The Fetal and Infant Mortality Review (FIMR) Process

Pacific Island Health Officers Association Meeting

Honolulu, HI

September 6, 2018

About the National Center

- The National Center for Fatality Review and Prevention is a resource and data center that supports child death review (CDR) and fetal and infant mortality review (FIMR) programs around the country.
- Supported with funding from the Maternal and Child Health Bureau at the Health Resources and Services Administration, the Center aligns with several MCHB priorities and performance and outcome measures such as:
  - Healthy pregnancy
  - Child and infant mortality
  - Injury prevention
  - Safe sleep

The Center is funded in part by Cooperative Agreements UG7MC28482 and UG7MC31831 from the U.S. Department of Health and Human Services (HHS), Health Resources and Services Administration (HRSA), Maternal and Child Health Bureau (MCHB).

NATIONAL CFRP Saving Lives Together

MCHB's Vision for the Center

- Through delivery of data, training, and technical support, the Center will assist state and community programs in:
  - Understanding how CDR and FIMR reviews can be used to address issues related to adverse maternal, infant, child, and adolescent outcomes
  - Improving the quality and effectiveness of CDR/FIMR processes
  - Increasing the availability and use of data to inform prevention efforts and for national dissemination

Ultimate goal: improving systems of care and outcomes for mothers, infants, children, and families

HRSA adopts CoIIN

Collaborative Improvement and Innovation Networks (CoIINs) are multidisciplinary teams of federal, state, and local leaders working together to tackle a common problem. Using technology to remove geographic barriers, participants with a collective vision share ideas, best practices, and lessons learned, and track their progress toward similar benchmarks and shared goals.

Gloor PA. Swarm Creativity: Competitive Advantage through Collaborative Innovation Networks. New York: Oxford University Press, 2006.

HRSA's vision for CoIIN

Each successful CoIIN does the following:

- Works together to identify common aims and specific, measurable, action-oriented, realistic, and time-specific objectives to clearly describe what they are setting out to achieve;
- Identifies and utilizes evidence-based strategies to show how these objective will be accomplished; and
- Uses clear-cut metrics and shares real-time data to show what's working and determine if the aim was achieved

Pacific Basin Infant Mortality CoIIN: 2015 - 2016

An 18 months, the Pacific Basin Infant Mortality Collaborative Improvement & Innovation Network (CoIIN), a partnership of federal, island, and local leaders, explored how to improve access to quality birth and death certificate data in the islands

Pacific IM CoIIN Data Capacity Learning Network: Backbone & Partner Organizations

Partner orgs and Faculty

- Centers for Disease Control & Prevention (CDC)
- Secretariat for the Pacific Community (SPC)
- Pacific Island Health Officer Association (PIHOA)
- National Fetal & Infant Mortality Review (NFIMR)
- AMCHP, NICHQ, NAPHSIS

Backbone Leadership Team

- HRSA Maternal & Child Health Bureau (DHSPS, DSCH Title V & SSDI, OER)
- Assoc. of Maternal & Child Health Programs (AMCHP)

Data Advisors, Faculty

MCHB/OER, CDC, SPC, NICHQ, PIHOA, AMCHP, Hawaii Dept. of Health

Affiliates:
HHS/OASH Region IX Office of Pacific Health
Hawaii & Pacific Basin AHEC

Infant Mortality CoIIN Common Agenda: More first (+++) birthdays

Quality and accessible data *leads to…*

- Informed and timely decision-making,

which leads to…

- More effective actions

which leads to…

More first birthdays, *and beyond.*

Pacific Infant Mortality CoIIN: Data Capacity Learning Network

COMMON AIM

To improve access to quality birth and death certificate data in the U.S. Affiliated Pacific Islands (USAPI)

- By July 2016, the six (6) USAPI jurisdictions will align with, and build upon, existing priorities, programs, initiatives, and successes to:
- Increase the coverage of total births and deaths registered by 10%
- Increase the item completeness of birth and death certificates by 10%
- Decrease the length of time between infant birth/death and submission of birth/death certificate by 10%
- Decrease the non-specific cause of death reported on death certificates by 10%

THANKS TO PARTNERS, ADVISORS & FACULTY

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CDC
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AMCHP
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Pacific Island Health Officer Association
Mark Durand, Haley Cash (CDC)

Hawaii State Department of Health
Alvin Onaka

NAPHSIS
Andrea Price

FIMR CoIN evolves Collaborative Innovation Network

- When the Pacific IM CoIIN Data Capacity Learning Network sun-setted in Fall of 2016, HRSA was able to continue Infant Mortality COIIN efforts through September 2017
- Jurisdictions identified the need to further explore the Fetal and Infant Mortality (FIMR) methodology as a strategy to reduce fetal and infant deaths

FIMR CoIN Participants

Island Jurisdictions in Region IX and Region II

Welcome !!

