NATIONAL CFRP

Center for Fatality Review & Prevention

The Benefits of Parental/Family Interviews: The Power of Stories

Telling Each Story to Save Lives Nationally

KEY FUNDING PARTNER

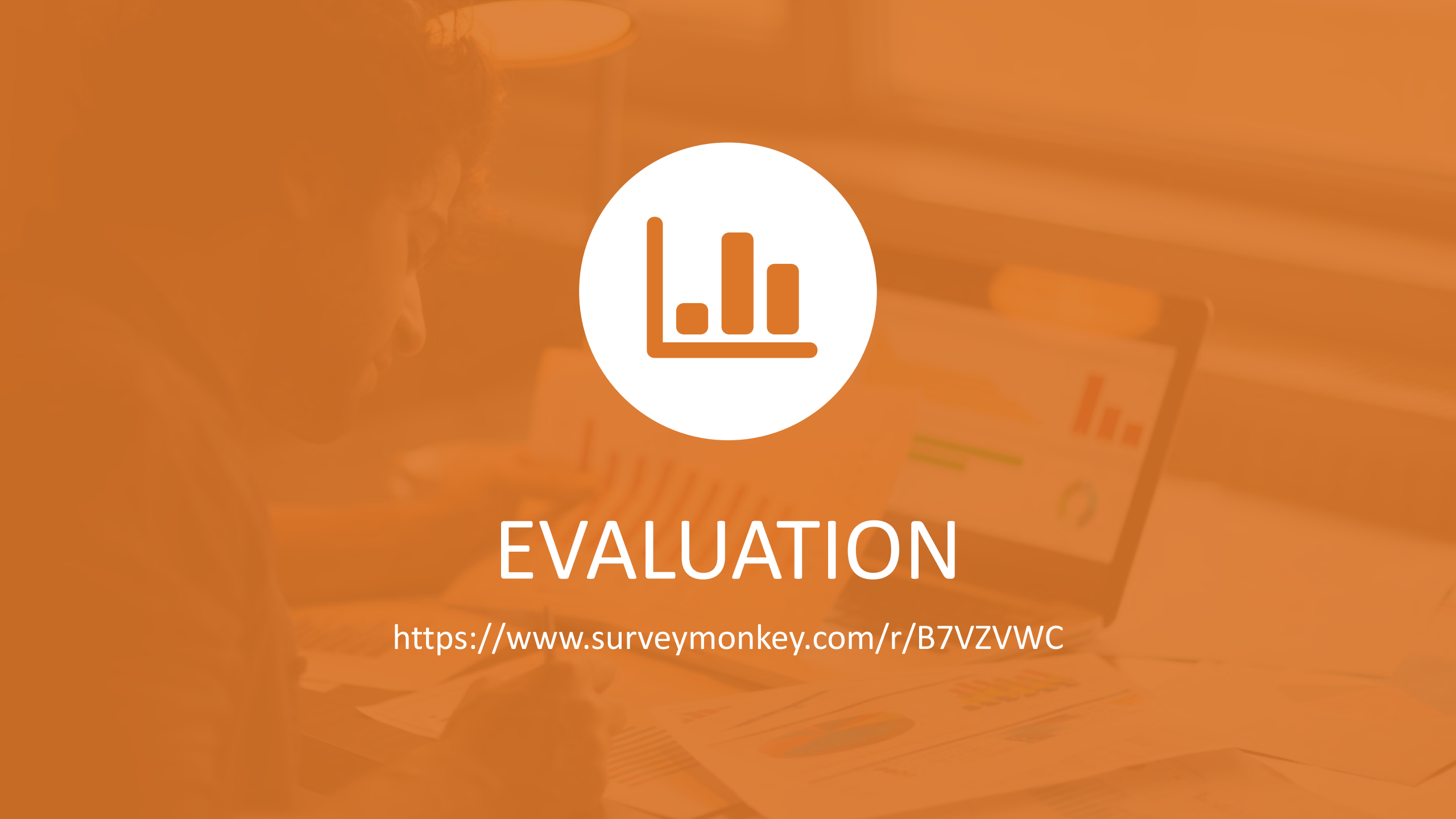
FEDERAL ACKNOWLEDGEMENT

The National Center is funded in part by Cooperative Agreement Numbers UG7MC28482 and UG7MC31831 from the US Department of Health and Human Services (HHS), Health Resources and Services Administration (HRSA), Maternal and Child Health Bureau (MCHB) as part of an award totaling $1,099,997 annually with 0 percent financed with non-governmental sources. Its contents are solely the responsibility of the authors and should not be construed as the official position or policy of, nor should any endorsements be inferred by HRSA, HHS or the U.S. Government.

HOUSEKEEPING

Before we get started

- This webinar is being recorded and will be available on the National Center's webpage (URL: www.ncfrp.org).
- Participants are muted. Use the question and answer box to ask questions.
- Due to the large number of participants, the speakers may be unable to answer all questions. Unanswered questions will be answered and posted with the recording.
- Contact the National Center (email: info@ncfrp.org) for any tech problems.



EVALUATION

https://www.surveymonkey.com/r/B7VZVWC

Mary Emanuele,
USPHS, RN, BAN, CNOR, CCHP

Welcome and Introductions

Program Management Officer

Division of Healthy Start and Perinatal Services,

Maternal and Child Health Bureau,

Health Resources and Service Administration

HRSA'S VISION FOR THE NATIONAL CENTER

IMPROVING SYSTEMS OF CARE AND OUTCOMES FOR MOTHERS, INFANTS, CHILDREN, AND FAMILIES

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

PRESENTATION GOALS

Value of the parental/family interview

Hear from an experienced FIMR site the value of interviews for understanding and acting on community issues related to fetal and infant mortality.

Stories from the Field

Hear the first-person story of a mother who participated in a Home Interview

Resources

Learn how to better support and assist families after an infant loss

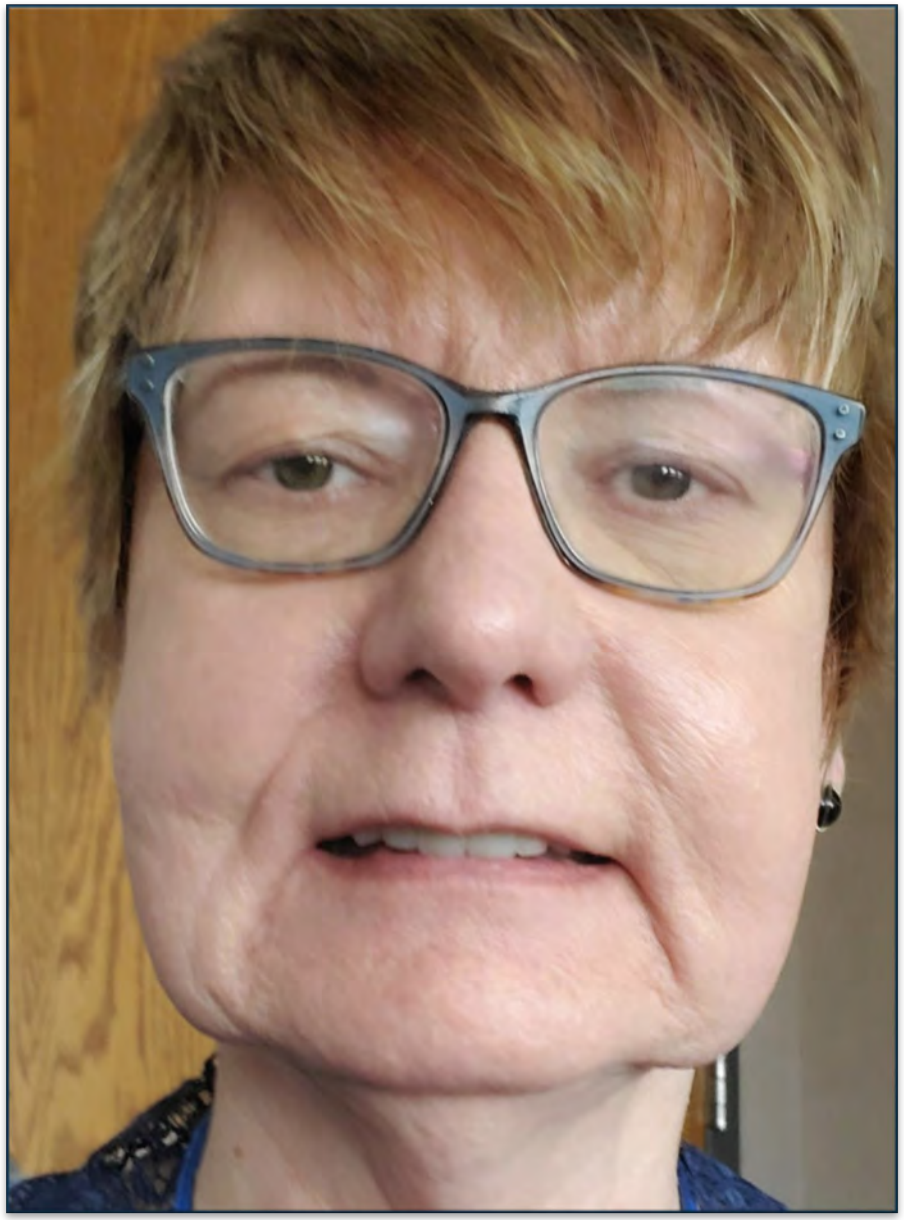
SPEAKERS

Teri Conard, MS, BSN, RN

FIMR Coordinator

Marion County Public Health Department,

Indianapolis, IN



SPEAKERS

Megan Williams, Jameson's Mother

In 2012, Megan Williams experienced the tragic death of her son, Jameson. Megan has been a frequent speaker and advocate for mothers and families who have experienced a loss, and has participated in the ***Walk to Remember,*** a national event dedicated to babies who die each year through miscarriage, ectopic pregnancy, stillbirth or newborn death. Megan and her 3 ½ year old daughter, Briley, now live in Indiana.


