Preterm Birth in Illinois: Understanding the Problem, Forging a Solution

House Joint Resolution 111

November 1, 2012

RECOMMENDATIONS FROM THE PERINATAL ADVISORY COMMITTEE

ILLINOIS DEPARTMENT OF PUBLIC HEALTH

SUMMARY OF FINDINGS

The Problem: **Preterm Birth and its Consequences**

Preterm birth affects one in eight babies in the United States, and 21,168 infants per year in Illinois (National Center for Health Statistics, 2009). Forging solutions to reduce preterm birth rates and improve pregnancy outcomes is one of the most urgent problems in maternal child health today. Infants born prematurely, or before 37 weeks completed gestation, suffer from increased risk of lifelong disabilities, including cognitive and learning problems, cerebral palsy, neurological problems, respiratory problems, and vision and hearing loss. These infants also are at an increased risk for Sudden Unexpected Infant Death (SUID), conditions such as Attention Deficit-Hyperactivity Disorder (ADHD), and recurrent hospitalizations. Preterm birth is the leading cause of infant mortality and newborn death. The significant and persistent racial, ethnic, and socioeconomic disparities in the rate of babies born too soon are deeply concerning. The consequences of an infant born prematurely have considerable emotional and financial impact on families, communities, and public-sector services. According to the Institute of Medicine, the annual societal economic burden associated with preterm birth in the United States was at least $26.2 billion in 2005, or $51,600 per infant born preterm.

Purpose of this Report

With a renewed national focus on prematurity by public health organizations, and the severe global toll of preterm birth, the Illinois General Assembly passed in 2010 House Joint Resolution 111. The resolution stipulated that the Perinatal Advisory Committee of the Illinois Department of Public Health submit a written report by November 2012 providing findings and recommendations concerning reducing preterm births in Illinois. To catalyze nationwide action toward accomplishing this goal, the Association of State and Territorial Health Officials (ASTHO), in partnership with the March of Dimes, challenged all state health officials in early 2012 to reduce preterm birth by 8percent by 2014. The Illinois Department of Public Health accepted the challenge to initiate and accelerate programs and policies to reduce Illinois' high rate of preterm birth. This report is intended to raise the awareness of policy makers, advocacy groups, providers, and the public about this serious problem, and to recommend proven strategies that will move Illinois towards the reduction of premature births. Specifically, the intent of this report is to:

- Provide legislators with an overview of the extent and costs of preterm births. Identify known medical and social risk factors of preterm birth.
- Make recommendations for evidence-based medical and public health strategies, as well as state system and policy changes, to reduce preterm births.

It is important to bear in mind prematurity is a complex health problem; it is not a single disorder, and therefore does not have a single solution. It is estimated that as many as 50 percent to 70 percent of preterm births have no known cause (Iannucci, Tomich and Gianopoulos, 1996; Meis, Ernest, and Moore, 1987; Slattery and Morrison, 2002). Multiple, interrelated influences, including medical, biological, genetic, individual behavioral and psychosocial factors, and environmental considerations; rates of multiple births; and system issues must all be examined. The

recommendations made in this report will focus on those causes and risk factors that are known and can be ameliorated given adequate resources. Coordination and collaboration among disciplines and those state and local agencies and community-based organizations that aim to improve pregnancy outcomes in Illinois are essential.

Recommendations

Because of the multi-factorial causes of preterm birth, recommendations to reduce preterm birth must incorporate a combination of clinical and public health interventions at every level, including policy and system interventions. We also need consistent, coordinated approaches to collect and retrieve state perinatal data for public health planning and community assessments, health policy research, quality assessment and performance improvement, public health surveillance and disease registries, and for informing public policy and legislation. What follows are seven recommendations, each with background, rationale, and required actions. Details about the recommendations may be found in the document.

I. CONSOLIDATE AND LINK DATA SYSTEMS T0 BETTER UNDERSTAND AND PREVENT PREMATURE BIRTHS IN ILLINOIS

Recommendation: Create a comprehensive dataset to enable a more systematic approach to understanding prematurity in Illinois.

II. ELIMINATE ELECTIVE (NON-MEDICALLY INDICATED) DELIVERIES BEFORE 39 WEEKS GESTATIONAL AGE

Recommendation: Provide resources to ensure Regional Perinatal Centers and all network hospitals implement a "hard stop" policy to eliminate elective, early term deliveries. Provide necessary clinician education to implement the change process and to monitor progress through ongoing data collection and rapid return of data reports. Implement a statewide consumer awareness campaign directed to women of child-bearing age consistent with the message that "healthy babies are worth the wait."