Federated States of Micronesia

American Samoa

Puerto Rico

Republic of the Marshall Islands

Commonwealth of the Northern Mariana Islands (CNMI)

U.S. Virgin Islands

Republic of Palau

Guam

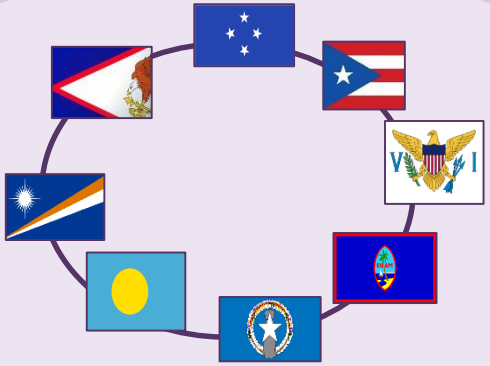
FIMR COIN

Common Agenda

Improve fetal and infant mortality review and prevention systems in the U.S. affiliated island jurisdictions….

FIMR COIN

Backbone Organizations



FIMR COIN

NATIONAL CFRP
Center for Fatality Review & Prevention

AMCHP
ASSOCIATION OF MATERNAL & CHILD HEALTH PROGRAMS
1825 K Street NW, Suite 250, Washington, DC 20006-1202

HRSA
Maternal & Child Health

FIMR COIN
Continuous Communication

Kickoff
FIMR 101

Reflections from
1-1 TA &
Self-assessments

Maternal
Interview

FIMR & EMSC
Collaboration:
FIMR Community
Action Teams

Grief & Loss

Using FIMR to
Examine Zika Cases

Sustainability

Sunset

Nov 2016 Kickoff | Dec 2016 | Jan 2017 | Feb 2017 | Mar 2017 | Apr 2017 | May 2017 | Jun 2017 | Jul 2017 | Aug 2017 | Sep 2017 | Oct 2017 Sunset

1-1 Technical Assistance to Jurisdiction Teams

Jurisdiction Team
Formation &
Self-Assessments

FIMR Session at
Title V TA Meeting

FIMR Session
at AMCHP

FIMR Session
at Title V
Region IX TA
Meeting

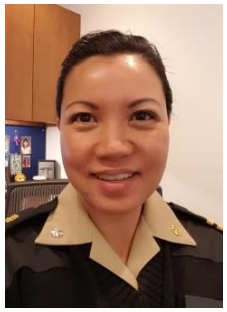
FIMR Session
at EMSC
Meeting

Jurisdiction
Team Self-
Assessments

Staff and Faculty

Rosemary Fournier
CFRP

Nadia Laniyan,
AMCHP



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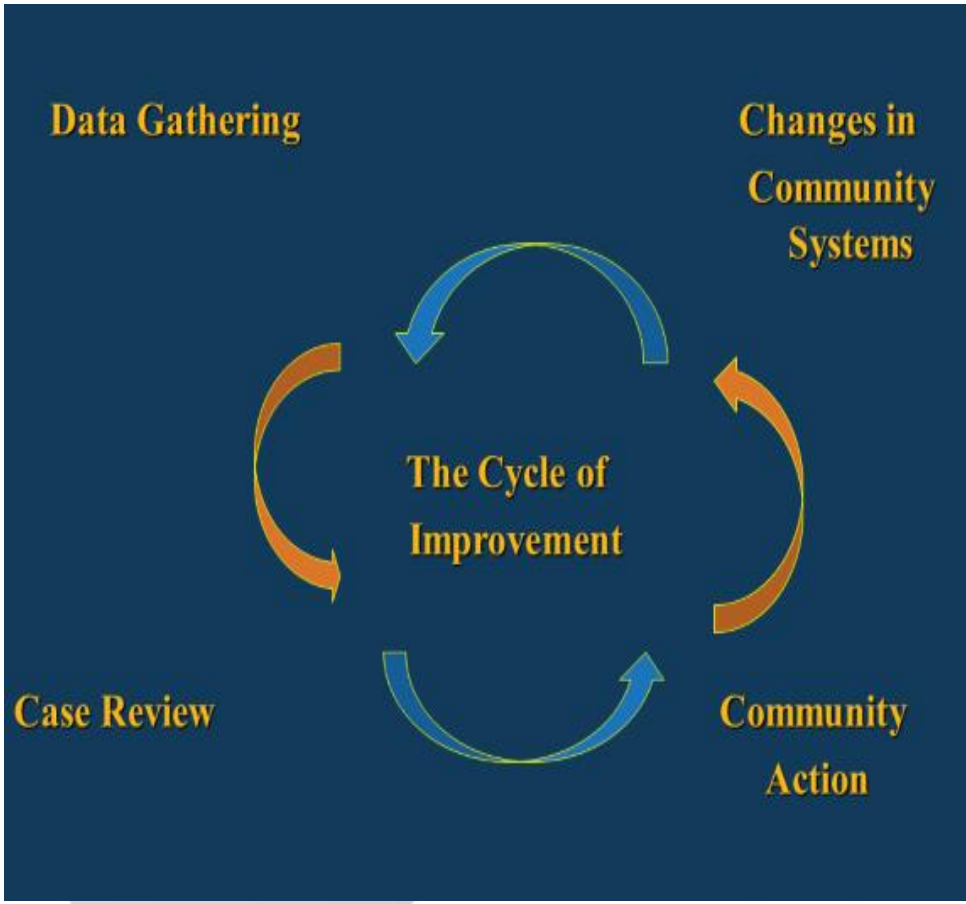
MCHB/EMSC