I"ll love you FOREVER,
I'll like you for ALWAYS,
As long as I'm living
my baby you'll be.
Jameson Matthew
Williams.
November 1, 2012
ALL BECAUSE TWO PEOPLE...
...FELL IN LOVE


I'll like you for always


Jameson
Matthew Williams
" If there ever comes a day
when we can't be together,
put me in your heart and
I'll stay there forever."

Indianapolis Healthy Babies Fetal Infant Mortality Review (IHB-FIMR) Program

"The mission of FIMR is to tell the stories of mothers whose infants represent the fetal & infant mortality rates in Marion County by "painting the faces behind the numbers" through studying fetal and infant death information, listening to the mothers and protecting their privacy, with the goal of improving maternal child services and infant mortality through community partnerships."

“Maybe Stories are just data with a soul.”
Brene Brown

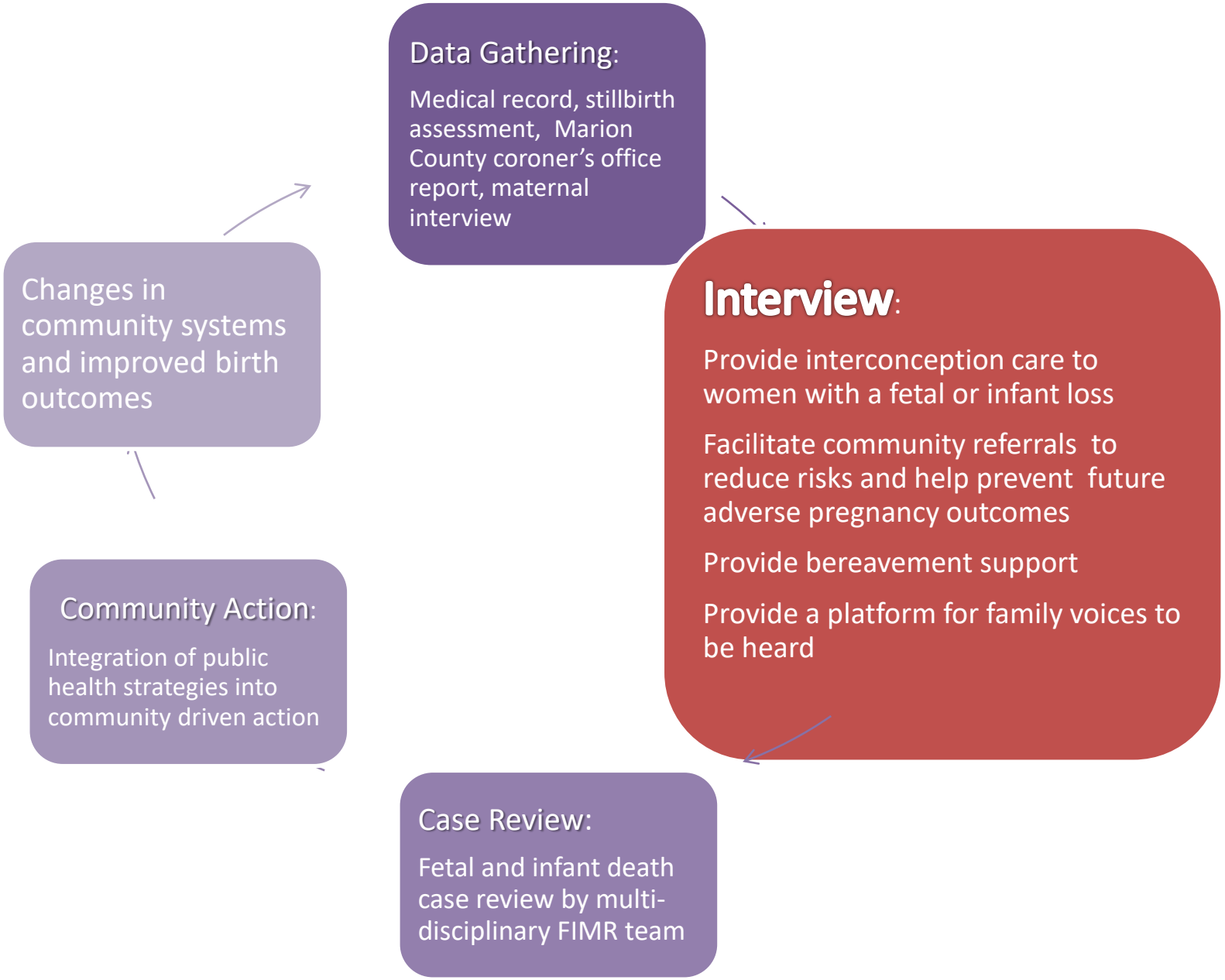
Objectives:

- Overview of home interviews in IHB-FIMR History

- Showing the value of the home interview in the review of fetal and infant mortality cases

- Examples of ways to share qualitative data in FIMR presentations

- Painting the faces behind the numbers.


Data Gathering:
Medical record, stillbirth assessment, Marion County coroner's office report, maternal interview
Interview:
Provide interconception care to women with a fetal or infant loss
Facilitate community referrals to reduce risks and help prevent future adverse pregnancy outcomes
Provide bereavement support
Provide a platform for family voices to be heard
Case Review:
Fetal and infant death case review by multi-disciplinary FIMR team
Community Action:
Integration of public health strategies into community driven action
Changes in community systems and improved birth outcomes

Allen County FIMR
Erin Norton, RN, BSN, FIMR Coordinator
(260)266-7969; Erin.norton@parkview.com

Bartholomew County FIMR
Patty Pigman, MSW, LCSW
Columbus Regional Hospital
2400 E 17th St, Columbus, IN 47201
812.376.5862; ppigman@crh.org

Daviess County Regional FIMR Team
Kathy Sullender, BSN, RN, FIMR Coordinator
Daviess County Public Health Department
812.254.8667; kathy.sullender@daviess.org

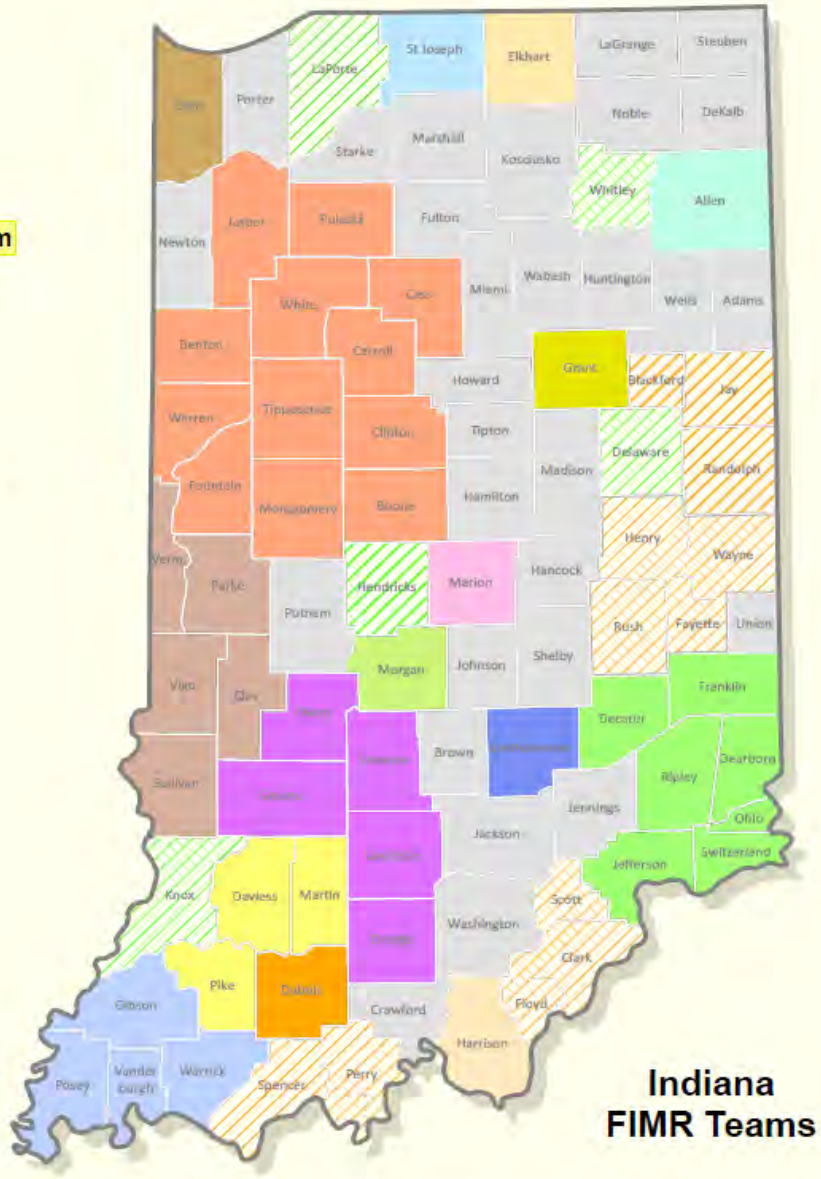
Dubois County FIMR
Jo Ann Spaulding, Administrative Director
Dubois County Health Department
1187 South St. Charles St, Jasper, IN 47546
jaspaulding@duboiscountyin.org; 812-481-7050

Elkhart County FIMR
Marti Conrad, FIMR Coordinator
Elkhart County Health Department
1400 Hudson St, Elkhart, IN 46516
574.522.0104; elkhartcountyhealth.org

