Infant Fatality Reviews

Secretary's Advisory Committee on Infant Mortality

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Presentation Objectives

At the conclusion of this presentation, participants should be able to:

- Explain HRSA's role in supporting infant fatality reviews.
- Identify how the National Center for Fatality Review and Prevention's partners nationally to achieve priorities
- Distinguish the different approaches of the infant review teams
- Recognize the opportunities provided by the Case Reporting System.

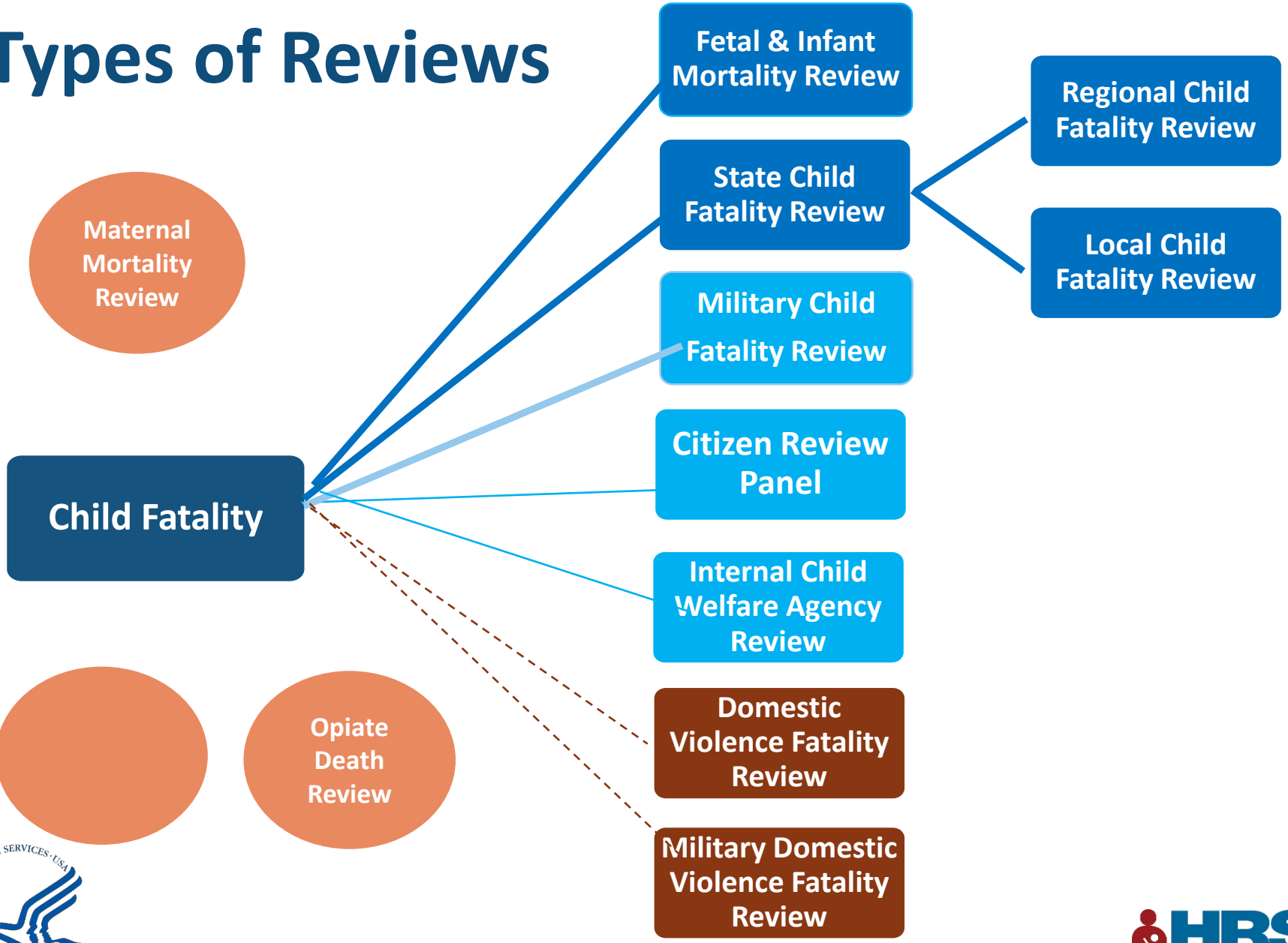
HRSA / MCHB support of infant fatality reviews

- *Division of Healthy Start and Perinatal Services* funded the National Fetal and Infant Mortality program since 1990 to provide training and technical support for Fetal Infant Mortality Review (FIMR) programs nationwide.
- *Division of Child Adolescent and Family Health* funded a Child Death Review (CDR) national Center since 2002 to provide training and technical support and create and host a web-based reporting system for state and local CDR teams, which was expanded to FIMR programs in 2018.
- In 2018, both the FIMR and CDR Resource Center cooperative agreements were awarded to the Michigan Public Health Institute.

