# FETAL AND INFANT MORTALITY REVIEW 2008

ILLINOIS DEPARTMENT OF HUMAN SERVICES
CHICAGO DEPARTMENT OF PUBLIC HEALTH
THE UNIVERSITY OF CHICAGO MEDICAL CENTER FIMR

# FETAL AND INFANT MORTALITY REVIEW 2008

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# EXECUTIVE SUMMARY

Fetal Infant Mortality Review (FIMR) is a national program supported by the American College of Obstetricians and Gynecologists, Healthy Start, and the Department of Human Services. It is designed to identify the nonmedical factors that contribute to adverse pregnancy outcomes. Once identified, FIMR empowers the community and its leadership to develop and implement solutions and systems to break down barriers and to optimize perinatal outcomes.

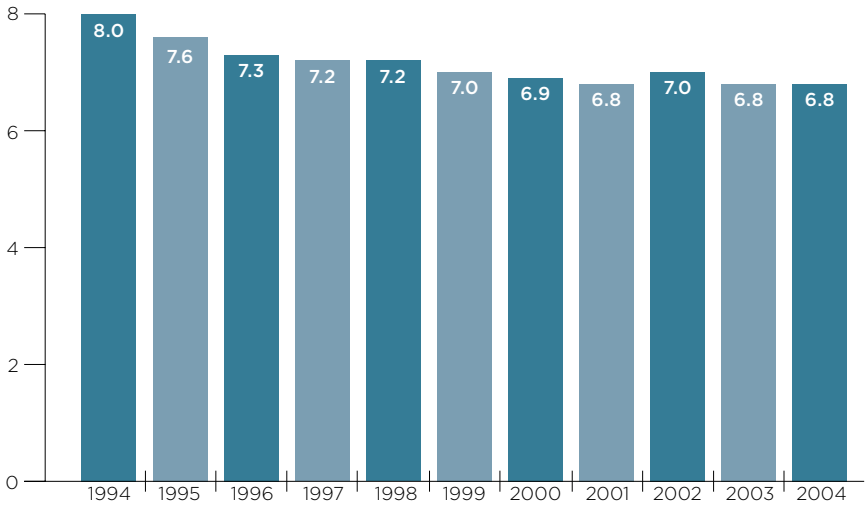
The Illinois FIMR Program is a voluntary program supported by a federal grant in collaboration with the Illinois Department of Human Services and the Chicago Department of Public Health. It identifies fetal deaths (infants born dead after 20 weeks gestation) and neonatal deaths (any live born infant regardless of gestational age and weight), and neonates who die with in the first 28 days of life. These parameters were chosen for the following reasons:

- An Illinois state-mandated process is in place within the hospitals to review these cases from a medical perspective.
- Social and economic factors are rarely available during the state-mandated medical reviews.
- Based on the stated statistics, early losses, whether fetal or neonatal, are prevalent within the city of Chicago.
- The program consists of case identification (residents within the 606 zip code), outreach to enroll women into the program through an informed consent process, an in-home interview, medical record abstraction, and case reviews by a multidisciplinary team.

# INFANT MORTALITY

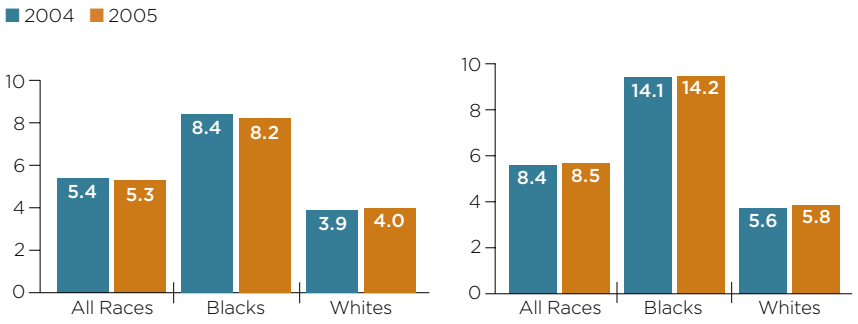
Infant mortality is an important measure of a nation's health and a worldwide indicator of health status and social well-being. As of 2004, the United States infant mortality rates (infant deaths per 1000 live births) ranked 29th among industrialized nations (National Center for Health Statistics). However, the U.S. spends more on health per capita than any other country. In 2005, national health care expenditures in the U.S. totaled 2 trillion dollars, a 7% increase from 2004. Additionally, more than 40 million adults (about 19%) did not receive "needed services" because they could not afford them. (Executive Summary, Chart Book on Trends in the Health of Americans, 2007)

