# Fetal Infant Mortality Review (FIMR) Project

# TOOLKIT FOR STATEWIDE PARTNERS 2017









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# What is Infant Mortality?

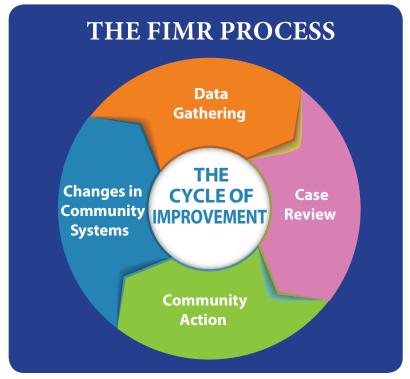
Infant mortality is the death of a baby before his or her first birthday. The infant mortality rate is the number of infant deaths for every 1,000 live births annually and is often used as an indicator to measure the health and well-being of a community. Circumstances that affect the health of a population can also impact the mortality rate of infants.

### What is a FIMR Project?

Fetal and Infant Mortality Review (FIMR) is an action-oriented community process that can address these circumstances that affect the health of a population. The overall goal of FIMR is to enhance the health and well-being of women, infants and families by improving the community resources and service delivery systems available to them. FIMR is an evidence-based program endorsed by the American College of Obstetricians and Gynecologists, the March of Dimes Birth Defects Foundation, and the federal Maternal and Child Health Bureau.

### FIMR Process – The Cycle of Improvement

The FIMR process brings together key members of the community to review information from individual cases of fetal and infant death. The group can identify factors associated with those deaths, determine if they represent system problems that require change, develop recommendations for change, assist in the implementation of change and verify community effects.

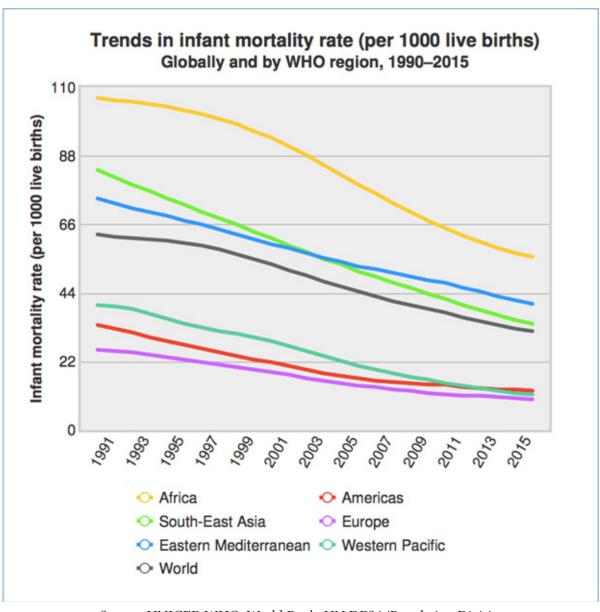


Source: FIMR Overview, Publication of the National Fetal and Infant Mortality Review Program, ACOG, 2014.

# **Infant Mortality**

Infant mortality rate is often used as an indicator to measure the health and well-being of a community or society. Many factors can affect infant mortality including medical complications, environmental conditions, and social barriers. On a global scale, the risk of an infant dying is higher in developing nations, however, developed countries and some geographic and racial groups may face similar infant mortality risk.

According to the World Health Organization (WHO) Global Health Observatory data, the risk of a child dying before completing the first year of life was highest in the WHO African Region (55 per 1000 live births), over five times higher than that in the WHO European Region (10 per 1000 live births). Globally, the infant mortality rate has decreased from an estimated rate of 63 deaths per 1000 live births in 1990 to 32 deaths per 1000 live births in 2015.



Source: UNICEF, WHO, World Bank, UN DESA/Population Division. Levels and Trends in Child Mortality 2015. UNICEF, 2015.

# Infant Mortality in the U.S.

### **United States Infant Mortality Rate: 6.1**

The United States infant mortality rate has been decreasing steadily, but trails behind compared to other countries. A report from the World Health Organization (WHO) ranked the U.S. 29th among the 35 other Organization for Economic Co-operation and Development (OECD) countries. There are only six other countries that have higher rates than the United States. In addition, the Central Intelligence Agency World Fact Book currently ranks the U.S. 169th among the 225 countries.

