



The death of a baby is like a stone cast into the stillness of a quiet pool;  
the concentric ripples of despair sweep out in all directions, affecting many, many people.

*John DeFrain*

*American author and university professor*

# Douglas County Health Department Fetal and Infant Mortality Review (FIMR) 2014 Annual Report



# Douglas County 2014 Annual FIMR Report

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*"I've had the honor of serving on the FIMR CRT for some years now. The in-depth study of each of these tragedies has been tremendously useful in helping us truly understand risk factors and help attempt to fashion recommendations to decrease losses. The ability and input of multiple disciplines markedly adds to the richness of the discussions. I feel that the information that FIMR provides the Health Department is vitally important to the crafting of public policy."*

**Howard Needelman, MD**

Associate Professor of Pediatrics UNMC

Board certified in Pediatrics/Neonatal Perinatal Medicine/Developmental Behavioral Pediatrics

# Douglas County 2014 Annual FIMR Report

## Overview

Infant mortality rate has **increased** from **4.2** (2012) to **7.0** (2013)

Source: 2013 Douglas County population-based infant only data

**Data Gathering**

African-American mothers experience a **1/3 higher** infant mortality rate than caucasian mothers

**9.9** compared to **7.5**

Source: 2013 Douglas County population-based infant only data

**Case Review**

Hispanic mothers **(4.8)** Have a lower infant mortality rate than caucasian mothers **(7.5)**

Source: 2013 Douglas County population-based infant only data

**Community Action**

**Top 4 single causes of infant mortality**

1. Congenital Anomalies
2. Maternal Complications of Pregnancy
3. SIDS/SUID
4. Prematurity

Source: 2013 Douglas County Vital Statistics information using ICD-10 codes.

**Changes in Community System**

# Douglas County 2014 Annual FIMR Report

## Highlights of the Community Plan

### Preconception Health

**Goal:** To provide access to information regarding the Life Course Model to Douglas County families to ensure future positive birth outcomes across generations.

Utilizing Life Course Theory, preconception health messaging continued to be interfaced with youth development using the TOP® Curriculum, a broad-based asset building curriculum for teens.

- In 2014, the TOP® Curriculum was expanded to 2 new sites for a total of 4 community sites.
- With the assistance of trained facilitators, teens continued to learn, explore & practice life skills on a weekly basis. Topics included teenage pregnancy, STIs, romantic relationships, gender roles, dealing with pressure situations & reproductive growth and development.
- Participating teens completed a total of 483 community service hours for the 2013-2014 school year.
- Program sustainability was obtained by a “train the trainer” method where a certified DCHD staff TOP® facilitator trained additional facilitators on the TOP® program.

### Safe Sleep

**Goal:** Increase awareness and access to resources to promote safe sleep practices among care givers.

#### Educational efforts

- Trends show that SUID (sudden unexpected infant death) rates are increasing at national, state and local levels due to overlay and accidental suffocation. DCHD is currently working with BBC partners to determine a feasible community-wide educational campaign to address the rising SUID rates in Douglas County.
- In 2014, 88 SIDS/back to sleep education visits were completed by home visitors with the Maternal, Infant and Early Childhood Home Visiting (MIECHV) Program in Douglas County. MIECHV is an evidence-based home visitation program which targets Douglas County women 19 years of age and older who are pregnant or 3 months post-partum and are at or below 150% of the federal poverty level.

### Prenatal Care

**Goal:** Intergenerational and multicultural education focused on preterm labor and healthy pregnancy signs shall occur through medical, social work and other community providers.

In 2014, a train the trainer session was developed by the Prenatal Care Affinity Group, in partnership with the Nebraska March of Dimes, to promote preterm labor education. Home visitation providers were targeted for this half day training and training objectives included:

- define the impact of preterm birth
- identify at least 3 signs of preterm labor
- cite at least 2 tools a provider can use to empower clients

Five agencies with a total of 12 staff members attended the training, representing a variety of disciplines (social workers, nurses, educators and peer support workers). A major outcome of the training was a toolkit built by the participants for use during home visitation.