**United States Infant Mortality** (Rate per 1,000 live births)




Source: March of Dimes Foundation

**Chicago Neonatal / Infant Mortality** (Rate per 1,000 live births)




Chicago Neonatal Mortality Rates
(under 28 days)

Chicago Infant Mortality Rates
(under 12 months)

**United States Rates**

Today's data indicates that fetal and perinatal mortality rates in the U.S. are still higher than many other developed countries (National Vital Statistics Center for Disease Control). The infant mortality rate and the risk of death during the first year of life is related to the underlying health of the mother, public health practices, socioeconomic conditions, and the availability and appropriate use of health care for infants and pregnant women (Chartbook on Trends in the Health of Americans, 2007). In 2004 the white infant mortality rate was 5.6 deaths per 1000 live births, and in 2005 it was 5.8 deaths per 1000 live births. In 2004 the rate for white infants under 28 days (neonatal) was 3.9 deaths per live births, and in 2005 it was 4.0 deaths per 1000 live births. In 2004 the rate for all races under 28 days (neonatal) was 5.4 deaths per 1000 live births, and in 2005 it was 5.3 deaths per 1000 births. In 2004 the rate for black infants under one year was 14.1 deaths per 1000 live births, and in 2005 it was 14.2 deaths per 1000 live births. The rates for those under 28 days (neonatal) were 8.4 deaths per 1000 live births in 2004 and 8.2 deaths per 1000 live births in 2005. The rates for Hispanics were not given separately in this report. (IDPH, Illinois Center for Health Statistics by Race June 2007)

**Illinois Rates**

According to the Illinois Department of Public Health News Release (July 13, 2007), the overall infant mortality rate in Illinois decreased from 7.3 in 2004 to 7.2 infants deaths (less than one year of age) per 1000 state resident live births in 2005. The Illinois neonatal mortality rate (less than 28 days) remained unchanged in 2005 from 4.8 in 2004. The rate for white infants in 2004, 5.9, decreased in 2005 to 5.7. The rate for black infants was 14.8 in 2004, with an increase in 2005 to 15.4. The rates for Hispanics were not given separately in this report.

**Chicago Rates**

In 2004 Chicago's infant mortality rate for all races under 1 year was 8.4 deaths per 1000 live births, and in 2005 it was 8.5 deaths per 1000 live births. In 2004 the white infant mortality rates was 5.6 deaths per 1000 live births, and in 2005 it was 5.8 deaths per 1000 live births. In 2004 the rate for white infants under 28 days (neonatal) was 3.9 deaths per live births, and in 2005 it was 4.0 deaths per 1000 live births. In 2004 the rate for all races under 28 days (neonatal) was 5.4 deaths per 1000 live births, and in 2005 it was 5.3 deaths per 1000 births. In 2004 the rate for black infants under one year was 14.1 deaths per 1000 live births, and in 2005 it was 14.2 deaths per 1000 live births. The rates for those under 28 days (neonatal) were 8.4 deaths per 1000 live births in 2004 and 8.2 deaths per 1000 live births in 2005. The rates for Hispanics were not given separately in this report. (IDPH, Illinois Center for Health Statistics by Race June 2007)

## FETAL INFANT MORTALITY REVIEW (FIMR)

Fetal Infant Mortality Review (FIMR) is a national program supported by the American College of Obstetricians and Gynecologists, Healthy Start, and the Illinois Department of Human Services. It is designed to identify the nonmedical factors that contribute to adverse pregnancy outcomes. Once identified, FIMR empowers the community and its leadership to develop and implement solutions and systems to break down barriers and to optimize perinatal outcomes.

## CHICAGO, ILLINOIS FIMR

The Chicago, Illinois FIMR Program is a voluntary program supported by a federal grant in collaboration with the Illinois Department of Human Services and the Chicago Department of Public Health. It identifies fetal deaths (infants born dead after 20 weeks gestation) and neonatal deaths (any live-born infant death regardless of gestational age and weight), and neonates who die within the first 28 days of life.