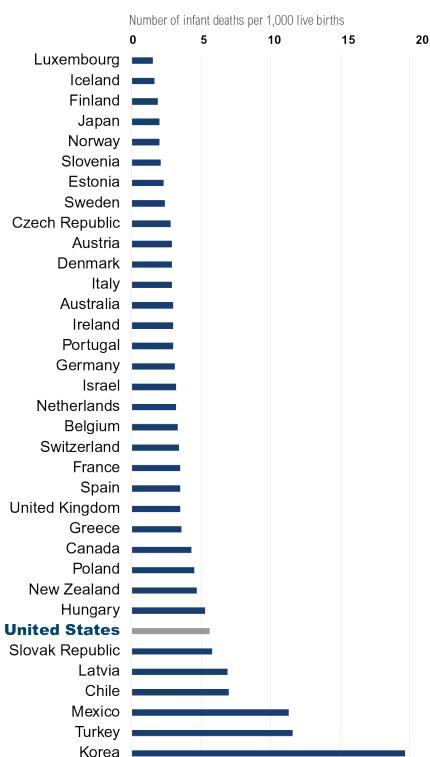
Nations may have differing definitions of a live birth making it hard to compare these numbers across countries. Because of these differences in the recording of live births, a report from the CDC analyzed rates excluding births at less than 24 weeks of gestation in order to make the numbers more comparable. This comparison put the U.S. infant mortality rate in 2010 at 4.2, still higher than most European countries.

The CDC report found the U.S. infant mortality rates for very preterm infants (24–31 weeks of gestation) compared favorably, however, the U.S. mortality rate for infants at 32–36 weeks was second-highest, and the rate for infants at 37 weeks of gestation or more was highest, among the countries studied.

According to the WHO, inequalities in survival rates include factors such as low-income settings, lack of feasible, cost-effective care, such as warmth, breastfeeding support, and basic care for infections and breathing difficulties. In high-income countries, such as the U.S., almost all of these very preterm babies survive.

### FIGURE 13

### **Infant Mortality Rate Among OECD Countries, 2015**

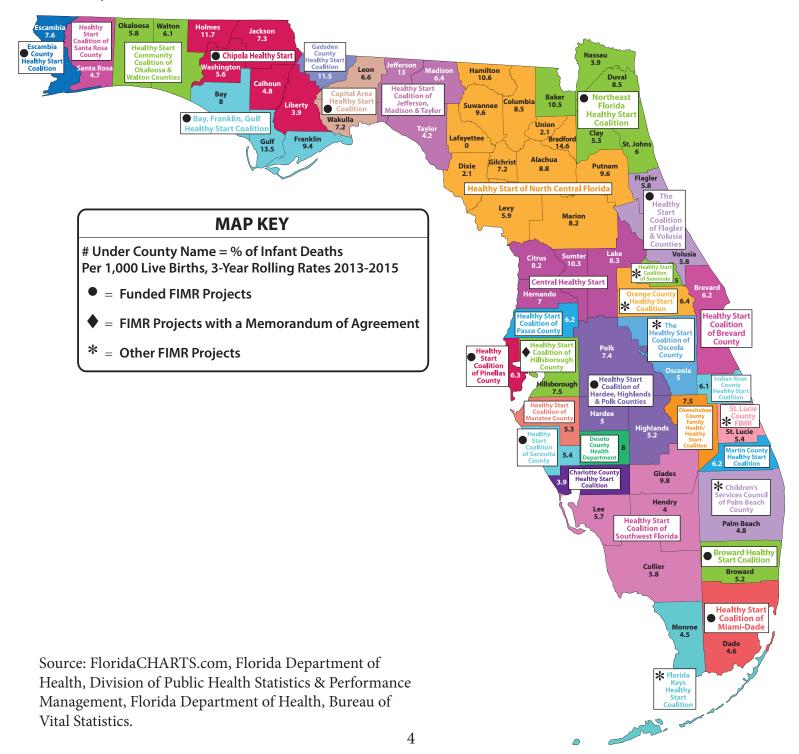


Source: http://www.americashealthrankings.org/learn/reports/2016-annual-report/comparison-with-other-nations. WHO. Infant mortality rate (probability of dying in the first year after birth per 1,000 live births) Mortality and global health estimates. 2015.

# **Infant Mortality in Florida**

### Florida Infant Mortality Rate: 6.1

The Florida Department of Health, Bureau of Vital Statistics, provides infant mortality rates by county. Florida CHARTS.com offers Florida rates as well as county specific information. Infant mortality rates in Florida have dropped since Healthy Start Coalitions began. The three-year rolling rate from 1992-1994 for Florida was 8.5, and the three-year rolling rate from 2013-2015 is 6.1. The map below shows each county, each Healthy Start Coalition and the 2013-2015 rolling infant mortality rates.

