

# SUID and SDY Case Registry Health Equity

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**Centers for Disease Control and Prevention**  
**National Center for Chronic Disease Prevention and Health Promotion**

Division of Reproductive Health



# Disclaimer

The findings and conclusions in this report are those of the authors and do not necessarily represent the official position of the Centers for Disease Control and Prevention.

- ① Background
- ② SUDEP in the Case Registry
- ③ Social Determinants of Health among SUID
- ④ Health Equity work

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**2009-2012**

7 states funded for  
SUID surveillance



**2012-2015**

9 states funded for  
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**2015-2018**

SDY component added &  
18 states/jurisdictions funded



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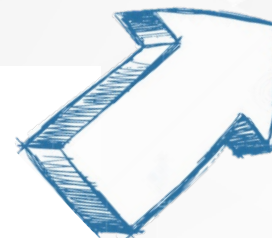


**2015-2018**

SDY component added &  
18 states/jurisdictions funded

**Circulation**  
JOURNAL OF THE AMERICAN HEART ASSOCIATION

American Heart  
Association  
Learn and Live



## Screening for Sudden Cardiac Death in the Young

Report from a National Heart, Lung, and  
Blood Institute Working Group

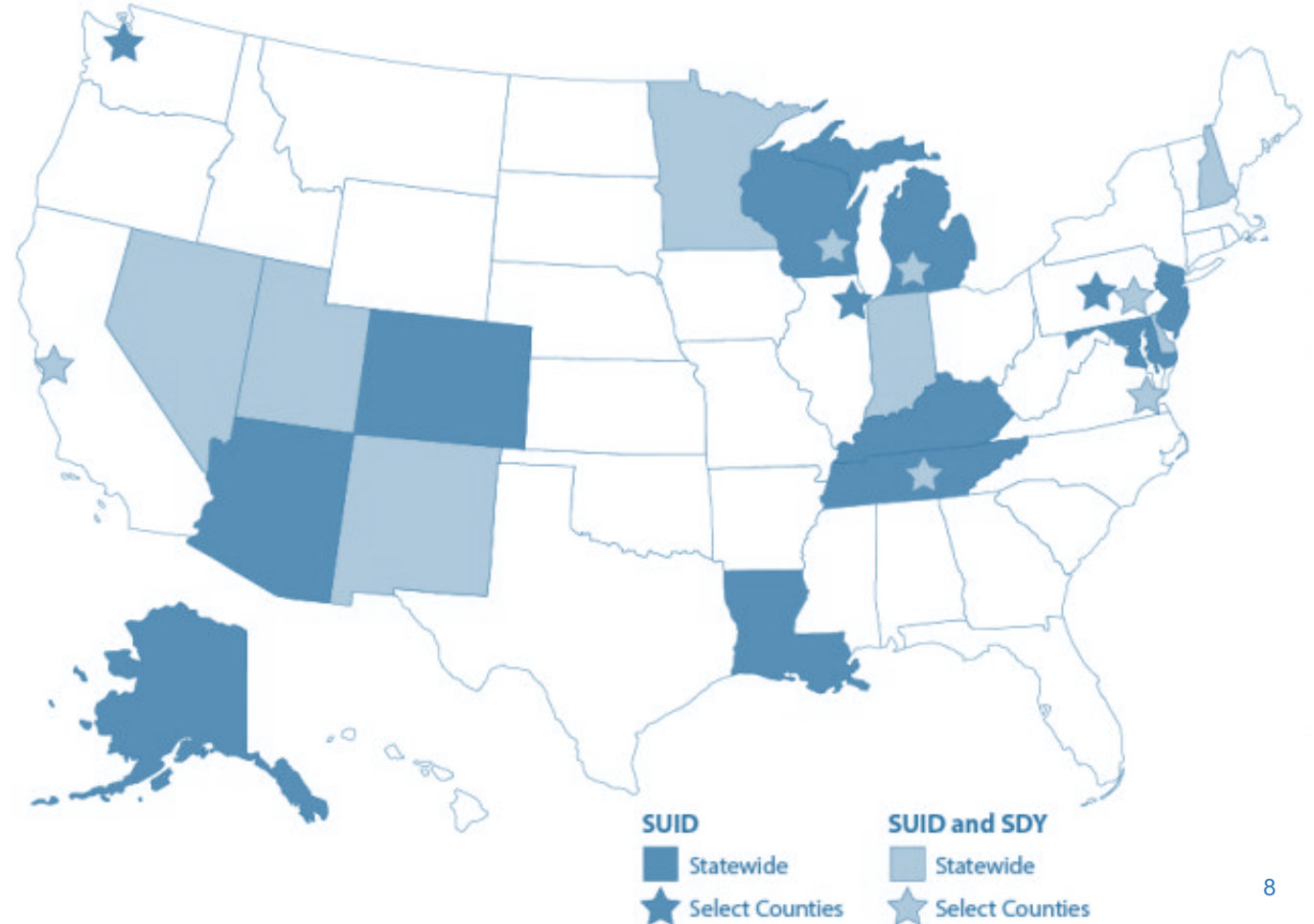
Jonathan R. Kaltman, MD; Paul D. Thompson, MD; John Lantos, MD; Charles I. Berul, MD; Jeffrey Botkin, MD, MPH; Joshua T. Cohen, PhD; Nancy R. Cook, ScD; Domenico Corrado, MD, PhD; Jonathan Drezner, MD; Kevin D. Frick, PhD; Stuart Goldman, MD; Mark Hlatky, MD; Prince J. Kannankeril, MD; Laurel Leslie, MD, MPH; Silvia Priori, MD, PhD; J. Philip Saul, MD; Carrie K. Shapiro-Mendoza, PhD, MPH; David Siscovick, MD, MPH; Victoria L. Vetter, MD; Robin Boineau, MD; Kristin M. Burns, MD; Richard A. Friedman, MD