**These parameters were chosen for the following reasons:**

- An Illinois state-mandated process is in place within the hospitals to review these cases from a medical perspective.
- Social and economic factors are rarely available during the state-mandated medical reviews.
- Based on the stated statistics, early losses, whether fetal or neonatal, are prevalent within the city of Chicago.

**The program consists of case identification (residents within the 606 zip code):**

- outreach to enroll women into the program through an informed consent process
- an in-home interview
- medical record abstraction
- case reviews by a multidisciplinary team

**Case identification consists of:**

- neonatal deaths reported to the Adverse Pregnancy Outcome Reporting System, a statewide reporting system to identify infants born with birth defects, infants requiring specialized nursing follow-up, and neonatal deaths
- fetal death (stillborn) referrals through a reporting form generated by the individual hospitals and sent directly to the FIMR office

**Case review process includes:**

- summarization of in-home interview and medical record abstract
- case presentation with input from the interviewer
- team discussion of factors that impacted the pregnancy
- dispositions, either unavoidable (everything was done to promote a positive outcome) or potentially avoidable (issues arose, either for the patient or health care system that, if changed, may have resulted in a different outcome), are assigned to each case reviewed by committee consensus
- definition of general and individual factors and recommendations for each case reviewed

## Summary of Chicago, Illinois FIMR 2004

A review of the 2004 report reveals information on 65 cases that was collapsed into four general categories: Lifestyle, Systems, Medical, and Environmental Issues. This report represented a summary of the individual case findings and documented dispositions, along with a summary of the factors and recommendations identified through the review process.

The category highlighted in this report was Lifestyles, which represented the highest percentage of all categories (62%). Within Lifestyles, Stress ranked highest (59%), which was further divided into subcategories with debt/loss of job ranking highest (24%). The next highest category was Medical Issues (22%). However this category was not highlighted.

**Fetal and Infant Mortality Report For Year 2004**

| Types of Death | Total | Potentially Avoidable | Unavoidable |
|---|---|---|---|
| Fetal death | 28 (43%) | 9 (39.1%) | 19 (45.2%) |
| Infant death prior to discharge | 4 (6.2%) | 1 (4.3%) | 3 (7.1%) |
| Neonatal death after discharge | 2 (3.1%) | 0 | 2 (4.8%) |
| Neonatal death prior to discharge | 31 (47.7) | 13 (56.5%) | 18 (42.9%) |
| **Total** | **65** | **23 (35.4%)** | **42 (64.6%)** |

**2004 Recommendations**

The review of 65 cases by the multidisciplinary Case Review Team generated specific recommendations. In cases with similar factors recurring, there was repetition of the same recommendations. The recommendations listed in this report are the result of collapsing and combining the original recommendations. Emerging from these, the recommendations were placed in the following categories:

**Community/Agency/Systems Recommendations**

- Provide referral for obstetrical evaluation and services for homeless women
- When women are arrested or incarcerated, provide health/pregnancy evaluations
- Evaluate provision of services in healthcare settings, especially in areas of communication and consistency
- Recommend more frequent case management contacts with patients during pregnancy, especially those identified as high risk
- Provide reproductive education in schools
- Recommend schools identify pregnancy early and make appropriate referrals
- Educate emergency room staff on need for comprehensive obstetrical assessments
- Increase local agency outreach regarding:
  - Case-finding and referral to appropriate social or medical agency
  - Education for the community on expanded medical coverage for women during pregnancy
  - Community awareness of housing, safety, and environmental issues

**Education Recommendations**

Provide educational programs for providers in the following areas:

- Domestic violence assessment multiple times during pregnancy
- Depression assessment
- More effective family planning instructions with assessment of client understanding
- Kick-count education with assessment of patient understanding
- Risk assessment/general health evaluation with referral to higher level of care
- Understanding of cultural differences
- Providing information at a level that the client can understand and evaluating client understanding
- Need for nonjudgmental assessment and provision of services for clients with risk behaviors
- Evaluation of pregnancy status during routine or sick visits
- Resources available for social and community services and how to access the services