III. IDENTIFY MEDICAID-ELIGIBLE WOMEN AT RISK OF ADVERSE PREGNANCY OUTCOMES (e.g., women who have had prior preterm birth, perinatal loss, low birthweight infant, baby with birth defect, or present with multiple gestations). PROVIDE ENHANCED PRENATAL CARE THAT LINKS THESE WOMEN TO A MEDICAL HOME AND CARE COORDINATOR AND PRENATAL EDUCATION.

Recommendation: Create and implement a risk-assessment system for identifying early in pregnancy Medicaid-eligible women who are at risk for preterm birth. Provide coordinated, enhanced prenatal care with a maternity medical home provider and intensive care management. Integrate clinical care with nutritional counseling; social support; referrals to appropriate community resources; psychosocial counseling; and coordinated links to WIC, smoking cessation, substance abuse, or other relevant programs that may reduce risk.

IV. INCREASE NUMBER OF SITES AND ENHANCE IMPLEMENTATION OF CENTERINGPREGNANCY® GROUP MODEL OF PRENATAL CARE IN COMMUNITIES WHERE INCIDENCE OF ADVERSE PREGNANCY OUTCOMES IS HIGH

Recommendation: Pursue sources of funding to increase the capacity of current CenteringPregnancy® sites that have been approved by Centering Healthcare Institute (CHI), and expand number of sites to additional Illinois communities where incidence of adverse pregnancy outcomes is high. Consider augmenting content of CenteringPregnancy® groups for women at risk of preterm delivery, such as women with gestational diabetes or hypertension. Monitor outcomes of pregnancies of women participating in this group model of care and compare with outcomes of comparable women in traditional care.

V. PRECONCEPTION, WELL-WOMAN, AND INTERCONCEPTION CARE STRATEGIES

Recommendation: Provide well-woman preventive care for uninsured and underinsured women, and expand availability, access to, quality of, and utilization of a medical home for care during the pre and interconception periods.

VI. ENHANCE REGIONAL PERINATAL SYSTEM TO ENSURE HIGH QUALITY CARE STANDARDS ARE CONSISTENTLY APPLIED IN ALL DELIVERING HOSPITALS AND PREGNANT WOMEN DELIVER THEIR BABIES AT "THE RIGHT PLACE AND THE RIGHT TIME."

Recommendation: Provide additional support, personnel, resources, and expertise to develop, implement, and monitor perinatal quality improvement initiatives through the development of a Perinatal Quality Collaborative working in tandem with the Regional Perinatal System. Assess current perinatal system functioning to ensure pregnant women deliver at the right place at the right time and that consistent, high quality perinatal care is provided to mothers and babies.

VII. ADVOCATE FOR INITIATIVES THAT PROMOTE SOCIAL EQUITY AND FOCUS ON REDUCING LONGSTANDING RACIAL AND ETHNIC DISPARITIES IN PREGNANCY OUTCOMES

Recommendation: Raise awareness in the health community of the effects of racism and marginalization on health outcomes. Ensure equal access to culturally-sensitive, patient-centered medical homes coupled with social support and linkages to community resources. Collaborate with and build upon efforts across the state to invest in communities, to provide job-skills training, adequate housing, access to nutritional food sources, and family-centered support services. Train the health care workforce in culturally and linguistically appropriate service delivery. Invest research dollars in determining strategies that are effective in increasing healthy pregnancy outcomes in women of color.