Diane Pilkey,
MCHB/CDR

What is Fetal and Infant Mortality Review?

- FIMR serves as a type of ongoing continuous quality improvement (CQI).
- Review of cases serves as a spring board for local community action and change for the better in service systems and resources for women, infants and families.



Why FIMR?

When Vital Statistics alone cannot tell us the story . . . .

. . . Communities turn to FIMR to tell us how and why babies are dying

Infant mortality

- Definition: The death of any live born infant prior to his/her first birthday.

- " . . . the most sensitive index we possess of social welfare . . . "

  Sir Arthur Newsholme

Fetal mortality

- “Fetal death”, or still birth, refers to an infant born without signs of life, generally after 20 weeks of gestation

MacDorman MF, Gregory ECW. Fetal and perinatal mortality: United States, 2013. National vital statistics reports; vol 64 no 8. Hyattsville, MD: National Center for Health Statistics, 2015

Why Examine Fetal and Infant Deaths?

- Key indicators of a community's social, economic, civic, and environmental well-being
- Healthy communities nurture healthy women, infants, and families

FIMR's Role in Public Health

Surveillance:

The ongoing systematic collection and analysis of data about a health problem that can lead to action being taken to control or prevent the problem. An infant death is a sentinel event that triggers surveillance activities.

A bit of History . . .

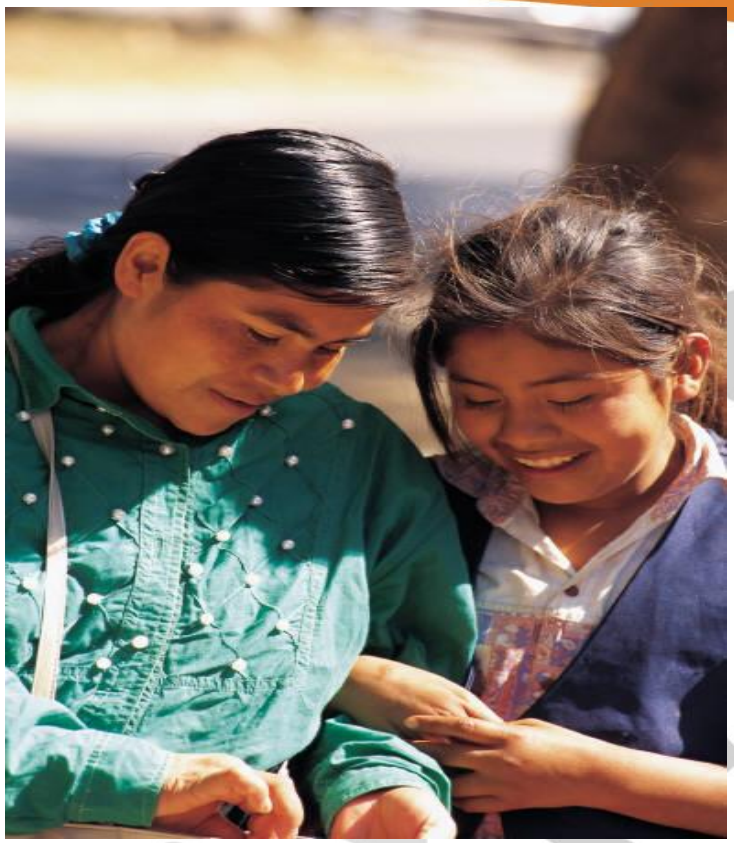
- The first Infant Mortality Review Programs were launched in 1988
- Initially, 10 programs funded by the Maternal Child Health Bureau (MCHB) as demonstration projects
- Program changed its name to FIMR, Fetal and Infant Mortality Review in 1991, following a cooperative agreement with MCHB the American College of Obstetricians and Gynecologists (ACOG)

A bit of History . . .

