Using Fetal, Infant, and Child Death Review to address disparities and improve health equity

Michigan Premier Public Health Conference

October 4, 2017

Mackinac Island, MI

The National Center for Fatality Review and Prevention

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

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MCHB's vision for the venter

- 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
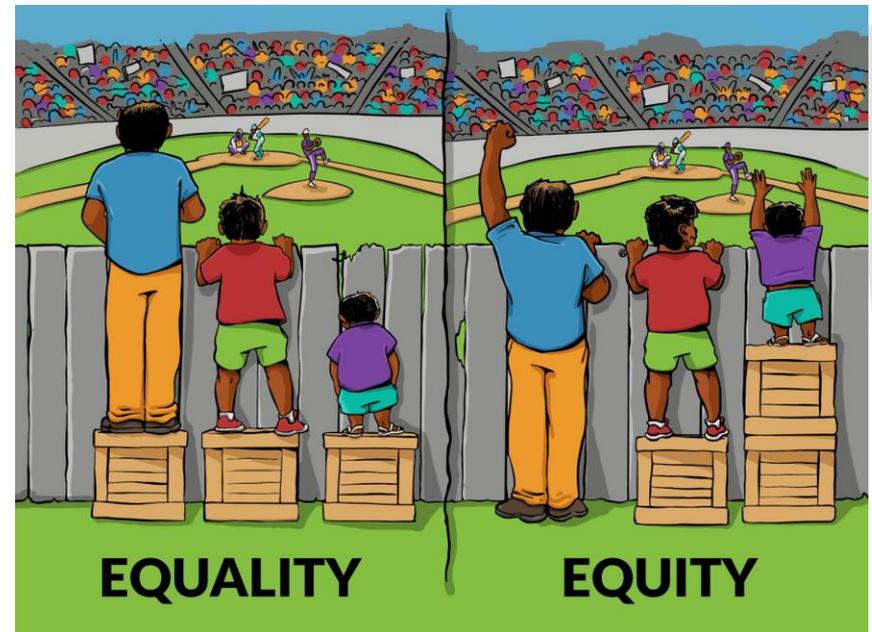
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Session objectives

- Describe fatality review practice methodologies and their common goal: to serve as an effective system intervention and public health strategy and to help teams develop recommendations and implement promising or best practice prevention strategies

- Verbalize how fatality review teams use information from their findings to inform communities of their determinants of infant and child deaths and how mothers' and families' experiences with racism have impacted infant and child outcomes

- Describe how fatality review teams interact with the Community to develop and implement mortality and disparity reduction efforts
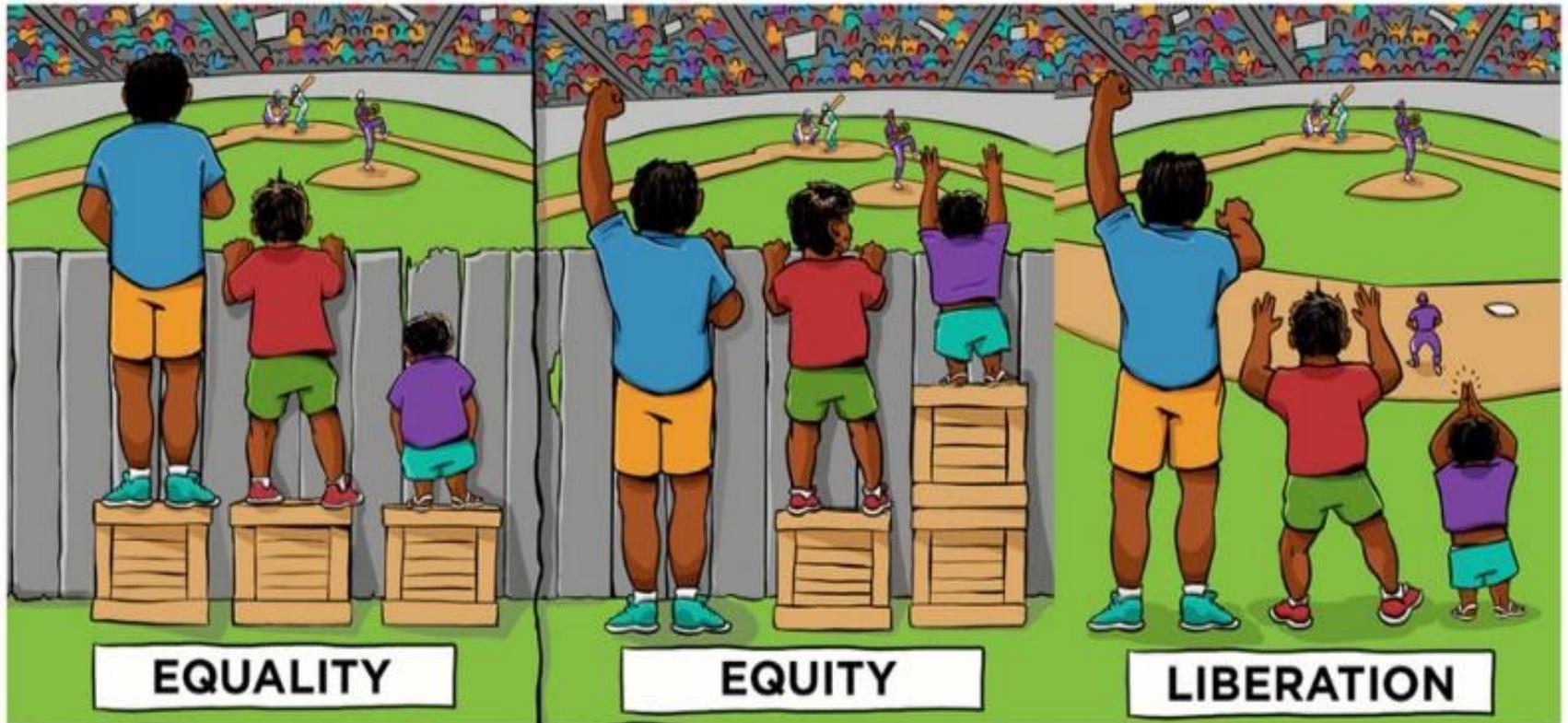
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Health Disparities and Health Equity

- **Health disparities** are preventable differences in the burden of disease, injury, violence, or opportunities to achieve optimal **health** that are experienced by socially disadvantaged populations. (CDC)

- **Health Equity** is a fair, just distribution of the social resources and social opportunities needed to achieve well being.
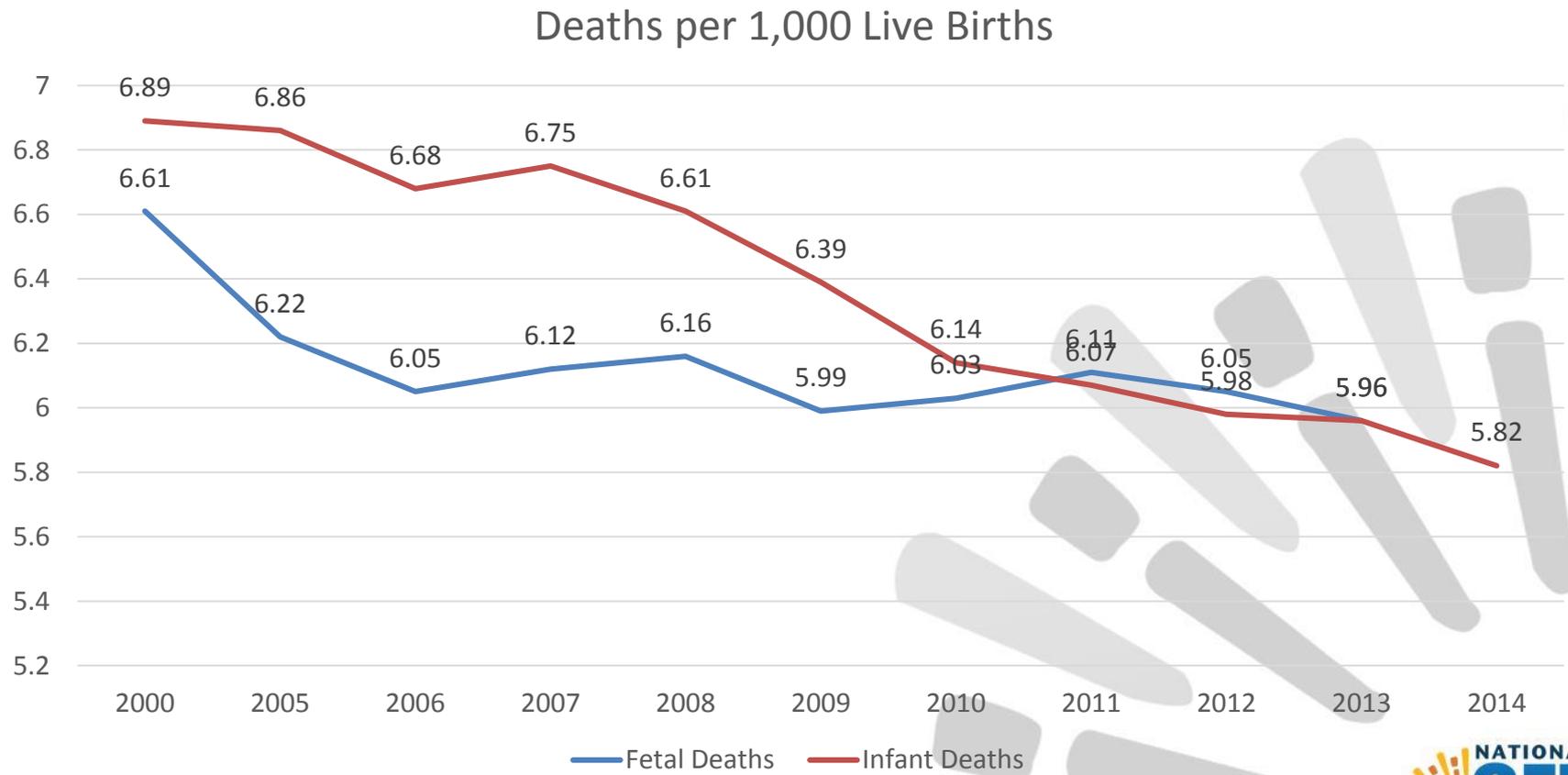