*Circulation*, 2011; 123: 1911-1918



**2018-2023**

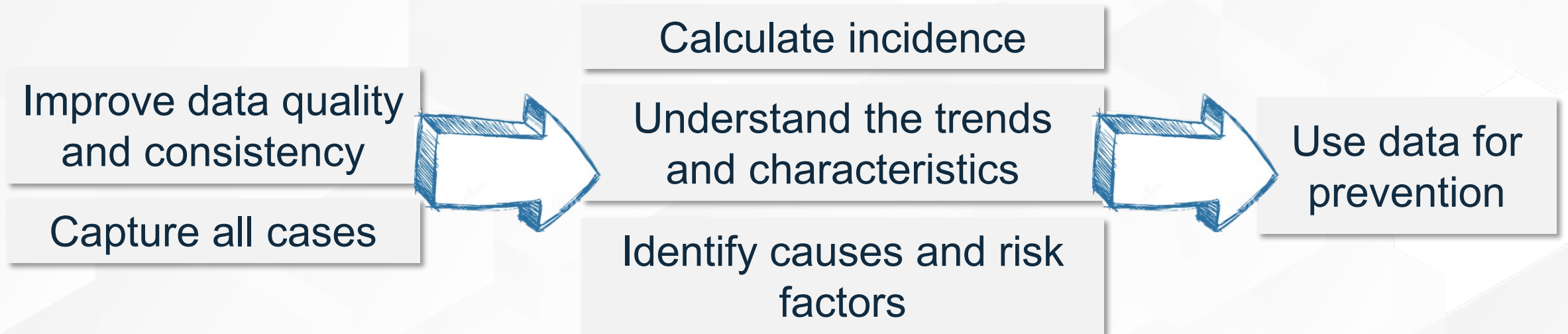
SDY component expanded,  
22 states/jurisdictions funded  
& about 30% of US SUID  
cases captured





# SUID and SDY Case Registry Purpose

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# SDY Case Process



# National Heart Lung and Blood Institute Funded Research

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Northwestern  
University



THE  
UNIVERSITY  
OF UTAH

- Began December 2016
- Working collaboratively to do genome sequencing
- Focusing on cardiac and epilepsy genes
- 212 genomes sequenced – initial results will be published this year

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# SUDEP in the Case Registry

THE JOURNAL OF PEDIATRICS: X



ORIGINAL  
ARTICLES

## Epidemiology of Sudden Death in a Population-Based Study of Infants and Children

Kristin M. Burns, MD<sup>1</sup>, Carri Cottengim, MA<sup>2</sup>, Heather Dykstra, MPA<sup>3</sup>, Meghan Faulkner, MA<sup>3</sup>, Alexa B. Erck Lambert, MPH<sup>4</sup>, Heather MacLeod, MS CGC<sup>3</sup>, Alissa Novak, BSc<sup>5,\*</sup>, Sharyn E. Parks, PhD, MPH<sup>2</sup>, Mark W. Russell, MD<sup>5</sup>, Carrie K. Shapiro-Mendoza, PhD, MPH<sup>2</sup>, Esther Shaw, MSIS<sup>3</sup>, Niu Tian, MD, PhD<sup>6</sup>, Vicky Whittemore, PhD<sup>7</sup>, and Jonathan R. Kaltman, MD<sup>1</sup>, on behalf of the Sudden Death in the Young Case Registry

3% (n=32) of SDY were categorized as SUDEP

1% (n=9) of SDY were categorized as Possible Cardiac and SUDEP

# SUDEP in the Case Registry

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72% of SUDEP cases occurred during sleep/rest and were not witnessed



69% of SUDEP were autopsied (as compared to 92% of all SDY)

# SUDEP in the Case Registry

## Population-Based Surveillance of Sudden Unexpected Death in Epilepsy using the Sudden Death in the Young Case Registry

Vicky Whittemore<sup>1</sup>, Kristin M. Burns<sup>2</sup>, Michelle Udine<sup>3</sup>, Esther Shaw<sup>3</sup>, Meghan Faulkner<sup>3</sup>, Niu Tian<sup>3</sup> on behalf of the Sudden Death in the Young Case Registry

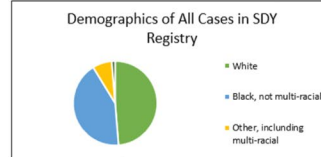
<sup>1</sup>National Institute of Neurological Disorders and Stroke; National Institutes of Health  
<sup>2</sup>National Heart, Lung, and Blood Institute; National Institutes of Health  
<sup>3</sup>Michigan Public Health Institute  
<sup>4</sup>Center for Disease Control and Prevention

**Rationale:** Surveillance of pediatric sudden unexpected death in epilepsy (SUDEP) in the United States has largely been based on convenience samples to date; few population-based studies have been performed. Incidence rates of 0.16/100,000 – 0.33/100,000 infants and children have been estimated in previous studies. The NIH/CDC Sudden Death in the Young (SDY) Case Registry provides an opportunity to explore population-based data on pediatric SUDEP and identify associations that may inform prevention efforts.

**Methods:** Using data from the SDY Case Registry from 2015 to 2017, cases of sudden, unexpected deaths among residents 0-17 years of age in up to 9 states/jurisdictions were analyzed cases categorized as *SUDEP* or *Possible Cardiac/SUDEP* in order to determine incidence.

Cases were categorized as:

- *SUDEP* - history of epilepsy, with or without evidence of seizure at the time of death (but excluding status epilepticus)
- *Possible Cardiac/SUDEP* - history of epilepsy and one or more of the following factors suspicious for a cardiac cause:
  - family history of a heritable cardiac condition or sudden death before age 50 years;
  - personal history of cardiac disease; or
  - clinical history suggestive of a cardiac cause (e.g., death during exertion).



### Results:

1. 73% of the SUDEP cases were in children ages 0-14 years of age in the SDY Registry
2. Overall incidence of SUDEP is 0.26 cases per 100,000 infants and children
3. Incidence of SUDEP in Whites is 0.22 cases per 100,000 infants and children
4. Incidence of SUDEP in Non-Whites (Black and Other) is 0.32 cases per 100,000 infants and children

### Mortality Rate by Age Group:

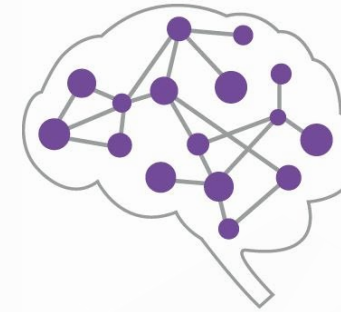
- | Age Group   | Mortality Rate (per 100,000) | n  |
|-------------|------------------------------|----|
| 0-1 years   | 0.53                         | 12 |
| 2-5 years   | 0.18                         | 8  |
| 6-9 years   | 0.26                         | 12 |
| 10-13 years | 0.17                         | 8  |
| 14-17 years | 0.31                         | 15 |

### Conclusions and Discussion:

1. The incidence of SUDEP is higher in Non-Whites than in Whites, and additional analysis is needed to determine the factors leading to this difference. Potential factors to be explored are socioeconomic status and access to care issues that may result in poor seizure control.
2. The underlying syndromes and conditions in the children who died from SUDEP is also being analyzed.