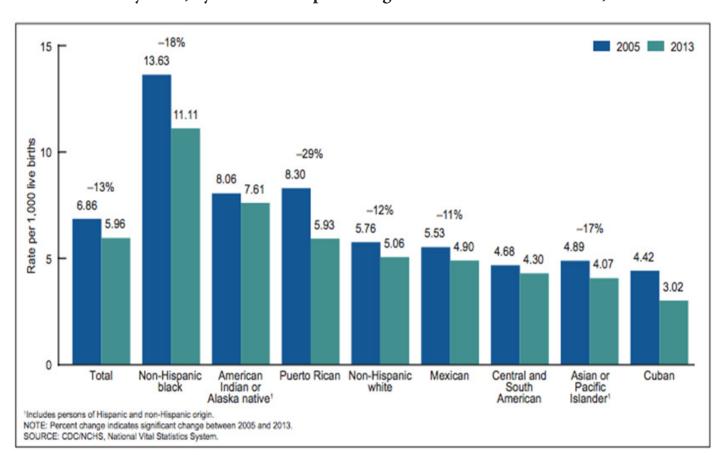


# **Health Disparity**

When a health outcome is greater or lesser between populations, there is health disparity. Race or ethnicity, sex, sexual identity, age, disability, socioeconomic status, and geographic location can all contribute to an individual's health and infant mortality. Racial and ethnic based health disparities have been occurring in the United States for centuries and these disparities in infant mortality continue to persist as well.

The figure below from the CDC National Vital Statistics Report depicts infant mortality rates, by race and Hispanic origin of mother in the United States during 2005 and 2013. There has been an overall decline with a 13% decrease in infant mortality rates among all the races and Hispanic origin of mother. Percent declines from 2005 to 2013 were largest among the Puerto Rican mothers with a 29% decrease in infant mortality rates. Non-Hispanic Black mothers had the second largest decline percentages with a 18% decrease in infant mortality rates. In 2005, the non-Hispanic black infant mortality rates were about 2.3 times the non-Hispanic white infant mortality rates were about 2.2 times the non-Hispanic white infant mortality rates.

### Infant mortality rates, by race and Hispanic origin of mother: United States, 2005 and 2013



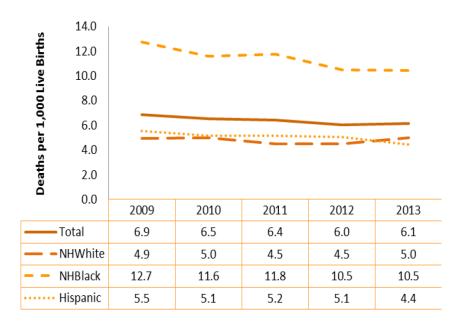
Source: Matthews, TJ, M.S., et. al. Infant Mortality Statistics from the 2013 Period Linked Birth/Infant Death Data Set. Divisionof Vital Statistics. National Vital Statistics Report, Vol 64, No. 9, August 6, 2015.

# **Health Disparity**

According to the Florida Department of Health, the overall infant mortality rate declined from 6.9 infant deaths per 1,000 live births in 2009 to 6.1 infant deaths per 1,000 live births in 2013. During the same time period, non-Hispanic White infant mortality stayed relatively flat with an infant mortality rte of 4.9 infant deaths per 1,000 live births in 2009 and 5.0 infant deaths per 1,000 live births in 2013. However, between 2009 and 2012, non-Hispanic Black infant mortality rate declined significantly from 12.7 to a historic low of 10.5 infant deaths per 1,000 live births and remained at the same infant mortality rate in 2013.

With Florida's recent declines in non-Hispanic Black infant mortality, the infant mortality disparity between non-Hispanic Black and non-Hispanic White infants decreased from a ratio of 2.6:1 in 2009 to 2.1:1 in 2013. Despite this decline in this disparity, non-Hispanic Black infant mortality rates have consistently remained more than two times higher than non-Hispanic White and Hispanic infant mortality rates. Disparities in infant mortality are also present and consistent at the national level.

Figure 1. Infant Mortality Rates by Race/Ethnicity, Florida 2009-2013



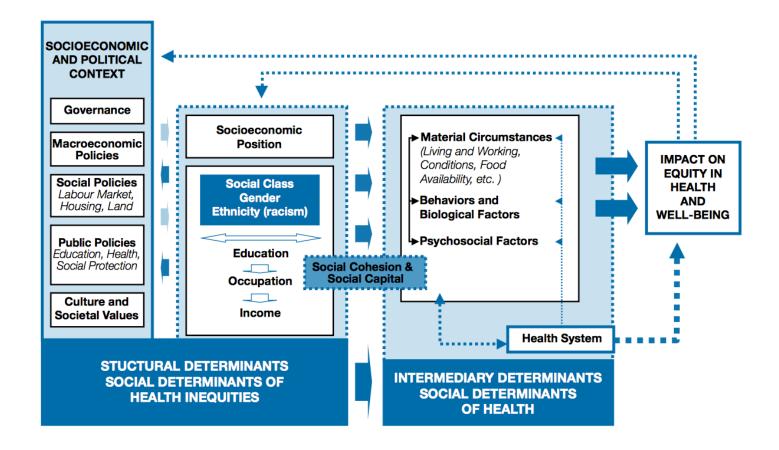
Source: Florida Department of Health Vital Statistics Tables

Source: Black-White Disparities in Infant Mortality. file://hsc-fs/User%20Folders/jreynolds/Desktop/Design%20 Files/FIMR%20Toolkit/2017/3\_\_2015-title-v-brief-bw-disparities-in-infant-mortality-final-11-06-2014.pdf.