### Provide educational programs for clients concerning:

- Identification of signs and types of problems during pregnancy
- Sexually transmitted diseases and HIV
- Importance of kick counts and assessment of fetal movement to avoid fetal deaths
- Importance of well-baby care
- Reproductive health issues for all ages
- Nutritional issues and weight management
- Need for routine general health follow-up
- Need for grief counseling and social support systems
- Importance of providing good reproductive history to medical providers for current and future pregnancies
- Necessity of early, consistent prenatal care and post partum follow-up
- Stress management skills before, during, and after pregnancy
- Adverse effects of drugs, alcohol, and tobacco on overall health

### Funding and Policy Recommendations

- Develop linkage between Medicaid and SSI coverage to trigger case management/WIC referral
- Increased community resources for:
  - preconceptual counseling
  - family planning resources
  - genetic counseling
  - smoking cessation programs specifically for pregnant women
  - counseling for drug/alcohol usage
  - counseling for mental health issues and depression
  - community programs for job training
  - parenting classes
  - home health and hospice services within the community
  - domestic violence
  - services for anger management and aggressive behavior issues
  - bereavement counseling and support

## Conclusion

The strength of the FIMR Program is its ability to look at individual cases with a holistic view and make recommendations that transcend various disciplines, organizations, systems, and specialties. A unique feature of the Illinois FIMR Program is the in-home interview, which allows the client (and sometimes family members) to share her individual perspective of her adverse pregnancy with the interviewer. She also has the opportunity to accept referrals, when the need is identified. This approach gives the Case Review Team members both the client's and medical providers' perspectives on the events that led to the adverse outcome. It is the expectation that this will be reviewed by community, local, and state leadership. Innovative, comprehensive, culturally competent community-based programs will be developed to improve overall perinatal outcomes.

## Summary of Chicago, ILLINOIS FIMR 2007

The first report was published four years ago. In preparing the second report, looking back generates the urge to compare data before looking to the present and the future. The 2010 target is to reduce fetal and infant deaths to 4.1 per 1,000 live births (Healthy People 2010 Objectives 16-1). Where do we stand in meeting this goal?

**Program Update**

Staff changes include resignation of the original Outreach Coordinator/Interviewer in 2006 and the retirement of the Program Coordinator in 2007. A new Outreach Coordinator was hired with the challenge of continuing the project and raising it to the next level. A bilingual consultant was hired to interview Spanish-speaking clients and to translate letters, consents, and the questionnaire to Spanish.

**Collaborations have been established with:**

- The Illinois Maternal Child Health Coalition (Save Our Babies Campaign)
- Sudden Infant Death Services of Illinois, Inc.
- Illinois Chapter March of Dimes
- Health and Faith Summit
- Chicago Healthy Start

A total of 1,661 Adverse Pregnancy Outcome Reporting System referrals from 2004 through 2007 have been received from Chicago area hospitals via the Chicago Department of Health. A total of 1,867 FIMR referrals were received directly from Chicago-area hospitals for a total of 3,528 referrals received. Both groups of referrals were sent letters of introduction to the FIMR program and a request to participate with informed consent. Currently 141 cases have been registered and interviewed. Abstracts are created from the medical record and the standardized questionnaire for review by the review team. The last report included the first 65 cases. In this report the focus will be the next 76 cases, 2004 through mid 2007.

The majority of referrals lived in the 606 zip code areas. The community areas and zip codes are included here to show the general distribution and location of reported clients by residence (see table and map).

**Fetal and Infant Mortality for Year 2007**

| Types of Death | Total | Potentially Avoidable | Unavoidable |
|---|---|---|---|
| Fetal Death | 45 (59.2%) | 9 (75%) | 36 (56.3%) |
| Infant Death after discharge | 1 (1.3%) | 0 | 1 (1.6%) |
| Infant Death prior to discharge | 1 (1.3%) | 1 (8.3%) | 0 |
| Neonatal Death prior to discharge | 29 (38.2%) | 2 (16.7%) | 27 (42.2%) |
| **Total** | **76** | **12** | **64** |