### References:

- Burns KM, Cottogno C, Dykstra H, Faulkner F, Erick Lambert, MacLeod H, Novak A, Parks SE, Russell MW, Shapiro-Mendoza CK, Shaw E, Tian N, Whittemore V, Kaltman JR, on behalf of the Sudden Death in the Young Case Registry (2020) Epidemiology of Sudden Death in a Population-Based Study of Infants and Children. *J Pediatr* X, 2:100023
- Chan E, Hestorffer DC, Brandtzy M, Li L, Fowler DR, Graham JK, Karlovich M, Donner EJ, Devinsky D, Friedman D (2020) Socioeconomic disparities in SUDEP in the US. *Neurology*, 94:e2555-e2566
- Thurman DJ, Hestorffer DC, French JA (2014) Sudden unexpected death in epilepsy: Assessing the public health burden. *Epilepsia*, 55(10):1479-1485



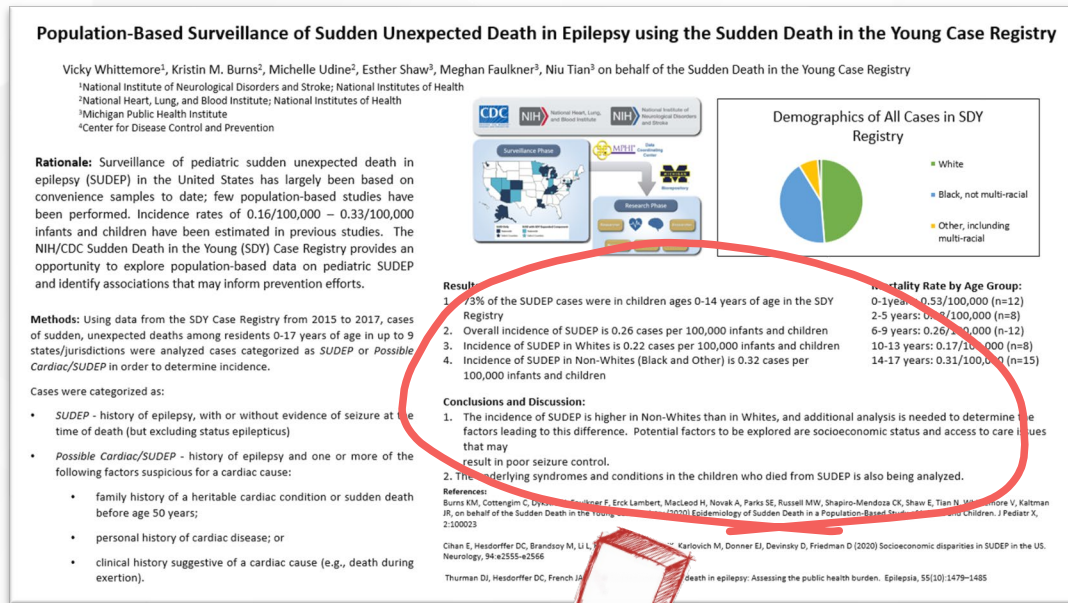
# AMERICAN EPILEPSY SOCIETY

## Population-Based Surveillance of Sudden Unexpected Death in Epilepsy using the Sudden Death in the Young Case Registry

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# SUDEP in the Case Registry

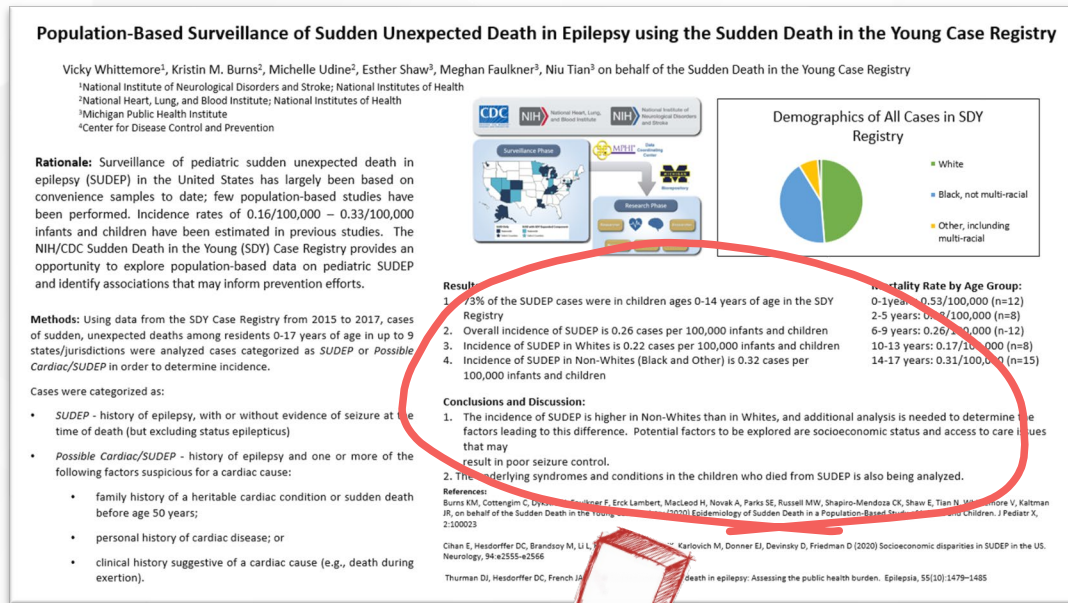


## Results:

- 73% of SUDEP cases were in infants/children ages 0-14 years of age
- SUDEP incidence
  - Overall = 0.26 per 100,000 infants/children
  - Among White infants/children = 0.22 cases per 100,000
  - Among non-White infants/children = 0.32 cases per 100,000



# SUDEP in the Case Registry



**Conclusions and Discussion:** The incidence of SUDEP is higher in non-White infants/children than in White infants/children, and additional analysis is needed to determine the factors leading to this difference. Potential factors to be explored are socioeconomic status and access-to-care issues that may result in poor seizure control.