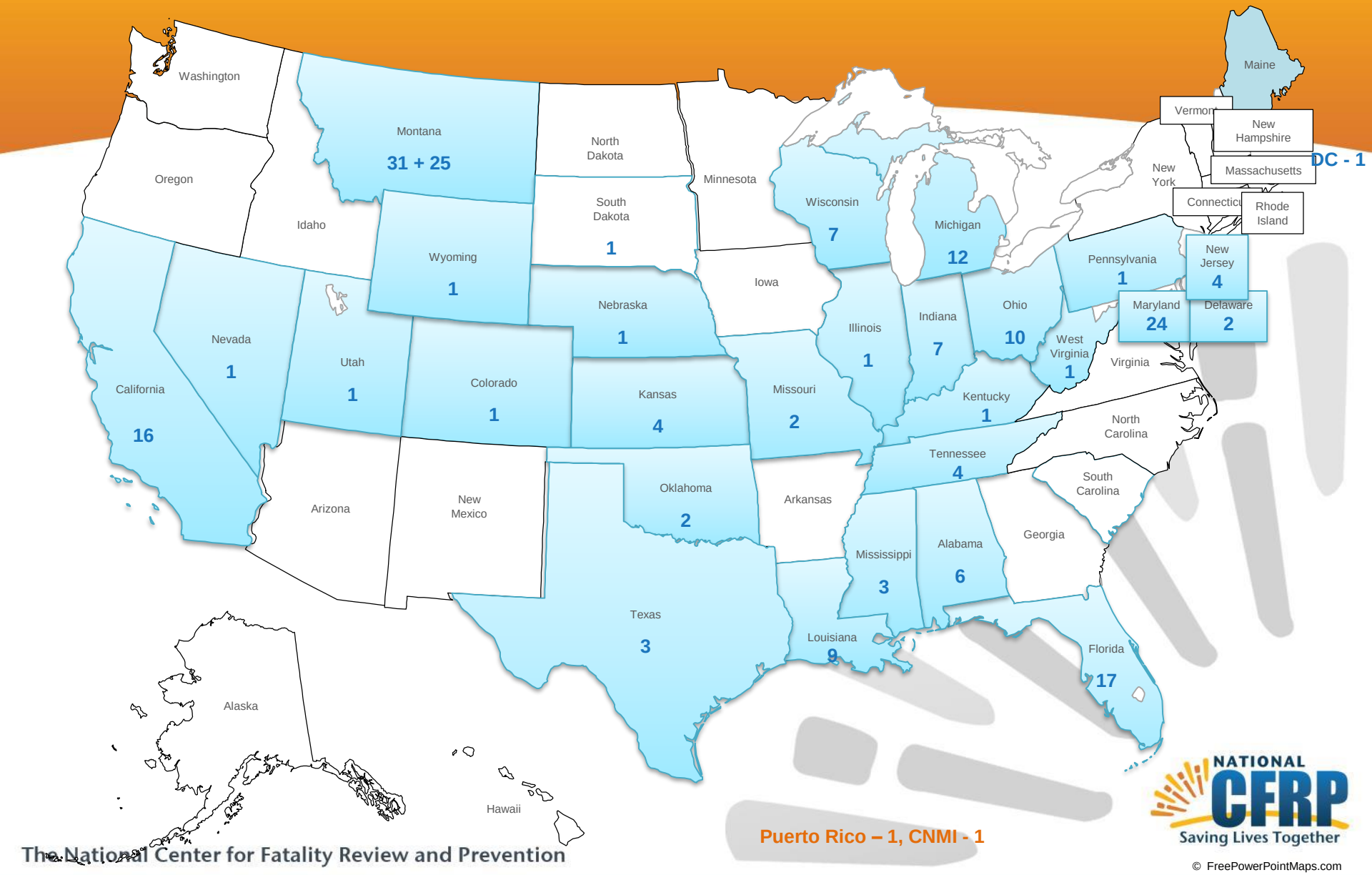
- In 2015, MCHB brought together the two resource centers supporting Child Death Review (CDR) and FIMR under one cooperative agreement
- The Michigan Public Health Institute was just awarded a four year cooperative agreement to continue the work of supporting CDR and FIMR across the country, 7/1/18 to 6/30/22
- An integrated case reporting system for CDR/FIMR was launched this year (April 2018)

FIMR Today

- FIMR has a presence in 28 states, DC, Puerto Rico, and CNMI
- 175 local programs
- Tribes plan and participate in FIMR in WI and WY
  - MI Intertribal Health Council has own FIMR



176 FIMR Programs in 28 States, DC, Puerto Rico, and CNMI



The National Center for Fatality Review and Prevention

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Saving Lives Together

The FIMR Process

FIMR brings a multidisciplinary community team together to examine confidential, de-identified cases of infant deaths.