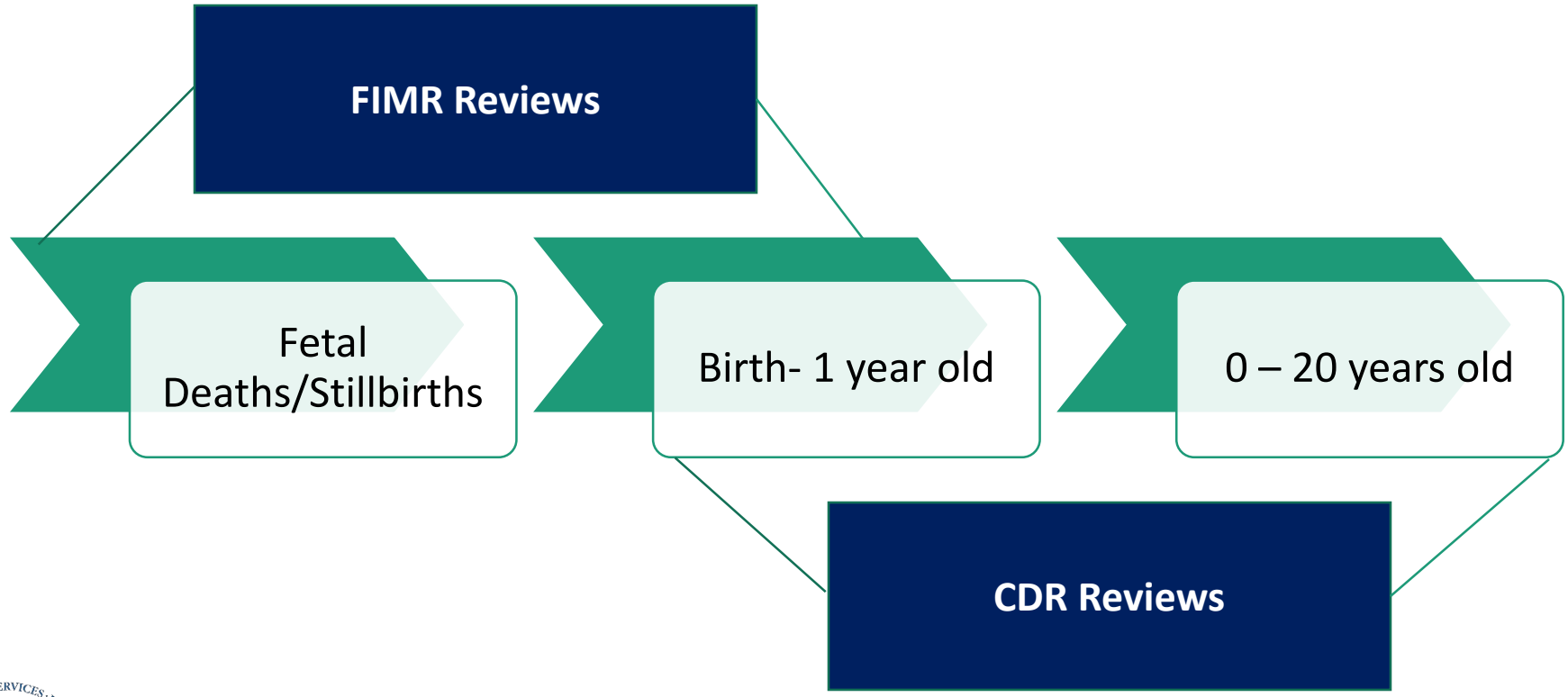
National Center for Fatality Review and Prevention (NCFRP) Objectives

- Provide technical assistance and training to CDR teams and FIMR programs .
- Maintain and support a web-based CDR and FIMR Case Reporting system to support standardized data collection.
- Disseminate information and findings from these reviews.
- Facilitate translation of team recommendations into action and practice.
- **Ultimate goal: Prevent fetal, infant, child, and adolescent deaths.**

Types of Reviews



CDR and FIMR fatality reviews



Child Death Review

An engaged, multidisciplinary community, telling a child's story, one child at a time, to better understand the circumstances that contribute to a child's death and identify pre-existing vulnerabilities- in order to identify how to interrupt this pathway for other children

Local Team: Case Selection

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Teams bring records to review

↓

Case Review

↓

Recommendations and Data Entry into National CDR-CRS

→

State Advisory Board if available

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State Action for Policy, Practice, Prevention

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Local Action for Policy, Practice, Prevention

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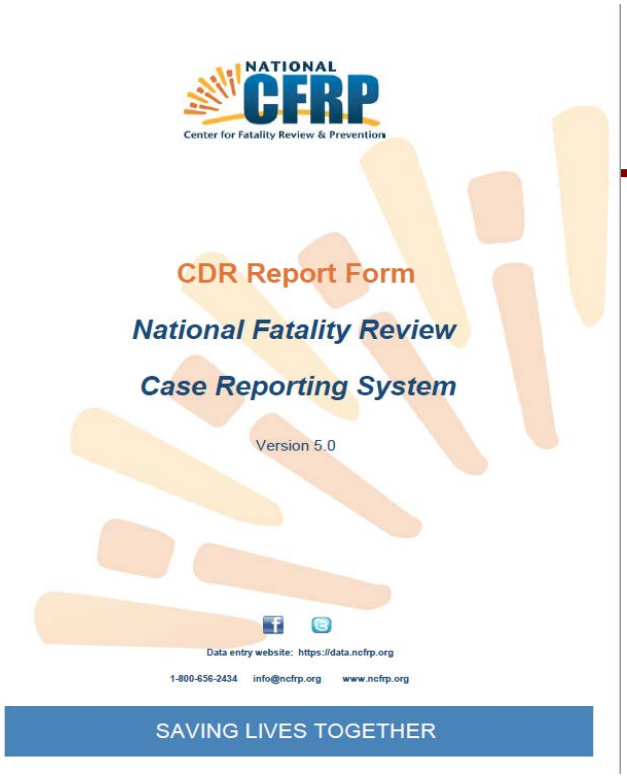
Why CDR?