# **Health Disparity**

According to the WHO, social determinants of health are the circumstances in which people are born, grow up, live work, and age, and the systems put in place to deal with illness. These circumstances are in turn shaped by a wider set of forces: economics, social policies, and politics. These social determinants of health affect pregnancy and childbirth including, but not limited to, family income, access to care, educational status, and poverty. In addition, many social factors can influence maternal health including pregnancy outcomes and infant health.

A journal article from the International Journal of Environmental Research and Public Health, The Social Determinants of Infant Mortality and Birth Outcomes in Western Developed Nations: A Cross-Country Systematic Review, examines the social determinants that affect the variations in infant mortality and birth outcomes across and within countries. The study found that individual level intermediary determinants, including behavioral, biological, and psychosocial factors, play a significant role in inequities in infant mortality and birth outcomes. Quality of health care and access to health care also affect infant mortality and birth outcomes, but play a lesser role compared to other determinants of health.



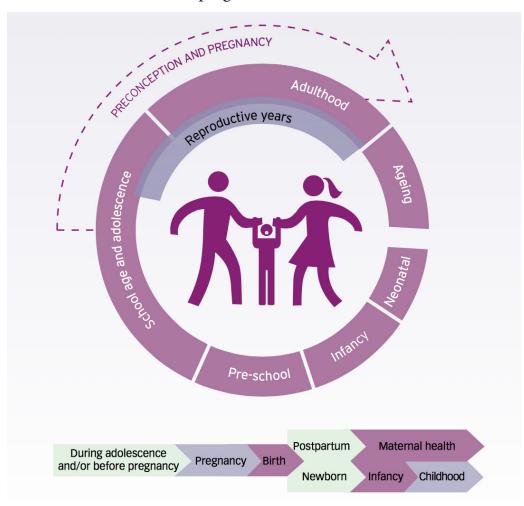
Source: The National Academies Press. Frameworks for Addressing the Social Determinants of Health.

# **Interconception Care Curriculum**

Interconception Care (ICC), also known as preconception health, refers to the health of women and men during their reproductive years. Interconception care is the medical care a woman or man receives from a doctor or other health professional that focuses on care that increases the chance of having a healthy baby. The ICC framework is a cornerstone of infant mortality prevention. The framework focuses on reducing individual, behavioral, and environmental factors that may contribute to poor maternal and child outcomes.

Interconception care includes a framework that women and men can do before, after, and between pregnancies to increase the chances of having a healthy baby and reducing child and maternal mortality. According to the WHO, interconception health has a wide range of benefits including prevention of birth defects, still births, vertical transmission of HIV/STIs, neonatal infections, and complications during pregnancy.

The Florida Association of Healthy Start Coalitions recently produced an Interconception Care Curriculum as a component of the FIMR toolkit to provide education to families across Florida to improve health before, after and between pregnancies.



Source: World Health Organization, WHO. Preconception Care: Maximizing the Gains for Maternal and Child Health.

# FIMR Framework

The FIMR process examines fetal and infant deaths, determines preventability, and engages communities to take action by bringing together two multi-disciplinary community teams. The Case Review Team (CRT) examines circumstances surrounding an infant death to identify system gaps and make recommendations, while the Community Action Team (CAT) takes those recommendations to make the changes needed in the community's service delivery system.

### FIMR Sequence for Case Review and Community Action



### FIMR Leadership

Many FIMR projects across the country are implemented by local health departments and a few are sponsored by local hospitals or regional perinatal centers. In the state of Florida, FIMR projects are implemented by Healthy Start Coalitions. Coalitions have the advantage of partnership with all community organizations and individuals with an interest in maternal and child health. There are currently 11 funded FIMR projects in Florida and a few others who are unfunded. These FIMR projects and local contacts are listed in the FIMR Projects section.

### Case Selection and Data Collection

Some FIMR projects review all fetal and infant death cases in their area, others randomly select cases, and many select cases based on Perinatal Periods of Risk (PPOR). Often cases are selected from areas with higher disparities in an effort to address contributing factors. Cases are reviewed to determine the family's situation, what happened from all perspectives, services the family received, and any events since loss. The family interview is the hallmark of the FIMR process because it obtains their perspective.

# **FIMR Framework**

### FIMR information is collected from:

- Family interviews
- Birth and death certificates with a Data Use Agreement with the Florida Department of Health's Bureau of Vital Statistics
- Autopsy reports
- Hospital records including labor and delivery, newborn, neonatal and pediatric care units, emergency room
- Outpatient records including prenatal, pediatric well baby and sick baby visits
- Others services such as WIC, Healthy Start services, Healthy Families, DCF, arrest records

NFIMR has data collection forms and software to generate a summary of each case.