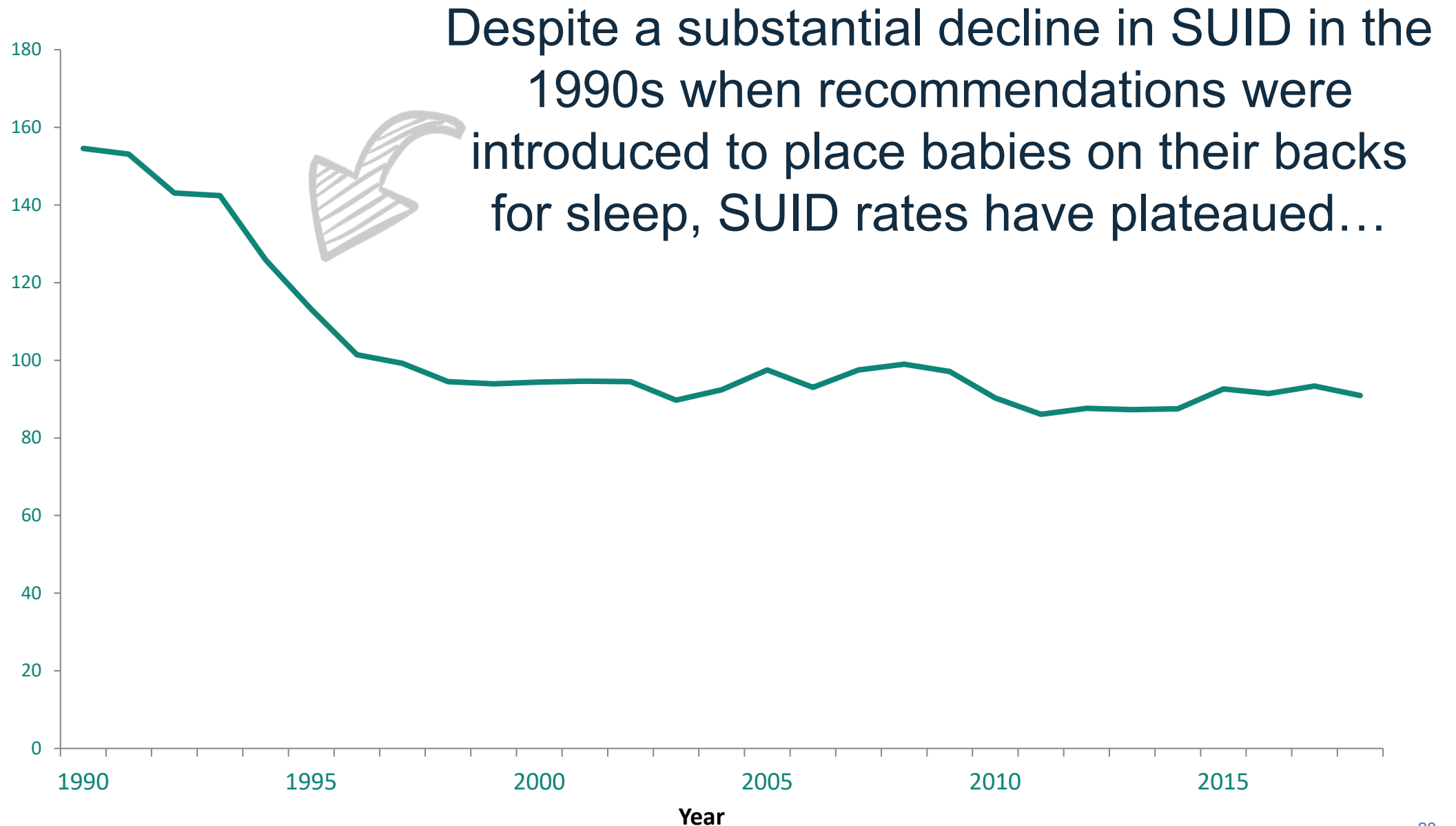
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# Social Determinants of Health among SUID

Authors: Alexa B. Erck Lambert, Sharyn Parks Brown, Carri Cottengim,  
Tiffany Riehle-Colarusso and Carrie Shapiro-Mendoza

# SUID Rates Over Time

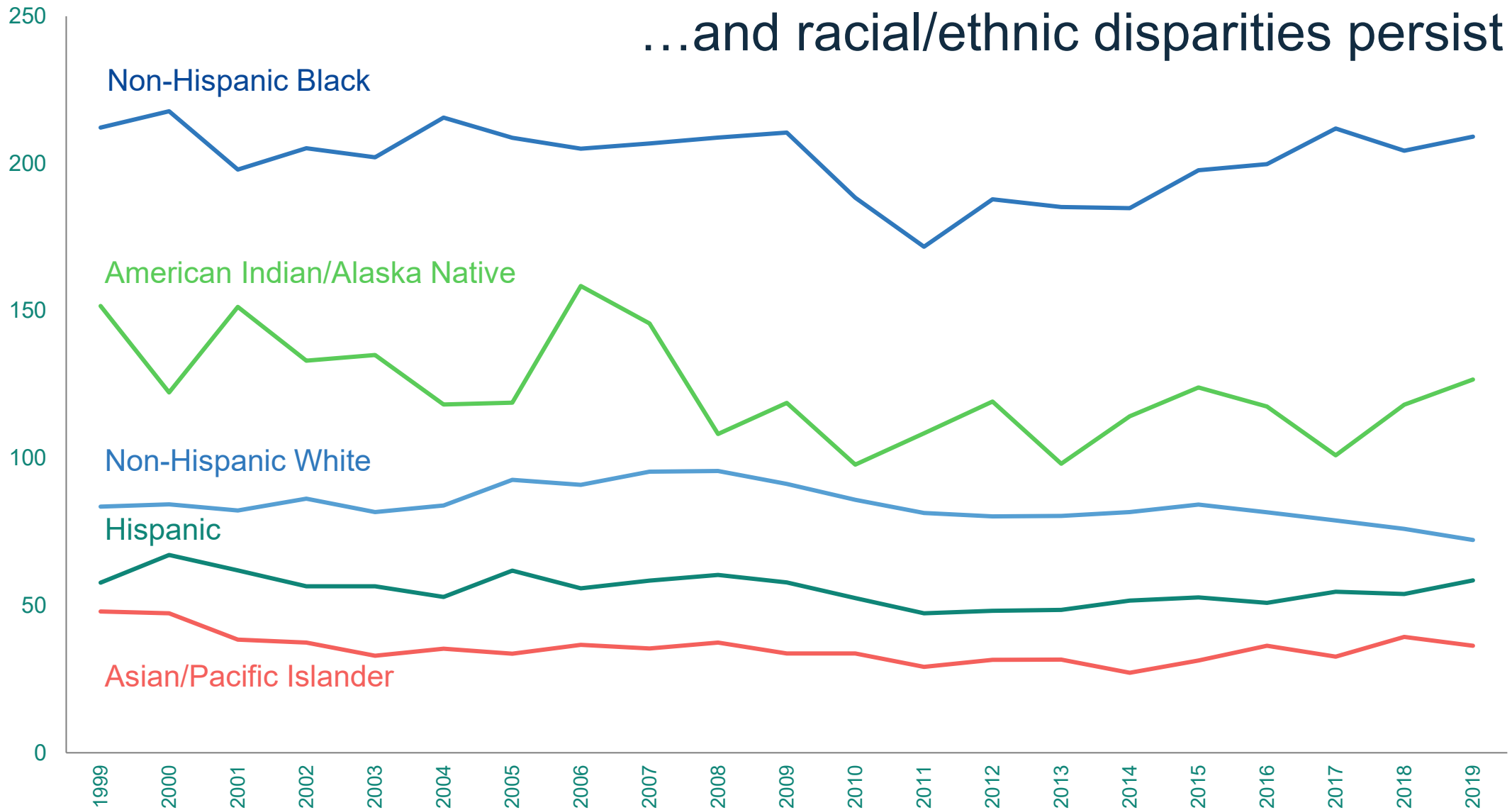
Per 100,000 Live Births



SOURCE: CDC/NCHS, National Vital Statistics System, Mortality Files.