- Examine the circumstances surrounding that child's life and death to identify mitigatable circumstances
- Provides insight into gaps in services, systems, and modifiable risk factors not obtained from administrative surveillance systems.
- Focus is on improving systems and prevention of deaths; not culpability.
- Review findings can be used to improve agency practices/policies/services and for primary prevention

CDR Today

- ~1,350 local and state teams in all 50 states and DC, Department of Defense, Guam and some tribes
- Most teams are voluntary, limited funding
- Standardized case reporting form
- Free, web-based case reporting system (with ~106,000 infant deaths)
- Best practice is to review all deaths but some focus on unexpected deaths.



Information collected in CDR- circumstances surrounding the death

- Child, family, supervisor and perpetrator demographics and community information.
- Investigation actions (including autopsy information).
- Services accessed or needed.
- Specific risk factors related to the specific cause of death.
- Recommendations made by teams for, and actions taken, to prevent deaths
- Factors affecting the quality of case review.

CDR Team Members include

- Physician
- Other health providers
- Public health
- Medical examiner/ coroner
- Law enforcement
- CPS
- Other social services
- Hospital
- EMS
- Mental Health
- Military
- Prosecutor/ District Attorney
- Education
- Others

Fetal and Infant Mortality Review

- A warning system that can describe effects of health care systems change.
- A method for implementing continuous quality improvement .
- A means to implement needs assessment, quality assurance and policy development which are essential public health functions, at the local level.

The FIMR Process

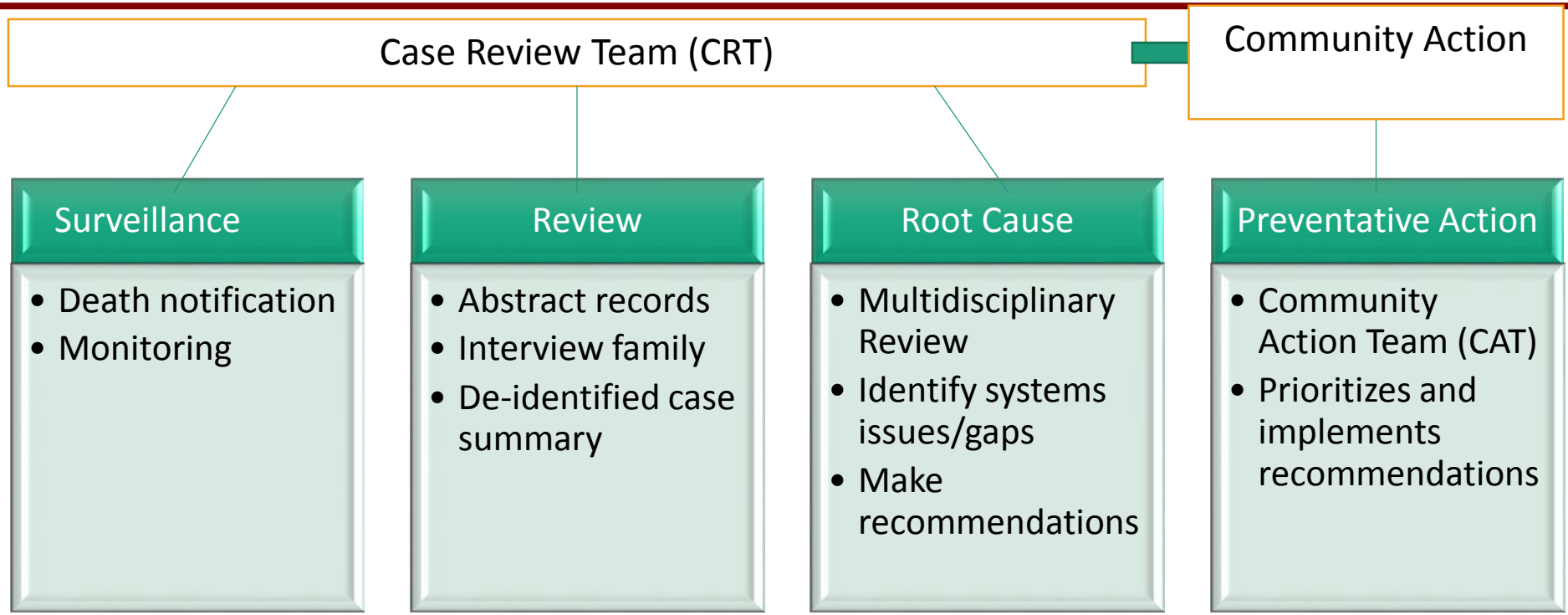
A multidisciplinary, community team examines a fetal or infant death case that is:

- Comprehensive
- De-identified
- Confidential
- Giving voice to mothers' experiences (maternal Interview)
- Includes a Community Action Team

The Maternal Interview in FIMR

- Provides insight into the mother's experience before, during, and after pregnancy.
- Tells the story of mothers' encounters with local service systems.
- **About half of FIMR reviews do this interview.**

The FIMR Process



Role of the Case Review Team (CRT)

- **Review cases**
  - Sentinel events
  - Trends
  - Incidental findings
  - Present and contributing factors
- **Develop initial recommendations**

The Case Review Team

- Reviews the story: What happened to this baby and family from the time his/her mother got pregnant until the time of death?
- Identifies the issues: Were there clinical, community or health system factors that contributed to the death?
- Makes recommendations: Provides recommendations to professional groups and local Community Action Teams.