### Importance of Confidentiality to the FIMR Framework

Confidentiality is critical to the FIMR framework. All cases are de-identified in order to preserve the privacy of all parties. The goal of the FIMR process is to determine any underlying systemic issues, not to place blame. All Community Review Team members sign a pledge of confidentiality that prohibits them from discussing specifics outside the meeting.

In the State of Florida, information obtained through the FIMR process is confidential (381.0055. FS) and FIMR Committee members are given immunity (766.101.FS). Additionally, HIPAA allows for release of information without consent for public health investigation and there is a letter from Dr. Celeste Philip, Florida Surgeon General and Secretary of Health, on confidentiality.

### Case Review Team

The Case Review Team (CRT) should include consumers as well as professionals and agencies that provide services or community resources for families in the community. This may include obstetricians, pediatricians, social workers, nurse-midwifes, hospital and community nurses, coroners or medical examiners, interviewers, abstractors, community outreach workers, mental health counselors, public health nutritionists and others important to the individual reviews.

# **FIMR Framework**

### Roles of the Case Review Team

- 1. Information processor of the FIMR program
- 2. Review and analyze the information collected in interviews and medical data abstractions
- 3. Summarize findings and create recommendations to improve the community's service delivery systems and community resources

Source: FIMR Overview for new CRT and/or CAT members, Publication of the National Fetal and Infant Mortality Review Program, ACOG, 2014.

### **Community Action Team**

The Community Action Team (CAT) should include individuals with political drive and fiscal resources to affect large-scale system change and members who have community perspective on how best to create the desired change in the community. This may include community leaders representing government, consumers, key institutions, and health & human service organizations.

### Roles of the Community Action Team

- 1. Develop new and creative solutions to improve services and resources for families from the recommendations made by the case review team
- 2. Enhance the credibility and visibility of issues related to parents, infants and families within the broader community by informing the community about the need for these actions through presentations, media events and written reports
- 3. Work with the community to implement interventions to improve services and resources
- 4. Determine if the needs of the community are changing over time and decide which interventions should be added or altered to meet the needs
- 5. Safeguard successful FIMR systems changes from being discontinued in the future

Source: FIMR Overview for new CRT and/or CAT members, Publication of the National Fetal and Infant Mortality Review Program, ACOG, 2014.

# **Building an Infant Mortality Taskforce**

### **Beginning Steps**

Setting up FIMR usually takes about six to eight months before becoming fully functional. Community engagement plays a huge role in the establishment of the FIMR process. Everyone in the community plays a vital role in planning the FIMR program. Members of the planning group usually include staff of the organization or agency implementing FIMR, but can also include community members, professional leaders, and volunteers. Planning needs to include the FIMR initiation tasks below, however the order in which they are addressed may vary based on each program. Some communities may have already accomplished multiple tasks listed before the planning stage.

### **FIMR Initiation Tasks**

- Identify the community/geographic area of focus
- Identify community resources/assets
- Determine the type and number of cases to be reviewed
- Determine FIMR's relationship to other types of death review
- Identify and address legal and institutional issues related to the review
- Establish systems to maintain confidentiality and anonymity
- Establish a system to identify cases
- Select data collection and processing methods
- Identify costs and funding sources
- Designate the program director and coordinator
- Formalize policies and procedures
- Build in opportunities for initial and ongoing training

Source: FIMR Manual, Publication of the National Fetal and Infant Mortality Review Program, 2006.

# **Building an Infant Mortality Task Force**

### Designating the Program Director and Program Coordinator

In many cases, the person in the sponsoring agency or organization will take the role of the FIMR program director. This person may or may not be involved in the planning group. To be most effective, the program director should have influence in the sponsoring agency or organization and be able to work alongside the head of the sponsoring organization. The FIMR program director assumes responsibility for building and maintaining relationships with community members and oversees the planning process. The program director's major roles include hiring FIMR staff, supervising staff training, chairing all team meetings, developing grant proposals and publishing annual reports with assistance of the FIMR coordinator.

The FIMR coordinator will be designated by the lead organization or agency. Coordinator tasks include preparing and supervising the development of case summaries that the CRT reviews, scheduling meetings for the CRT and CAT, and drafting the meeting minutes. The role may include conducting home interviews and serving as a liaison to the other community interviewers. The coordinator should not be expected to fulfill the FIMR program director's role at any time.

### Selecting FIMR Team Members

The team members selected for the FIMR project should include individuals that reflect diversity, influence, commitment and consumer participation. The Community Participation FIMR Member checklist can be utilized when selecting FIMR members to participate in the FIMR process.

### Case Review Team and Community Action Team Member Selection

The CRT members should be comprised of representatives of consumers, professionals, and agencies/organizations that provide services or resources for the community. Other representatives may include, but are not limited to, minority rights advocates, Medicaid supervisors, WIC program nutritionists, family planning providers and members from the local SIDS community.