Harrison County FIMR
Jennifer Caffrey, MA
Harrison County Health Dept
241 Atwood Street, Suite 100
Corydon, IN 47112
(812) 738-3237, Option 2
JenniferC@harrisoncounty.in.gov

Grant County FIMR
Gail Elbert, MSN, RN
Marion General Hospital
441 N. Wabash Ave.
Marion, IN 46952
(765) 660-6881; gail.elbert@mgh.net

Indianapolis Healthy Babies FIMR
Teri Conard RN BSN MS, FIMR Coordinator
MCPHD, MCH Dept
3838 N. Rural St, Rm 613, Indianapolis, IN 46205
317.221.3103; TConard@MarionHealth.org



Indiana FIMR Teams

Future County Teams Future Regional Teams

Lake County FIMR
Risë Ratney, Project Director
Northwest Indiana Health Dept Cooperative
839 BroadwayGary, IN 46402
219.793.4367;rratney@nwihs.com

Morgan County FIMR
Stephanie Brock, RN
Franciscan Health Mooresville
1201 Hadley Rd Mooresville, IN 46158
Stephanie.Brock@franciscanalliance.org

Monroe County Regional FIMR
Emily Bock, LBSW, MPA
Family Vitality Initiative
333 E. Miller Drive, Bloomington IN 47401
812.353.3139 (o); Ebock1@IUHealth.org

St Joseph County FIMR
Sally A. Dixon, RN, FIMR Coordinator
Fetal Infant Mortality Review Program
St. Joseph County HD,
8th Floor, County-City Building
227 W Jefferson Blvd, South Bend, IN 46601
574.245.6756; sdixon@co.st-joseph.in.us

Southeastern Regional FIMR
Debbie Gloyd
Margaret Mary Health
321 Mitchell Ave Batesville, IN 47006
812.933.5275; Debra.Gloyd@mmhealth.org

Southwestern Indiana FIMR
Lynn A. Herr BSN, RN, CPN, FIMR, CFR
and PHAB Coordinator
Vanderburgh County Health Department
420 Mulberry St, Evansville, IN 47713
812.435.5761; lherr@vanderburghcounty.in.gov

Wabash Valley FIMR
Matthew Herrick
West Central Indiana Healthy Start,
1433 N 6-1/2 St. Terre Haute, IN 47807;
healthystart@uhhg.org; 812-238-8171

West Central FIMR
Aubrey Baker, RN, BSN
Tippecanoe County Health Department
629 N 6th St Suite A Lafayette, IN 47901
765-423-9131abaker@tippecanoe.in.gov

Map Author: ISDH PHG; March, 2020

Indianapolis Healthy Babies Fetal Infant Mortality Review Program (IHB-FIMR)

Indiana FIMR Program- Indiana State Department of Health

IHB-FIMR is in the MCPHD Maternal Child Health Department
Dr. Virginia Caine, M.D. MCPHD Director
Yvonne Beasley MSN, RN MCH & Indianapolis Healthy Start Director

- **Indianapolis Healthy Start**
- **WIC Program**
- **Beds & Britches Etc. (B.A.B.E.)**
- **Community Nutrition**
- **Indianapolis Healthy Babies Consortium**
- **IHB-FIMR Program**

MARION COUNTY PUBLIC HEALTH DEPARTMENT
Prevent. Promote. Protect.

FIMR

MATERNAL & CHILD HEALTH

The Family Perspective, the home interview

“What is most painful for me is my empty, aching arms.”

As a component of the Marion County FIMR Project, 63 mothers who experienced a fetal or infant death agreed to be interviewed. Case reviewers often remarked that the **mother’s interview gave the most valuable information about what gaps exist in services.** From the interview, we saw the mother’s perspective on **social and personal factors** that may have affected the pregnancy. We gained insight on the **personal impact** of the loss, the **circumstances** of the infant's death, what **services helped her** the most, and her perception of what **services she needed but did not receive**.

Source: HEALTHY BABIES in the NEW MILLENNIUM, Marion County Public Health Dept. 1999

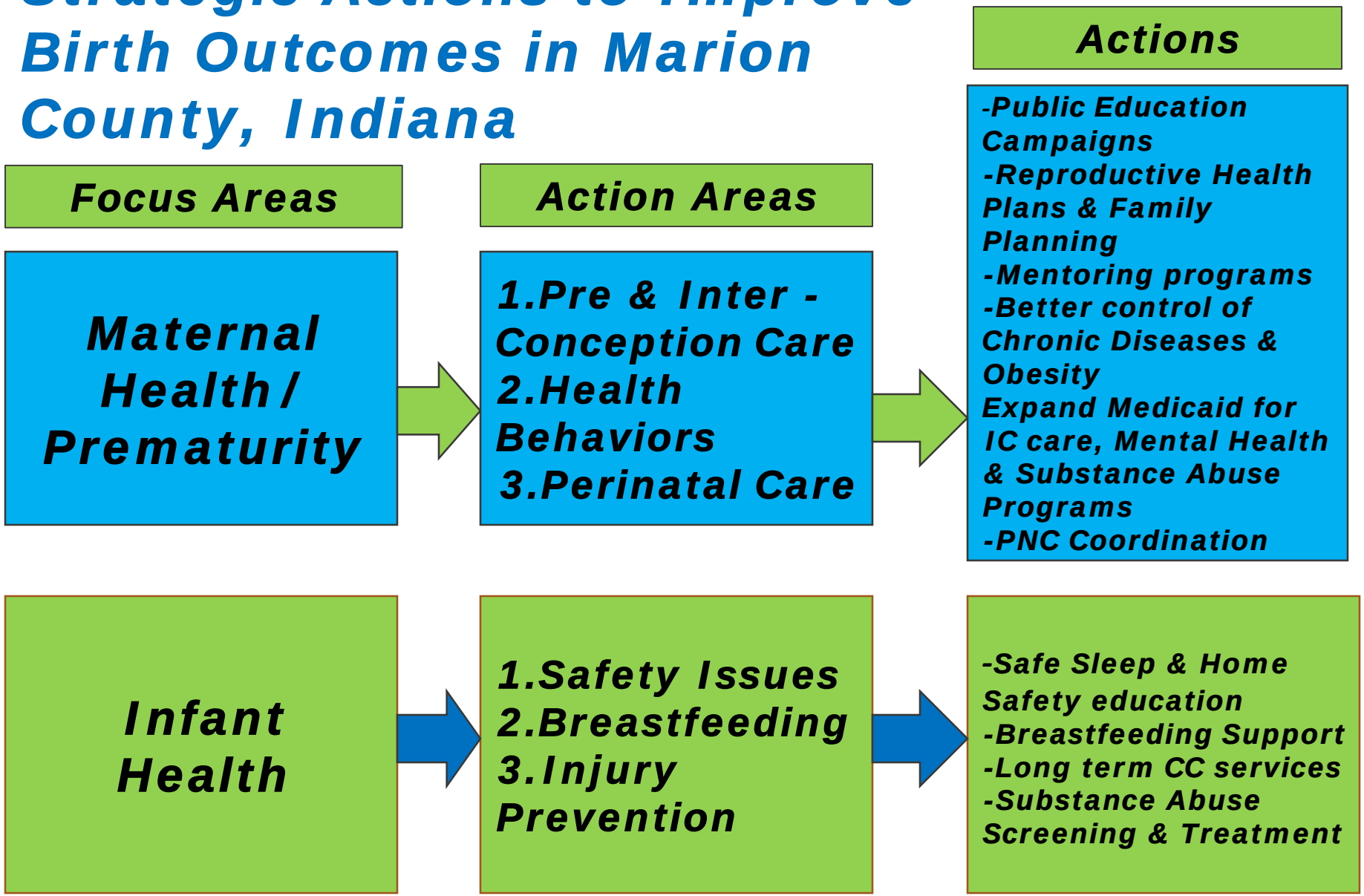
IHB-FIMR Program Process

DATA Gathering:
Case Referrals: Fetal and Infant deaths 23 weeks gestation and/or 500 grams birthweight
Resident of Marion County
Review all Indianapolis Healthy Start cases and all Sudden Unexpected Infant Death cases.

FIMR Nurse Staffing:
Full time FIMR Nurse Coordinator
Full time FIMR Nurse
Two Part time FIMR Nurses who work 60 hours per month
All staff have Public Health Nurse backgrounds
Each staff nurse has RTS Bereavement training.
Each staff nurse both abstracts and does the interview for assigned cases.

