INVESTING in HEALTHY Mothers & Babies

Lessons Learned and New Directions

The Maternal, Child and Family Health Coalition

The Maternal, Child and Family Health Coalition (MCFHC) is a partnership of private and public organizations, community and civic leaders, businesses and consumers committed to improving birth outcomes, promoting healthy families and building healthy communities by uniting and mobilizing the St. Louis Region. The MCFHC promotes best practice strategies and increases coordination and communication between community agencies, other coalitions and the healthcare system. Members participate in the MCFHC because far more can be accomplished collectively than alone.

The MCFHC vision is that all women and children in the St. Louis community are healthy.

The Maternal, Child and Family Health Coalition (MCFHC) celebrates its 10th anniversary in 2009. Founded in 1999 under the leadership of the March of Dimes and support from Vision for Children at Risk, the MCFHC's first priorities, derived from the St. Louis Children's Agenda, were to address health care access and utilization for low-income women and children, the rising infant mortality rate, and to establish a sustainable infrastructure.

The purpose of this report is to share lessons learned from ten years of focusing on infant mortality in St. Louis and to call the community to action to renew and expand investments in healthy mothers and babies.

The MCFHC Values

- **The St. Louis region should have quality, evidence-based health services delivered by qualified providers who are accountable to the consumer.**
- **All families have an equal right to barrier free access that supports health and wellness.**
- **We value advocacy that includes education, policy development, and empowerment as a means of supporting the health and well-being of all families.**
- **We focus resources on programs with the potential to address disparate health outcomes.**
- **Collaborative partnerships are essential to improving the health and well being of families.**

Addressing Infant Mortality: 1999-2009

Ten years ago, Coalition members established a strategy for addressing infant mortality. It included implementing programs and **data collection systems** to *better understand the reasons babies die* in St. Louis and ***brokering federal resources*** to expand case management for at-risk expectant and new parents.

Data collection systems

When the MCFHC formed in 1999, Coalition leaders were concerned about rising infant mortality rates. To better understand and monitor this trend, in 2000, Dr. Louise Flick and Dr. Terry Leet developed a surveillance system for infant mortality epidemiology. Since that time they collected and analyzed 16 years of data from birth and death certificates of infant deaths which enable coalition members to understand trends. This data set was used again in 2008 to look more closely at smoking during pregnancy to better understand high risk populations.

In 2003, the St. Louis Fetal and Infant Mortality Review (FIMR) program was launched in collaboration with the Missouri Department of Health and Senior Services. It was based on a model developed by the American College of Obstetrics and Gynecologists. FIMR allowed a diverse group of health and social service providers to review the social, environmental, medical and economic contributors to fetal and infant deaths in the region.

Brokering resources

In 1998, St. Louis had some of the highest infant mortality rates in the country; however it could not qualify for the only major federal investment in infant mortality reduction because it lacked a coalition. In 2001, while housed with the March of Dimes, the MCFHC was awarded a $2.2 million federal Healthy Start grant which expanded services for at-risk pregnant women and new parents in three zip codes of North St. Louis City and County. The St. Louis Healthy Start program was renewed for another four years with $2.2 million in 2005 and $2.75 million in 2009. By 2014, the MCFHC will have leveraged over $7 million dollars of federal funds that would have otherwise not been available to the community. Partnering with a direct case management provider, Nurses for Newborns Foundation, has allowed the MCFHC to better understand the needs of women and children living in the project area.