Perinatal Advisory Committee

Howard T. Strassner, MD, Chairman
Maternal Fetal Medicine Specialist

J. Roger Powell, MD, Vice Chair
Obstetrician

Janet Albers, MD
Family Practice

Bree Andrews, MD, MPH
Neonatologist, Neuro-development

Richard Besinger, MD
Maternal Fetal Medicine Specialist

Harold R Bigger, MD
Neonatologist

Cathy Gray, RN, MBA
Genetics Representative

Dennis T. Crouse, MD, PhD
Neonatologist

Leonard Gibeault, MSW
Ex Officio

José L. González, MD
Neonatologist

William Grobman, MD
Maternal Fetal Medicine Specialist

Edward Hirsch, MD
Family Practice

Janet Hoffman, RD
Dietitian

Robín L. Jones, MD
Maternal Mortality Review Committee

Susan Knight, MA
Consumer Representative

Omar LaBlanc, MSW, MPH
Social Service

Phyllis Lawlor-Klean, RNC, MS
Advanced Practice Nurse

Janine Lewis, MPH
Consumer Representative

Nancy Marshall
Respiratory Practitioner

Bruce Merrell
Hospital Administrator

Barbara Prochnicki, RN, MS
Nurse

David Crane
Hospital Administrator

Charlene Wells, RN, BS
Illinois Department of Public Health

Prematurity Task Force, Consultants, and Contributors

Harold R Bigger, MD, Chairman
Perinatal Advisory Committee Member

Richard Besinger, MD
Perinatal Advisory Committee Member

Ian Grable, MD
NorthShore University Health System

Ann Borders, MD
Perinatal Advisory Committee
Subcommittee Member

Dennis Crouse, MD, PhD
Perinatal Advisory Committee Member

Jacquetta Ellinger
Illinois Department of Healthcare and
Family Services

Claudia Fabian
Illinois Department of Public Health

Jane Fornoff
Illinois Department of Public Health

State Rep. Robyn Gabel
18th District

Susan Knight, MA -Vice Chairperson
March of Dimes – Illinois Chapter

Janine Lewis, MPH
Illinois Maternal and Child Health
Coalition

State Rep. JoAnn D. Osmond
61st District

Glendean Sisk
Illinois Department of Human Services

State Sen. Donne E. Trotter
17th District

Charlene Wells
Illinois Department of Public Health

Linda Wheal
Illinois Department of Healthcare and
Family Services

Maripat Zeschke
UIC Perinatal Center

Arden Handler, DrPH
Professor
Community Health Sciences and
Maternal-Child Health
University of Illinois School of Public
Health

HOUSE JOINT RESOLUTION 111

WHEREAS, Nearly one in 8 babies born in Illinois is born preterm, 13.3% of Illinois babies in total; and

WHEREAS, The percentage of preterm births in Illinois has increased by 15%; and

WHEREAS, The rate of preterm births in Illinois is highest for African-American infants (19.3%) followed by Native Americans (15.6%), Hispanics (12.1%), Caucasians (11.9%) and Asians (10.7%); and

WHEREAS, African-American infants (19.3%) are about two times as likely as Asian infants (10.7%) to be born preterm; and

WHEREAS, Major risk factors for preterm and very preterm births include multiple births, history of preterm delivery, stress, infection, smoking, and illicit drug use; and

WHEREAS, In the United States, preterm birth or low birth weight is the 2nd leading cause of all infant deaths during the first year of life and the leading cause of infant deaths among African-American infants; and

WHEREAS, The global toll of preterm births is severe; and an estimated 28% of the 4 million annual neonatal deaths are due to preterm births; and

WHEREAS, Children born preterm have higher rates of learning disabilities, cerebral palsy, sensory deficits, and respiratory illnesses compared to children born at term; and

WHEREAS, To be most effective, preventive strategies should involve strengthening existing reproductive, maternal, newborn, and child health care programs to encourage synergies of preterm birth care while, at the same time, stimulating fresh thinking and innovative new approaches to prevention; therefore, be it

RESOLVED, BY THE HOUSE OF REPRESENTATIVES OF THE NINETY-SIXTH GENERAL ASSEMBLY OF THE STATE OF ILLINOIS, THE SENATE CONCURRING HEREIN, that we urge the Perinatal Advisory Committee within the Illinois Department of Public Health to investigate how Illinois can reduce the incidence of preterm births in Illinois; and be it further

RESOLVED, That the Perinatal Advisory Committee shall consult with a representative of the Illinois Department of Human Services, a representative of the Illinois Department of Healthcare and Family Services, a representative of an organization whose main focus is on preterm births; 2 members of the Illinois House of Representatives, one of whom shall be named by the Speaker of the House, and one of whom shall be named by the Minority Leader of the House; and 2 members of the Senate, one of whom shall be named by the President of the Senate and one of whom shall be named by the Minority Leader of the Senate; and be it further;

RESOLVED, That the Perinatal Advisory Committee shall, in a written report that is to be delivered to the General Assembly on or before November 1, 2012, make findings and recommendations concerning reducing preterm births in Illinois; and be it further

RESOLVED, That a copy of this resolution be presented to the Director of the Department of Public Health.

Table of Contents

Prematurity in Illinois: Understanding the Problem, Forging a Solution

Introduction

Preterm birth affects one in eight babies in the United States, and 21,168 infants per year in Illinois (National Center for Health Statistics, 2009). Forging solutions to reduce preterm birth rates and to improve pregnancy outcomes is one of the most urgent problems in maternal child health today. Infants born prematurely, or before 37 weeks completed gestation, suffer from increased risk of lifelong disabilities, including cognitive and learning problems, cerebral palsy, neurological problems, respiratory problems, and vision and hearing loss. These infants are also at an increased risk for conditions such as Sudden Unexpected Infant Death (SUID), Attention Deficit-Hyperactivity Disorder (ADHD), and recurrent hospitalizations. Preterm birth is the leading cause of infant mortality and newborn death. The significant and persistent racial, ethnic, and socioeconomic disparities in the rate of babies born too soon are deeply concerning. The consequences of an infant born prematurely have considerable emotional and financial impact on families, communities, and public-sector services.