Role of the Community Action Team (CAT)

- Develop new and creative solutions to improve services and resources for families from the recommendations made by the case review team.
- Enhance the credibility and visibility of issues related to women, infants, and families within the broader community by informing the community about the need for these actions through presentations, media events, and written reports.

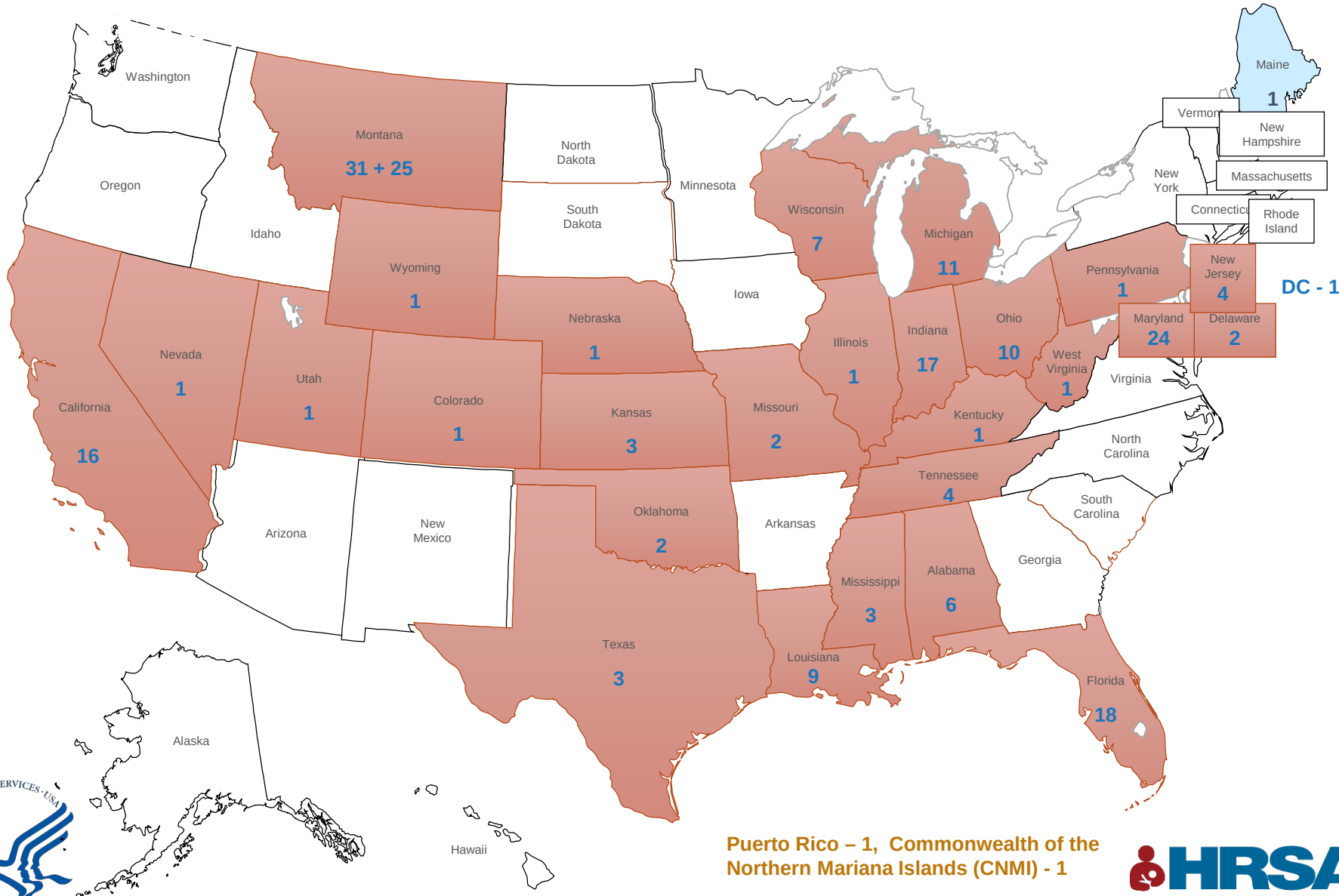
Role of the CAT, continued

- Work with the community to implement interventions to improve services and resources.
- Determine if the needs of the community are changing over time and decide which interventions should be added or altered to meet them.
- Safeguard successful systems changes initiated by FIMR that have been implemented from being discontinued in the future.