Healthy Start Select Accomplishments:

- **Program participants had a 44% lower rate of low birth weight births than the rate for the project area as a whole (9% of Healthy Start births compared with 15.5% for all births in the project area)**
- **91% of one-year olds in the program were current with immunizations**
- **Over 95% of the women enrolled have a source of primary care**
- **A culturally competent depression screening and referral protocol was developed and became a model for other Healthy Start programs nationally**

Infant Mortality Trends

The St. Louis region has reason to be hopeful for improvements in maternal and child health – the MCFHC efforts have increased provider coordination and collaboration and our children's hospitals offer the most advanced medical care. Despite best efforts, St. Louis lags behind the state and nation in healthy births. ***Every year, 4,500 babies are born too early or too small in the St. Louis region and approximately 300 babies die before their first birthday.*** St. Louis City and County's infant mortality rates have been persistently higher than state and national rates. While St. Louis City's rate has been decreasing significantly, it still remains higher than the stagnant rate in St. Louis County. St. Louis City's preterm delivery and low birth weight birth rates have been relatively unchanged while St. Louis County's rates on the same indicators have risen. African American infants have consistently fared worse with their rates averaging three times higher than white infants[I].

Lessons Learned and New Directions:

Over the last ten years, the information learned through data collection and Healthy Start was used to form collaborative workgroups that plan and implement recommendations to improve systems of care for mothers and their children. Drawing from 16 years worth of infant mortality trend data, six years of the Fetal and Infant Mortality Review program and eight years of learning from participants in the St. Louis Healthy Start program, the MCFHC recommends focusing and investing in the following key areas in the next ten years to reduce infant deaths:

- **Women's Health and Health Care Services – Preconception Care**
- **Early and Ongoing Prenatal Care**
- **Maternal Mental Health**
- **Safe Sleep for All Infants**

> **"At some point, we must recognize that the tragedy of poor birth outcomes in the United States is largely a legacy of the poor general health status of women in the United States."** [II]
>
> **Paul H. Wise, MD, MPH**

Women's Health and Health Care Services – Preconception Care

It is widely understood now that many adverse birth outcomes - miscarriage, preterm birth, or congenital anomalies- originate in early pregnancy, before a woman may know she is pregnant. Risks include 1) lifestyle behaviors such as substance use, poor nutrition, sexually transmitted disease, 2) undiagnosed and treated chronic diseases such as hypertension and diabetes, and 3) social and emotional factors such as mental illness and environmental exposures.

Since 50% of all pregnancies are unplanned, it is likely that women are not actively preventing risks that could lead to poor birth outcomes. Furthermore, good prenatal care occurs too late to impact the early pregnancy period. St. Louis surveillance data of birth and infant death records also points to the health of women before they become pregnant as a major predictor of fetal and infant mortality.

Preconception care is the set of interventions necessary to improve pregnancy outcomes and the overall health of women of childbearing age[III]. In response to the growing research, the Centers for Disease Control set a goal that all women of reproductive age receive preconception care services such as risk screening, health promotion, and interventions that will enable them to enter pregnancy healthy. Research however emphasizes that preconception care is important for all women, whether they intend to become pregnant or not.

Example of Importance of Preconception Care

"As obesity has increased in the US, so too has the prevalence of diabetes. Many women of reproductive age with diabetes are unaware of the risks that this condition may impose on a developing fetus. In one managed care study, only 52% of the women of reproductive age with diabetes recalled any discussion with their providers about the need for glucose control before pregnancy, and only 37% of the women said they had received any family planning advice from their providers." [IV] **Similar to national trends, the rate of women in St. Louis City and County who are more than 20% overweight has been increasing significantly. Low income women are often uninsured before and after pregnancy, increasing their chances of having undiagnosed or untreated diabetes as they enter pregnancy. Uncontrolled glucose levels during the first weeks of pregnancy can have severe repercussions on the birth outcome.**

The American Journal of Obstetrics and Gynecology identified several barriers to providing preconception care including: those most in need are the least likely to get services, service provision is badly fragmented, health promotion messages are not effective unless received by a motivated couple, lack of available treatment for high risk behavior, reimbursement for these activities is inadequate, and lack of clinical training in risk assessment and health promotion skills[v].