**Goal:** To create a coordinated community response system to perinatal depression which includes a tiered multi-disciplinary response for appropriate interventions.

In an attempt to identify the extent of perinatal depression in our community, the Douglas County MIECHV Program was identified as one viable source to assess change in pregnant women within Douglas County. The Douglas County MIECHV Program assessed over 131 families since November, 2013, and **has completed 156 maternal depression screens** during that time. The home visitors provide ongoing education on perinatal depression during pregnancy and post-pregnancy visits, making appropriate mental health referrals when there is an elevated screening score, and/or the mother is exhibiting symptoms of perinatal depression.

# Background

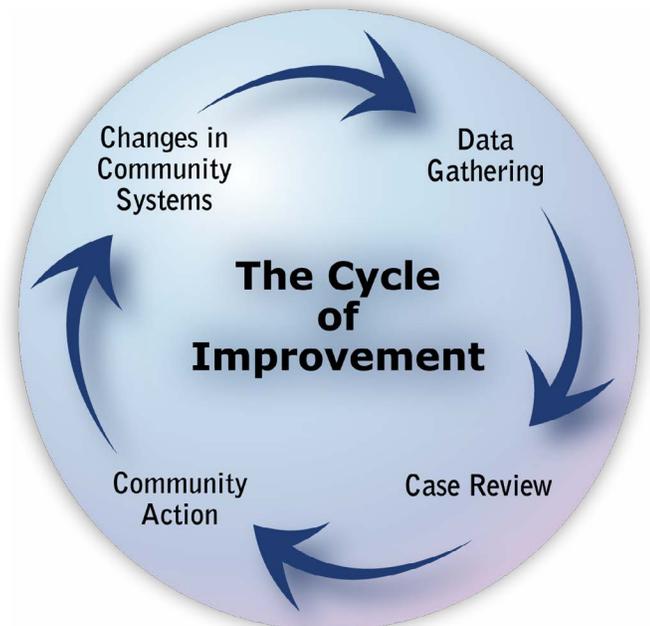
Infant mortality serves as a measure of a community's general health status as well as its social and economic well-being. Even though the U.S. infant mortality rate has steadily decreased over the last decade, racial and ethnic disparities continue to persist.<sup>1</sup> Fetal and Infant Mortality Review (FIMR) is a best practice model aimed at improving systems and resources for women, infants and families of all races and ethnicities.

A national evaluation of FIMR has systematically documented that the presence of FIMR appears to significantly improve a community's performance of public health functions as well as enhance the existing perinatal care system's goals, components and communication mechanisms.<sup>2</sup> In addition, the focus of FIMR on systems of care and identifying gaps in services results in action being taken in a way that interpretation of vital statistics data alone does not necessarily promote.

In 2006, a 40 agency coalition known as the Baby Blossoms Collaborative (BBC), made up of interested community members-leaders, elected officials, providers, agencies, advocates and consumers initiated the FIMR process to address feto-infant mortality in Douglas County. A community team convened to examine confidential, de-identified cases of feto-infant deaths, with a goal of understanding how a wide array of local, social, economic, public health, educational, environmental and safety issues relate to the tragedy of feto-infant loss. In 2013, the community team, also known as case review team (CRT), incorporated life course model (LCM) into the FIMR process. This model integration added a philosophy of generational health to the case review process while prompting the CRT to identify protective factors found in infant mortality cases. In addition, risk factors were categorized as social, economic or environmental determinants of health, with a goal of eliminating the health disparity. Having gained a comprehensive understanding of contributing factors to infant mortality from data analysis and case reviews, the Baby Blossoms Collaborative worked together to develop an ongoing community action plan to improve services for mothers and families in Douglas County.