Most pregnancies last approximately 40 weeks. Infants born between 37 and 42 completed weeks of pregnancy are called full term. Babies born before 37 completed weeks of pregnancy are called premature or preterm. Infants born between 34 and 36 weeks gestation account for more than 70 percent of preterm births, and are known as late-preterm births. Infants born during the late-preterm period account for most of the increase in preterm births in the U.S. over the past 20 years. About 12 percent of preterm infants are born between 32 and 33 weeks gestation, about 10 percent between 28 and 31 weeks, and about 6 percent at less than 28 weeks gestation (Martin, et al, 2006). Infants born between 32-33 weeks, 28-31 weeks, and less than 28 weeks gestation have neonatal (in the first 28 days of life) mortality rates of 19, 65, and more than 183 times greater than infants born at full-term.

Purpose of this Report

With a renewed national focus on prematurity by public health organizations, and the severe global toll of preterm birth, the Illinois General Assembly passed House Joint Resolution 111 in 2010. The resolution stipulated that the Perinatal Advisory Committee of the Illinois Department of Public Health submit a written report by November 2012 providing findings and recommendations concerning reducing preterm births in Illinois. To catalyze nationwide action toward accomplishing this goal, the Association of State and Territorial Health Officials (ASTHO), in partnership with the March of Dimes, challenged all state health officials in early 2012 to reduce preterm birth by 8 percent by 2014. The Illinois Department of Public Health accepted the challenge to initiate and to accelerate programs and policies to reduce Illinois' high rate of preterm birth. This report is intended to raise the awareness of policy makers, advocacy groups, providers, and the public about this serious problem, and to recommend proven strategies that will move Illinois toward the reduction of premature births. Specifically, the intent of this report is to:

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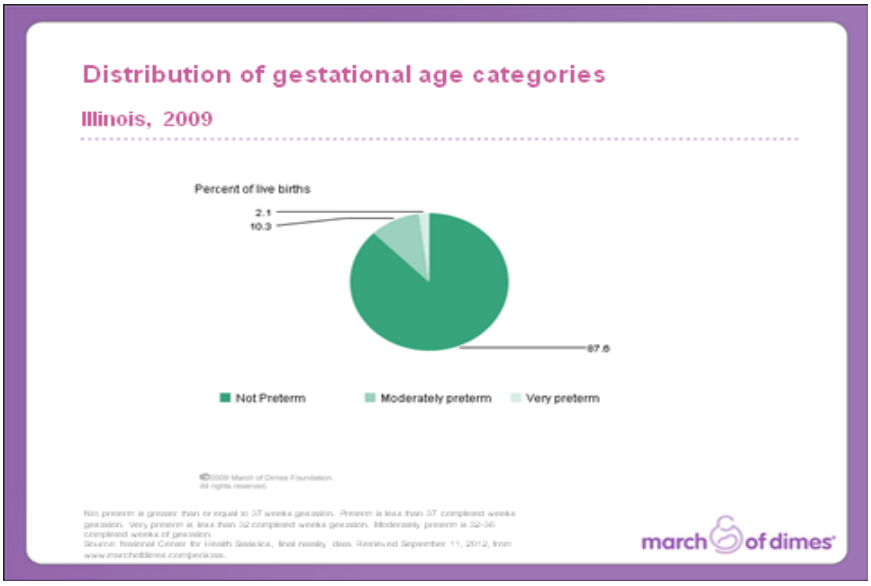
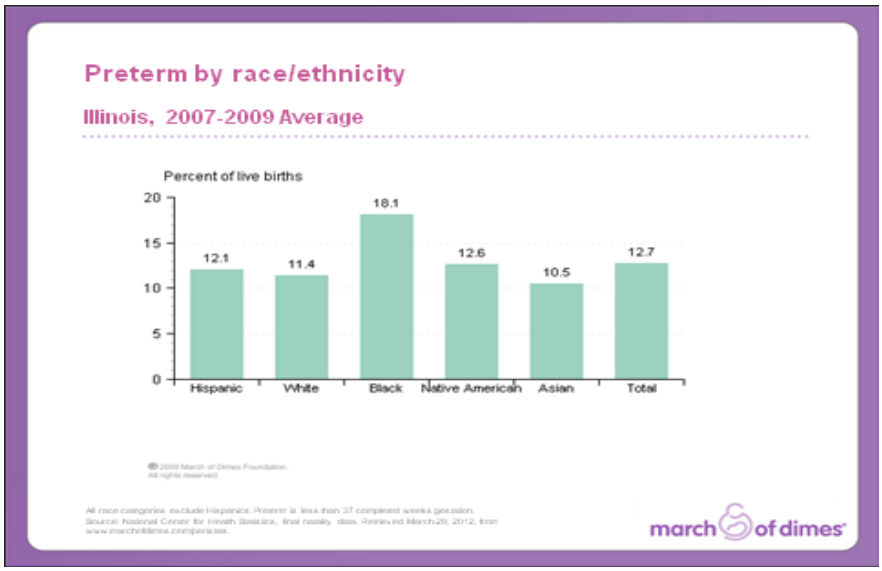
It is important to bear in mind prematurity is a complex health problem; it is not a single disorder, and therefore does not have a single solution. It is estimated that as many as 50 percent to 70 percent of preterm births have no known cause (Iannucci, Tomich and Gianopoulos, 1996; Meis, Ernest, Moore, 1987; Slattery, Morrison, 2002). Multiple, interrelated influences, including medical, biological, genetic, individual behavioral, psychosocial factors and environmental considerations; rates of multiple births; and system issues must all be examined. The recommendations made in this report will focus on those causes and risk factors that are known and can be ameliorated given adequate resources. Coordination and collaboration among disciplines and those state and local agencies and community-based organizations that aim to improve pregnancy outcomes in Illinois are essential.