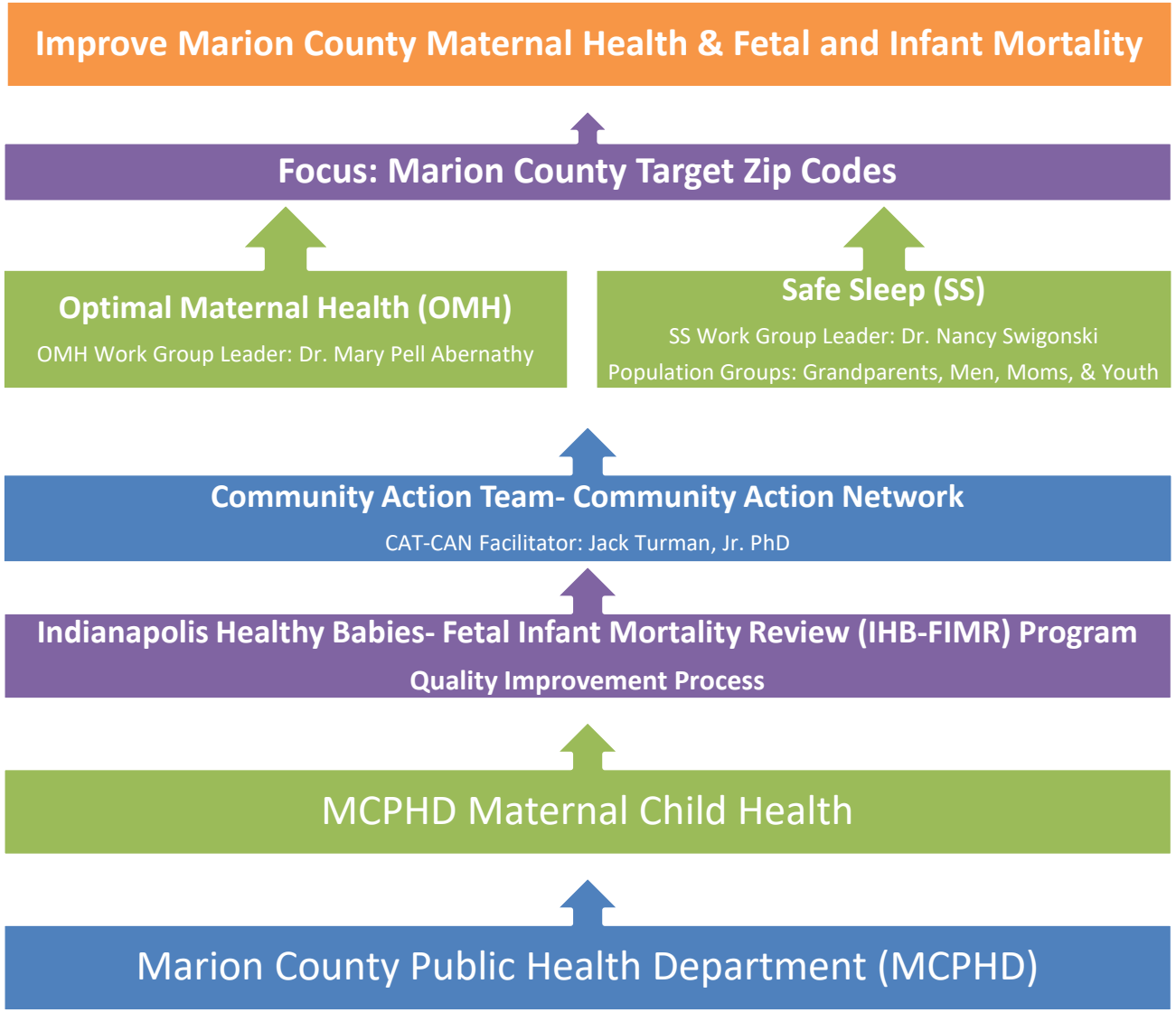
Types of Interviews:
1) Phone 2) Family Interview Surveys 3) Home

Strategic Actions to Improve Birth Outcomes in Marion County, Indiana



IHB-FIMR STAFF

Community Action Team-Community Action Network (CAT-CAN) Organizational Chart

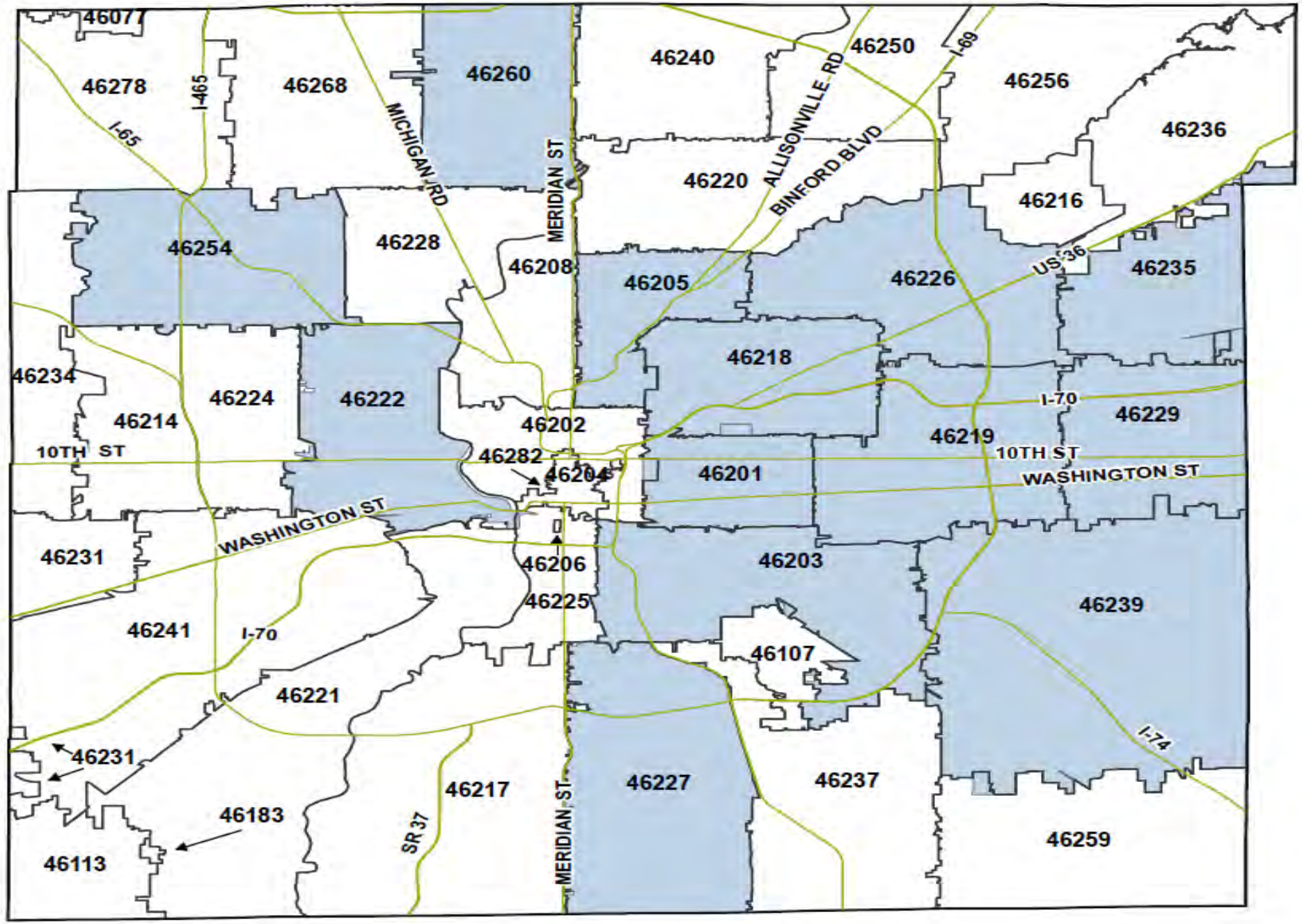


- The FIMR interview is unique among other case review processes.

- Families are invited to share their experiences before, during and after the pregnancy with a FIMR staff member through a home/phone interview or via a written survey.

- The interview is not only an opportunity for parents to tell their story, but it is also chance for FIMR staff to facilitate bereavement support and connect the family with needed resources in the community.

- The interview is presented to the FIMR review team so providers can learn about the pregnancy through the families' perspective.



TARGET ZIP CODES IN MARION COUNTY, IN FOR INFANT MORTALITY

2013 - 2017
Infant Mortality Rates by Zip Code

Zip Code	County	Births	Deaths	Infant Mortality Rate (IMR)	White IMR	Black IMR
46404	Lake	1,093	22	20.1	**	**21.2**
46312	Lake	2,350	37	15.8	11.2*	**23.4**
46324	Lake	1,409	22	15.6	15.0*	24.1*
46806	Allen	2,333	36	15.4	13.1*	**22.2**
46619	St. Joseph	1,631	23	14.1	5.7*	19.8*
46218	Marion	2,490	36	14.5	**	**18.7**
46226	Marion	3,483	44	12.6	6.5*	**14.8**
46203	Marion	3,093	39	12.6	**10.2**	16.4*
46205	Marion	2,417	30	12.4	8.9*	**15.3**
47130	Clark	2,966	36	12.1	**12.3**	15.6*
46628	St. Joseph	2,059	24	11.7	4.2*	**20.8**
46229	Marion	1,976	23	11.6	6.3*	13.8*
46235	Marion	3,191	37	11.6	6.3*	**13.0**

*Numerator less than 20, the rate is unstable.
**Rate has been suppressed due to five or fewer outcomes.

Emotional Stress

Medical Records:

She watched a family member take their life

Father of Baby: Incarcerated

Household income: 0-$9,999

Prenatal care:

- Weekly Makena injections
- Previous premature baby

"I did not have any events during my childhood or prior to pregnancy that caused any hardship"

"My family was my support; the father of the baby was also supportive"

"I went to a lot of visits since I had to take shots due to [the previous pregnancy] being a preemie "
"I stopped working because they were not flexible with my work schedule"

"I did not have any financial concerns or stress"
" I was not stressed at all"

Immune, Endocrine, and Cardiovascular factors & Health Behavior Risks

Medical Records:

Medical:

- Former smoker
- BMI 45.7

OB History:

- Hypertension in prior pregnancy
- Preterm delivery around 32 weeks

Prenatal care:

- Started in 1st trimester
- Had 12 visits,
- Followed up with referrals
- Compliant with care

" I do not have any health issues"

" I threw up a lot, I was sick a lot. I did not have any difficulty caring for myself or following medical advice"

" I received a lot of education..."