EQUALITY   EQUITY
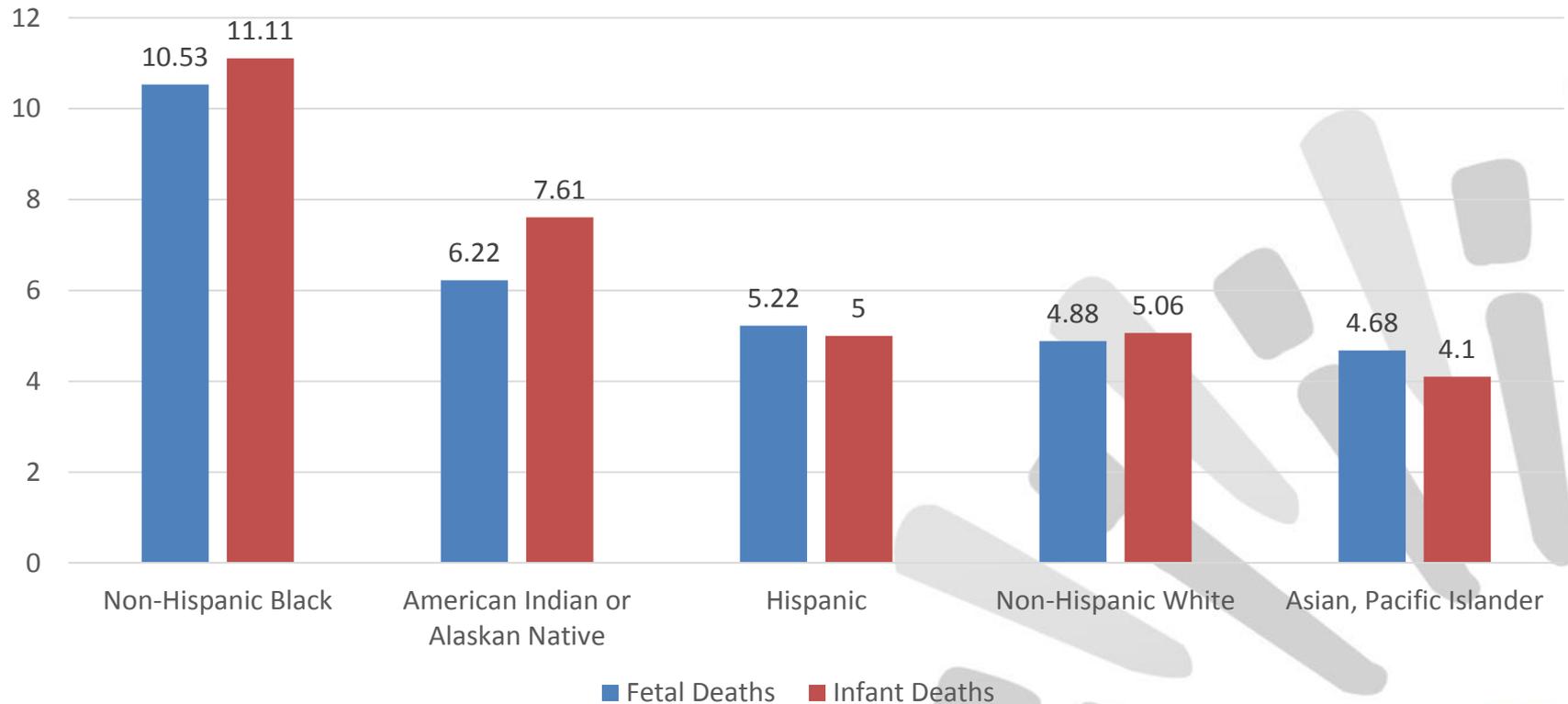
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Inequity addressed . . .

Systemic barriers removed

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US fetal and infant mortality trends

Deaths per 1,000 Live Births

Fetal Deaths: 6.61 (2000), 6.22 (2005), 6.05 (2006), 6.12 (2007), 6.16 (2008), 5.99 (2009), 6.03 (2010), 6.11 (2011), 5.98 (2012), 5.96 (2013)

Infant Deaths: 6.89 (2000), 6.86 (2005), 6.68 (2006), 6.75 (2007), 6.61 (2008), 6.39 (2009), 6.14 (2010), 6.07 (2011), 6.05 (2012), 5.96 (2013), 5.82 (2014)

Legend: Fetal Deaths, Infant Deaths

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Disparities in fetal and infant mortality rates

Deaths per 1,000 Live births

Race/Ethnicity	Fetal Deaths	Infant Deaths
Non-Hispanic Black	10.53	11.11
American Indian or Alaskan Native	6.22	7.61
Hispanic	5.22	5
Non-Hispanic White	4.88	5.06
Asian, Pacific Islander	4.68	4.1

■ Fetal Deaths ■ Infant Deaths

Data Source: https://www.cdc.gov/nchs/nvss/linked-birth.htm

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Infant mortality rates, Michigan compared to the US