Recommendations to address these barriers and reach the goal to provide preconception care to all women of reproductive age must address the fundamental way health care is provided to the population. There must be a focus on primary, preventive care and use of a patient-centered medical home, realignment of incentives to support this work, monitoring outcomes and maximizing patient adherence through education and awareness.

Investments needed include:

- **State level leadership to incorporate preconception care into the local healthcare system**
- **Local employer and public health insurance coverage and financing for preconception care services**
- **Contributions to the national research agenda in areas of community-based implementation and consumer awareness**
- **Expansion of community efforts to improve healthy lifestyles among all women, including focusing on good nutrition, increasing physical activity and not smoking**

Early and Regular Quality Prenatal Care for All Women

While a national shift toward focusing on preconception health is occurring, prenatal care has been, and will continue to be, the cornerstone of the health care system for pregnant women. The benefits of prenatal care are strongest for socially disadvantaged because it helps identify conditions and behavior that can result in low birthweight babies, such as smoking, drug and alcohol abuse and inadequate weight gain during pregnancy. Prenatal care also serves as a gateway into other support services such as case management and home visitation.

While early and adequate prenatal care rates in St. Louis City and County increased significantly since the early 1990's, most of the improvement occurred by 2000. And in some zip codes of St. Louis City and County as many as 25 – 30% of women do not start care in the first trimester and 20 – 25% do not obtain the optimal amount of care. Babies born to mothers without prenatal care are three times more likely to be born low birthweight and five times more likely to die before the age of one.

Those most in need of prenatal care are often the women who do not access care. Risk factors for inadequate prenatal care include young maternal age, low education level, use of drugs, alcohol and tobacco, unintended pregnancy, stress, lack of social support, low income, and unmarried women. A survey of St. Louis City residents in the 27th Ward revealed the following perceived barriers:

- **Lack of money or insurance**
- **Uncertain where to go for care**
- **Unplanned pregnancy**
- **Belief that prenatal care is unimportant**
- **Hiding pregnancy**
- **Transportation, scheduling, and child care limitations**

Last year the Maternal, Child and Family Health Coalition helped start the Prenatal Care and Infant Wellness Collaborative with St. Louis City Department of Health and Alderman Gregory Carter that includes Healthcare USA, Myrtle Hilliard Davis Comprehensive Health Centers, Harmony Health Plan, Molina Healthcare, Nurses for Newborns Foundation, SIDS Resources and the Missouri Department of Health and Senior Services' Office of Minority Health. The initiative will pilot a coordinated, comprehensive outreach and marketing campaign for early and regular prenatal care in the 27th Ward of St. Louis City. The purpose of the campaign is to improve health literacy about prenatal care and increase knowledge about navigating complex health systems.

The quality of prenatal care is as important as the quantity of prenatal care visits. Quality prenatal care includes good communication between provider and patient and use of evidenced based screening, counseling, health education and referrals for health and risk behaviors. Pregnancy is an ideal window of time to identify women in need of support and services, encouraging behavior change, and connecting her to supportive programs like case management, substance abuse treatment and mental health services. Despite availability of model screening tools, the MCFHC's Fetal and Infant Mortality Review program found inconsistent screening, counseling and referrals for smoking and substance abuse during pregnancy. As a result of training, over 150 professionals who work with pregnant women have learned how to use evidence based screening and counseling techniques.

Prenatal care is the primary opportunity women have to obtain and understand health information needed to make appropriate health decisions. The lack of actionable health information and communication between provider and patient can even result in the death of a baby. For example, a woman with gestational diabetes who does not receive effective nutritional counseling or does not understand how to inject insulin as prescribed is at high risk of having a stillborn infant. Culturally competent and low literacy level prenatal curricula are available for use by health care providers and community based programs who serve pregnant women. For example, one MCFHC program uses the *Baby Basics* curriculum as the basis of all prenatal education. The *Baby Basics* book, planner and curriculum have been proven to improve health literacy and communication with health care providers.