The FIMR Process:

1. Fetal and Infant Deaths Selected
2. Maternal Interview Conducted
3. Records Abstracted & Summarized
4. FIMR Team Reviews & Makes Recommendations
5. Community Action Team Prioritizes and Takes Action
6. Improved Systems, Services & Resources for Families
7. Improved Health of the Community

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FIMR Goals

- To examine significant social, economic, cultural, safety, health and systems factors that are associated with mortality
- To design and implement community-based action plans founded on information obtained from the reviews

Confidentiality

- FIMR cases are de-identified so that the names of families, providers and institutions are confidential – the FIMR focus is on improving systems, **NOT** assigning blame.

FIMR: A two tiered process

CRT

Case Review Team

CAT

Community Action Team

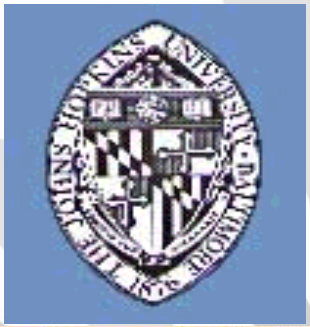
Evaluation of FIMR Programs Nationwide

U.S. Department of Health and Human Services

HRSA

Health Resources and Services Administration

Maternal and Child Health Bureau



Women's and Children's Health Policy Center

The Johns Hopkins University

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Methods

- 193 participating communities
- Cross-sectional observational study (Telephone interview, written survey & site visits)
  - Communities with FIMR
  - Communities with Perinatal Initiative
  - Communities with both (FIMR & PI)
  - Communities with neither

FIMR-Specific Influences

- Data assessment and analysis
- Client services and access
- Quality improvement for systems of care
- Partnerships and collaboration
- Population advocacy and policy development

Results

FIMR Programs contribute significantly to improvements in systems of health care for pregnant women and infants through enhanced public health activities in Communities.

Women's and Children's Health Policy Center, Johns Hopkins University. The evaluation of FIMR programs nationwide: early findings. [Online, 2004]. Available from: http://www.jhsph.edu/research/centers-and-institutes/womens-and-childrens-health-policy-center/projects/fimr.html

Synergy

The national evaluation suggests that a community where FIMR and Perinatal Initiatives were both present could achieve as much as **nine times** more progress in systems improvement!

Community Empowerment

Through the fetal-infant mortality review process, the community becomes the *expert* in the knowledge of the entire local service delivery systems and community resources for childbearing families.

Placeholder for CNMI slides . . .

Using FIMR Methodology for MCH Sentinel Events Review

- Reviews focus on ***morbidity***, not limited to mortality
- Examples:
  - FIMR – FAS
  - Congenital Syphilis (Maryland)
  - FIMR HIV (FHPM)
  - Prevention of Mother to Child transmission of ZIKA (Puerto Rico)

FIMR - FAS

- In 2004, The CDC (National Center for Birth Defects and Developmental Disabilities) and NFIMR funded 2 pilot projects to examine ways to adapt the FIMR process to prevent Fetal Alcohol Syndrome Disorders
  - Detroit, Michigan
  - Baltimore, Maryland
- Cases were reviewed of women who consumed alcohol during pregnancy and had a fetal or infant loss, and any woman who consumed alcohol during pregnancy and had a live born infant

FIMR - FAS

- Both Detroit and Baltimore found a need to raise awareness among health and human service providers and community members on the adverse effects of alcohol use during pregnancy
- Detroit focused on increasing availability and access to contraception for women at risk of delivering an infant with FAS
- In Detroit, review of post neonatal deaths found that parents using alcohol at the time of the infant death contributed to un-safe sleep related deaths.

Congenital Syphilis Review

- The Baltimore FIMR program did a time limited review to explored the increase in congenital syphilis rates over a two year period. Over that period, cases were reviewed, service systems were improved and syphilis rates dropped significantly
- CS review has resumed in many jurisdiction, due to rise in cases of Congenital Syphilis, thought to be associated with the opioid crisis

FIMR HIV Prevention

- City MatCH, in collaboration with CDC and ACOG, modified the FIMR methodology to investigate and address barriers to further reduction of mother-to-child HIV transmission in communities.
- This examination allows communities to identify missed opportunities for prevention and implement improvements to systems of care for women who are HIV-positive.
- Three pilot sites (Baton Rouge, LA; Detroit, MI; and Jacksonville, FL)

FIRM HIV Prevention Expansion 2008 - 2012

- Baltimore, MD
- Broward County, Florida
- Chester, PA
- Illinois
- Indianapolis, IN
- Michigan
- Newark, NJ
- New Orleans, LA
- Philadelphia, PA
- Washington, DC