" I was satisfied with the care I received"

Inflammatory & Reproductive Tract Changes

Medical Records:

Family planning:

- Unplanned
- 14 month pregnancy interval

Prenatal care:

- Urinary infection,
- Makena injection site infection,
- Bacterial vaginosis,
- Group B strep +

Delivery:

- Elevated blood pressure on admission

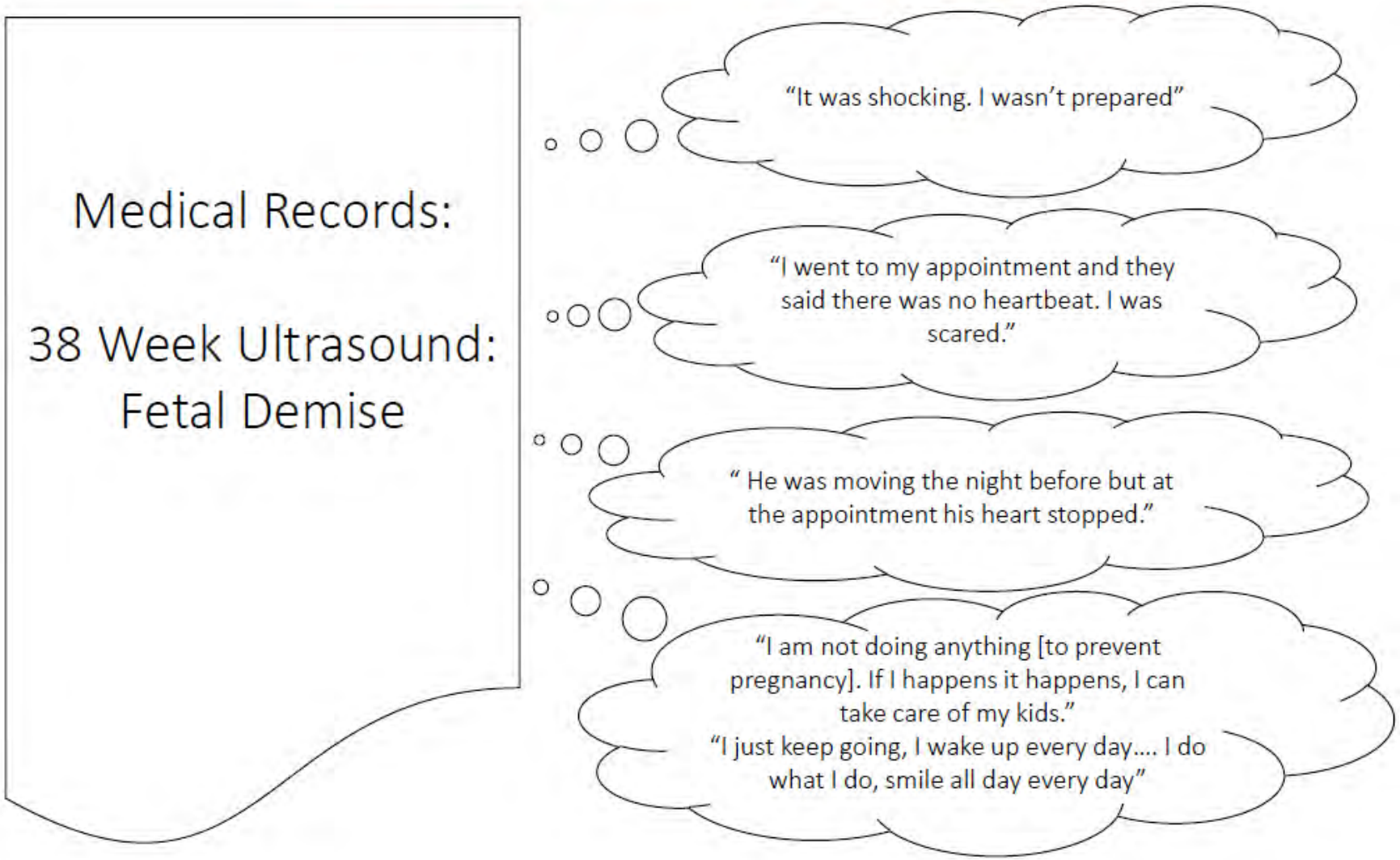
" I was not taking any birth control"

" The pregnancy was a surprise but I was ok with it, not sad about it"

" I did not have any health issues with this pregnancy"

"I was not told to do anything to prevent preterm labor"

Adverse Birth Outcome



MATERNAL VOICES: Identifying Social and Environmental Factors Contributing to Prematurity

Contributors: Anne Lise Sullivan, RN, BSN, MA • Teri Conard, RN, MS • Jessica Craig, MPH • Sandra Minor, RN • Jackie Reedy, RN

BACKGROUND

- Prematurity is the leading cause of infant death in Marion County, Indiana.
- The Fetal Infant Mortality Review (FIMR) program seeks to understand the interaction between the social, biological and environmental factors that contribute to prematurity and infant loss.

- The FIMR process supports the Institute of Medicine's (IOM,2006) research agenda on understanding the causes of prematurity by:
  - Simultaneously assessing the risk factors associated with prematurity.
  - Evaluating the quality of services available to women and children.
- Some of the most compelling data to date on the complex circumstances surrounding premature births has come from interviews with mothers. Data from the maternal interviews completed in Marion County:
  - Highlights factors contributing to prematurity, information that cannot be ascertained from vital records or medical record data alone.
  - Provides a first-hand account of the strengths and weaknesses of services and potential gaps in needed services.

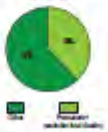
MATERNAL INTERVIEW

- The FIMR interview is unique among other case review processes.
- Mothers are invited to share their experiences before, during and after the pregnancy with a FIMR staff member through a home/phone interview or via a written survey.
- The interview is not only an opportunity for mothers to tell their story, but it is also chance for FIMR staff to facilitate bereavement support and connect mom with needed resources in the community.
- The interview is presented to the FIMR review team so providers can learn about the pregnancy through the mother's perspective.

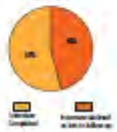
INTERVIEW DATA

- Maternal quotes highlight issues the FIMR team has identified as the top three contributing factors to infant death in Marion County: preexisting conditions, poverty and unplanned pregnancy
- Maternal quotes are selected from interviews with Marion County's most at risk and affected population.

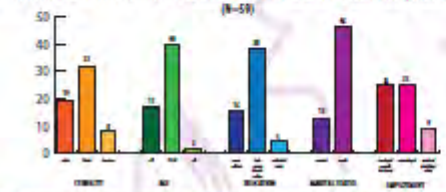
TOTAL NUMBER OF PREMATURITY CASES, 2006-2010 (N=289)



MATERNAL INTERVIEW RATE FOR PREMATURITY CASES, 2006-2010 (N=108)



SOCIOECONOMIC CHARACTERISTICS OF MATERNAL INTERVIEWS FROM PREMATURITY CASES, 2006-2010 (N=59)



This select group of maternal quotes from interviews from 2006 through 2010 demonstrate how maternal voices enrich our understanding of the social and environmental barriers preventing optimal birth outcomes in Marion County.

"... I was sexually abused by a cousin when I was 3 years old until 11 years old. I tried to commit suicide and got counseling to help. My father was an alcoholic and my family and I were subjected to mental and verbal abuse ... I didn't work during my pregnancy and my husband hasn't worked since July. It causes a lot of tension and financial problems for us. We're going to have to move soon because we can't afford the rent now. We get food stamps and social security for my son for his health problem and me, for post-traumatic stress.. I smoked cigarettes while I was pregnant because of the stress ... I have trouble with my pregnancies because my diabetes goes way out of control when I'm pregnant. I didn't get any teaching during my prenatal visits. My Endocrinologist told me I shouldn't have any more children. I became pregnant soon after and lost that pregnancy three and a half weeks ago. I was on a new birth control pill for a week and got pregnant because we were to use a condom and my husband doesn't like using them."

-Medicaid, married, 31 years old, unemployed, 13 years of education -
Infant: renal agenesis, 936 grams

"...I didn't want to get pregnant again so soon; I guess I was so stressed out [after the first baby died in NICU]. I was on birth control pills when I got pregnant but I guess they didn't work. I was really sick with bronchitis and then discovered I was pregnant again ... Now I have a prescription for pills, but I don't need them now. I don't have the money to get them anyway .... The baby's father is not around anymore. The store fired me from my job when the doctor sent the note during the second pregnancy that I couldn't work. I think this is discrimination. They wouldn't give me a reference for the job I had and that makes it worse. So I have no job and no babies ..."

– African American, single, 26 years old, unemployed with 13 years of education
Infant: extreme prematurity

"There were times I couldn't afford a place to stay. I was evicted from my home. I didn't talk to a health care provider about family planning and I wasn't using birth control or taking folic acid three months before I became pregnant. I had trouble getting birth control because I didn't have any insurance. I was 12 - 13 weeks pregnant when I first thought I was pregnant and found out from a pregnancy test done in ER. [After] The doctor talked to me about birth control. I'm not using any birth control because I can't pay for it."

-White, single, 27 years old, unemployed with an 11th grade education
Infant: diaphragmatic hernia, 2612 grams

"... We rent this two bedroom Section 8 apartment. We have mold all over. The rain comes in the windows and the toilet overflows sometimes. We get roaches coming out of the vents. The whole place has roaches. They [owners] have sent in exterminators. They say the mold and roaches are my fault. They are trying to evict me. My two year old has asthma and my 5 year old has chronic lung disease, so I need to get this place cleaned up or move .... I have been diabetic since I was 14 and on insulin since I was 19. I have a meter now, but don't test very often. It hurts to stick myself. When I stick myself here [tools of hands] my hands get numb, so I won't do it. I think I weigh 230 lbs now [5'6, BMI 37.6]. I didn't gain much weight with her, so not much to lose. I had blackouts with my first pregnancy, blood sugar problems. I believe they [hospital staff] killed both my babies ... [Since the death] I stopped taking my Zoloft, it makes me sleepy. My thyroid left me. I'm facing eviction ... somebody turned me in for child abuse, which I have never done. I can't sleep. I'm a nervous wreck. I have no closure. I've got a lot of rage against everyone ..."