# SUID Rates Per 100,000

...and racial/ethnic disparities persist



SOURCE: CDC/NCHS, National Vital Statistics System, Period Linked Birth/Infant Death Data.  
SUID includes R95, R99 and W75

An association between...

SUID  $\Leftrightarrow$  Adverse economic  
social determinants  
of health

....has been observed



# STUDY QUESTION

What proportion of SUID  
found in an unsafe sleep  
environment experience  
economic disadvantage?

# Study Population

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- ☑ Infant deaths
- ☑ Occurred in states/jurisdictions participating in the SUID Case Registry from 2011-2018\*
- ☑ Cause of death reported on the death certificate:
  - SIDS/SUID
  - Undetermined/Unknown
  - Unintentional sleep-related asphyxia/suffocation
  - Other ill-defined causes with unsafe sleep factors
- ☑ Had complete and consistent data
- ☑ Found in an unsafe sleep environment\*\*
- ☑ With death scene investigation and autopsy, including toxicology, imaging, pathology, and known found position and location

\*AK, AZ, CO, San Francisco CA, DE, GA, KY, LA, MI, MN, NV, NH, NJ, NM, PA, TN, Tidewater Region of VA, WI.

\*\*In a crib or bassinet, on a firm sleep surface, supine, alone, with no soft bedding.



## 6 Economic Factors Investigated

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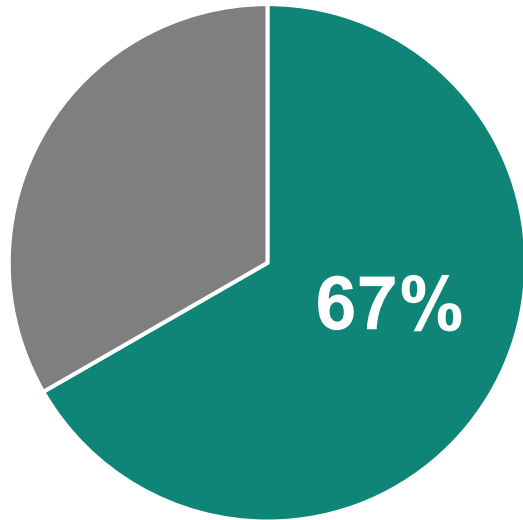
1. Infant insured by Medicaid
2. Infant was ever homeless
3. Parents/caregivers were unemployed (excluding parents who opted to stay home) or received disability benefits at the time of death

*In the past 12 months, parents/caregivers received:*

4. Women, Infants and Children (WIC) benefits
5. Temporary Assistance for Needy Families (TANF)
6. Food Stamps

# Among 4,260 SUID cases...

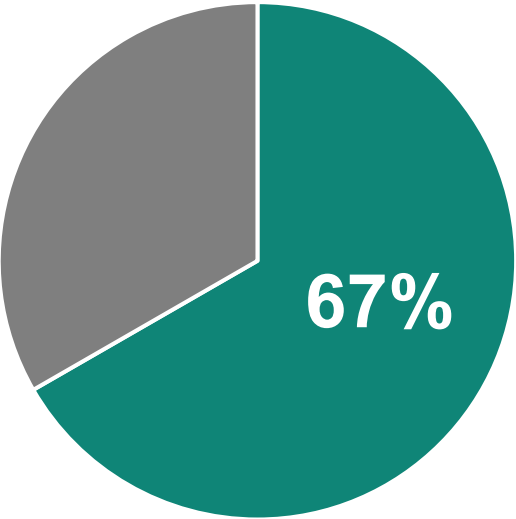
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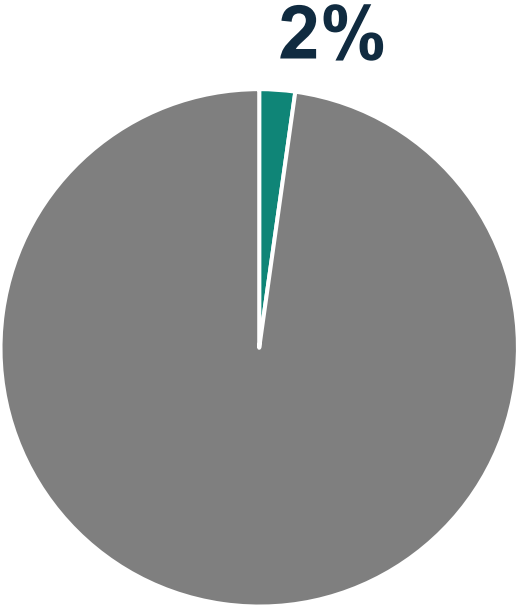
**Insured by Medicaid**

# Among 4,260 SUID cases...

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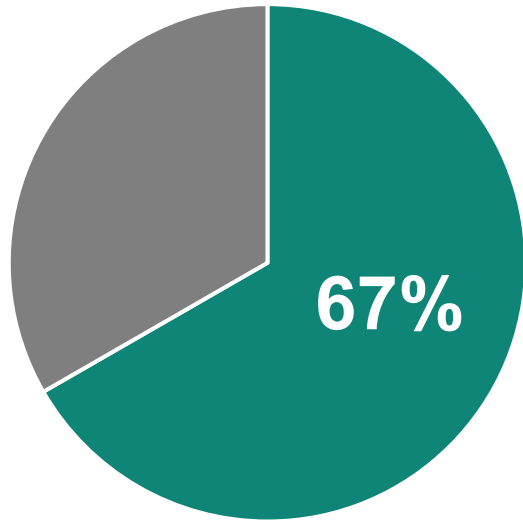
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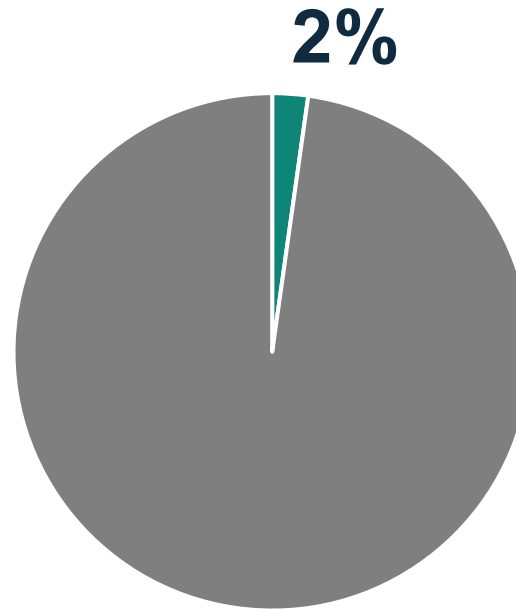
**Ever homeless**