# FETAL AND INFANT MORTALITY ZIP CODES 2007

| Codes | Cases | Community |
|---|---|---|
| 60605 | 1 | Loop, Near South Side |
| 60607 | 2 | Loop, Near West Side, Near South Side |
| 60608 | 2 | Grand Blvd., North Lawndale, South Lawndale, Lower West Side, McKinley Park, Bridgeport |
| 60609 | 1 | Armour Square, Douglas, Fuller Park, Grand Blvd., McKinley Park, Bridgeport, New City, |
| 60610 | 1 | Near North Side |
| 60612 | 1 | Near West Side, West Town |
| 60614 | 1 | Lincoln Park, Logan Square |
| 60618 | 1 | Avondale, Irving Park, North Center |
| 60619 | 4 | South Shore, Chatham, Avalon Park, Burnside, Calumet Heights, Roseland, Greater GrandCrossing |
| 60620 | 7 | Chatham, Roseland, Greater Grand Crossing, Auburn Gresham, Beverly, Washington Heights |
| 60621 | 4 | Washington Park, Chatham, Englewood, Greater Grand Crossing |
| 60623 | 2 | North Lawndale, South Lawndale, Brighton Park |
| 60626 | 2 | Rogers Park |
| 60628 | 3 | Roseland, Pullman, South Deering, West Pullman, Riverdale, Washington Heights |
| 60629 | 3 | West Elston, Gage Park, West Lawn, Chicago Lawn, Ashburn |
| 60630 | 1 | Albany Park, Forest Glen, Irving Park, Jefferson Park, Portage Park |
| 60632 | 3 | Archer Heights, Brighton Park, Gage Park, Garfield Ridge, West Elston |
| 60634 | 1 | Belmont Cragin, Dunning, Montclare, Portage Park |
| 60636 | 3 | West Englewood |
| 60637 | 3 | Washington Park, Hyde Park, Woodlawn, South Shore, Greater Grand Crossing |
| 60638 | 1 | Clearing, Garfield Ridge |
| 60639 | 1 | Austin, Belmont Cragin, Hermosa, Humboldt Park, Logan Square |
| 60644 | 3 | Austin |
| 60646 | 1 | Forest Glen, Jefferson Park, Belmont Cragin |
| 60647 | 2 | Hermosa, Logan Square, Humboldt Park, West Town |
| 60649 | 1 | South Shore |
| 60651 | 5 | Humboldt Park, Austin |
| 60652 | 2 | Ashburn |
| 60655 | 3 | Beverly, Morgan Park, Mount Greenwood |
| 60657 | 1 | Lakeview, North Center |
| 60660 | 1 | Edgewater |
| 60804 | 1 | Cicero |
| **Total** | **76** | |

# ANALYSIS

### Similarities and Differences

In an analysis of the case composition of those reviewed by the team in the 2007 report, it was determined that some of the variables have changed. In the graphs below are some of the similarities and differences that were noted.

**2004 and 2007 Fetal and Infant Deaths**

| Types of Death | 2004 | 2007 |
|---|---|---|
| Fetal Deaths | 43% | 59% |
| Infant and Neonatal Deaths | 57% | 41% |
| **Total Number of Cases Reviewed** | **65** | **76** |

**Mother's Race**

| Race | 2004 | 2007 |
|---|---|---|
| African American | 65% (42) | 66% (50) |
| White | 9% (6) | 16% (12) |
| Latino | 15% (10) | 14% (11) |
| Others (Asian, Biracial, etc.) | 11% (7) | 4% (3) |
| **Total** | **65** | **76** |