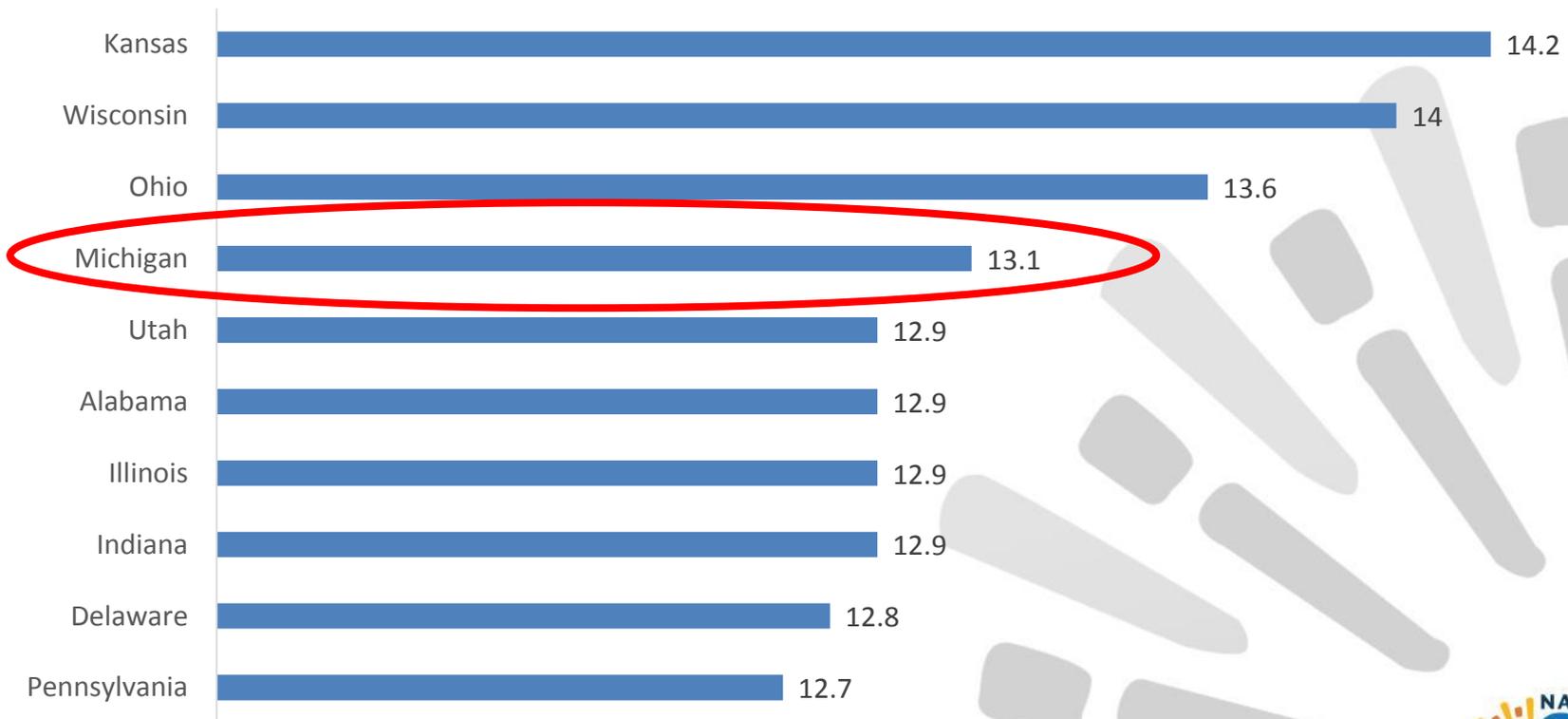## Infant deaths per 1,000 live births

Sources: Centers for Disease Control and Prevention, National Center for Health Statistics.
CDC WONDER On-line Database, accessed on 6/30/17

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Black infant mortality rates, Michigan compared to the US

Infant deaths per 1,000 live births

Legend: US Black, MI Black
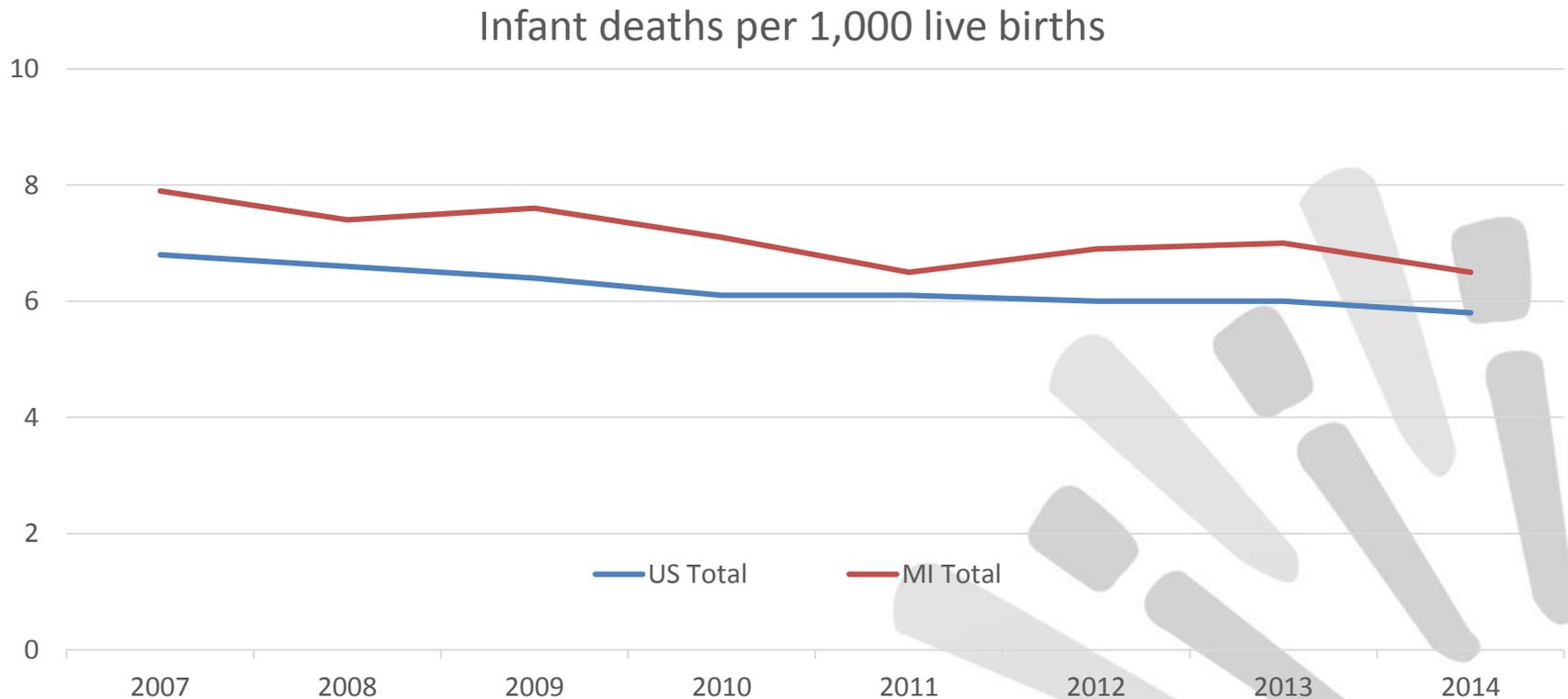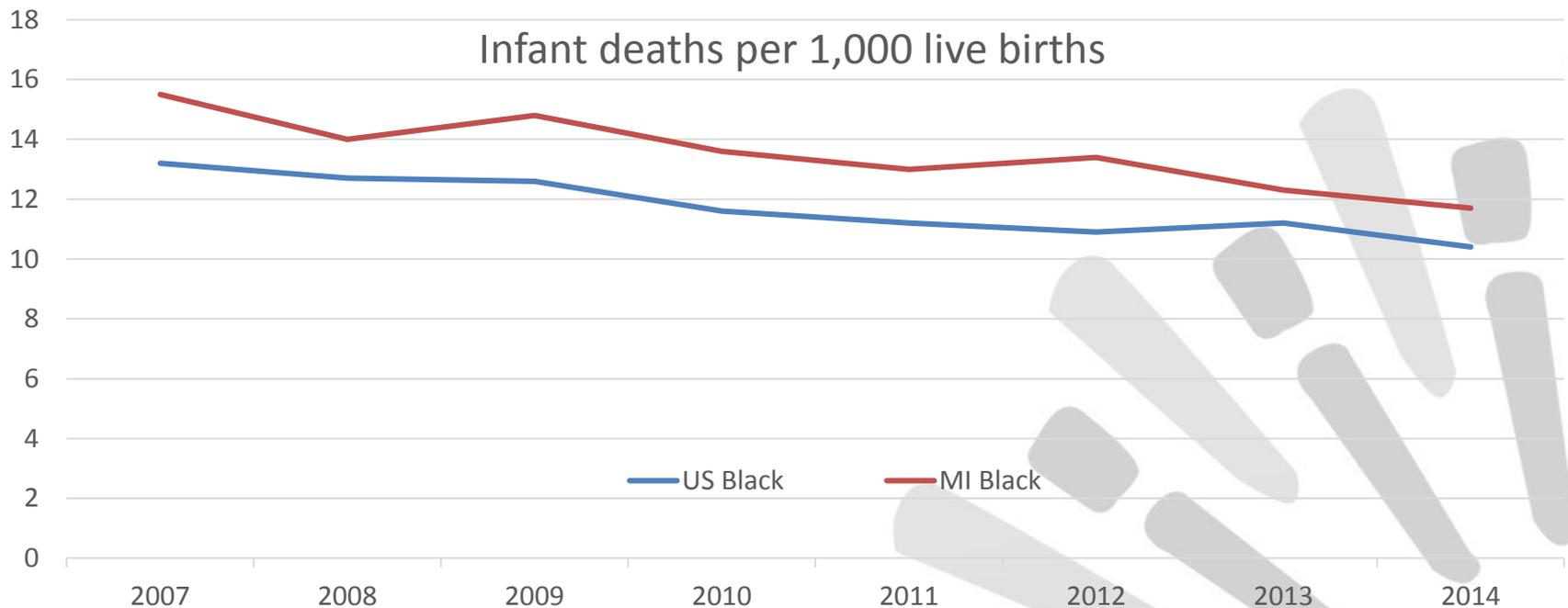
Sources: Centers for Disease Control and Prevention, National Center for Health Statistics.
CDC WONDER On-line Database, accessed on 6/30/17

State ranking for black infant mortality

Three Year Average, 2011 – 2013

State	Rate
Kansas	14.2
Wisconsin	14
Ohio	13.6
Michigan	13.1
Utah	12.9
Alabama	12.9
Illinois	12.9
Indiana	12.9
Delaware	12.8
Pennsylvania	12.7

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US Cities with the highest infant mortality rate

- Cleveland – 13.5
- Detroit – 13.4
- Milwaukee – 11.3
- Memphis – 10.5
- Baltimore – 10.2

- Jacksonville – 9.6
- San Juan – 9.5
- Philadelphia – 9.3
- Indianapolis – 9.2
- Fresno – 9.2

The Annie E. Casey Foundation. (2016) Kids Count. Baltimore, MD: Speer, L. www.aecf.org.