Preterm Births in Illinois

In 2009, there were 21,168 preterm births in Illinois, representing 12.4 percent of live births, or 1 in 8 infants. Between 1998 and 2008, the rate of infants born preterm in Illinois increased 5 percent, although, as is true nationally, there has been a recent slight decrease in babies born too soon.

The rate of preterm birth in Illinois is highest for black infants (18.1%), followed by Hispanics (12.1%), Native Americans (12.6%), whites (11.4%), and Asians (10.5%). Black infants were almost two times as likely as Asian infants to be born preterm during 2007-2009. Mirroring national perinatal disparities, the average infant mortality rate among Illinois black infants was more than double that for whites (13.4 for blacks compared to 5.7 for whites) from 2006-2008. (National Center for Health Statistics, 2008)





Compared with singleton births (one baby), multiple births in Illinois were about six times as likely to be preterm in 2009 (59.2% vs.10.5%) (National Center for Health Statistics, 2009). More than 70 percent of premature infants are born between 34 and 36 weeks gestation.

Costs of Preterm Birth

Preterm birth touches everyone. The emotional costs for families can be devastating and life-changing. In a study published in the *Journal of Early Human Development* among mothers of infants born at less than 32 weeks gestation, 40 percent had symptoms of significant depression. The financial costs of preterm birth affect all of us. **Based on the Institute of Medicine's estimates, the annual societal economic burden associated with preterm birth in the United States was at least $26.2 billion in 2005, or $51,600 per infant born preterm** (Institute of Medicine, 2006).

Nearly two-thirds of the societal cost of preterm birth is accounted for by the costs of **medical care**. In 2005, the share that medical care services contributed to the total cost was $16.9 billion ($33,200 per preterm infant), with more than 85 percent of those medical care services delivered in infancy. **Maternal delivery costs** contributed another $1.9 billion ($3,800 per preterm infant). **Early intervention services** cost an estimated $611 million ($1,200 per preterm infant), whereas **special education services** associated with a higher prevalence of four disabling conditions, including cerebral palsy, mental retardation, vision impairment, and hearing loss, among premature infants added $1.1 billion ($2,200 per preterm infant). **Lost household and labor market productivity** associated with those disabilities contributed $5.7 billion ($11,200 per preterm infant) (Institute of Medicine, 2006).

Using the Institute of Medicine's calculation of the averaged societal economic burden associated with preterm birth of $51,600 per premature infant, **the cost to care for the 21,168 infants born too soon in Illinois in 2009 is estimated to amount to more than $ 1.09 billion for the first year of life ($51,600 X 21,168 = $1,092,268,800).**

The cost to employers for maternal health care, including prenatal care, delivery, and postpartum care, increases 75 percent with a diagnosis of prematurity. The direct health care costs to employers for a preterm baby, from birth through the first year of life, average $49,033 – almost 11 times higher than the average $4,551 for a healthy baby (Institute of Medicine, 2006).

Of significant note, in 2009 in Illinois, 53.9 percent of all births were paid for by Medicaid or other public programs (Medicare for women on disability), accounting for more than 89,621 deliveries (Hamos, 2012). **The total cost for Medicaid covered women for prenatal care, delivery, postpartum care, and baby's first year of life in 2009 was $890,364,285. While preterm births comprise less than 10 percent of babies born to moms covered by Medicaid in Illinois, they account for 50 percent of the total costs. More than 39 percent of births covered by the Illinois Department of Healthcare and Family Services (IDHFS) in 2009 were considered "non-normal"**(i.e., premature, low birth weight, very low birth weight, and infant death). The almost 40 percent of IDHFS-covered births that were non-normal accounted for 70 percent of the total birth costs covered ($626,674,584) (Hamos, 2012). While very low birth weight (VLBW) infants represent just over 1 percent of births, they account for almost 59 percent of the average costs of births through first year of life.