FIMR today

- FIMR has a presence in 28 states, DC, Puerto Rico, and Commonwealth of the Northern Mariana Islands
- ~181 local programs
- Tribes plan and participate in FIMR in Wisconsin and Wyoming
    - Inter-Tribal Council of Michigan has its own FIMR

181 FIMR Programs in the US and Affiliated Islands



Puerto Rico – 1, Commonwealth of the Northern Mariana Islands (CNMI) - 1

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FIMR Team composition

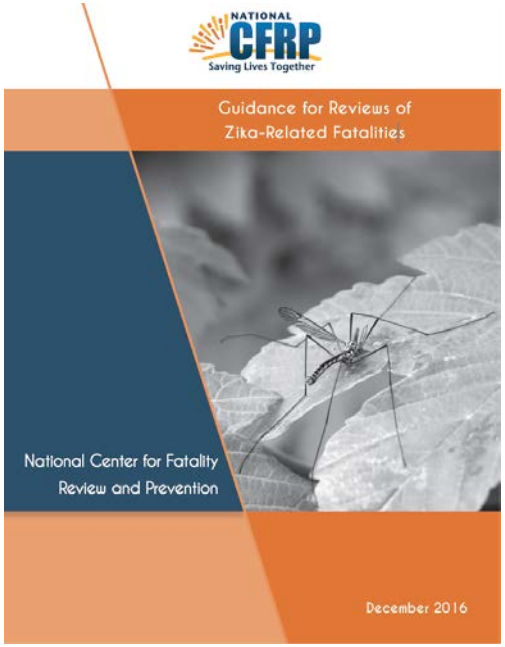
- **Medical Expertise**
  - E.g. OB, Peds, Pathology, ED, FP, Psychiatry
- **Other Health Care Providers**
  - Nurses
  - Social Workers
  - Discharge Planning
  - Home Care & Home Visiting
- **Emergency Medical Personnel**
- **Medical Examiners**
- **Human Service Providers**
  - Child Welfare Agencies
  - Mental Health
  - Substance Abuse
- **Public Health**
  - Medicaid/Health Plans
  - WIC
  - Family Planning
- **Community Health Leaders**
- **Advocacy Groups**

Components of effective infant death reviews

- Clear purpose
- Are coordinated and comprehensive
- Includes key partners who share a common vision and are committed to prevention
- Identify and analyze the risk factors contributing to the deaths
- Identify agency practices and policies and gaps in community systems and services
- Make effective recommendations that can lead to Prevention- Actions implemented to improve systems and care

Sentinel and emerging issues

- Opioid related deaths
- Tribal reviews
- Using FIMR Methodology to review other MCH Sentinel Events
  - Review of births impacted by Zika (including non fatalities)
  - Review of mother to child transmission of HIV
  - Review of Congenital Syphilis
  - FIMR – Fetal Alcohol Syndrome
  - Pre-term/low birth weight births



CDR and FIMR Data Collection-Case Reporting System (CRS)

- Web-based CRS available free to CDR and FIMR teams
- Also used by CDC SUID registry and NIH- SDY Registry
- To systematically collect, analyze and report comprehensive fatality review data on the deaths of each child.
- Total number of deaths in CDR CRS: 200,906*
  - Infant deaths: 106,900
  - SUID deaths: 32,402
- Researcher database
  - 128,768 cases of which 69,677 (54%) are infants