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We have what and where, can we dive into why?

- Nearly 2/3 of the babies we lose under age one are born too early too small.
  - Prematurity as a cause of infant mortality affects blacks at a rate 3 times higher than whites.

- There is no genetic variation among humans that can explain the gap

- Poverty and lack of education cannot fully account for the disparity

- Discrimination, stacked up over a lifetime, can cause chronic stress, which in turn can damage the biological systems necessary for a healthy pregnancy and birth

- A woman's entire life experience matters, the situations in which she grew up, developed and lives

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Disparities in childhood injuries

- Unintentional injuries: 9 million children, ages 0-9 are treated for injuries in emergency departments, 225,000 requiring hospitalizations and over 9,000 deaths each year. 37% of all deaths after infancy are from injuries.

- Males die at twice the rate as females.

- Children living in poverty, crowded conditions, with young mothers in single family homes, and with moms with low educational status are at highest risk.

- American Indian and Alaskan Native children have the highest rates.

- Geography is important: the lowest rates are in the northeastern US.

Unintentional injury rates by state, ages 0-19, 2000-2006

6.92-12.90   12.91-16.36   16.37-20.96   20.97-28.04
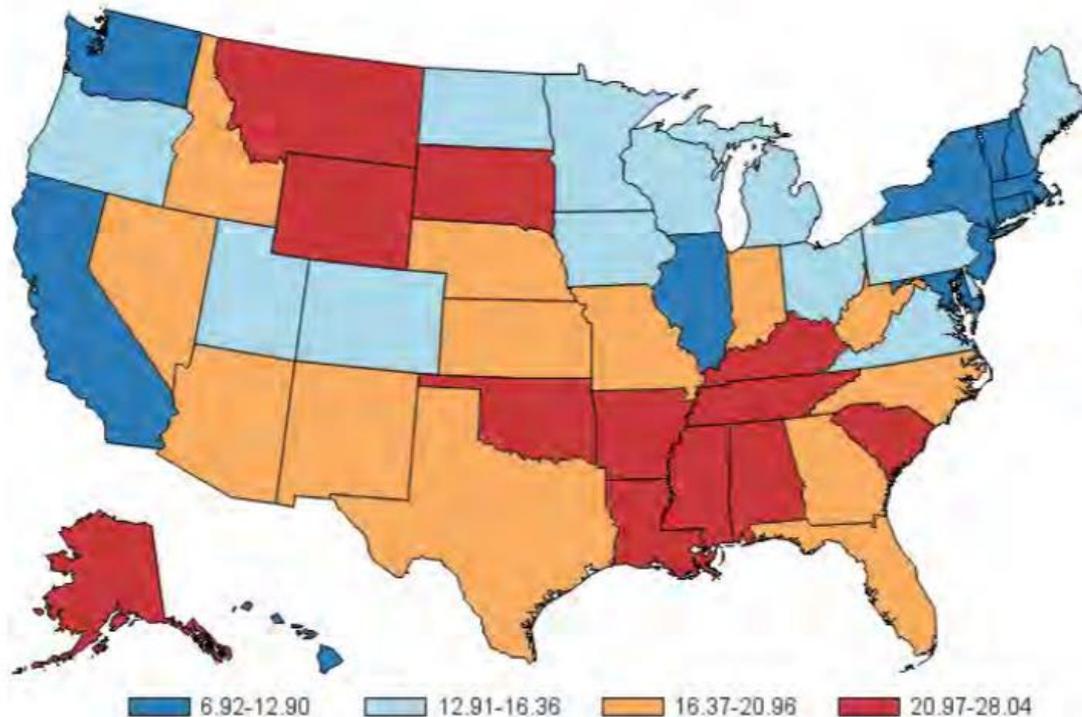
SOURCES: CDC National Center for Injury Prevention and Control, Office of Statistics and Programming. Deaths from the NCHS Vital Statistics System. Population estimates from the U.S. Census Bureau. NOTE: Rates based on 20 or fewer deaths may be unstable. These rates are suppressed for counties. The

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Intentional Injuries: suicides and homicides

- Again: more boys than girls

- African American and American Indians have higher rates of homicides, both child abuse and youth homicides..

- African American children die from maltreatment at a rate 2.5 times higher than Whites.

- Whites have higher rates of suicides but the gap is closing.

US Injury Rates in African American Children

2008-2014, United States
Death Rates per 100,000 Population
All Injury, Unintentional, Black, All Ethnicities, Both Sexes, Ages 0-17 Years
Annualized Crude Rate for United States: 10.42

Legend:
- Suppressed/Unstable/Undefined
- 1.91-6.63
- 6.64-10.01
- 10.02-12.64
- 12.65-19.24
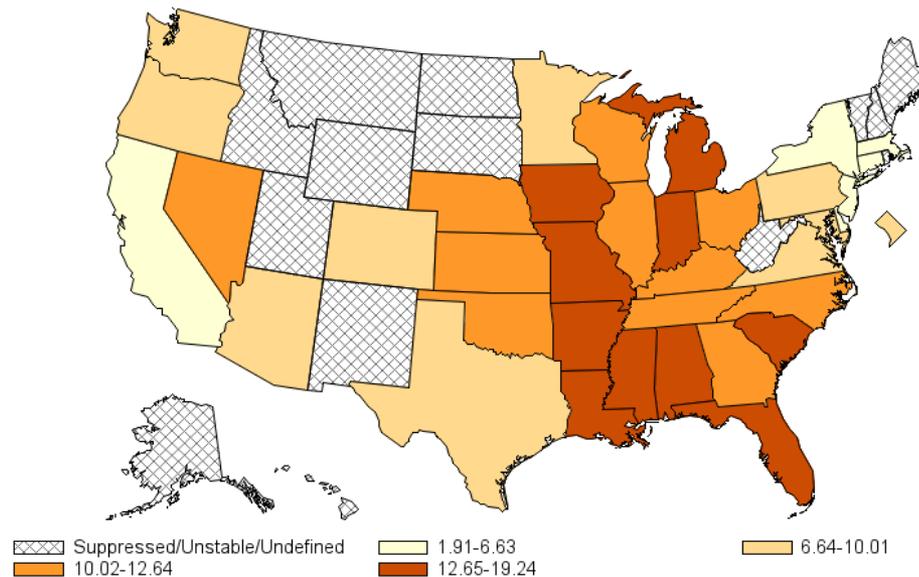
Reports for All Ages include those of unknown age.
* Rates based on 20 or fewer deaths may be unstable. States with these rates are cross-hatched in the map (see legend above). Such rates have an asterisk.

Produced by: the Statistics, Programming & Economics Branch, National Center for Injury Prevention & Control, CDC
Data Sources: NCHS National Vital Statistics System for numbers of deaths; US Census Bureau for population estimates.

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Within Our Reach

A National Strategy to Eliminate Child Abuse and Neglect Fatalities

COMMISSION TO ELIMINATE
CHILD ABUSE AND NEGLECT FATALITIES

Final Report, 2016

The National Center for Fatality Review and Prevention

"Many researchers believe that discussions of race obscure the true contributing factor of poverty, which affects roughly one in two American Indians and one in three African American and Hispanic families, but only one in nine white or Asian families. Others have suggested to this Board that the problem is not poverty, but psychological stress caused by dealing with limited opportunities and the effects of racism. These important questions remain unanswered."
—U.S. Advisory Board on Child Abuse and Neglect, in A Nation's Shame, 1996

The differential standard for neglect and abuse of black and white families can actually push families, black families, further outside the safety net. And that's not what we want. One of the things that does that is a differential response of child welfare. We have often times identical risk factors for black families and white families, but when the risk factors are identical, white families are more likely to get family and home support, and black families are more likely to have their children removed.

—Dr. Rita Cameron Wedding, California State University, in testimony to the Commission

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Who studies death now?