Selected Findings:

- Prenatal Care is limited ➔ to ED visits

  Assist EDs in linking pregnant women to ongoing HIV care; educate on importance of prenatal care

- Mother/baby dyad ➔ leaving the hospital without a minimal supply of meds for baby

  Pharmacies worked to provide 7 day supple of Zidtovudine to mom at discharge

Selected Findings:

Mothers lost to follow-up when child dies or is placed in foster care → Use existing resources in the family center care programs to conduct outreach to mothers

The need exists for mental health assessment and linkage to care → Provide counseling and education about mental illness when there is a family history; providers should increase knowledge about available options and referrals for identified depression

FIMR response to Zika virus emerging threat

Evaluate morbidity before mortality Strikes.

Used with permission of Cindy Calderon, MD, FAAP
PRFIMR Coordinator & Pediatric Consultant
PRMCAH Division
PR Department of Health
presented at CityMatCH conference 2017, Nashville, TN

ZIKA virus morbidity case: HVP participant/November 2016

19 y/o first pregnancy, prenatal care since 9 wks. gestation

Referred by the WIC program to HVP because of age and diagnose of ZIKA at 17 wks. gestation

Single, homeless living by charity in Aunts house sleeping on a mattress on the floor, finished high school, un-employed.

Past history of living in a foster home.

The father of the baby 22 y/o, high school graduate, works as a cook. Acknowledges he is the father of the baby.

Negative history of smoking, drugs or alcohol. Couple do not live together.

Pregnancy not planned.

At 7 weeks gestation developed a rash and fever, visited ER, lab for ZIKA ordered. Prior to her first prenatal visit, May 2016.

Home were she was living had screens and she reports often used mosquito repellent.

Positive ZIKA result notified at 17 weeks gestation and sonogram demonstrated findings suggestive of fetal damage by ZIKA virus: small head for gestational age, skin folds in head, calcifications.

Pregnancy termination was offered which patient refused.

The HVP nurse helped her transfer to a patient centered prenatal care clinic for ZIKA positive women. Due to severe depression, in response to the stress of her situation, the clinic referred her for immediate psychological evaluation and support.

During pregnancy she received nutritionist services, WIC, and Social Welfare Services with the help and guidance of the HVP nurse.

Subsequent sonograms confirmed previous findings.

.

Interviewed at 26 wks. gestation :

- " After I was informed of my babies condition I have looked up information on ZIKA and its effect on the fetus on the internet." "I don't want to continue to receive messages from the doctors about my babies defects. I feel lonely, sad and desperate"
- Because she is a minor she had to skip some prenatal visits while accomplishing changes In her Medicaid status from her tutor to her own during pregnancy.
- Baby born term, with severe microcephaly and dysphagia requiring a stay in the hospital until feeding was established. Actually followed in Clinics for infants born to Zika positive Mothers or infants born with ZIKA related defects, program within the Children with Special Medical Needs Clinic.

What we learned about ZIKA in the PRFIMR

- The importance of establishing a **ZIKA vigilance system** during pregnancy in an endemic area for mothers at risk for ZIKA V.
- Evaluate and promote Mothers **access to testing** and obtaining **early results for ZIKA**, and identify barriers to early testing.
- Early diagnose for **options and support in case ZIKA test is positive.** Identify resources and promote emotional support and mental health services to ZIKA positive pregnant women.
- Evaluate maternal **knowledge of risk of Zika virus** during pregnancy and promote knowledge on how to **protect** herself.
- Continue to educate the general population how **ZIKA is transmitted and mechanisms to avoid transmission**.
- **Promote collaboration between all agencies and organizations** that provide services to pregnant woman for early detection and referral for support services. Increase communication and collaboration between agencies and programs for the support and management of this population.

Five Key Characteristic of the FIMR Process

1. **Confidentiality** – FIMR does not assign blame
   - De-identified
   - anonymous
2. FIMR Focuses on **systems**
   - Each FIMR case review provides an opportunity to improve communication among medical, public health and human service providers
   - strategies are developed to improve local services, care and resources for women, children, and families