## Among 4,260 SUID cases...

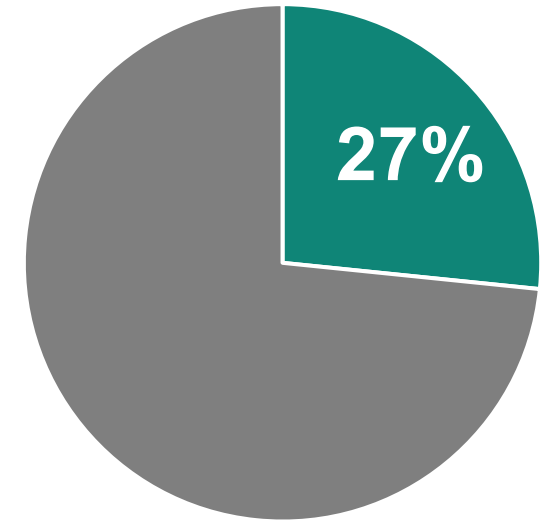
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**Insured by Medicaid**



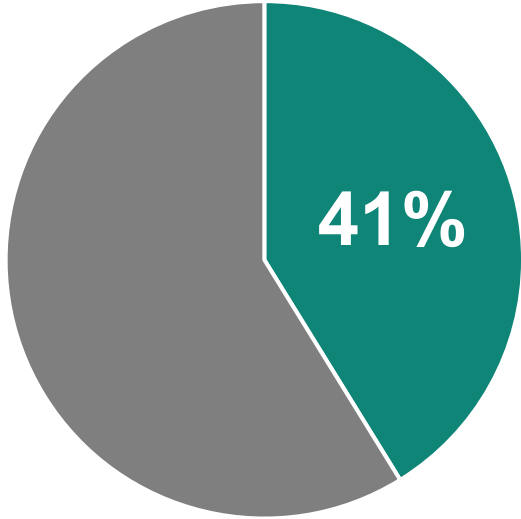
**Ever homeless**



**Parents/caregivers were unemployed (excluding those who opted to stay home) or received disability benefits**

## Among 4,260 SUID cases, *in the past 12 months...*

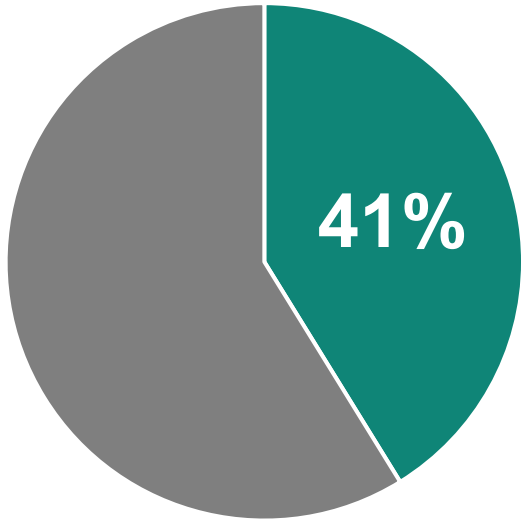
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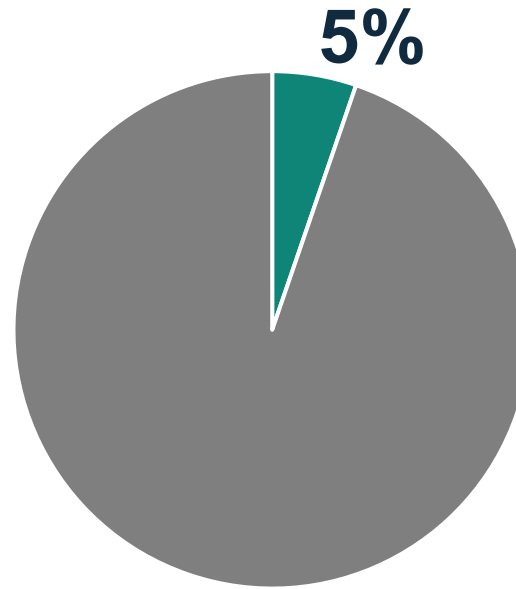
**Parents/caregivers received  
Women, Infants and Children  
(WIC) benefits**

## Among 4,260 SUID cases, *in the past 12 months...*

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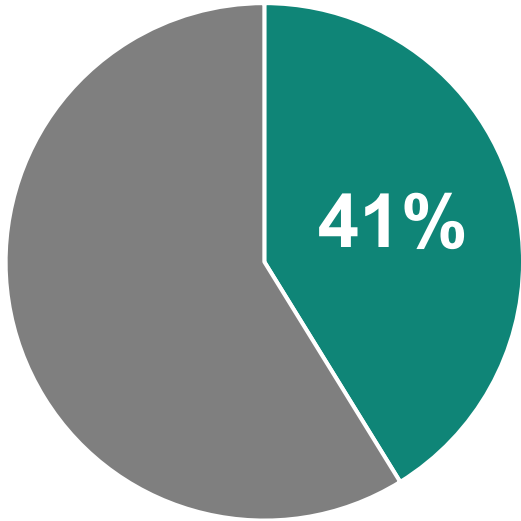
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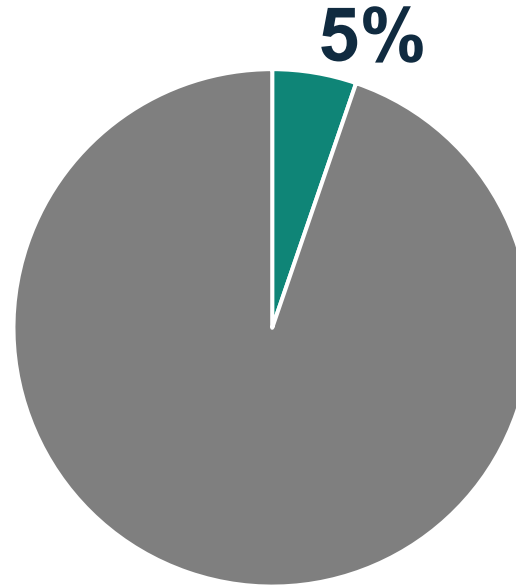
**Parents/caregivers received  
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Needy Families (TANF)**