– African American, single, 25 years old, employed, 10 years of education
Infant: pulmonary hypoplasia, 1406 grams

DISCUSSION

Common themes identified through interview data include:

- Barriers to patient compliance with and comprehension of chronic disease management.
- The effect of social and economic insecurity on maternal mental health and implications for motherhood.
- The impact of mental health disorders on functionality and motherhood.
- Obstacles to securing safe, healthy and affordable housing.
- The economic, emotional and biological impact of being unemployed and uninsured/underinsured.

Resulting FIMR recommendations and interventions:

- Recommendations:
  - Ongoing evaluation and improvement of social services at the local level.
  - Advocacy for policy change at the local and national level.
  - Increase recognition of maternal mental health issues and improve resources available to women with mental health issues.
  - Increase awareness and education about the reproductive life course.
  - Increase provider knowledge of available community resources.
- Interventions:

1. In the coming year, the Marion County FIMR program will focus prematurity prevention efforts on addressing interconceptional health management, in an effort to reduce the number of unplanned pregnancies and increase the well being of mothers prior to pregnancy.
   - As a first step, with the support of the March of Dimes, FIMR staff will provide mothers with an educational guide for subsequent pregnancies ("When you want to try again" March of Dimes, 2010), to encourage delivery of full term, healthy infants.
2. Additionally, FIMR wants to ensure that local providers, and their patients, have access to the most up-to-date information on services available to women and children in Marion County.
   - In collaboration with the Marion County Public Health Department's Social Services Department, FIMR staff will provide local provider offices with Mother Baby Healthline pamphlets.
   - The Mother Baby Healthline, staffed by social workers, provides information about pregnancy and childcare and links callers to local community resources that address transportation, housing and financial needs.

CONCLUSIONS

FIMR supports prematurity prevention efforts through:

- Holistically evaluating cases of premature birth to better understand the complex interaction between society, the environment and individual biology.
- Gathering data directly from women who can provide insight into circumstances surrounding their pregnancy, information that cannot be obtained from any other source.
- Providing a regular venue where health providers and policy planners can meet and discuss new and ongoing issues related to prematurity and infant death.
- Continually evaluating the resources and services in place to help reduce prematurity and infant loss.
- Identifying modifiable risk factors leading to targeted interventions aimed at reducing prematurity and infant loss.
- Using qualitative and quantitative data to make informed recommendations for change on the local level.

This select group of maternal quotes from interviews from 2006 through 2010 demonstrate how maternal voices enrich our understanding of the social and environmental barriers preventing optimal birth outcomes in Marion County, IN

Source: MATERNAL VOICES: Identifying Social and Environmental Factors Contributing to Prematurity. *IHB-FIMR 2006-2010*

"…I didn't want to get pregnant again so soon; I guess I was so stressed out [after the first baby died in NICU]. I was on birth control pills when I got pregnant but I guess they didn't work. I was really sick with bronchitis and then discovered I was pregnant again ... Now I have a prescription for pills, but I don't need them now. I don't have the money to get them anyway … The baby's father is not around anymore. The store fired me from my job when the doctor sent the note during the second pregnancy that I couldn't work. I think this is discrimination. They wouldn't give me a reference for the job I had and that makes it worse. ***So I have no job and no babies ...*** *"*

African American, single, 26 years old, unemployed with 13 years of education
Infant: extreme prematurity

Source: MATERNAL VOICES: Identifying Social and Environmental Factors Contributing to Prematurity. *IHB-FIMR 2006-2010*

“There were times I couldn't afford a place to stay. I was evicted from my home. I didn't talk to a health care provider about family planning and I wasn't using birth control or taking folic acid three months before I became pregnant. I had trouble getting birth control because I didn't have any insurance. I was 12 - 15 weeks pregnant when I first thought I was pregnant and found out from a pregnancy test done in ER. [After]The doctor talked to me about birth control. I'm not using any birth control because I can't pay for it.”

White, single, 27 years old, unemployed with an 11th grade education

Infant: diaphragmatic hernia, 2612 grams

Source: MATERNAL VOICES: Identifying Social and Environmental Factors Contributing to Prematurity. IHB-FIMR 2006-2010

... We rent this two-bedroom Section 8 apartment. We have mold all over. The rain comes in the windows and the toilet overflows sometimes. We got roaches coming out of the vents. The whole place has roaches. They [owners] have sent in exterminators. They say the mold and roaches are my fault. They are trying to evict me. My two-year-old has asthma and my 5-year-old has chronic lung disease, so I need to get this place cleaned up or move ... I have been diabetic since I was 14 and on insulin since I was 19. I have a meter now, but don't test very often. It hurts to stick myself. When I stick myself here [heels of hands] my hands get numb, so I won't do it. I think I weigh 230 lbs. now [5'6, BMI 37.6]. I didn't gain much weight with her, so not much to lose. I had blackouts with my first pregnancy, blood sugar problems. I believe they [hospital staff] killed both my babies ... [Since the death] I stopped taking my Zoloft, it makes me sleepy. My fiancé left me. I'm facing eviction ... somebody turned me in for child abuse, which I have never done. I can't sleep. I'm a nervous wreck. I have no closure. I've got a lot of rage against everyone ... "

– African American, single, 25 years old, employed, 10 years of education

Infant: pulmonary hypoplasia, 1406 grams

Source: MATERNAL VOICES: Identifying Social and Environmental Factors Contributing to Prematurity. *IHB-FIMR 2006-2010*

“ ... I was sexually abused by a cousin when I was 3 years old until 11 years old. I tried to commit suicide and got counseling to help. My father was an alcoholic and my family and I were subjected to mental and verbal abuse ... I didn't work during my pregnancy and my husband hasn't worked since July. It causes a lot of tension and financial problems for us. We're going to have to move soon because we can't afford the rent now. We get food stamps and social security for my son for his health problem and me, for post-traumatic stress. I smoked cigarettes while I was pregnant because of the stress ... I have trouble with my pregnancies because my diabetes goes way out of control when I'm pregnant. I didn't get any teaching during my prenatal visits. My Endocrinologist told me I shouldn't have any more children. I became pregnant soon after and lost that pregnancy three and a half weeks ago. I was on a new birth control pill for a week and got pregnant because we were to use a condom and my husband doesn't like using them.” **Hispanic, married, 31 years old, unemployed, 13 years of education** • Infant: renal agenesis, 936 grams

Source: MATERNAL VOICES: Identifying Social and Environmental Factors Contributing to Prematurity. IHB-FIMR 2006-2010

Common themes identified through interview data include:

- Barriers to patient compliance with and comprehension of chronic disease management.
- The effect of social and economic insecurity on maternal mental health and implications for motherhood.
- The impact of mental health disorders on functionality and motherhood.
- Obstacles to securing safe, healthy and affordable housing.
- The economic, emotional and biological impact of being unemployed and uninsured/underinsured.

Source: MATERNAL VOICES: Identifying Social and Environmental Factors Contributing to Prematurity. IHB-FIMR 2006-2010

Resulting FIMR recommendations and interventions:

Recommendations:

- Ongoing evaluation and improvement of social services at the local level.
- Advocacy for policy change at the local and national level.
- Increase recognition of maternal mental health issues and improve resources available to women with mental health issues.
- Increase awareness and education about the reproductive life course.
- Increase provider knowledge of available community resources.

Source: MATERNAL VOICES: Identifying Social and Environmental Factors Contributing to Prematurity. IHB-FIMR 2006-2010

Interventions:

1.In the coming year, the Marion County FIMR program will focus prematurity prevention efforts on addressing interconception health management, in an effort to reduce the number of unplanned pregnancies and increase the well being of mothers prior to pregnancy.

- As a first step, with the support of the March of Dimes, FIMR staff will provide mothers with an educational guide for subsequent pregnancies (“When you want to try again” March of Dimes, 2010), to encourage delivery of full-term healthy infants.

- Additionally, FIMR wants to ensure that local providers, and their patients, have access o the most up-to-date information on services available to women and children in Marion County. Brochures on the Mother Baby Healthline were mailed to all provider office managers. Up to date information on MCH and community resources are available through the Healthline.

EXPANDING INTERCONCEPTION CARE THROUGH THE FETAL INFANT MORTALITY REVIEW (FIMR) PROGRAM MODEL

Indianapolis Healthy Babies Fetal Infant Mortality Review Program (IHB-FIMR) | Contributors: Yvonne Beasley, RN, MSN · Teri Conard, RN, MS · Anne Lise Sullivan, RN, BSN, MA · Sandra Minor, RN , MSN · Jackie Reedy, RN, MSN · Corinne Reynolds, FIMR intern

PROBLEM

- Providing interconception care to women following a perinatal loss is an ongoing challenge for healthcare providers in Marion County, Indiana (Indianapolis). Women who have experienced a perinatal loss are more likely to experience a poor birth outcome.
- In Marion County, Indiana (Indianapolis) interconception care is a top Perinatal Periods of Risk (PPOR) defined Action Area for strategies to improve birth outcomes.
- There is an urgent need to create innovative strategies to identify, connect, and address the interconception needs of these women prior to their next pregnancy.