Consequences of Babies Born Too Early

Preterm birth is the leading cause of newborn death. Those that survive face an increased risk of lasting disabilities, such as cognitive and learning problems, cerebral palsy, respiratory problems, and vision and hearing loss. These infants also are at an increased risk for conditions, such as SUID, ADHD, and re-hospitalizations. Two recent studies suggest preterm infants may be at increased risk of symptoms associated with autism (social, behavioral, and speech problems) (Schendel and Bhasin, 2008). Studies have shown infants born very preterm may be at increased risk of certain adult health problems, such as diabetes, high blood pressure, and heart disease (Hovi, et al., 2007). Compounding the physical, cognitive, and mental health risks of preterm births, research has suggested premature infants are at an increased risk of being maltreated by their caregivers, particularly if there are parental risk factors, such as lack of education or lower socioeconomic status (Hunter, Kilstrom, and Loda, 1978; Strathearn, Gray, O'Callaghan and Wood, 2001; Fullar, 2008). This appears to be particularly true for infants with prolonged stays in neonatal intensive care units (NICU), or whose caregivers were unable to spend significant time with them during their hospitalizations (Carroll, Doria, and Paul, 2007; Lynch and Roberts, 1977). Additionally, infants who are discharged from NICUs needing continued technology-dependent care, such as those who need monitoring for apnea or who receive tube feedings, are at increased risk of abuse or neglect.

The ongoing health issues faced by these infants as they grow through childhood into adulthood compound the health, financial, personal, family, and societal impacts of preterm birth. Preterm birth has been associated with lower levels of education, lower income levels, lower rates of starting a family, and a higher rate of receipt of Social Security benefits. For those individuals who also experienced maltreatment as an infant, there is an even greater risk of negative life outcomes as adults (Fullar, 2008). Internationally known researcher Dag Moster, MD, PhD, states:

"The increased prevalence of medical disabilities, learning difficulties, and behavioral and psychological problems among surviving preterm infants has raised concerns that these infants may have difficulties coping with adult life" (Moster, Lie and Markestad, 2008).

Medical Risk Factors for Preterm Birth

While 70 percent of preterm births are caused by spontaneous preterm labor, either by itself or following spontaneous premature rupture of membranes, the remaining 30 percent are caused by fetal or maternal indications for preterm delivery, such as preeclampsia, antepartum bleeding, multiple gestations, and fetal and maternal medical problems. The latter excludes preterm births resulting from C-sections or inductions without medical indications (Slattery and Morrison, 2002).

Spontaneous preterm labor is the most common final precursor leading to preterm birth, but the underlying causes are poorly understood. Until the process of labor and preterm labor is better understood, effective strategies to dramatically reduce preterm births will be limited and primarily rely on reducing known risk factors associated with preterm labor. Many factors are not modifiable. Other factors are potentially modifiable by medical and public health intervention, but few studies showing the efficacy of specific interventions exist.
According to the Institute of Medicine report, a number of medical conditions, such as hypertension, diabetes, cardiac disease, asthma, and obesity, have been linked to increased risk for adverse pregnancy outcomes (Institute of Medicine, 2002). Cigarette smoking has been found to be related to preterm birth and an increased risk of low birth weight (Shiono, Klebanoff, and Rhoads, 1986). Cocaine use has also been associated with an increased risk for preterm birth (Behrman and Butler, 2006). Other risk factors include late or no prenatal care, short interpregnancy intervals, anemia, bacteriuria/urinary tract infection, genital infection, and high levels of personal stress.

Infection and inflammation also loom large as risk factors for preterm birth. Microbiologic studies suggest infection may contribute to approximately 25 percent of preterm births. However, antibiotic treatment of these infections has not revealed a decreased rate of preterm birth, suggesting that the infections alone are not causal or that the treatments have been insufficient (Muglia and Katz, 2010).

Three major factors have been shown to increase the risk of preterm birth. Interventions directed at these risk factors could have an impact on the prematurity rate. These risk factors include:

(1) Prior history of preterm birth
(2) Multiple gestations
(3) Short cervical length

Prior Preterm Birth

The most significant risk for spontaneous preterm birth (PTB) is a prior history of preterm delivery. A history of multiple PTBs places a woman and her infant at even higher risk.