## Among 4,260 SUID cases, *in the past 12 months...*

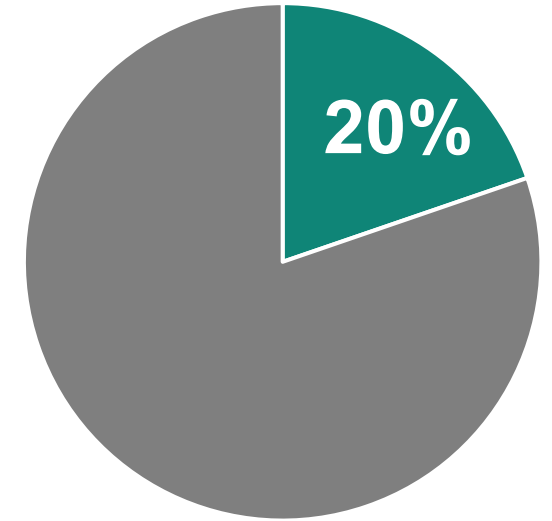
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**Parents/caregivers received  
Women, Infants and Children  
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**Parents/caregivers received  
Temporary Assistance for  
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**Parents/caregivers received  
Food Stamps**

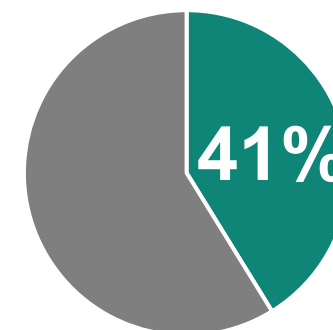
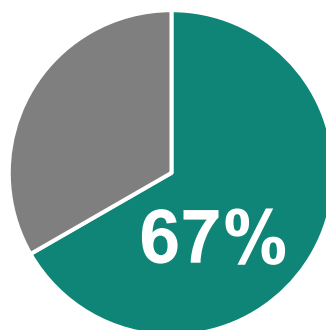
# Comparison to Birth Population

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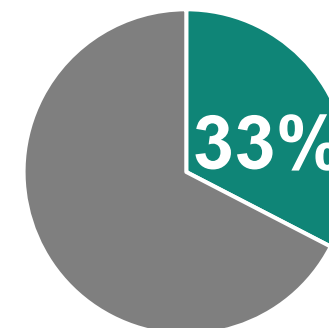
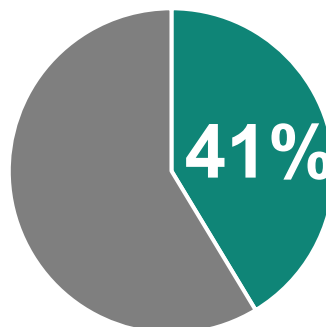
Insured by Medicaid

Parents/caregivers received Women, Infants and Children (WIC) benefits

**CDC SUID  
Case Registry  
2011-2018**



**2018 Births in SUID  
Case Registry  
States/Jurisdictions\***



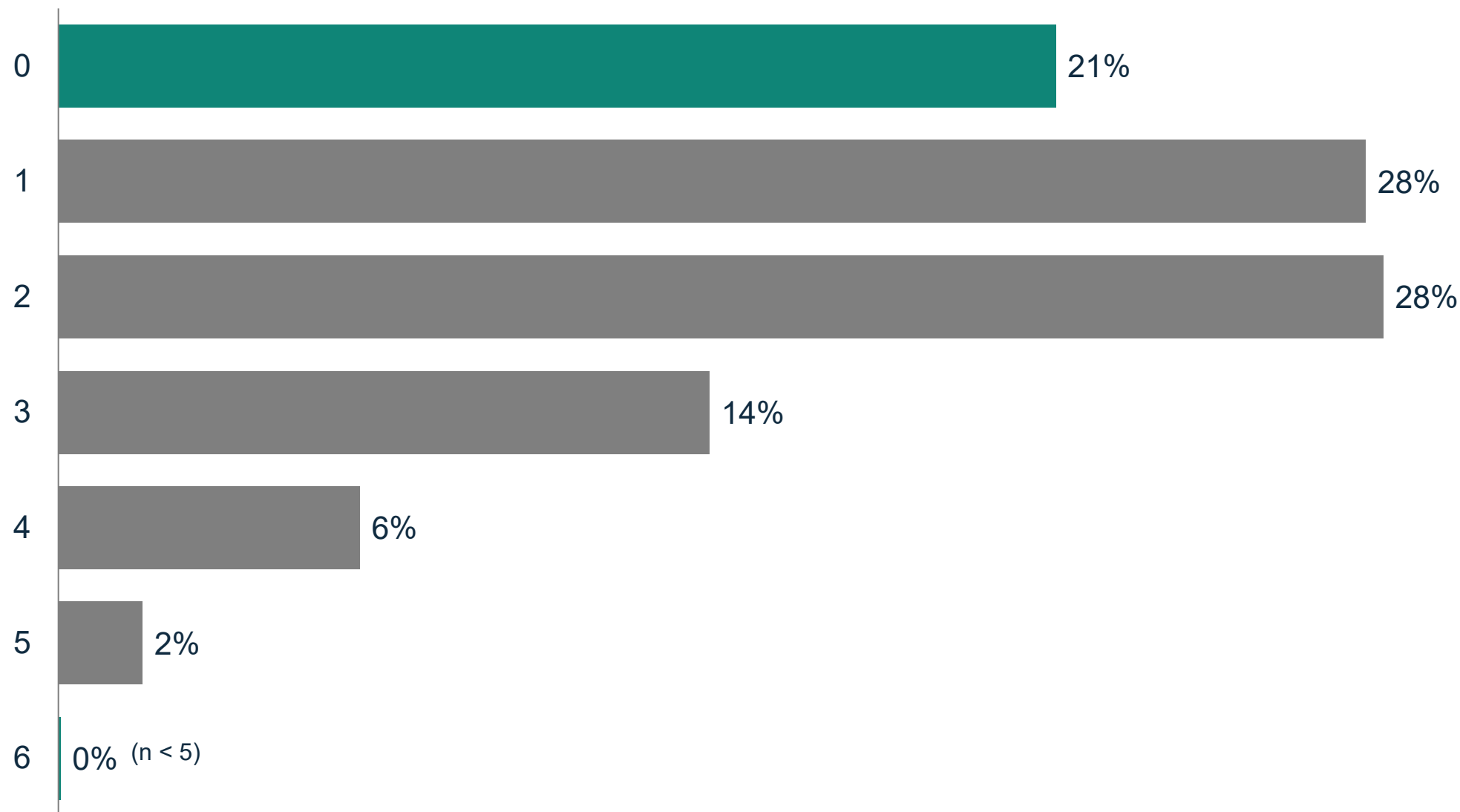
*\*SOURCE: CDC/NCHS, National Vital Statistics System, Mortality Files.*