- Health care providers

- Institutions

- Medical researchers

- County and state health officers

Fatality Review complements existing efforts, but takes a different approach

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CDR, FIMR and other MCH initiatives
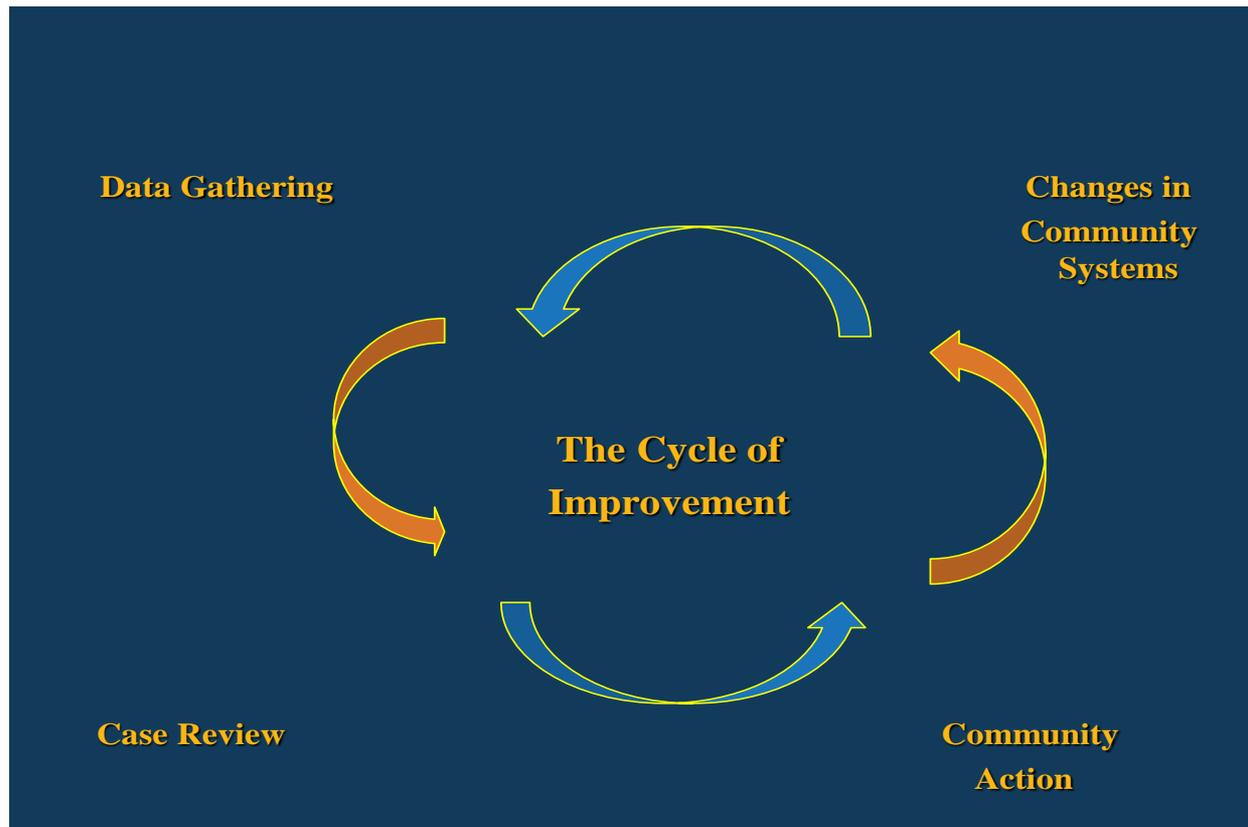

Expanded MCH Planning Cycle with Corresponding Stages of PPOR
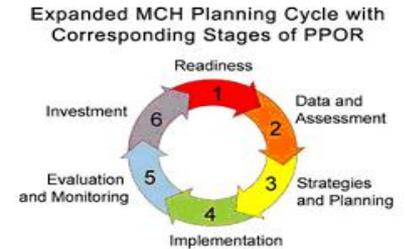
- Vital Statistics
- PRAMS (Pregnancy Risk Assessment Monitoring)
- MMS (Maternal Mortality Surveillance)
- PPOR (Perinatal Periods of Risk)
- BRFSS (Behavioral Risk Factor survey System)

National Vital Statistics System

Fetal and Infant Mortality Review (FIMR)

Data Gathering

Changes in Community Systems

The Cycle of Improvement

Case Review

Community Action

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The FIMR process

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

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The maternal interview

- Gives insight into the mother's experience before and during pregnancy

- Conveys the mother's story of her encounters with local service systems

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Can Fatality Review tell us why?

Quote from a maternal interview: "I did everything right, took prenatal vitamins, stayed in shape, kept all my appointments, did not drink or smoke or do drugs . . . Yet every time I saw my provider, I was made to feel like just another poor black mom on welfare having another kid . . . "

CDR: Where the Good Shift Happens

Tell the story

Collect data

Take action
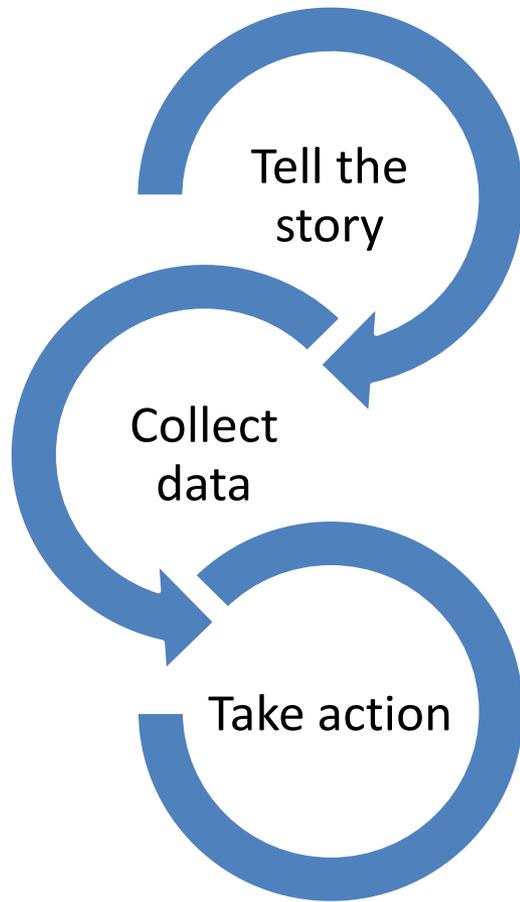
Michigan has a team in every county

Child Death Review

- Multi-disciplinary
- Telling a story through the sharing of case information from multiple sources
- Focused on improving systems and prevention of deaths; not culpability
- Balance between individual cases and accumulation of fatal and non-fatal data for trends

Healthy People 2020 has a goal that:

90% of all states will review 100% of all injury and all SUID deaths."

Reviews are an opportunity to identify disparities and health inequities

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Fatality review in the US

CDR in 50 states

FIMR in 29 States and DC

1350 local and state teams

175 local teams

Dept. of Defense

Puerto Rico

Guam

Pacific Jurisdictions

Tribes

Tribes

Formation of a disparities work group for CDR and FIMR

- Purpose: To focus on FIMR and CDR reviews in communities with high health disparities, including conducting analysis and recommendations to improve outcomes

- Mission: We hope to use the information from our review processes to inform communities on factors that contribute to disparities in infant and child outcomes, and, most importantly, to create tools and best practices to help communities translate those finding into action

FIMR/CDR disparities work group

- More than 40 members
- Representation from 20+ states
- Diverse Membership
- Support from national organizations
  - HRSA
  - ACOG
  - NACCHO
  - Center for Health Equity Practice, MPHI

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Team Orientation

- City MatCH Life Course Game
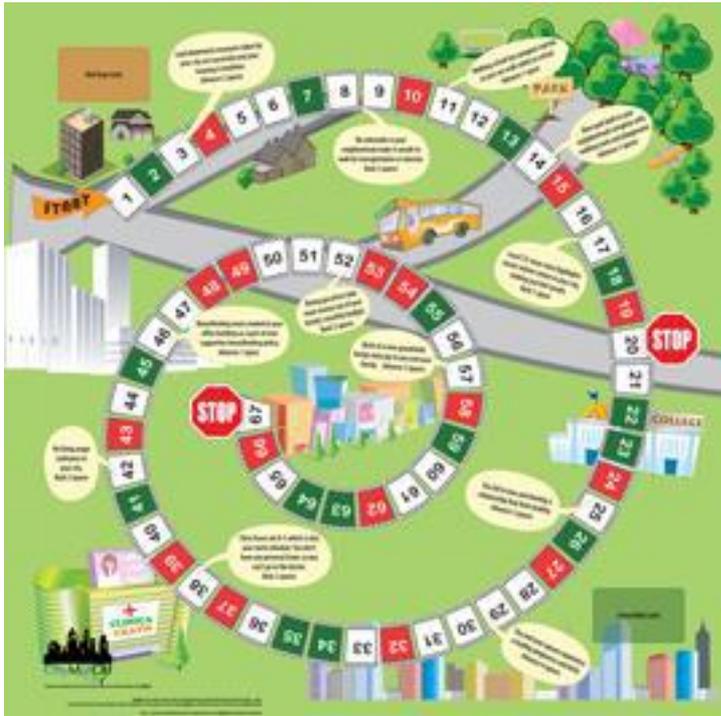
Implicit Bias

- http://www.ted.com/talks/verna_myers_how_to_overcome_our_biases_walk_boldly_toward_them

- Implicit Association Test (IAT) : Harvard University

- https://implicit.harvard.edu/implicit/takeatest.html

Data Gathering

- Ask the right Questions:
  - When you think back to your pregnancy, did you ever feel you were treated with less respect than other people or received poorer service than other people?
    - What about your healthcare; how were you treated by your doctor, the office and the hospital compared to other people?
    - Why do you think you were treated differently?
    - How did this affect you?
  - When you think back to your child's death, did you ever feel you were treated as a suspect or criminal?