Investments needed include:

- **Expand health literacy efforts like those of the Prenatal Care and Infant Wellness Collaborative**
- **Expand use of evidence based health literacy tools and techniques**
- **Provide consistent screening and advice on prenatal health behaviors such as smoking, substance abuse, sexually transmitted diseases and nutrition**
- **Expand availability of support services such as case management and home visitation for high risk women**
- **Implement employer policies and benefits that support access to early and regular prenatal care**

Maternal Mental Health

Maternal mental health problems pose a human, social and economic burden to women, their infants, their families, and society and constitute a major public health challenge. Although the overall prevalence of mental disorders is similar in men and women, women's mental health requires special considerations in view of women's greater likelihood of suffering from depression and anxiety disorders and the impact of mental health problems on both childbearing and childrearing.

- **Depression and anxiety are approximately twice as prevalent globally in women as in men, and are at their highest rates in the lifecycle during the childbearing years, from puberty to menopause.**
- **Studies of depression and anxiety show their incidence to be approximately 5% in non-pregnant women, approximately 8-10% during pregnancy and highest (13%) in the year following delivery.**
- **Suicide is one of the most common causes of maternal death in the year following delivery in developed countries.**
- **Psychosis, by contrast, is relatively rare and occurs in only 1 to 2 women for every 1,000 giving birth.**

Mental health problems are often undiagnosed because many of the core features such as fatigue and poor sleep are also commonly associated with motherhood itself and/or part of the gender stereotype of what motherhood should include. These symptoms and signs are not trivial conditions. Pregnant women or mothers with mental health problems often have poor physical health and also have persistent high-risk behaviors including alcohol and substance abuse. They have increased risk of obstetric complications and preterm labor. These women are less likely to seek and receive care before birth or postnatal care or adhere to prescribed health regimens[VI].

Addressing maternal mental health will require a varied, multi-disciplinary approach. Efforts to improve maternal mental health should include measures to prevent and manage mental health problems during pregnancy and after childbirth. A mental health component should be incorporated as an integral part of maternal health policies, plans and activities. There are simple, reliable and affordable tools for the recognition of mental health problems in women during pregnancy and after childbirth within the context of primary health care.

One MCFHC program adapted an existing tool with culturally-specific questions to better identify African-American women at risk of depression. Over 30% of participants had screening scores above the suggested cut-off score for depression, suggesting that symptoms of possible depression are a frequent and common occurrence in the daily lives of women served through this Healthy Start project. Screening should result in more than just a score. It should allow the provider to discuss the client's symptoms and discuss options for intervention, support and/or empowered decision-making for mental health promotion.

A focus on maternal mental health must include a broad range of mental health issues, not just depression and other diagnosable illnesses. There is research to indicate that long-term chronic stress from issues like racism, economic difficulties or domestic violence, can cause the body to produce hormones that can perhaps cause miscarriage and that can bring on preterm labor. The emotional consequences of stress can range from a mild sense of being overwhelmed to severe episodes of depression. They can eventually lead to pregnant women feeling withdrawn and being unable to function. The cumulative effects of stress from racism on African-American women may be one reason why African-American women are more likely to experience a fetal or infant death. FIMR case reviews found 58% of women who experienced a death were under multiple stresses during pregnancy.

A number of community-based interventions have been demonstrated to be useful and effective for women with mental health problems during pregnancy and after childbirth. For example, health care providers working in sexual and reproductive health services and caring for pregnant women can be trained to recognize symptoms and signs suggestive of a mental health problem and provide counseling to the women about stress as well as provide effective psychological support and other interventions[VII].