*AK, AZ, CO, San Francisco CA, DE, GA, KY, LA, MI, MN, NV, NH, NJ, NM, PA, TN, Tidewater Region of VA, WI*



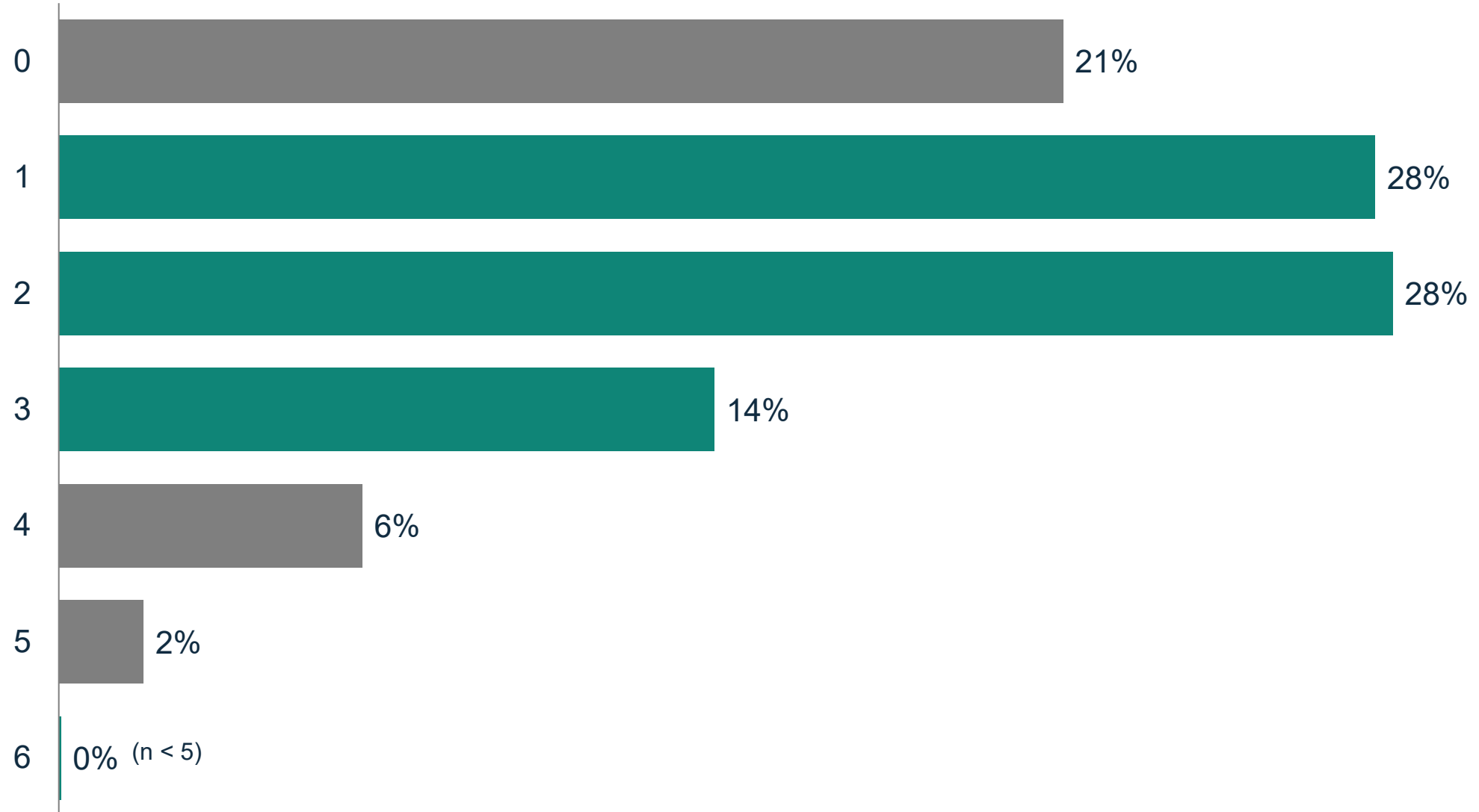
# 21% of Infants had 1 Adverse Economic Factor

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# 70% of Infants had 1-3 Adverse Economic Factors

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4/5 SUID found in an unsafe sleep environment had at least 1 of the adverse economic factor investigated



# Conclusions

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Identifying adverse economic factors among infant deaths occurring in an unsafe sleep environment may help prioritize safe sleep interventions

# Next Steps

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Expanding this analysis to  
assess additional Social  
Determinants of Health



# Additional Analysis


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Examining child,  
environmental and  
caregiver characteristics  
among SUID and SDY  
cases by race/ethnicity

# Data Completeness Improvement Project

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GOAL: Improve completeness of  
social determinants of health  
variables for use in future  
analyses

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# We are all learning

- Expert-led in-person learning sessions
- Virtual learning collaborative discussion
- Unconscious bias training module
- Conference session for awardees to share their efforts

# Examples of Health Equity Efforts by Awardees

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- Shifting the prevention discussion and efforts away from the individual and toward systems changes
- Tracking and reporting Social Determinants of Health and Adverse Childhood Experiences (ACEs)
- Making review teams more representative/diverse

# Acknowledgements

## **Students**

Shama Tajani and Austin Whitted

## **Centers for Disease Control and Prevention**

Carri Cottengim, Sharyn Parks Brown, Carrie Shapiro-Mendoza,  
Tiffany Colarusso, and Emily Osteen Johnston

## **Data Coordinating Center**

Meghan Faulkner, Heather MacLeod, and Erik Buczkowski

## **SUID and SDY Case Registry Awardees**

Alaska, Arizona, San Francisco (CA), Colorado, Delaware, Cook County (IL),  
Indiana, Kentucky, Louisiana, Maryland, Michigan, Minnesota, Nevada, New  
Hampshire, New Jersey, New Mexico, Pennsylvania, Tennessee, Tidewater Region  
(VA), Utah, Pierce County (WA), and Wisconsin

# Thank You

ALEXA ERCK  
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**Centers for Disease Control and Prevention**  
**National Center for Chronic Disease Prevention and Health Promotion**

Division of Reproductive Health