Risk of recurrent preterm birth (PTB) in a second pregnancy

Obstetrical history	*Risk of PTB in next pregnancy*	*Risk of PTB before 28 weeks gestation*
No Prior PTB	9%	
Prior PTB	22%	
Prior PTB at 23-27 weeks		5%
Prior PTB at 28-34 weeks		3%
Prior PTB at 35-36 weeks		1%

(Mercer, Goldenbert, Moawad, Meis, Iams, Das, Caritis, Miodovnik, Menard, Thumau, Dombrowski, Roberts, and Mcnellis, 1999)

Risk of recurrent preterm birth (PTB) in a third pregnancy

Obstetrical history	Risk of PTB
Two Prior PTBs	42%
Both at 32-36 weeks	33 %
Both at less than 32 weeks	57%
Term birth followed by PTB	21%
PTB followed by term birth	13%
Two prior term births	5%

(McManemy, Cooke, Amon, and Leet, 2007)

Of the 171,077 infants born in Illinois in 2009, 2,615 babies were born to women with a previous premature birth or small-for-gestational-age (SGA) infant (Illinois Department of Public Health, 2009). Of the 17,109 preterm births in Illinois that year as reported by the Illinois Department of Public Health (IDPH), there were 793, or approximately 5 percent, born to women with a previous premature birth or SGA infant (IDPH, e-correspondence, 2012).

Multiple Pregnancies (women pregnant with twins, triplets, or more)

The use of assisted reproductive technology (ART) procedures has resulted in increased number of multiple gestations over the last 20 years. Pregnancies with twins, triplets, and higher order fetuses are associated with prematurity. The higher the order, the more likely the babies are to be born preterm.

The multiples delivery rate per 1,000 live births in 2009 in Illinois was 38.4 compared to the national rate of 34.8. Between 1999 and 2009, the multiple birth rate in Illinois increased more than 14 percent.

The rate of twin deliveries in 2009 in Illinois was 36.6 (33.2 nationally) and has followed a trend similar to all multiple deliveries (National Center for Health Statistics, 2009). The rate of triplet and higher order deliveries in 2009 was 0.18 per 1,000 live births in Illinois compared to the national average of 0.15. This is a 30 percent decrease over the previous decade, occurring primarily after the rate peaked in 2003 at 0.26.

The decline in higher order multiple deliveries is due to a change in clinical care of women receiving ART. Because the transfer of multiple gestation embryos leads to increased pregnancy success, but also an increased risk of preterm birth and related neonatal morbidity and mortality, recommendations were made by the American Society for Reproductive Medicine to reduce the number of embryos transferred per cycle. While limiting the number of fetuses to two or three, the rate of higher order deliveries has declined considerably; however twin deliveries continue to rise.

Short Cervical Length

Compelling data indicate that a short cervical length is associated with a greater probability of preterm birth. Several promising studies suggest that treatment with vaginal progesterone may help to reduce premature birth in women with a short cervix. In randomized clinical trials, daily vaginal progesterone use reduced the risk of preterm birth by 45 percent in low risk women identified with short cervical length (Fonseca, Celik, Para, et al., 2007 and Hassan et al, 2011). For women with multiple gestations, progesterone has not been shown to reduce the chance of preterm birth, although it remains uncertain whether progesterone will benefit the subgroup of women with multiple gestations who have a short cervix. Active research is currently underway to determine whether universal screening of cervical length measurement by transvaginal ultrasound is cost-effective in predicting women who might be at risk for preterm birth. Recommendations in regard to use of vaginal progesterone to reduce risk of preterm birth among women with short cervical length are under debate as the efficacy of this intervention is further investigated.

Elective Early Term Deliveries (Deliveries between 37 and 0/7 weeks and 38 and 6/7 weeks that are not medically indicated)

While not technically preterm, infants delivered between 37 weeks and 39 weeks gestational age for non-medical indications also are at increased risk for neonatal morbidity and mortality and their associated emotional and financial costs. Despite long standing efforts by the American College of Obstetrics and Gynecology (ACOG) and more recently by the Joint Commission on Accreditation of Healthcare Organizations and the National Quality Forum, rates of non-medically indicated deliveries between 37 and 39 weeks gestation have continued to rise, particularly over the last decade, accounting for 10 percent to 15 percent of all deliveries. Most importantly, in the context of reducing preterm births, these deliveries are entirely preventable.