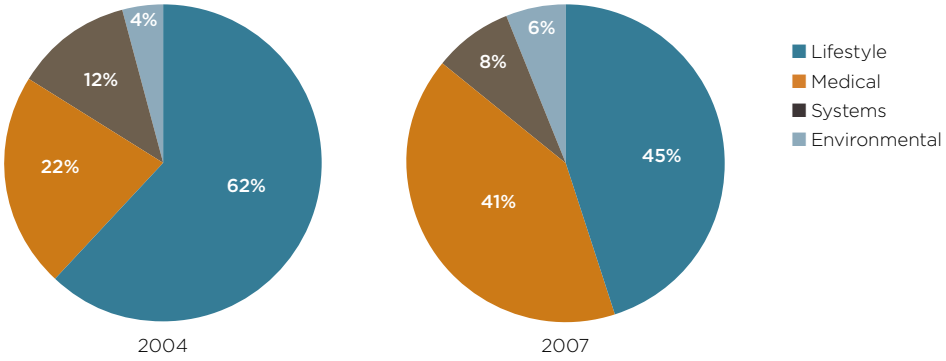
**Annual Income**

| Annual Income | 2004 | 2007 |
|---|---|---|
| $0–5,000 | 16 | 21 |
| $5,001–10,000 | 7 | 8 |
| $10,001–15,000 | 5 | 5 |
| $15,001–20,000 | 5 | 3 |
| $20,001–25,000 | 3 | 5 |
| $25,001–30,000 | 3 | 3 |
| > $30,000 | 23 | 28 |
| Unknown | 3 | 3 |
| **Total** | **65** | **76** |

### Lifestyles

Elements included within the Lifestyle 2004 category included stress and smoking. Stress ranked 11% and smoking 13%. There was an overall decrease in the Lifestyle category from 62% (2004) to 45% (2007). See case categories below.

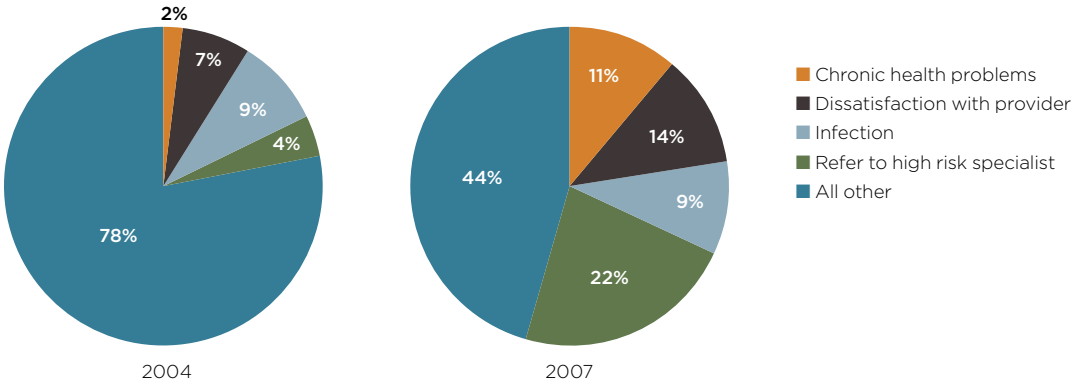
**Case Categories**




### Medical Issues

In 2007, the Medical Issues category had an overall increase to 148 from 46 in 2004. Chronic health problems in 2007 made up 11% of the Medical Issues category, dissatisfaction with provider 14%, and the need to refer to a high-risk specialist 22% (the greatest increase in numbers). The area of infection remained 9%. In the "all other" category for 2007, issues such as asthma, congenital anomaly, depression, family planning, and multiple pregnancy losses, were listed. The "all other" category for 2004 included issues such as congenital anomalies, delay in recognizing pregnancy, delay in seeing medical provider, and no prenatal care, were included.

**Medical Categories**



# RECOMMENDATIONS

**2007 Recommendations**

Some of the most frequently occurring recommendations in 2007 were similar to recommendations in 2004. Listed below are the additional recommendations:

- Educate family on merits of Women Infants and Children (WIC) and Family Case Management (FCM)
- Heighten community awareness of housing and safety issues
- Provide resources for family counseling

**2004 and 2007 Specific Recommendations**

The previous recommendations for 2004 were subdivided into four specific areas: physician education, systems issues, medical issues, and client issues. The most frequently occurring were:

- Improve instruction of kick counts/awareness by client
- Improve communication with multiple providers
- Decrease case management system failures
- Improve physician/client relationship and communication
- Educate women in overall women's health issues
- Increase awareness of the signs and symptoms of preterm labor

In 2007 some of the subdivided category results were the same as those of 2004 with the addition of the following:

- Improve risk assessment with referrals and specific referrals to high-risk specialists
- Educate client about the necessity of early, consistent prenatal care
- Encourage healthcare professionals to reinforce health education at every prenatal visit
- Improve education on the use of birth control methods and accessibility to family planning
- Address the need for grief counseling
- Provide interconceptual case management

The fact that the recommendations remain unchanged is an indication of the continuing presence of the high rate of fetal and infant mortality. There is a definite need to implement changes if the 2010 Healthy People challenge is to be met. The dissemination of these recommendations to the appropriate leaders and policy makers should be classified as "Urgent."