The Douglas County Health Department (DCHD) uses a nationally recognized best practice model known as the **FIMR Cycle of Improvement**. Key steps of the FIMR process include:

- Gathering information about the feto-infant death from medical and public health records.
- Conducting voluntary interviews with the mother of loss by a Public Health Nurse (PHN) who is trained in grief counseling, assessment and community resources.
- Utilizing the Case Review Team (a diverse group of medical and community experts) to review summaries of case information, identify risk and protective factors present in the case, and make recommendations for community change.
- Employing the Community Action Team/ BBC membership through the review of CRT recommendations, to prioritize identified issues and design/ implement interventions to improve service systems and resources.



<sup>1</sup> American College of Obstetricians & Gynecologists (2008). Fetal and Infant Mortality Review Manual: A Guide for Communities, 2nd Ed., *NFIMR*, 3-5.

<sup>2</sup> Ibid.

*“My biggest problem right now remains grief.”*

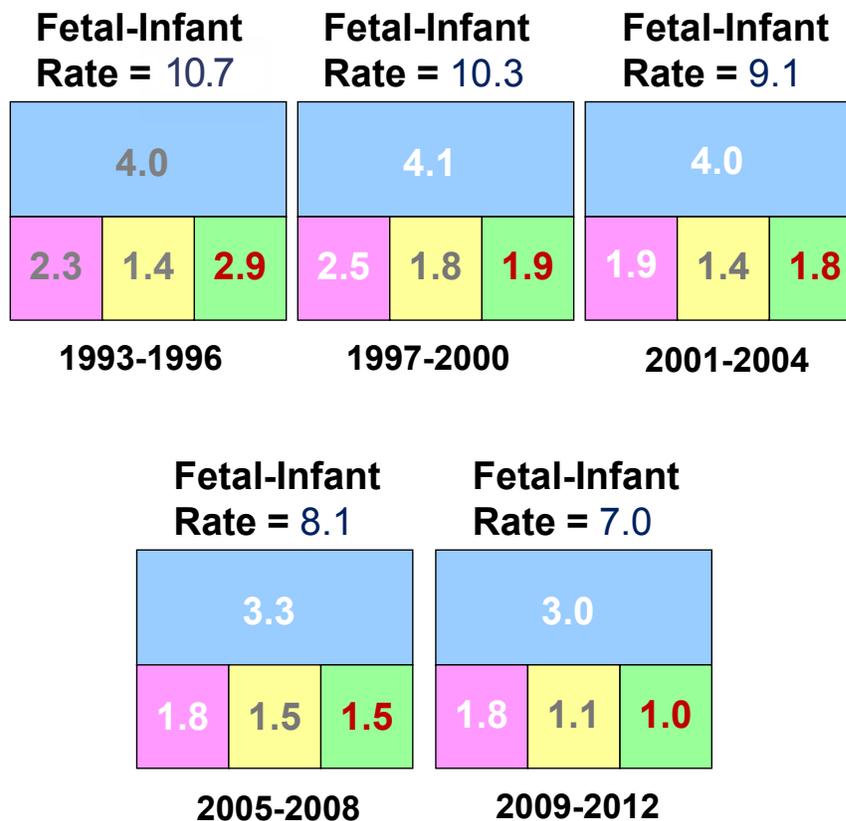
36-year-old bereaved mother

# Perinatal Periods of Risk (PPOR):

Over the years, BBC has used the Perinatal Periods of Risk (PPOR) model to assist with data review and analysis. In addition, CRT has used PPOR data in selecting the medical criteria utilized for case review. This is accomplished by determining where excess deaths are occurring in fetoinfant mortality.

PPOR is an approach utilized by CityMatCH and the CDC for analyzing fetoinfant mortality at the local level. It divides mortality into four periods of risk based on age at death and birth weight. It also compares Douglas County as a whole to a reference population to determine which period of risk has the most preventable deaths, and then investigates the underlying cause of preventable deaths by period of risk. The blue box represents fetal and infant deaths which are very low birth weight, while the pink box represents larger fetal deaths, or stillbirths. In comparison, the yellow box represents larger neonatal infant deaths, with the green box representing larger post-neonatal infant deaths.