Local examples of how a FIMR team translated findings into action

- Kalamazoo, Michigan

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cradlekalamazoo.com

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eliminating racism
empowering women
ywca
Kalamazoo

History & Collective Impact Process

- **Collective Impact:** Framework used to tackle complex social problems. Multi-sectors partners align efforts and support a collaborative agenda with shared outcomes.

2014
- **Awareness**
- **Dialogue**

2015
- **Strategic Planning**

2016
- **Goals and Metrics**
- **Infrastructure**

2017
- **Engagement**
- **Strategic Realignment**

Awareness ⬄ **Equity Focus** ⬄ **Intentional**
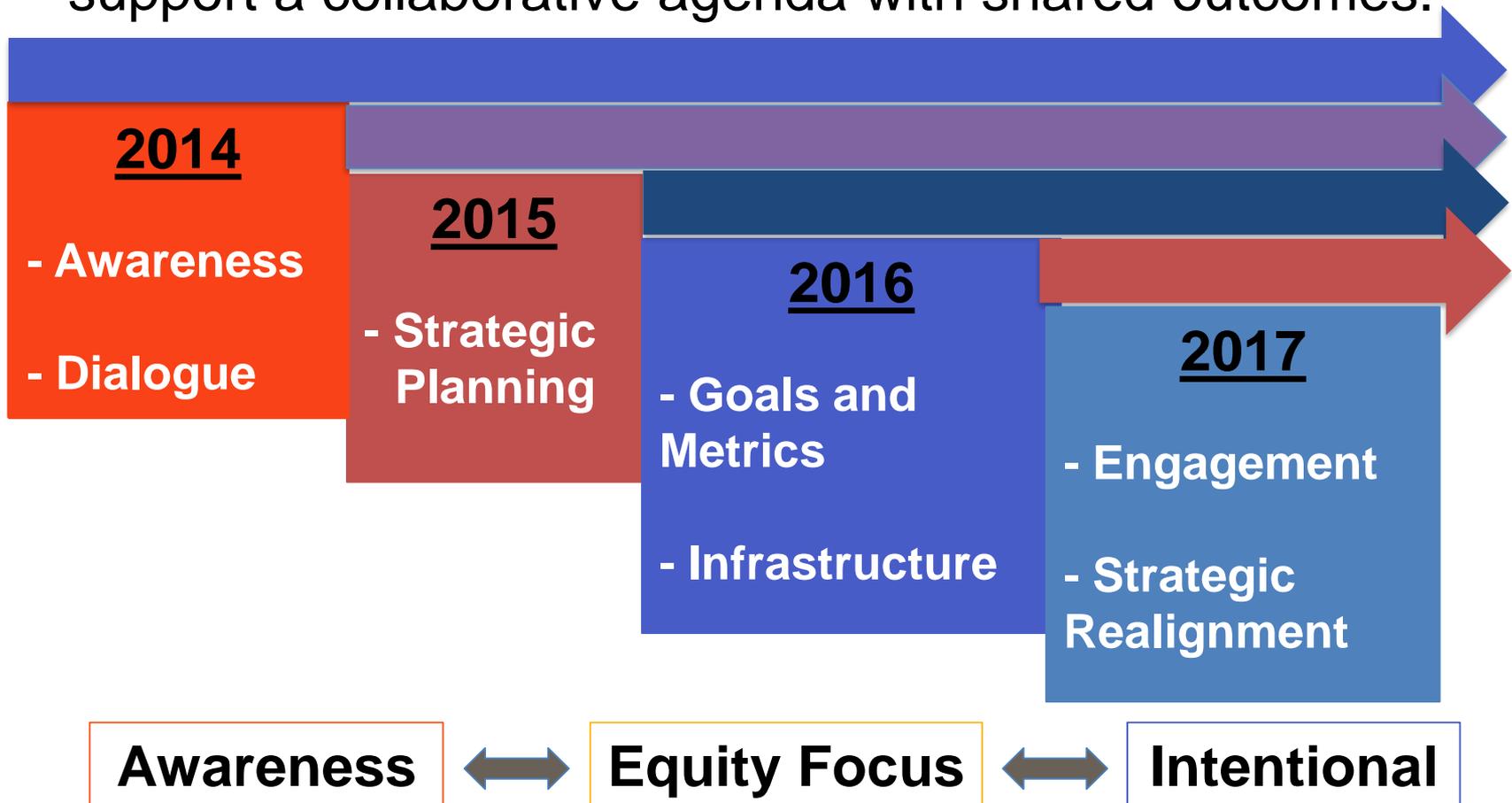
Strategic Direction

Goal: Overall Child Well-being

Strategic Objective: Perinatal Home Visitation Network

Objective 1:
Universal process between clinics and community services for maternal and infant health

Objective 2:
Building outreach capacity through community health workers

Objective 3:
Realign resources/investment to support the overall well-being of children and families

Objective 4: Equity assessment of policies/procedures that impact maternal & infant health

COORDINATION OF COMMUNITY REFERRALS / LINKAGES

PREGNANT POPULATION:

4160 women

16 month period (January 1, 2016 through May 5, 2017)

COORDINATION OF COMMUNITY REFERRALS / LINKAGES

2240 women

PREGNANT POPULATION:

4160 women

COORDINATION OF COMMUNITY REFERRALS / LINKAGES

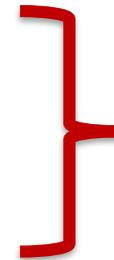**cradle** KALAMAZOO
ending infant mortality together

2240 women

INCOMING REFERRALS*

866 women

REFERRAL GAP: 1,374

38% REFERRAL RATE

PREGNANT POPULATION:

4160 women

* Prenatal referrals during a 16-month period: January 1, 2016 through May 5, 2017

COORDINATION OF COMMUNITY REFERRALS / LINKAGES

cradle KALAMAZOO
ending infant mortality together

2240 women

PREGNANT POPULATION:

4160 women

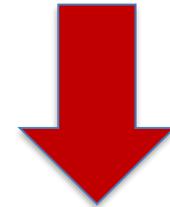**INCOMING REFERRALS***

866 women

ENROLLED**

420 women

RETAINED***
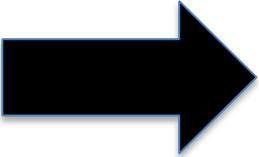
363 women

86% RETENTION RATE

* Prenatal referrals during 16-month period: January 1, 2016 through May 5, 2017

** Enrolled up through August, 2017

*** Retained through eligibility period as of August, 2017

WHY DOES THIS MATTER?

HV PARTICIPATION REDUCES BARRIERS

-IMPROVING PRENATAL CARE ACCESS

-IMPROVING BIRTH OUTCOMES

.... ESPECIALLY AMONG

WOMEN OF COLOR

Kothari, C.L., Zielinski, R., James, A., Charoth, R.M., Sweezy, L.C. (2014). Improved Birth Weight for Black Infants: Outcomes of a Healthy Start Program. *American Journal of Public Health.* 104 (S1): S96-S104.

COORDINATION OF COMMUNITY REFERRALS / LINKAGES

PROBLEM: CLINIC-BASED SAFETY NET HAS TOO MANY HOLES

SOLUTION: BUILDING DOORWAYS INTO A STREAMLINED SYSTEM OF CARE

Strategic Objective: Universal Process

Universal Access Into Prenatal Care
(pregnancy test, 1st trimester prenatal care)