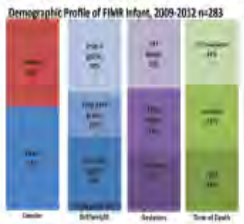
NEED

INTERCONCEPTUAL RISK FACTORS FOR FIMR CASES FROM 2009-2012 (N = 283)

- 57% of IHB-FIMR mothers had life course perspective risk factors.
- 62% of IHB-FIMR mothers had a pre-existing medical condition prior to their pregnancy.
- 38% of IHB-FIMR mothers had a pre-pregnancy BMI of 30 or greater.
- 44% of IHB-FIMR mothers had a previous history of a preterm or low birth weight baby.
- 31% of IHB-FIMR mothers had a previous history of a fetal or infant loss prior to their recent loss.
- 33% of IHB-FIMR pregnancies are unintended with pregnancy intention not documented in 36% of cases.
- 53% of IHB-FIMR mothers had an STD or other infection during pregnancy.
- 33% of IHB-FIMR mothers had substance abuse use with Tobacco being the highest.
- 41% of IHB-FIMR mothers do not return for their 6 week postpartum appointment. Maternal grief limits the efficacy of interconception care in the immediate postpartum period.
- 70% of IHB-FIMR mothers are on Medicaid. After 60 days postpartum, the pregnancy Medicaid package ends and many mothers become uninsured. This is a barrier from receiving appropriate interconception care. In 2013, Indiana expanded Medicaid family planning services.

SETTING

IHB-FIMR serves families in areas of Marion County, Indiana with the highest incidence of fetal and infant mortality.

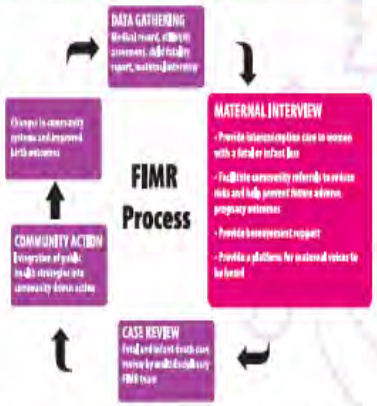


These graphs may not equal 100% due to rounding and/or missing data

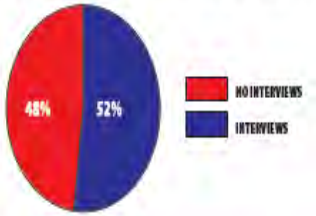
PROJECT

Interconception care: IHB-FIMR maternal interview

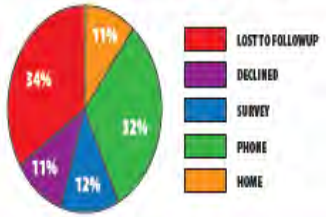
The IHB-FIMR maternal interview provides multiple avenues of support for mothers after a fetal or infant loss (see FIMR Process). Of the many support services, interconception care is of primary importance. The IHB-FIMR nurse facilitates discussion about the loss and through this discussion encourages mothers to report ongoing concerns and unmet needs. In this way, the IHB-FIMR nurse is in a unique position to engage moms in a discussion about their own self-identified needs, rather than approaching women with a predetermined "to do" list. This life course approach encourages trust between the nurse and grieving mom and promotes a client-centered approach to interconception care that not only addresses medical needs, but also social and economic. Based on the mutually agreed goals, referrals are made for ongoing care.



FIMR CASES & PERCENTAGE OF MATERNAL INTERVIEWS 2009-2012 (n=147 of 283)



TYPES OF MATERNAL INTERVIEWS 2009-2012 (n=147 of 283)



CDC MATERNAL SUMMIT ON PRECONCEPTION CARE

GOAL 2: Reduce risks indicated by a prior adverse pregnancy outcome through interventions in the interconception (inter-pregnancy) period that can prevent or minimize health problems for a mother and her future children.

RECOMMENDATION 3: Use the interconception period to provide intensive interventions to women who have had a prior pregnancy ending in adverse outcome.

RECOMMENDATION 7: Health coverage for low-income women. Increase Medicaid coverage among low-income women to improve access to preventative women's health, preconception, and interconception care.

RECOMMENDATION 9: Refine and integrate components of preconception health into existing local public health and related programs, including emphasis on those with prior adverse outcomes.

IHB-FIMR INTERCONCEPTION INTERVENTIONS:

- Utilize staff with program assessment to prioritize interconception care needs for mothers with a fetal loss.
- Provide "prescriptions" to the Indiana Tobacco Quitline for smoking cessation.
- Secure genetic counseling when indicated for uninsured mothers
- Educate and refer women to reduced or no-cost family planning programs in the community
- Administer depression screen (EPDS) and refer to public health social worker as needed.
- Refer women to reduced-cost or no cost mental health counseling in Indianapolis.
- Assist women in reestablishing care with primary care provider to manage chronic health conditions, STDs and weight loss.
- Connect ESL mothers with culturally appropriate resources in Indianapolis.
- Refer uninsured women to Covering Kids and Families for assistance obtaining insurance.
- Educate and refer women to The Excel Center—a tuition free school in Indianapolis.

LESSONS LEARNED

BARRIERS TO CONDUCTING MATERNAL INTERVIEWS

BARRIER #1: Locating mothers
Solution:
- Address verifications with post office
- Incorporate multiple tactics including: letter, phone calls, home visits
- Make 3 attempts to contact mothers

BARRIER #2: Mental health
Solution:
- Let mom dictate nature of discussion
- Start simple and establish trust
- Try to verify basics like presence of a medical home
- Refer to mental health counseling and provide contact information for future needs

BARRIER #3: Already pregnant
Solution:
- Assess circumstances of prior loss, if client willing
- Identify ongoing social and health needs
- Evaluate current prenatal care plan
- Refer to appropriate community services (ie. care coordination)

TAKE HOME

- IHB-FIMR women are at greater risk for experiencing a subsequent loss and so every effort must be made to provide comprehensive interconception care to this high risk population.
- IHB-FIMR data evidence suggests that providing comprehensive interconception care that addresses medical needs, family planning and socioeconomic needs prior to a women's next pregnancy improves birth outcomes.
- Because many IHB-FIMR women do not always return for their postpartum appointment or have a stable medical home, interconception care should also be delivered in non-traditional settings.
- Using the life course perspective, the IHB-FIMR maternal interview is a platform for providing interconception care to our high risk mothers.
- This successful IHB-FIMR model should be expanded and incorporated into the interconception curriculum of MCH public health programs to promote consistent and comprehensive interconception care to high risk mothers.

PROBLEM

Providing interconception care to women following a perinatal loss
is an ongoing challenge for healthcare providers in Marion County, IN (Indianapolis).
Women who have experienced a perinatal loss are more likely to experience another poor birth outcome.

Interconception case is a top Perinatal Periods of Risk (PPOR) defined Action Area for strategies to improve birth outcomes.

There is an urgent need to create innovative strategies to identify, connect, and address the interconception needs of these women prior
to their next pregnancy.

Source: EXPANDING INTERCONCEPTION CARE THROUGH THE
FETAL INFANT MORTALITY REVIEW (FIMR) PROGRAM MODEL, 2013

NEED Interconceptual Risk Factors for FIMR Cases 2009-2012 (N=283)

IHB-FIMR mothers experienced:

Life course perspective risk factors (37%)
Pre-existing Medical Condition prior to pregnancy (62%)
Pre-pregnancy BMI of 30 or greater (38%)
Previous History of preterm or very low birth weight baby (44%)
Previous History of fetal or infant loss prior to their recent loss (31%)
Unintended pregnancies (33%) or intention not documented (36%)
STD or other infection during pregnancy (53%)
Substance abuse use issue (33%) Tobacco was highest.
Not returning to their 6 week postpartum appointment (41%)
Insurance source as Medicaid (70%)

Source: EXPANDING INTERCONCEPTION CARE THROUGH THE FETAL INFANT MORTALITY REVIEW (FIMR) PROGRAM MODEL, 2013

Interconception care: FIMR Interviews (147/283)

The FIMR Home Interview provides multiple avenues of support
For mothers after a fetal or infant loss. Of the many support
services, interconception care is of primary importance. The FIMR Nurse facilitates discussion about the loss and through this discussion encourages mothers to report ongoing concerns and unmet needs. In this way, the FIMR nurse is in a unique position to engage moms in a discussion about their own self-identified needs. This life course approach encourages trust between the nurse and grieving mom and promotes a client-centered approach to interconception care that not only addresses medical needs, but also social and economic.
Referrals can be made for ongoing care.

Source: EXPANDING INTERCONCEPTION CARE THROUGH THE
FETAL INFANT MORTALITY REVIEW (FIMR) PROGRAM MODEL, 2013

Overcoming Barriers to Obtaining Interviews

- **Locating parents/families:**
  - Address verifications
  - Incorporate multiple tactics including: Letter, phone calls, in person home visits
  - Make 3 attempts to contact family
  - Use of translation services.

- **Mental health:**
  - Allow parents to dictate nature of discussion
  - Start simple and establish trust
  - Try to verify basics like presence of a medical home
  - Refer to mental health counseling, reconnect with hospital bereavement support, Social worker
  - Provide contact information for future needs

- **Already pregnant**
  - Access circumstances of prior loss, if client willing
  - Identify ongoing social and health needs
  - Evaluate current prenatal care plan
  - Refer to appropriate community services i.e. care coordination

- **Education, Education, Education**
  - “They wanted me to take a medication for my diabetes, but I didn't like it because I didn't want to take anything that would hurt my baby…”
  - “I have diabetes since I was 15 years old and take insulin. I take two types of insulin, my diabetes is always under control.” (HA1C 10.7)
  - “I don't have any medical or mental health problems.”
  - “I don't know about my diabetes status. I had it during my pregnancy. Diabetes is in my family; an aunt, and my grandmother. I don’t know if I have diabetes now.”
  - “Diabetes is so prevalent and common that it has lost it’s impact.” CRT

IHB-FIMR Recommendations

THANKS TO THE INDIANAPOLIS HEALTHY BABIES
FIMR CASE REVIEW TEAM AND
COMMUNITY ACTION TEAM/COMMUNITY ACTION NETWORK!

