth outcomes by race

- **White mothers**
  - Low SES – 7.7% low birthweight
  - High SES – 4.3% low birthweight
- **Black mothers**
  - Low SES – 10.9% low birthweight
  - High SES – 11.3% low birthweight
<table>
<thead>
<tr>
<th></th>
<th>White</th>
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<th>Black</th>
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<tr>
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<td>Higher-SES</td>
<td>Low-SES</td>
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<tr>
<td>Living in Higher SES</td>
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<td>N=99</td>
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<tr>
<td>Black Neighborhood</td>
<td>%</td>
<td>%</td>
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<tr>
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<td>8.3</td>
<td>7.1</td>
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<tr>
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<td>N=1316</td>
<td>N=224</td>
<td>N=55</td>
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<tr>
<td>White Neighborhood</td>
<td>%</td>
<td>%</td>
<td>%</td>
<td>%</td>
</tr>
<tr>
<td></td>
<td>7.5</td>
<td>4.1</td>
<td>10.3</td>
<td>14.5</td>
</tr>
</tbody>
</table>

Notes: Three subjects are excluded due to missing Medicaid-status values.
Maternal Age

• Typically, premature birth and infant mortality are highest in adolescent mothers and mothers delivering after mid-30s

• Women are “protected” having babies in their 20s – early 30s.
**IMR by Mother's Age**

- **Rate per 1,000 live births**
  - Under 20
  - 20-24
  - 25-29
  - 30-34
  - 35-39
  - 40-54

- **Legend**:
  - Non-Hispanic Black
  - Non-Hispanic White

*Figure 1. Source: CDC 2015. Infant Mortality Statistics from the 2013 Period Linked Birth/Infant Death Data Set, National Vital Statistics Reports.*

Smith et al, 2018
Mortality among Infants of Black as Compared with White College-Educated Parents

Kenneth C. Schoendorf, M.D., M.P.H., Carol J.R. Hogue, M.P.H., Ph.D., Joel C. Kleinman, Ph.D., and Diane Rowley, M.D., M.P.H.

- IMR 1.8 times higher for black infants than white infants
- Low birthweight deliveries more than 2 times higher for black infants than white infants
Infant mortality higher for middle-class blacks than lower-class whites

Death rate per 1,000 births

Maternal educational attainment

8th grade or less: Black 9.5, White 5.9
High school diploma or GED: Black 11.6, White 5.8
Bachelor's degree: Black 7.4, White 3.6
Advanced/professional degree: Black 6.1, White 2.8

Why?
Structural racism

• A system in which public policies reinforce and perpetuate historic racial group inequity
• Not policy makers intentionally “discriminating” – but also not working to change long standing practices that continue to reinforce the status quo
• Example – school funding, residential segregation
Explicit vs. Implicit biases

Explicit Bias
- Aware
- Voluntary
- Intentional

Implicit bias
- Unaware
- Involuntary
- Unintentional

Implicit bias is not racism!
Implicit Bias

Implicit bias among healthcare professionals

• We do “help people…”
• But we have similar rates of bias as the general population
Implicit bias among pediatric residents

Johnson 2017
Implicit bias affecting health care delivery

Pain management in children with appendicitis

Goyal 2015
Why America’s Black Mothers and Babies Are in a Life-or-Death Crisis

The answer to the disparity in death rates has everything to do with the lived experience of being a black woman in America.

By LINDA VILLAROSA APRIL 11, 2018
BIRTH JUSTICE IS SOCIAL JUSTICE

RACISM AFFECTS OUR BIRTH OUTCOMES
Striving for health equity

- Everyone has as fair and just opportunity to be healthy
EQUALITY SOUNDS FAIR

EQUITY IS FAIR

https://www.mmshealthycommunities.org/collective-action/health-equity/
Health equity as an outcome

- Reducing and ultimately eliminating health disparities in health and its determinants that adversely affect excluded or marginalized groups
How do we move towards health equity?

• Approaches should build on/optimize existing strengths and assets of groups
• Approaches should address not only overt discrimination but implicit bias and discriminatory efforts of structures and policies created by historical injustices, even when conscious intent to discriminate no longer exist
Achieving Health Equity

- Requires sustained societal action to remove obstacles to health and increase opportunities to be healthy for everyone, focusing particularly on those who face the greatest social obstacles and have worse health
What can we do to pursue health equity?

- Recognizing and addressing our own biases is a critical step towards eliminating health disparities and achieving health equity
- National Institute for Children’s Health Quality – Implicit Bias Resource Guide
  - 7 steps we can all take to address our implicit bias
Step 1: Acknowledge your bias

- Everyone experiences bias
- Human brains are wired to look for patterns and create shortcuts based on our environment
- Subconscious neural connections influence our actions, even when we are not aware of it
  - Everyone has it
  - No one should be embarrassed or shamed
  - We probably can’t make it go away
  - We must work to mitigate the effects of implicit bias in healthcare
Step 1: Acknowledge your bias

- Harvard Implicit Association Test
- Goal – to capture unconscious connections between groups and assigned values
- Works by measuring the time for the subject to match a social group with a positive or negative attribute
- Available for: race, gender, sexual orientation, weight, disability status
Step 2: Challenge your current negative bias

- If you find yourself treating someone differently because of a bias, take a moment and reflect carefully about your assumptions
- Reflect about what similarities you may have with the person you feel bias towards
- Expose yourself to others that counter the specific perceptions you possess
- Ex. Opioid exposed families
Step 3: Be empathetic

- You may not have a personal connection with the person/group you feel bias towards.
- Find ways to learn more about minority populations that you do not regularly interact with – through books, movies, documentaries.
Step 4: See differences

- The idea of being “colorblind” negates or minimizes a person’s lived experience.
- If we do not find opportunities to learn about other historically marginalized groups, we perpetuate bias.
Step 5: Be an ally

- Step up when we see people discriminated against based on stereotypes
- Ask permission first – don’t presume what the other person wants to happen
- “I see what is happening to you and it’s not fair.” “Do you want me to do something about this?” “Do you want me to help you do something.”
- Form a plan together
Step 6: Recognized that this is stressful and painful

- The natural reaction to an uncomfortable moment or conversation is “fight or flight”
- Stay present, stay inquisitive as you begin to counter your stereotypes
Step 7: Engage in dialogue

- Talk these thoughts through with someone who has a different perspective
- Ask them “how does it feel to be you in the health system?”
- Stop and listen to their response
- Ask yourself how you may have contributed to the bias he/she encountered
Step 7: Engage in dialogue

- “Oops…Ouch” approach
- Mutual assumption of the good intentions of others
  - When something offensive or harmful is said, it is addressed in the context of helpfulness rather than blame or shame
How do we get started?

- Have everyone take the implicit association test and reflect in a group on the results
- Share within a small group your reflections on bias
  - When have you experienced bias?
  - When has bias influenced your actions?
- Start by discussing an article, book, television show, documentary that explores bias.
- Ground rules – safe space, “Oops, Ouch” approach
If the black infant mortality rate was the same as the white infant mortality rate in 2017, 101 more 1 year olds would be alive today in Indiana.
Thank you!

- Lucia Wocial
- Jenny Durica
- Jeena Siela
- Jack Turman
- Nancy Swigonski
- Lisa Crane
- Kara Casavan
References


Indiana State Department of Health, Maternal & Child Health Epidemiology Division