Douglas County has successfully used the PPOR model to guide public health activities for over a decade. The following table provides an overview of fetoinfant deaths from 1993 to 2012. During this timeframe, the highest rates occurred in the blue box, which represents very low birth weight fetal and infant deaths.



Perinatal Periods of Risk "Maps", 1993-2012  
Douglas County, NE, All Races

From 2011 – 2013, the medical criteria for referral to the FIMR Program included a birth weight of < 1500 grams (blue box) and a diagnosis of SIDS/SUID (green box).

*"I wish someone would have talked to me more about SIDS and how serious it could be. How it could devastate you."*

27-year-old bereaved mother

# Recent Changes to FIMR Process

Since its inception, the Douglas County FIMR Program's authority to request medical records and initiate case review has been authorized by the Nebraska Child and Maternal Death Review Team (NCMDRT). Record review has included both fetal and infant deaths utilizing the following Program definitions:

- Infant death – A live birth that results in death within the first year (< 365 days).
- Fetal death – A death that occurs prior to delivery irrespective of the duration. Upon delivery, the fetus does not breathe or show any other evidence of life, i.e. heartbeat, pulsation of umbilical cord or definite movement of voluntary muscles.<sup>3</sup>

At the end of 2013, the NCMDRT requested that the Douglas County FIMR Program cease obtaining medical, legal and other records related to fetal deaths on their behalf. This request was based on Nebraska State Statute 71-606 which clarified fetal deaths as distinct from a live birth, and NCMDRT Statute 71-3405 (1993 updated in 2013) which specifies a child as "birth to 18 years of age" and states that a stillborn child shall be registered as a fetal death. The NCMDRT determined that they did not have the authority to issue subpoenas for fetal death records and, therefore, could not extend that authority to the Douglas County FIMR Program.

The Douglas County FIMR Program's response to this request was two-fold:

- Continue case review on infant only cases for 2014 and monitor for significant contributing factors
- Evaluate the importance of fetal case review from 2006 - 2013 and use that information to initiate program change.

**The remainder of this report highlights the Douglas County FIMR Program's two-fold response as outlined above.**

## 2014 Infant Case Review

Below is a summary of infant case review completed in 2014 using the following selection criteria: 1) Douglas County resident, 2) infant loss occurring from 20 weeks of pregnancy through one year of age, and 3) a goal of reviewing infant cases with extreme prematurity, specifically those of a very low birth weight (VLBW) and/or SIDS/SUID:

- Based on Perinatal Periods of Risk (PPOR) data, infant death cases of prematurity with a VLBW and/or SIDS/SUID were prioritized for review.
- 28 infant cases were reviewed from January 1, 2014 to December 31, 2014, including 5 twin cases.
- 25% of cases were reviewed less than 3 months after death while 43% were reviewed less than 6 months after death, with 32% reviewed less than 9 months after death.
- Phone contact was achieved with 14 out of 28 cases (50%) with 7 of these cases (25%) resulting in a home interview.

The top five contributing factors to infant mortality identified during 2014 case review were: 1) prematurity, 2) congenital anomaly, 3) incompetent cervix, 4) second hand smoke, and 5) infant in non-bed. These top contributing factors are determined by CRT members following case review where they "vote" on which factor(s) they feel contribute most to the infant death in that specific case. These factors are then documented and reviewed at the end of the year. The 2014 top five infant contributing factors seem to mirror the 2013 population based data which lists the top four single causes of infant mortality as congenital anomalies, maternal complications of pregnancy, SIDS/SUID and prematurity.<sup>4</sup>

<sup>3</sup> Barfield, D. (2011). Clinical Reports – Standard Terminology for Fetal, Infant and Perinatal Deaths. *Pediatrics*, 128 (1), 177-181.