## CONCLUSIONS

The validity of the FIMR findings improves as the number of participants increase. Encouraging referred women to participate remains a challenge. The interview process continues to provide a medium by which mothers who experienced a fetal or neonatal loss can express themselves and voice their concerns. They can reflect on the events that occurred before, during, and after the adverse pregnancy outcome, share this with others, and hopefully prevent sentinel events from occurring. Concerns stated by the clients interviewed included:

- "To help others not to have this same experience..."
- "Doctors are not really listening to what the patient is saying...
- "Stimulated me to form a nonprofit to address these situations and provide support to women with similar pregnancy losses..."
- "I was a student when my baby was born. After I returned to class we had a PowerPoint assignment. I decided to write up the experience of the loss of the baby and dedicate it to her. This really helped me through the grieving process..."
- "I was glad to have someone to talk to..."

Further investigations should be made into the statements from the PBS documentary series "Unnatural Causes, Is Inequality Making Us Sick?", which explores racial and socioeconomic and inequities in health (March 2008, Public Television, Channel 11; *http://www.unnaturalcauses.org*). Does the fact that the highest number of responders lived south of Roosevelt Road indicate environmental issues are significant indicators for fetal and infant mortality? Does the community help shape the health of people? What role does race and socioeconomics play in determining the causes of high fetal and infant mortality in the black community?

The Case Review Team continues to represent important members of the community and peruses information from the individual cases to identify factors that may be avoidable or unavoidable in each death. Their recommendations should be forwarded to health care providers and health policy makers.

# APPENDICES

## Appendix A: Combined Numbers at a Glance

**Fetal and Infant Mortality for Years 2004 and 2007**

| Types of Death | Total | Potentially Avoidable | Unavoidable |
|---|---|---|---|
| Fetal Death | 73 | 18 | 55 |
| Neonatal Death (Infant) | 68 | 17 | 51 |
| **Total** | **141** | **35** | **106** |

## Appendix B: Glossary of Terms, Diagnoses and Procedures

This appendix contains basic information to assist nonmedical members of the Case Review Team to understand common terms, diagnoses, and procedures that they might encounter in review of individual cases.

**Please do not feel that these terms need to be memorized. Use this document as a dictionary and refer to it as needed. Experience tells us that after a year or so of reviewing cases, all team members will naturally come to an understanding of these terms, as well as others, without making any special effort.**

**African American:** A black American of African ancestry

**Anomaly:** A malformation or significant deviation from the norm

**Apgar score:** A measurement of a baby's response to birth and life on its own, taken at one and five minutes after birth.

**Appropriate for gestational age (AGA):** The weight or a measurement of the fetus or infant falls between the 10th and 90th percentile based on the average of a large number of pregnancies of the same gestational age

**Black:** Of or belonging to an American ethnic group descended from African peoples having dark skin; African American

**Ectopic pregnancy:** A pregnancy in which the fertilized egg begins to grow in a place other than inside the uterus

**Fetal:** In utero development after the eight week

**Hispanic:** Of or relating to the language, people, or culture of Spain or Spanish-speaking Latin America

**Infant:** A child younger than one year

**Latino:** A native or resident of Latin America, a person of Hispanic, esp. Latin American, descent, often one living in the United States

**Lifestyle:** A way of life or style of living that reflects the values and attitudes of an individual or group

**Multiple pregnancy:** More than one fetus, i.e., twins, triplets, etc.

**Neonatal:** The period immediately following birth and continuing through the first 28 days of life

**Spontaneous abortion:** A miscarriage prior to the 20th week of gestation

**Sudden Infant Death Syndrome (SIDS):** The sudden death of a baby for no apparent reason

## FIMR Staff

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ILLINOIS DEPARTMENT OF HUMAN SERVICES
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THE UNIVERSITY OF CHICAGO MEDICAL CENTER FIMR