Five Key Characteristic of the FIMR Process

3. FIMR includes a **family perspective.**

The maternal interview conveys the mother's story to the team members

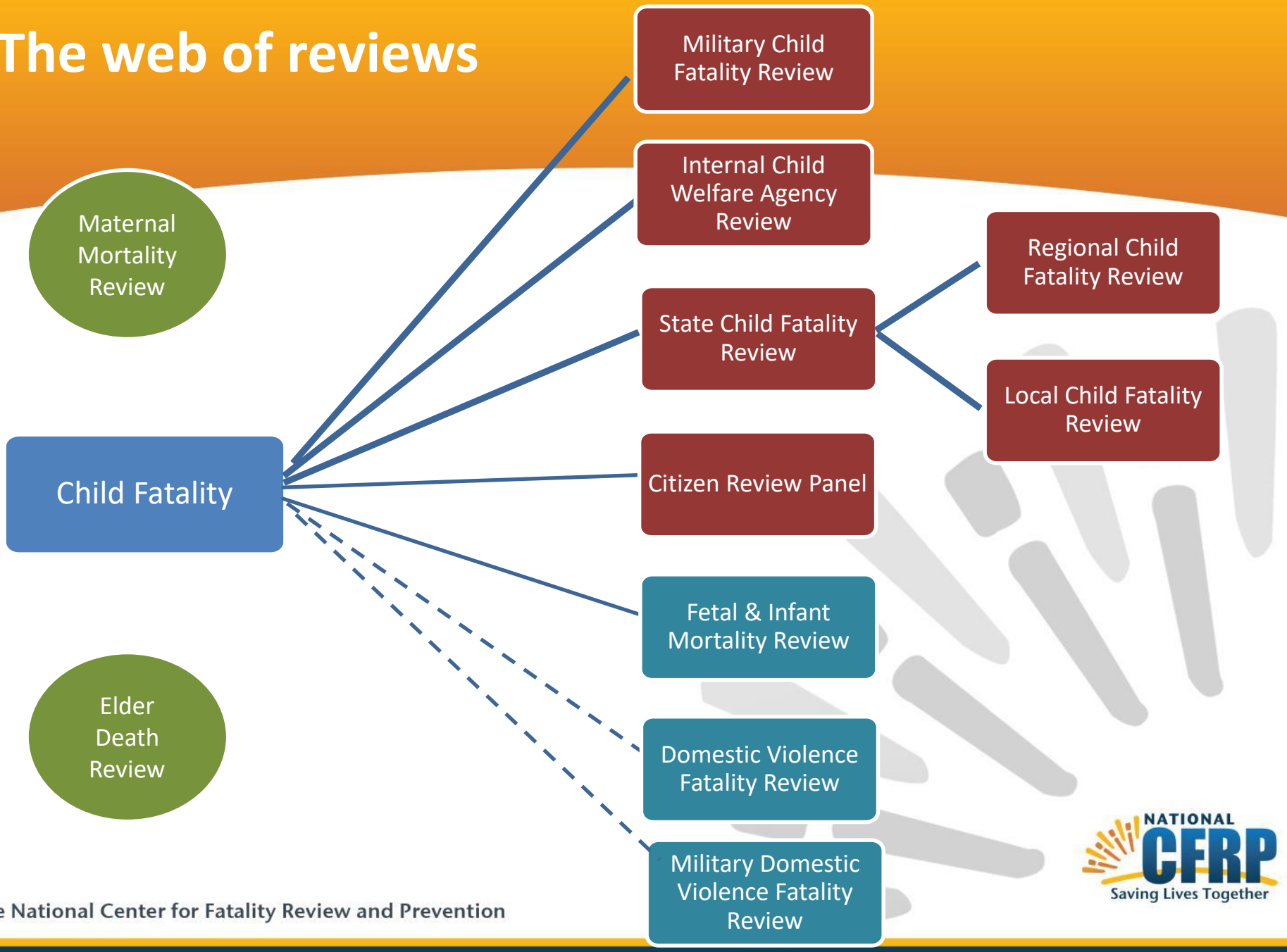
Five Key Characteristic of the FIMR Process

4. FIMR promotes broad **community participation** FIMR's two tiers of community teams involve many ethnic and cultural views that can lead to enhanced respect and understanding in the community.
5. FIMR is **action oriented**. Case Review Teams and Community Action Teams work together to implement multiple creative community improvements in care and resources for women, infants, and families.

FIMR and Collaboration with other Fatality Review Processes

- Child Fatality Review
- Maternal Mortality Review
- Domestic Violence Fatality Review
- Citizens Review Panels (child maltreatment review)