Universal Screening & Referral for Care Coordination
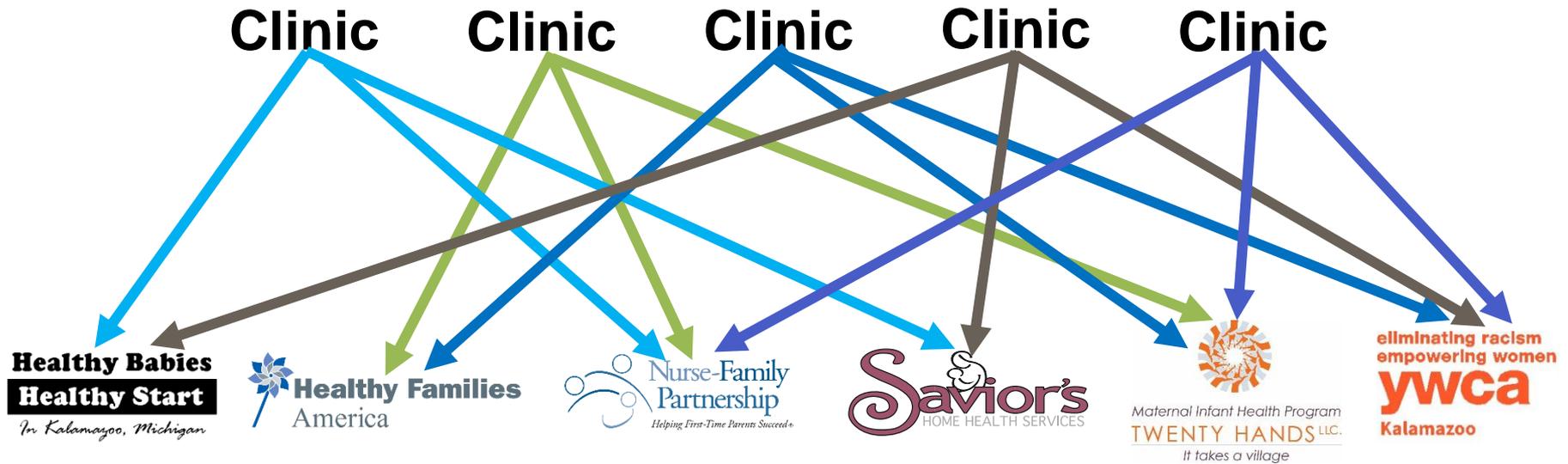*(algorithm for programs & link to Care Coordination Registry)*

Universal Outreach & Support
(support from CHWs)

Universal Communication between Medical & Support Services
(loopback with universal consent)

Strategic Objective: Coordinated System
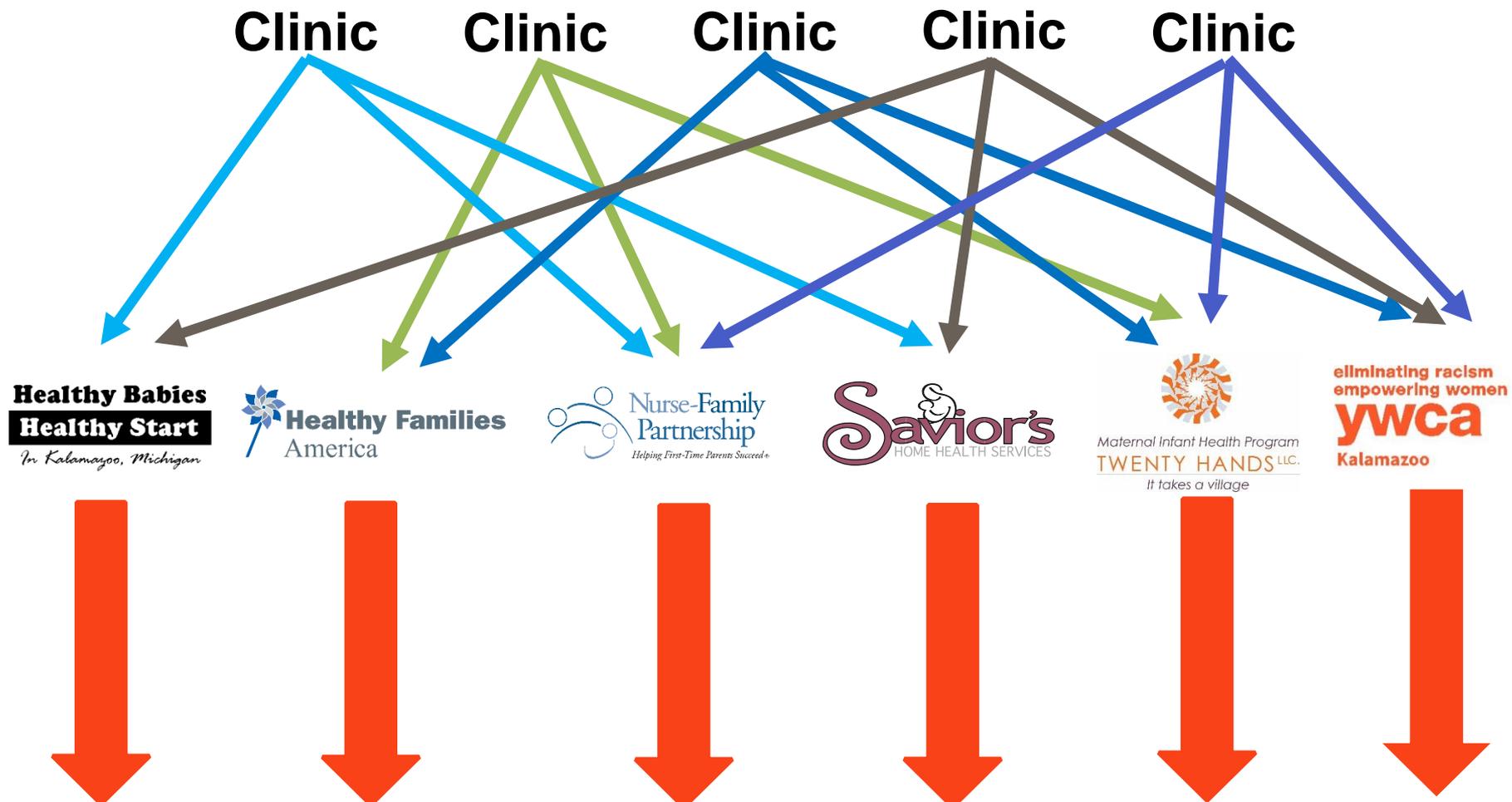

- Current system:
  - Every clinic has their own referral process
  - Every clinic has their own relationships with various community agencies/resources
  - Funding for this system is separate

Current Cradle Coordination: from the tail end of the referral process...

Coordinatir

Clinic   Clinic   Clinic   Clinic   Clinic

Healthy Babies Healthy Start
In Kalamazoo, Michigan

Healthy Families America

Nurse-Family Partnership
Helping First-Time Parents Succeed®

Savior's
HOME HEALTH SERVICES

Maternal Infant Health Program
TWENTY HANDS LLC.
It takes a village

eliminating racism empowering women
ywca
Kalamazoo

COORDINATION OF COMMUNITY REFERRALS / LINKAGES
Additional Community Navigation support from 211, CHAP, and CHWs

Alternative Cradle Coordination:
Coordinating from the _front_ end of the referral process…

Clinic **Clinic** **Clinic** **Clinic** **Clinic**

COORDINATION OF COMMUNITY REFERRALS / LINKAGES
Additional Community Navigation support from 211, CHAP, and CHWs

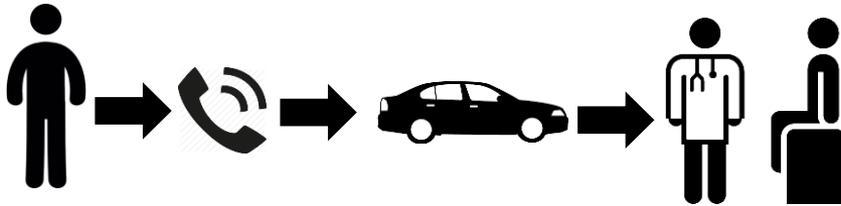# Communities are in motion
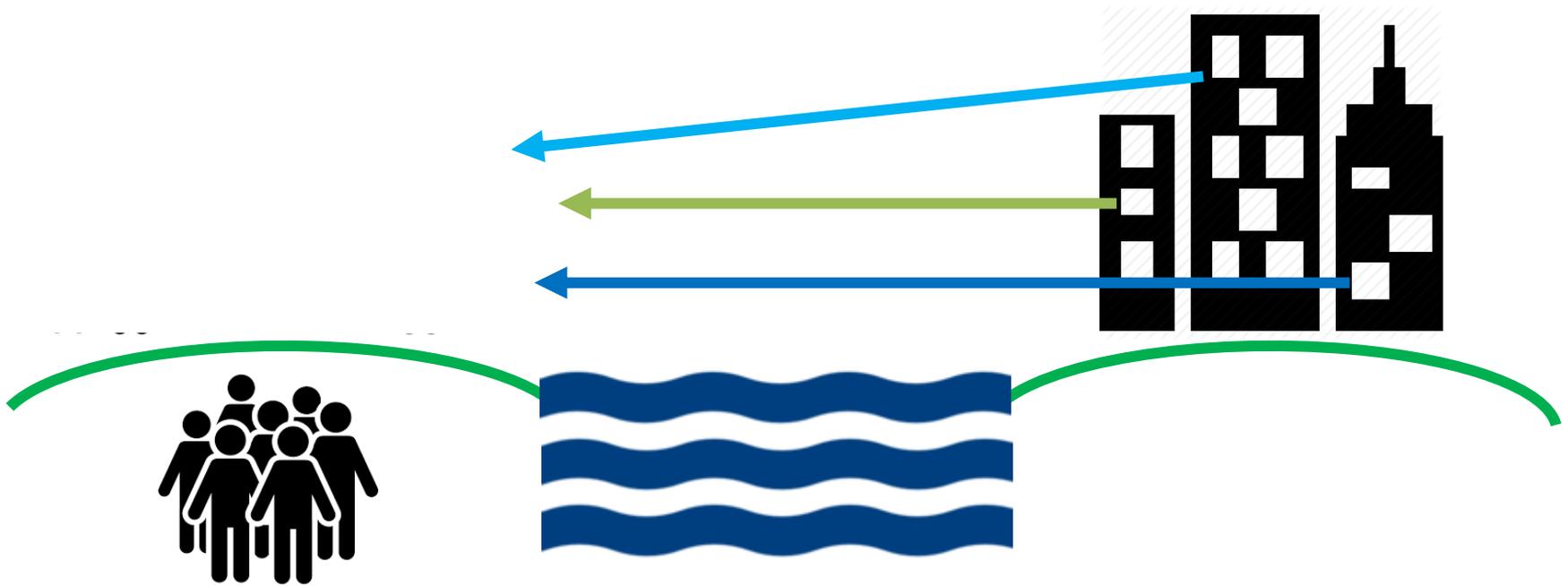
Strategies that bridge a gap