There are two types of members that compose the CAT, individuals with political will and fiscal resources and individuals with a strong desire to ensure change in the community. The CAT will have individuals and organizations to collaborate on policy development. In addition, some of the members may be on both teams, CRT and CAT, and often rotate between the two teams. After CAT and CRT members have been selected, the next step is to plan meetings and build local support.

# **Building an Infant Mortality Task Force**

### Fetal Infant Mortality Review Member Checklist

<ul> <li>Key Community Leaders</li> <li>Mayor, County Executive</li> <li>Religious Leaders</li> <li>Business Leaders, Chamber of Commerce</li> <li>Civic and Fraternal Groups, such as Kiwanis, Junior League, etc.</li> <li>Educators</li> <li>Others</li> </ul>	Health Care Providers  Obstetrician/Gynecologist Pediatrician/Maternal-Fetal Specialist Obstetric/Pediatric Nurse Social Workers State and/or County Medical Society Hospital Administrator MCO/HMO Representative EMS Others
<ul> <li>Public Health Providers</li> <li>City and/or County Health Departments</li> <li>Medicaid</li> <li>Medical Examiner</li> <li>WIC Supervisor</li> <li>Outreach Workers</li> <li>Family Planning Representatives</li> <li>Others</li> </ul>	<ul> <li>Human Service Providers</li> <li>Child Welfare Agencies</li> <li>Substance Abuse Services</li> <li>Mental Health Services</li> <li>Department of Corrections</li> <li>Housing Authority</li> <li>Transportation Authority</li> <li>Others</li> </ul>
<ul> <li>Consumer and Advocacy Groups</li> <li>March of Dimes</li> <li>Healthy Mothers/Healthy Babies</li> <li>MCH Coalitions</li> <li>Perinatal Infant Grief Professionals</li> <li>Bereaved Family and Other Consumer Representatives</li> </ul>	<ul> <li>Consumer and Advocacy Groups</li> <li>Family Support Groups (SIDS) Alliance, Compassionate Friends, etc.</li> <li>Minority Rights Groups</li> <li>Women's Rights Groups</li> <li>Union and Workers Rights Groups</li> <li>Housing and Tenants Rights Groups</li> <li>Others</li> </ul>

Source: National Fetal Infant Mortality Review Program. A Guide for Communities: Fetal Infant Mortality Review Manual. 2nd Edition. Adapted from: Striffler N, Coughlin, PA, Magrab, PR. Communities can workbook series: developing collaborative services for children. Washington, DC: Georgetown University Child Development Center. 1994:3 and Phelps, A. Florida Department of Health.

# **Conducting Home Interviews**

### **Conducting Maternal Interviews**

Maternal interviews are conducted to obtain information from the mother's perspective of her infant's death. The interviews allow the mother to describe her experiences from her perspective, which is not often collected in health records. Home interviews are extremely important because it provides the families with substance to the loss and helps with the process.

In addition, the mother is often times the one being interviewed. For sensitivity and confidentiality purposes, the mother may wish to conduct the interview in private without the family being present. There are cases in which the father participates in the interview process as well. It is the job of the interviewer to make decisions and make judgment calls regarding who is present during the time of the interview.

### The Interviewer

Many home interviewers are volunteers that have a thirst for the challenge of working with bereaved mothers and families. Interviewers are often health professionals, but are not limited to, trained social workers, nurses, public health nurses, and community health workers. These individuals usually have significant experience in bereavement counseling and maternal and child health. The interviewer should have personal characteristics that provide a caring and sincere environment for the families.

The maternal interviewer provides a case summary of the interview which is presented to the FIMR review team. The interviewer provides emotional support for bereaved mothers, but the role is not to provide professional counseling. During this time, the interviewer can provide the mother with resources such as professional counselors, local SIDS counselors, and peer support programs. This process provides the mother and her family with continuous support.

# **Conducting Home Interviews**

### **Interviewer Training**

Interviewer training is a vital part of the interview process. Training sessions should include role-playing exercises. Training areas should include information about how to:

- Maintain confidentiality
- Listen and record
- Prepare and conduct the interview
- Handle difficult situations
- Recognize personal safety situations
- Track, contact and engage families
- Ask open-ended and closed-ended questions
- Conduct a home assessment and standardized interview

### **Interview Ethics**

During this difficult time, it is important that the families be able to give informed consent and should not be pressured into participation. The bereaved families should be given a token of appreciation such as coupons to a local grocery store or flowers.

There may be times when there are interview refusals so it is important to be mindful of the needs of the families and the mother when trying to conduct an interview. If there is a refusal, the home interviewer may explain the importance of the interviews, explain the information gathered from the interview, ask the mother a few questions on a trial basis, or offer to call back at a later time.