The web of reviews



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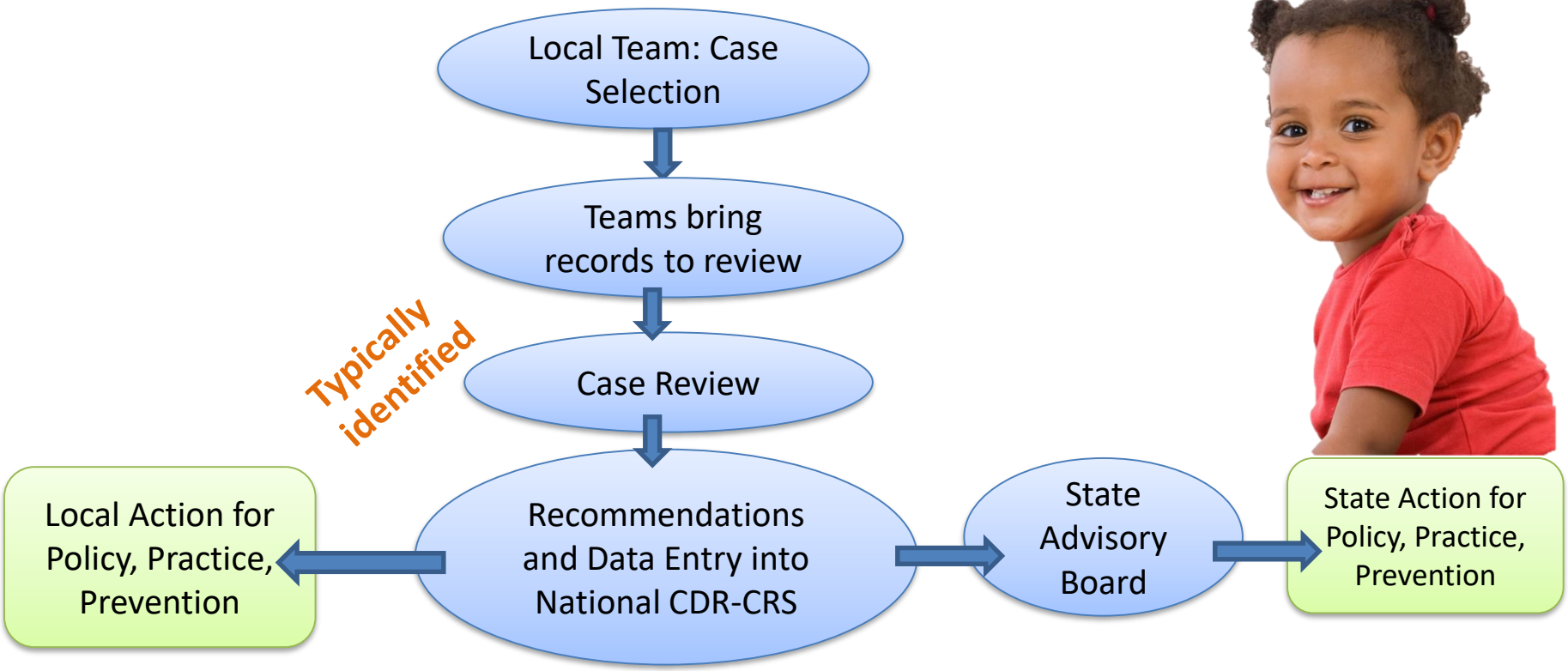
CDR is:

An engaged, multidisciplinary community, telling a child's story, one child at a time, to understand pre-existing vulnerabilities and circumstances and ultimately learn how to interrupt the causal pathway that leads to a child's death



Where are CDR Teams?

CDR in all 50 states and Washington DC

~1,350 local teams and 34 state teams

Guam

Military on Teams

Two tribe specific teams. Some tribes participate in MT, MI, AZ, OK

Summary of Components of Fatality Review

Review Elements	FIMR	CDR	MMR
Purpose	To improve services and resources for women, infants and families with the long-term goal of reducing fetal and infant deaths	Reviews all circumstances in child deaths to improve investigation, service delivery, and agency systems of care. Catalyze prevention initiatives across a broad spectrum of child health, safety, and protection	To improve services for women with the overall goal of preventing maternal mortality
Age	Stillbirths, and infants under the age of one	Children 0 – 18 years of age	N/A

Summary of Components of Fatality Review

Review Elements	FIMR	CDR	MMR
Scope of programs in the US	175 local FIMRs in 28 States, DC, Puerto Rico, and the Commonwealth of the Northern Mariana Island	All 50 states have a CDR program manager and support state and/or local review teams. There are approximately 1250 local review teams throughout the U.S.	31 State level and 3 local Maternal Mortality Reviews
Team Structure	Two Tiered: Case Review Team and Community Action Team	Most teams consist of one review board that conducts case reviews, usually includes agency professionals directly involved in the case.	Generally a single multidisciplinary state-wide team convened periodically or yearly.

Summary of Components of Fatality Review

Review Elements	FIMR	CDR	MMR
Case Preparation	Cases are abstracted from a variety of medical and social service records, a case summary is prepared in advance for team members	Team members bring their records to review and share information from them.	Generally a full case presentation with patient hospital record abstraction
Confidentiality	Confidential and Anonymous. Cases are de-identified	Reviews are confidential	Reviews are confidential
Family Involvement	Yes. A home interview with mother, if she agrees, is included in each case review.	No	Not is the US

Questions?

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THANK YOU!