*As of February 2019

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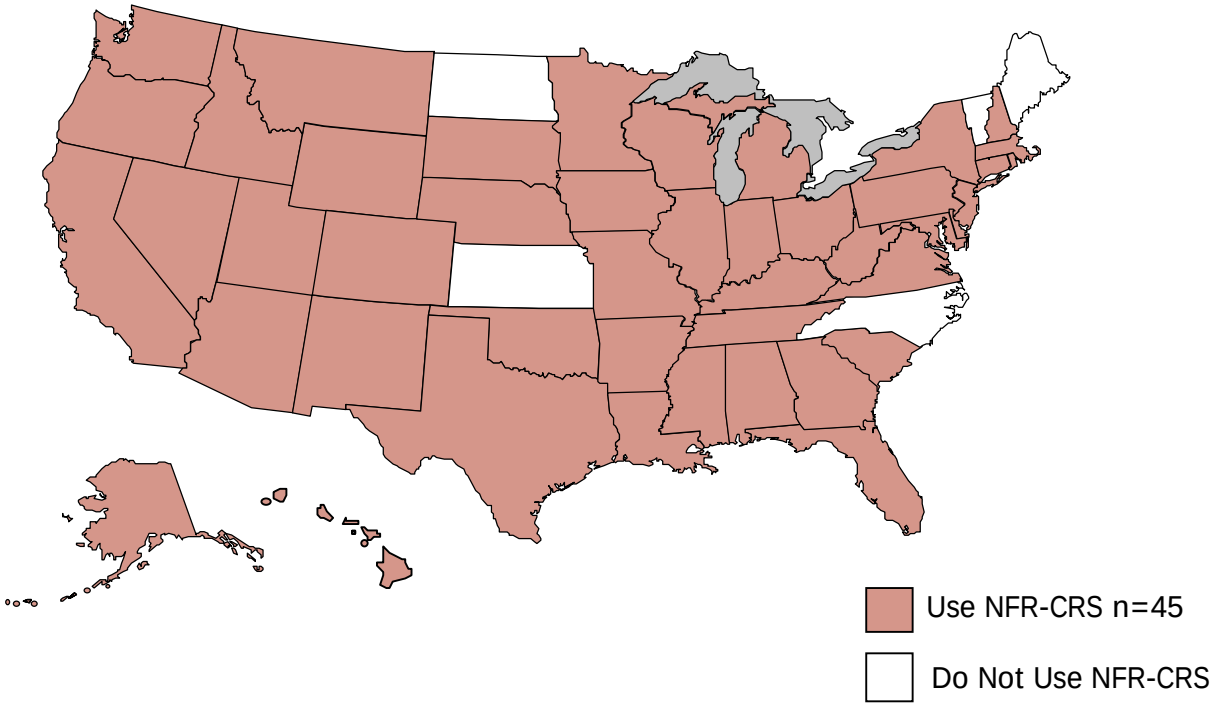
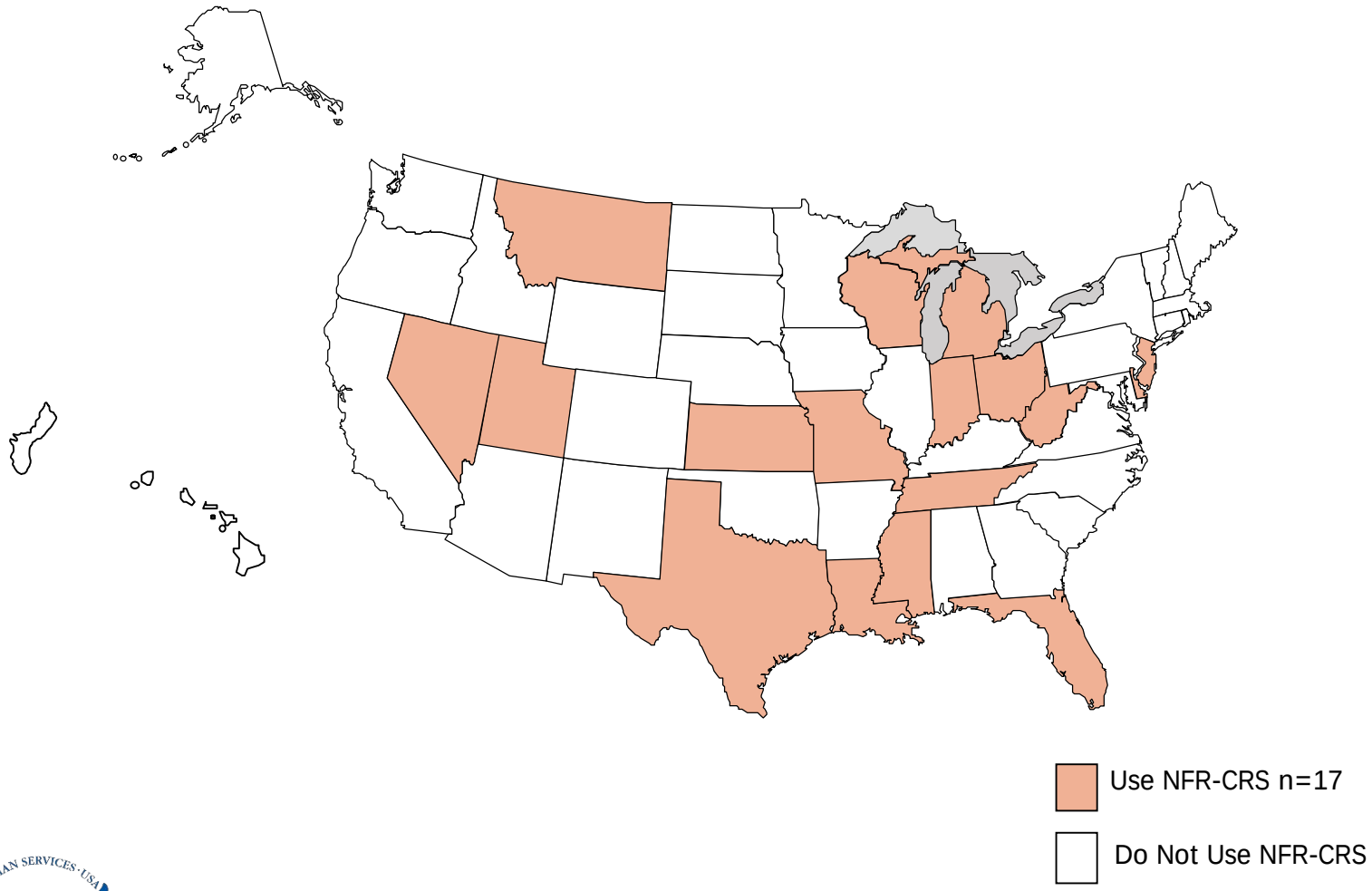
CDR States using the NFR-CRS
November 2019