Investments needed include:

- **Continue efforts to improve behavioral health system safety net**
- **Widespread adoption by primary care providers of standardized screening and treatment for perinatal mood disorders**
- **Creation of a wide range of community and mental health services to adequately address needs of women with range of mood disorders**

Safe Sleep for All Infants

Each year in the United States, more than 4,500 infants die suddenly of no obvious cause and about half of these sudden, unexpected infant deaths are diagnosed as Sudden Infant Death Syndrome (SIDS). Historically, the national *Back to Sleep* campaign's effort to reduce prone sleeping rates resulted in a 50% decline in SIDS deaths between 1992 and 1999. The decline in deaths due to the *Back to Sleep* campaign was one of the most successful public health education campaigns. Despite extensive education efforts and the decline, 7 babies still die every day in the United States, many of which may be preventable. In 2007, 127 Missouri infants died unexpectedly, 59 of which were determined to have been caused by accidental suffocation. 15 deaths were ruled SIDS, with only one of those sleeping on its back in a safe crib[VIII]. In 2008, 19 babies died in unsafe sleep environments in the City of St. Louis alone.

"We know that 80 percent of sudden infant deaths are related to their sleep environment. We need to focus on the preventability of these deaths…" said Dr. James Kemp, a researcher on infant sleep safety at Washington University School of Medicine in St. Louis[IX].

While experts agree about the recommendation to always place infants to sleep on their back and to remove soft bedding from the infants sleep area, there is not agreement about the risks to infants sleeping in an adult bed. Based on the best information currently available, the American Academy of Pediatrics recommends parents not fall asleep with a baby in an adult bed or on a sofa. Instead, bring them in bed to breastfeed and bond, but when it's time to fall asleep, place them alongside your bed in a separate, safe sleep area.

Representative cases of sudden, unexpected infant deaths in Missouri[X]

- **The father of an 8-week-old infant put her down to sleep prone on a standard size pillow, in an adult bed. He later found her unresponsive, after she had apparently slid off the pillow with her face down into the bedding.**
- **A child care provider placed a 10-week-old infant on his side in a playpen for a nap. A short time later, she found him lifeless on his stomach with his face down.**
- **A mother was lying in bed with her three-week-old infant cradled in her arm. When she awoke, she realized that she was lying on top of the baby, who was face down on the mattress, unresponsive.**

Local sudden unexpected infant death experts, SIDS Resources, have made great strides to ensure all new parents receive information from their health care provider and all child care providers practice safe infant sleep. The FIMR program partnered with SIDS Resources to create safe sleep displays in all community health centers and deliver safe sleep education to health care professionals. However, the unparalleled success of *Back to Sleep* has inadvertently led to the perception that sudden, unexpected infant deaths are no longer a priority. Members of the FIMR Case Review Team strongly encourage greater attention to preventing deaths in unsafe sleep environments.

Investments needed include:

- **Long lasting education efforts about safe sleep recommendations**
- **Institutionalize safe sleep education into all venues that reach pregnant women, new parents and caregivers**
- **Additional research into effective strategies for modifying unsafe sleep practices**

Conclusion and Call to Action

Healthy mothers and babies are the foundation of a healthy and vibrant community. The St. Louis region bears a heavy social and economic burden from the thousands of babies born too early and too small. The failure to ensure that all mothers and babies are healthy costs the community the initial expenses to care for sick babies with advanced medical care as well as long term costs of social services and special education.

Reducing infant deaths will require a long-term commitment to improving the health of all women, ensuring access to health care for all women and children, incorporating mental health into our definition of 'health', and remaining vigilant in efforts to promote life-saving infant care practices.

The scope of investment needed to change the complex systems that impact women and children requires strategic coordination, support and participation from all sectors of the community; residents, businesses and employers, health and social service professionals, media, and civic, government and academic leaders.

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The Maternal, Child and Family Health Coalition is grateful to the Pi Beta Phi Alumnae of St. Louis / Sign of the Arrow for funding the printing of this report.

Partial funding for this report was made possible through grant **# H49 MC05017** from the Department of Health and Human Services, Health Resources and services Administration, Maternal and Child Health Bureau, Division of Healthy Start and Perinatal Health.