Interviewing is not recommended when there are legal concerns and ethical considerations. Some possible situations include mothers that are in litigation regarding the infant's death and mothers under investigation or imprisoned regarding the infant's death.

### **Annual Baby Shower**

Educational events for expecting families involving community partners.

- Healthy Start Coalition of Orange County
- Healthy Start Coalition of Sarasota County
- Healthy Start Coalition of Seminole County

### Bereavement Package

A package for families who have suffered a fetal or infant loss containing a sympathy card, grief booklet and Perinatal Bereavement Resources.

- Healthy Start Coalition of Miami-Dade
- Escambia County Healthy Start Coalition
- Capital Area Healthy Start Coalition

### Black Infant Health Practice Initiative (BIHPI)

This statewide practice collaborative to address the issue of racial disparity in infant deaths in Florida.

- Broward Healthy Start Coalition
- Healthy Start Coalition of Hillsborough County
- REACHUP, Inc.
- Healthy Start Coalition of Miami-Dade
- Northeast Florida Healthy Start Coalition
- Healthy Start of North Central Florida Coalition
- Healthy Start Coalition of Orange County
- Gadsden County Healthy Start Coalition



### A Community Voice: Taking it to the People

A training offered to local community representatives by taking culturally relevant perinatal information directly to the people whom African-American women are most likely to trust and training them to be lay health advisors.

• Healthy Start Coalition of Miami-Dade

### **Grief Toolkits**

A toolkit to help providers support families that have suffered a fetal or infant loss.

• Healthy Start Coalition of Flagler and Volusia



### **Infant Mortality Task Forces**

A taskforce created to find ways to decrease the infant mortality rate and educate the public on the matter.

- Northeast Florida Healthy Start Coalition
- Escambia County Healthy Start Coalition
- Saint Lucie County Fetal & Infant Mortality Review

### Interconception Care Curriculum

A comprehensive women's health curriculum to improve health among women before or between pregnancies.

All Healthy Start Coalition's to be trained in August 2017

### Jasmine Project

A national Healthy Start program focused on promoting healthy outcomes for Black infants, pregnant women and new mothers.

• Healthy Start Coalition of Miami-Dade

### Last Rights for Little Ones

A program that offers financial assistance towards funeral costs to families in need that have a fetal or infant loss.

• Bay, Franklin, Gulf Healthy Start Coalition

### LifeSong Project

A positive faith-based initiative to reduce infant mortality in African American communities.

• Healthy Start Coalition of Flagler and Volusia

### **Memory Boxes**

A program that creates memory boxes for local hospitals to supply families suffering from a fetal and infant loss.

- Bay, Franklin, Gulf Healthy Start Coalition
- Capital Area Healthy Start Coalition

### Project INFORM and Project Impact

Publication to review infant, neonatal and fetal outcomes related to mortality.

- Healthy Start Coalition of Flagler and Volusia
- Northeast Florida Healthy Start Coalition

### Safe Baby Program

Safe Baby teaches parents how to choose a safe caregiver, prevent Shaken Baby Syndrome, and promote safe sleep to prevent infant mortality.

• Healthy Start Coalition of Hillsborough County

# SBSAFE" BBABY Healthy Start Coalition of Hillsborough County

### Save My Life Program

Prenatal and postpartum support for African-American families. Topics include childbirth education, breastfeeding education and breastfeeding help once the baby is born.

Healthy Start Coalition of Sarasota County



### Save Our Babies

Outreach and education program reaching non-traditional sites such as hair salons, churches and child care centers to inform the African American community that black babies are dying.

Healthy Start Coalition of Orange County

### Save Our Babies Toolkit

A toolkit to help case managers, doulas, fatherhood/male involvement facilitators and other community providers and BIHPI Community Action team members to teach families how to keep their infants and toddlers safe (Shaken Baby Syndrome, Choosing a Safe Caregiver, Safe Sleep for Baby and a Safe Environment for Baby). A DVD featuring program participants, staff, community members, providers and other stakeholders is included.

- REACHUP, Inc.
- Healthy Start Coalition of Hillsborough

### Walk to Remember

An event dedicated to babies who die each year.

- Bay, Franklin, Gulf Healthy Start Coalition
- Capital Area Healthy Start Coalition
- Broward Healthy Start Coalition

### When a Baby Dies: Sensitivity Seminar

This professional development seminar provides a general overview of the grief process and highlights the uniqueness of perinatal loss. Participants gain an increased awareness of families' needs after the loss of a baby and learn ways to assist families through the grief process. Local and national perinatal bereavement resources are reviewed. This program is offered to hospitals, organizations and community professionals who work with women of childbearing age. Continuing education made available for nurses and mental health professionals.