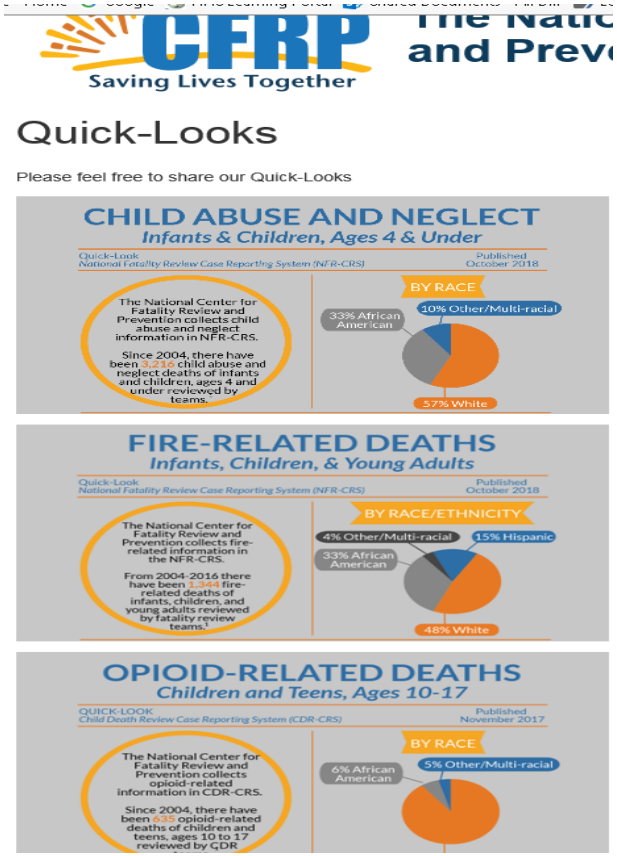


FIMR States Using the NFR-CRS
November 2019

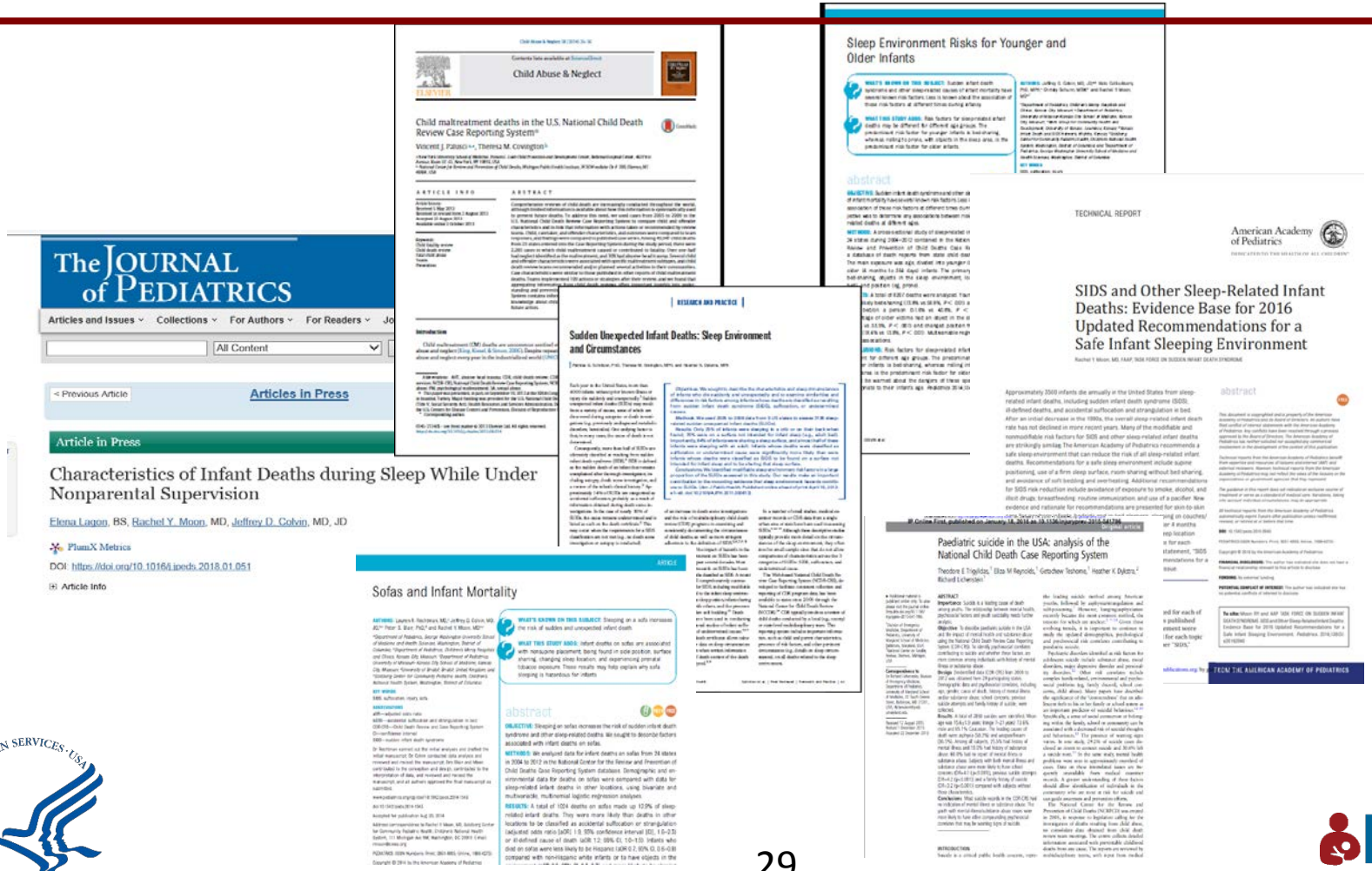


NCFRP Case Reporting System Data

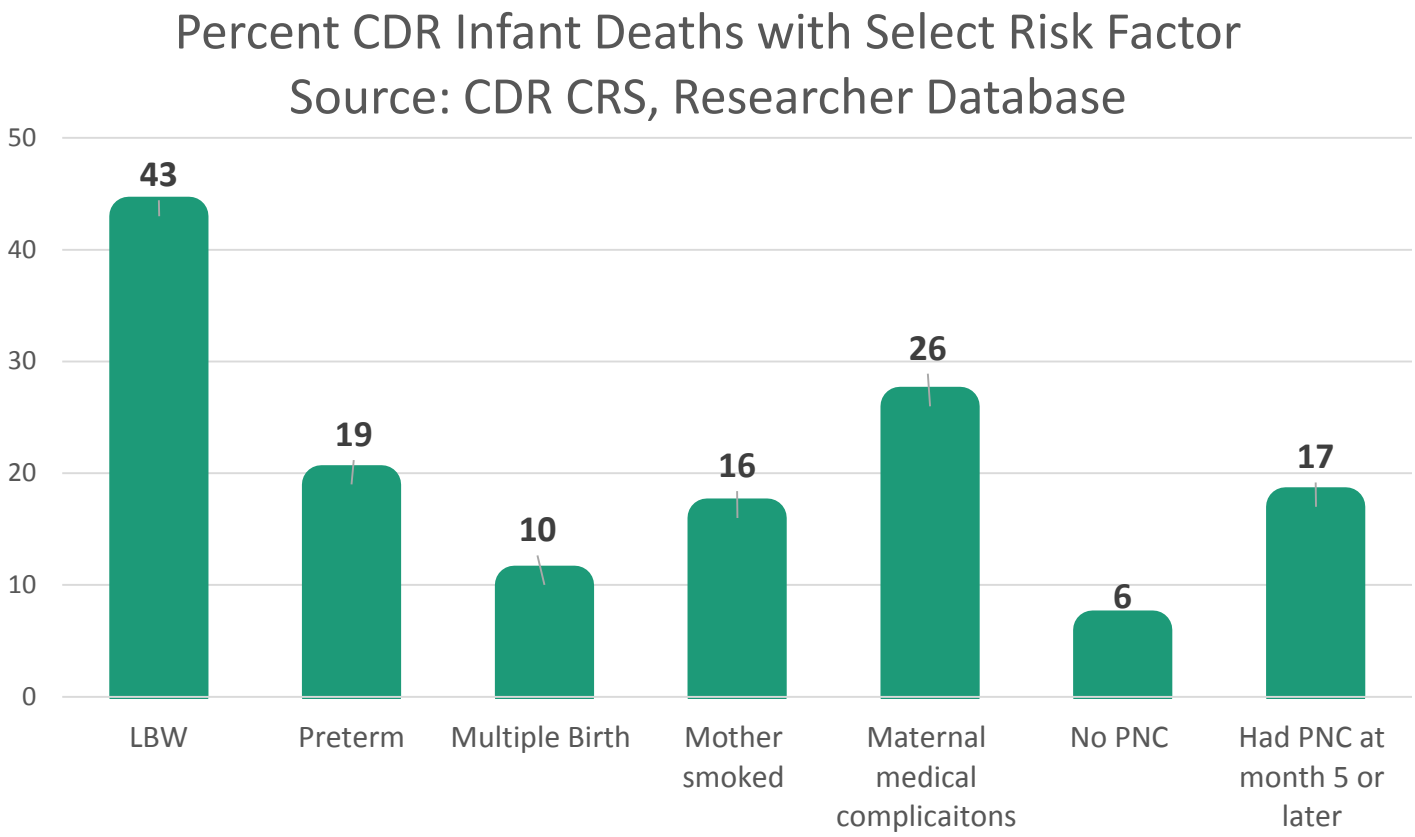
- Information on the data form and data system is available at: https://www.ncfrp.org/resources/national-cdr-case-reporting-system/



Select Publications using CDR-CRS Data



Select CDR Infant Death Data



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SUID Characteristics – CDR CRS

Source: CDR Researcher Database

- Race/ethnicity: 55% White, 32% AA, 4% multi-racial, <1% other
- Gender: 58% male
- LBW: 16%
- Found location: 22% crib/ basinet, 50% adult bed, 12% chair or couch
- Found position: 27% back, 28% stomach, 12% side, 24% unknown
- 58% sleeping on same surface as another person or an animal

Drug exposed and Opiates

Source: CDR Researcher Database

- ~3% infants were born (illicit) drug exposed and less than 1% reported the mother had heavy alcohol use during the pregnancy
  - Drug exposed- Increased from 1.8% in 2005 to 4.3% in 2015
- For the 216 infants in the researcher database with poisoning as cause of death:
  - 19% checked prescription pain killer (opiate)
  - 8% checked methadone
  - 1% other and specified opiates (e.g heroin)

For more information

National Center for Fatality Review and Prevention

https://www.ncfrp.org/

Questions ?

Contact Information

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