THANKS TO IHB-FIMR STAFF FOR THEIR DEDICATION IN WORKING TO OBTAIN Family INTERVIEWS

SPECIAL SHOUT OUT TO ANNE LISE MUSSELMAN,FORMER FIMR NURSE, FOR HER CONTRIBUTION TO ANALYSIS OF THESE CASES.

SPECIAL THANKS TO ALL Parents/Families WHO SHARED THEIR BABIES' STORIES WITH US THROUGH HOME, PHONE AND SURVEY.

Teri Conard MS BSN RN
IHB-FIMR Coordinator
tconard@marionhealth.org

Born to do this work: One interviewer's story

Kristin L. Koyne Joyce, BA

Senior Social Worker

Family Interviewer

Fetal and Infant Mortality Review Program,

Delaware

QUESTIONS

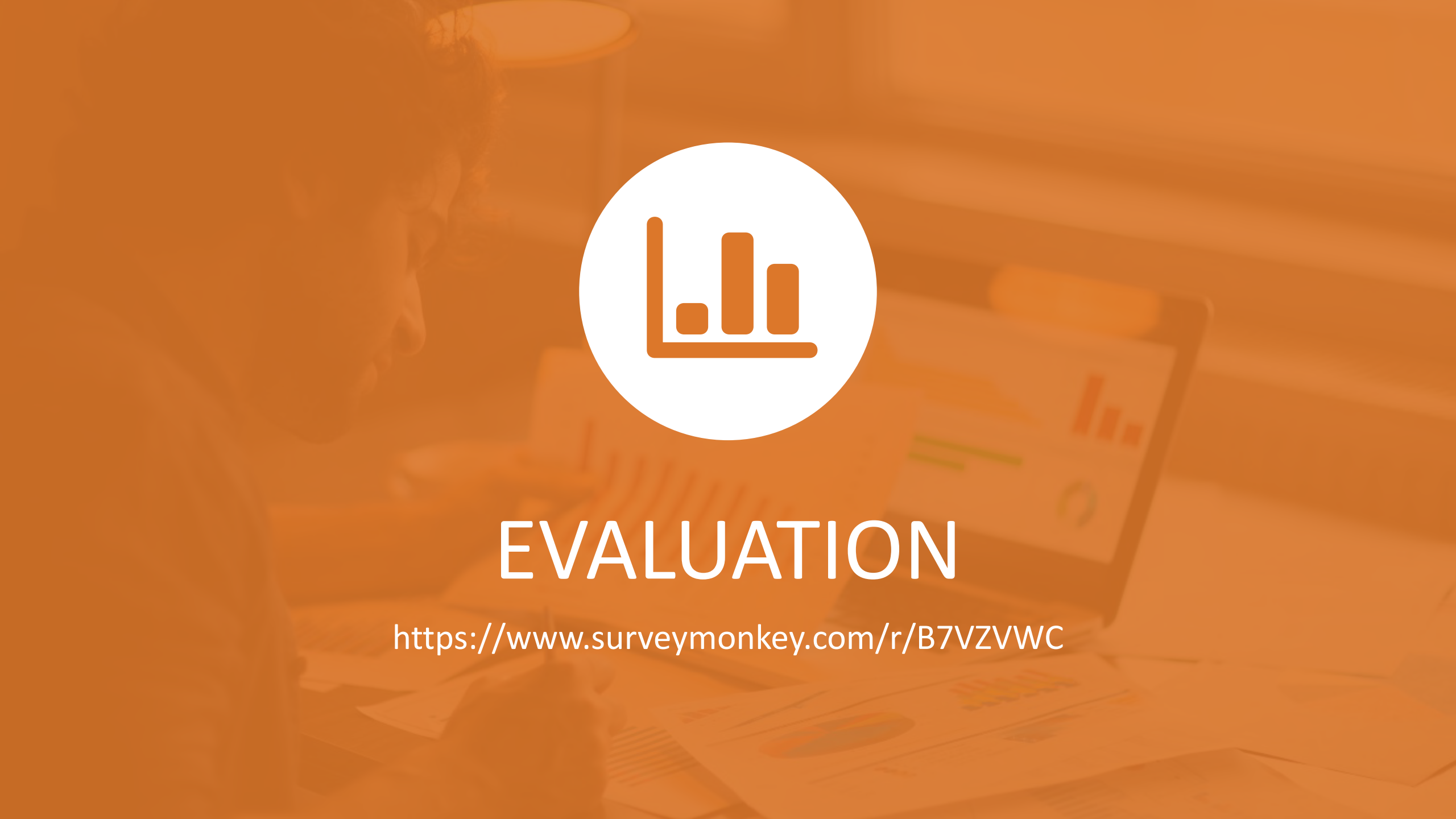
WHAT ADDITIONAL INFORMATION WOULD BE HELPFUL?

USE THE QUESTION AND ANSWER BOX

The box is located at the bottom of the screen

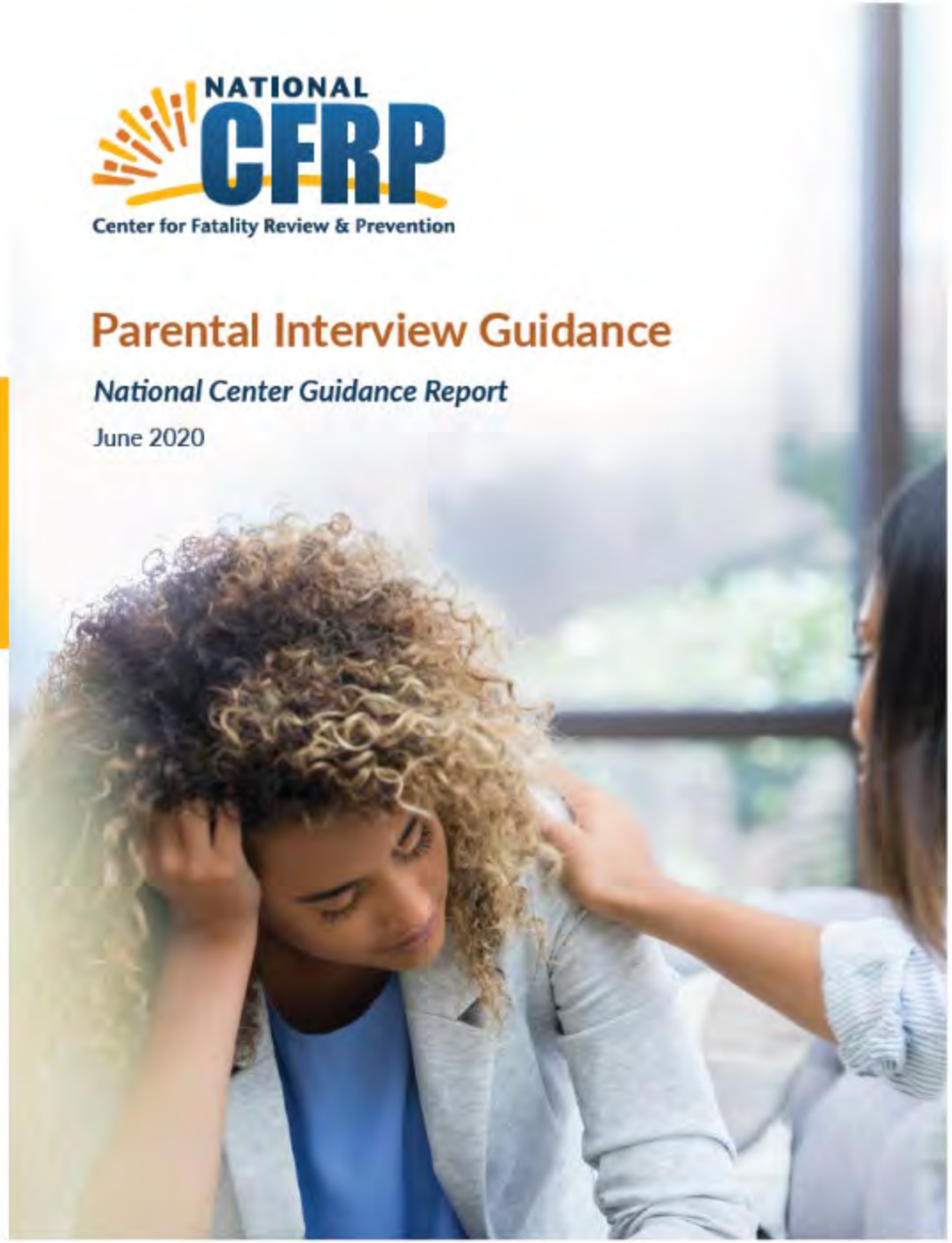
UNANWSERED QUESTIONS

All unanswered questions will be answered and posted on the National Center's website (URL: www.ncfrp.org).



EVALUATION

https://www.surveymonkey.com/r/B7VZVWC



". . . interviews are hard to get but they are most beneficial to understanding the death of the infant. Stories are data with a soul."

https://www.ncfrp.org/wp-content/uploads/FIMR_Parental_Interview_Guidance.pdf

National Center GUIDANCE REPORT

CONTACT INFORMATION

2395 Jolly Rd., Suite 120
Okemos, MI 48864

Phone: 800-656-2434

info@ncfrp.com

www.ncfrp.org


THANK YOU FOR YOUR TIME!
www.ncfrp.com