- Embed community within institution (e.g. patient advisory panel)
- Embed institution within community (mobile health unit)
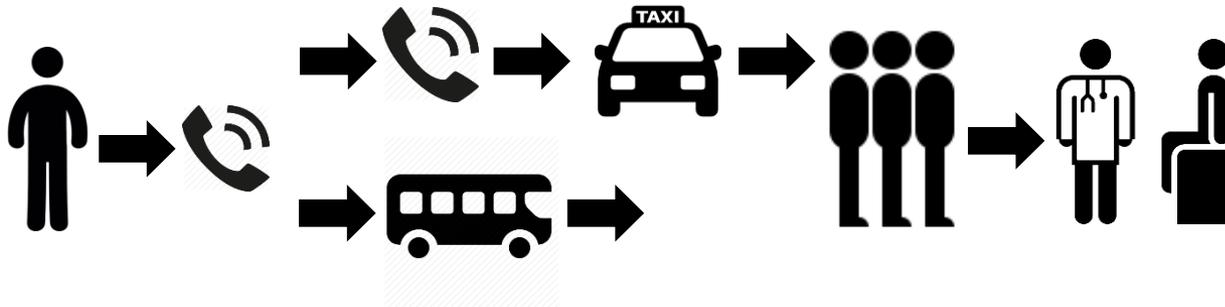- People (CHW, navigators, home visitors)
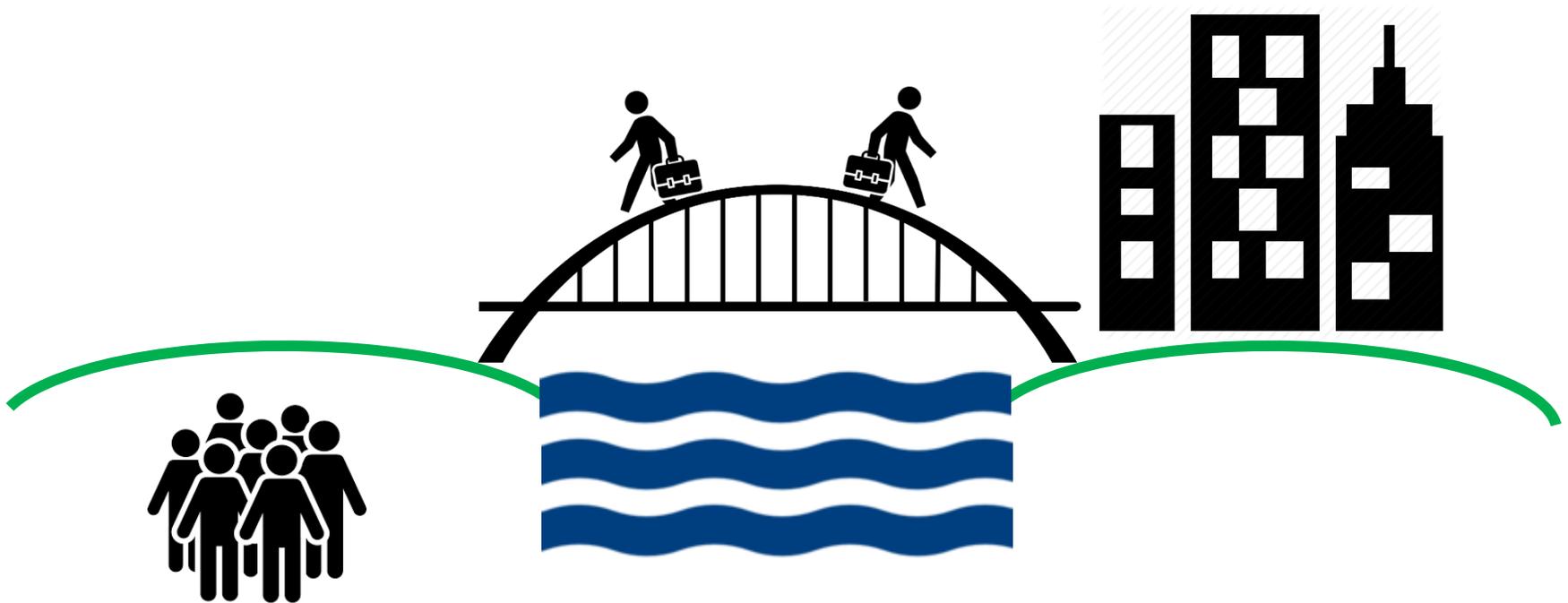
The issue: People have different barriers to overcome to receive same service

- Simple, easy access

- Multi-step, difficult access

Answer: Community Health Workers

Strategic Objective 2: CHWS

WHY

- National Best-Practice

- Grassroots Engagement

- Culturally affirming environment

- Supports client-centered case management

- Build Capacity

STRUCTURE

- Flexibility

- Street outreach in the community and not just within agencies

- Embedded in clinics and community service agencies

- Consistent messaging and training

IMPACT

- Builds social support

- Develops life skills

- Creates larger safety net

Requires admin and data backbone support

Cradle Kalamazoo Accomplishments

Required admin and data backbone support

Collective Impact

Care Coordination

Community Engagement

- 30+ multi-sector partners

- Organizing perinatal home visitation

- Increased Awareness
- Cradle Brand
- Faith-based Engagement

Together we have achieved …
National & State Recognition

Since January 2017
866 pregnant women have been referred into the Cradle Kalamazoo system managed by WMed

Cradle's Community Asks:

- Commitment to support a universal intake and referral process for maternal and infant health

- Building a CHW Work Core

- Support and sustain the backbone of the initiative

- Develop sustainable leadership structure that engages community voice

Thank You!

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eliminating racism
empowering women
ywca
Kalamazoo

cradle
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Examples of CDR translation of findings to action, prevention initiatives

- Washington State

- Baltimore, MD

- Sacramento, CA

Drowning in Washington

- Data analysis revealed drowning fatalities were disproportionately higher in Asian Pacific Islander children

- Higher rates of open child welfare cases

- Recommendations included targeted education, changes in intra-agency policies surrounding lifeguard staffing, enforcement of pool fence laws, implementation of life jacket loaner boards

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Reducing child abuse in Baltimore

Data from a variety of sources, including CDR was analyzed to identify risk factors for child abuse

HIGH IMPACT RECOMMENDATIONS FOR YEAR 1

Differential response for infants and toddlers by the child welfare system	Identification of young children at risk by health care and the community	Access to high quality services for families with caregivers who use substances	Safe, affordable child care through policy advocacy	Care coordination for families with history of abuse and neglect

25 year history in Sacramento

- Data analysis revealed African American children died at twice the rate of all other children

- Decedents are more likely to be enrolled in government aid programs

- Prevention recommendations include: Partnering with the Blue Ribbon Commission, enhancing Child Welfare Systems responses and screening and identify early identification and intervention for mental health issues

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Conclusions

- Fatality Review can offer a unique strategy for analyses of individual and community factors that significantly affect health disparities and are not discoverable through analyses of vital statistics and population based data.

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Public Health Implications

- Fetal, Infant, and Child Death review are core Public Health Surveillance activities and exemplify the 3 Core Public Health Functions:
    - Assessment
    - Policy Development
    - Assurance

Conclusions

- Racism is a pervasive problem throughout our culture

- Death Review and Prevention, with its in-depth exploration and identification of factors that contribute to poor maternal and child outcomes, is in a unique position to provide great insight into the problems families face in seeking and obtaining healthcare, and significant information about health equity and disparities.

Questions?

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