Healthy Start Coalition of Miami-Dade

### National Fetal Infant Mortality Review Program

The National Fetal and Infant Mortality Review (NFIMR) Program is a collaborative effort between the federal Maternal and Child Health Bureau and the American College of Obstetricians and Gynecologists. NFIMR develops publications, provides information and technical assistance, and facilitates opportunities for discussion among FIMR projects working in communities around the country. Assistance from NFIMR is available to individuals and communities interested in starting new FIMR projects, as well as established programs.

NFIMR Website http://www.nfimr.org/

FIMR Overview http://www.nfimr.org/site/assets/docs/NFIMR%20%20Overview.pdf

Description of FIMR http://www.nfimr.org/publications\_and\_resources/Description\_of\_NFIMR

Orientation Form for New Members: http://www.nfimr.org/publications\_and\_resources/Orientation\_form\_for\_new\_team members

### Evaluation of Fetal and Infant Mortality Review (FIMR) Programs Nationwide

Study shows that FIMR programs contribute significantly to improvements in systems of health care for pregnant women and infants through enhanced public health activities in communities. Communities with FIMRs were more likely to report activities in the areas of data assessment and analysis, client services and access, quality improvement for systems of care, partnerships and collaboration, population advocacy and policy development, as well as enhancement of the health workforce.

http://www.jhsph.edu/research/centers-and-institutes/womens-and-childrens-health-policy-center/projects/fimr.html

### **Infant Mortality Data**

World Health Organization http://www.who.int/gho/child\_health/mortality/neonatal\_infant\_text/en/

International Comparisons of Infant Mortality and Related Factors: United States and Europe, 2010 http://www.cdc.gov/nchs/data/nvsr/nvsr63/nvsr63\_05.pdf

March of Dimes Peristats

http://www.marchofdimes.org/peristats/ViewSubtopic.aspx?reg=99&top=6&stop=94&lev=1&slev=1&obj=1&dv=ms

CDC National Vital Statistics System http://www.cdc.gov/nchs/VitalStats.htm

CDC Pregnancy Risk Assessment Monitoring System http://www.cdc.gov/prams/index.htm

Florida Charts www.floridacharts.com/charts/DataViewer/InfantDeathViewer/InfantDeathViewer.aspx?indNumber=0053

Florida Department of Children and Families Child Fatality Prevention Website http://www.dcf.state.fl.us/childfatality/

### Health Equity

The National Standards for Culturally and Linguistically Appropriate Services in Health and Health Care (the National CLAS Standards) https://www.thinkculturalhealth.hhs.gov/Content/clas.asp

Healthy People 2020 https://www.healthypeople.gov/

Robert Wood Johnson Foundation to Build a Healthier America http://www.rwjf.org/en/about-rwjf.html

### Family Bereavement Resources

A Place to Remember http://www.aplacetoremember.com/

Center for Loss in Multiple Birth (CLIMB) http://www.climb-support.org/

Centering Corporation http://www.centering.org/

The CJ Foundation for SIDS http://www.cjsids.com/

Compassion Books http://www.compassionbooks.com/

The Compassionate Friends http://www.compassionatefriends.org/

First Candle http://www.firstcandle.org/grieving-families/

GriefNet http://griefnet.org/

March of Dimes http://www.marchofdimes.org/loss-grief.aspx#

MISS (Mothers in Sympathy and Support) Foundation http://www.missfoundation.org/

SHARE Pregnancy and Infant Loss Support, Inc. http://nationalshare.org/

Sudden Infant Death Syndrome Network http://sids-network.org

### Confidentiality

The Fetal and Infant Mortality Review Process: The HIPAA Privacy Regulations http://www.nfimr.org/site/assets/docs/NFIMRHIPAAPrivacyRegs.pdf
Dr. Celeste Philip, MD, MPH, Florida Surgeon General & Secretary of Health, Letter Confidentiality Protocol

### State Infant Mortality (SIM) Toolkit

This toolkit offers assistance with the analysis and interpretation of available perinatal-related data. It provides a standardized approach to the infant mortality assessment process to help those concerned with infant mortality programs and data in their states, counties, urban areas, tribal regions, or other population-based areas to identify needs and tailor programs aimed at improving maternal, child, and infant health.

http://www.amchp.org/programsandtopics/data-assessment/InfantMortalityToolkit/Pages/default.aspx

### **FIMR Toolkits**

NFIMR Manual http://www.nfimr.org/site/assets/docs/FIMR%20Manual.pdf

NFIMR Guide for Home Interviewers http://www.nfimr.org/site/assets/docs/Home%20Interviewers%20Guide.pdf

Voices from the Community: Cross Cultural Expressions of Grief at the Loss of an Infant http://content.yudu.com/Library/A1x08u/VoicesFromTheCommuni/resources/index.htm?refer-rerUrl=http://free.yudu.com/item/details/532382/Voices-From-The-Community

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Saint Lucie County Funded by the Allegany Franciscan Ministries to the Florida Department of Health in Saint Lucie County (772) 462-3946

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