<sup>4</sup> 2013 Douglas County Vital Statistics information using ICD-10 codes. This data is typically one year behind the current reporting year due to data availability.

*"I've been pregnant six times – this is my 2nd loss."*

34-year-old bereaved mother

During case review, the top contributing factors are also used as a guide to develop recommendations with the assistance of a Gap Analysis Form. This form allows findings to be linked with the appropriate recommendations and adjusted as needed. This process is completed at each CRT meeting, with recommendations presented to BBC every two years. BBC, functioning in the role of the Community Action Team, then prioritizes the recommendations and crafts an extensive two year Community Action Plan.

In 2014, a new recommendation was developed to address Infant Health based on the exclusive review of infant cases.

**The current CRT recommendations are listed below:**

**Preconception Health:**

Comprehensive preconception health education shall be offered at an early age that addresses four umbrella concepts:

- 1) need for consistent medical home
- 2) lifestyle issues
- 3) need for a culturally and religiously sensitive reproductive plan
- 4) education/management of chronic conditions including mental health and previous fetal loss

**Prenatal Care (1):**

Throughout the prenatal period of all women, “consistent and ongoing” screening for medical and nonmedical risk factors shall occur; noting any red flags in order to signal a tiered, multidisciplinary response to include appropriate referrals

**Prenatal Care (2):**

Intergenerational and multicultural education focused on preterm labor and healthy pregnancy signs shall occur through medical, social work and other community providers

**Safe Sleep:**

Safe sleep messages shall be repeated at every medical home visit (wellness and illness) for parents and other child care providers

**Other:**

All relevant medical and psychosocial data will be available for review by CRT

**New in 2014:**

**Infant Health:**

All infants should have a medical home as defined as an environment in which care is accessible, continuous, comprehensive, family-centered, coordinated, compassionate and culturally effective

## 2014 CRT Recommendations

*“The main stress for me was the stress of trying to get pregnant.”*

30-year-old bereaved mother

# Eight Year Summary Case Review (2006-2013)

A review was done of all cases from 2006-2013, understanding this was a biased sample based on Program priorities and not representative of all fetal and infant deaths in Douglas County. Our understanding of these cases (fetal and infant) came from medical criteria used for case selection, Perinatal Periods of Risk (PPOR), and the actual cases available for review. We discovered, with only infant cases, certain findings may not have been identified, and thus used for recommendation development and program change. It should be noted that the review of fetal deaths added significantly to our understanding of risks and health conditions in pregnancy. Infant review needs to continue, as the number of infant cases has exceeded the number of fetal cases in the past two years; and this trend warrants closer monitoring to assure pregnancy and childbirth are safe for all residents.

## Upon the Horizon

Now is the time for us to create a new community action plan.

Three highlights of the 2014 Community Action Plan include the following:

1. A total of four community sites implemented the teen-focused TOP® curriculum which incorporates components of the Life Course Model. Participating teens completed a total of 483 community service hours for the 2013-2014 school year.
2. A train-the-trainer curriculum, focused on Preterm Labor, was developed and presented to a total of 12 participants from varied disciplines representing five community agencies.
3. Over 56 maternal depression screens were completed on mothers enrolled in the Douglas County MIECHV Program.

The 2014 CRT Recommendations have been brought forth to BBC (the Community Action Team) and a new community plan will be developed in 2015 utilizing the following steps, 1) population-based data review (Vital Statistics, PPOR data & PRAMS data), 2) research/literature search, and 3) an in-depth planning meeting. The community plan will be published in January 2016, and distributed to all maternal-child health partners. In addition, it will be posted on the Douglas County Health Department website for community review and distribution.

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*"FIMR is a diverse group of individuals who come together to evaluate the best ways to promote, educate and empower mothers and families to create safe and healthy environments for their children."*

**Nicole Pearsall, M.D.**  
Obstetrics & Gynecology Associates in Womens Health