Other risk factors associated with preterm birth and low birth weight

Use of and exposure to cigarettes, alcohol, and illicit drugs during pregnancy are all associated with adverse pregnancy outcomes. Tobacco use while pregnant is associated with preterm birth, low birth weight, and increased pregnancy complications. Maternal depression and excessive stress during pregnancy are associated with inadequate prenatal care and poor nutrition and weight gain (March of Dimes, 2009; D'Angelo, Williams, Morrow, Morrow, Cox, Harris, Harrison, Posner, Richardson and Zapata, 2004). In a recent analysis conducted in Minnesota, mothers with a preterm infant were more likely to have five or more stressful life events within the previous year before the infant was born than women with full-term deliveries. Such stressful life events included emotional, financial, partner-related, and trauma related stressors (Minnesota Task Force on Prematurity, 2011). Intendedness of pregnancy and short spacing between pregnancies also are factors affecting healthy pregnancy outcomes.

IDPH has several programs that collect information about risk factors associated with preterm birth and low birth weight. The Pregnancy Risk Assessment Monitoring System (PRAMS) is a state, population-based surveillance system designed to monitor selected maternal behaviors and experiences that occur before, during, and after pregnancy among women who deliver live-born infants. The Behavioral Risk Factor Surveillance System (BRFSS) is a state-based system of health surveys that tracks health conditions and risk behaviors in the general population. The Adverse Pregnancy Outcome Reporting System (APORS) is a state, population-based surveillance system that collects information about deliveries where there are significant adverse outcomes, including very low birth weight. According to these programs in 2009:

- 21 percent of women in Illinois smoked cigarettes during the three months before they became pregnant, and 9 percent smoked during the last three months of pregnancy (PRAMS).
- 53 percent of women reported drinking alcoholic beverages on a weekly basis in the three months before becoming pregnant. That figure dropped to 7 percent during the last three months of pregnancy (PRAMS).
- While newborns are not routinely tested for drug exposure in Illinois, in 2008 approximately 1,691 babies were reported as drug-exposed; in 2009 there were 1,719; and in 2010, there were 1,598 babies (APORS).
- 29.4 percent of women reported having three or more stressors during the 12 months prior to delivery (PRAMS).
- 9.1 percent of Illinois women had a diagnosis of postpartum depression, with a higher incidence among women covered by Medicaid (11.2% v. 6.6% of non IDHFS women, BRFSS).

Multiple epidemiological studies have found associations between poverty, limited maternal education, young maternal age, unmarried status, inadequate prenatal care, and increased risk of preterm birth and low birth weight (Muglia and Katz, 2007). As noted earlier in this report, the rate of PTB among women of color is two times as high and the rate of recurrent PTB is four times as high as the rate among white women (Kriska, Polomar, Lee, et al., 2007). These differences persist even when controlling for other risk factors, such as socioeconomic status or access to care. Studies have revealed the contribution of mother's perceived experiences of racial discrimination and social stress to partially explain these disparities (Collins, David,

Handler, Wall and Andes, 2004). Women's cumulative stress impacted by a lifetime of discrimination takes a physical and emotional toll and is known as "the weathering hypothesis" (Geronimus, 1996). This is area in need of further exploration and understanding. Reducing persistent pregnancy outcome disparities among women of color must address not only health factors, but also factors related to living environment, educational and employment opportunities, access to healthy nutrition, and personal experiences.

Forging Solutions: Evidence-Based Recommendations to Reduce Prematurity in Illinois

The Committee on Understanding Premature Birth and Assuring Healthy Outcomes, convened by the Institute of Medicine, noted four key lessons about preterm birth:

- Preterm birth is "a complex expression of many conditions."
- Little is known about how preterm birth can be prevented.
- Racial and ethnic differences in pregnancy outcome are striking, but not fully understood.
- Infants born late preterm (34-37 weeks) and early term (between 37 and 39 weeks) are at increased risk for adverse developmental outcomes. If there is no medical indication for delivery prior to 39 weeks gestation, such deliveries should be avoided (Behrman, 2006).

Because of the multi-factorial causes of preterm birth, **recommendations to reduce preterm birth must incorporate a combination of clinical and public health interventions at every level, including policy and system interventions.** We also need consistent, coordinated approaches to collect and retrieve state perinatal data for public health planning and community assessments, health policy research, quality assessment and performance improvement, public health surveillance and disease registries, and for informing public policy and legislation.

While we have made progress in understanding causes and risk factors for prematurity, there continue to be uncertainties about the best way to prevent early birth. However, **we can focus our efforts on identifying women at risk of preterm birth and ensuring they get the comprehensive, quality care, education, resources, and support needed to increase the likelihood of a healthy pregnancy.** Therefore, the recommendations made in this report will focus on impacting those causes and risk factors amendable to intervention and can be ameliorated given adequate resources and collaboration among disciplines and those at state and local agencies and community-based organizations that focus on improving pregnancy outcomes in Illinois.

Recommendations

I. CONSOLIDATE AND LINK DATA SYSTEMS T0 BETTER UNDERSTAND AND PREVENT PREMATURE BIRTHS IN ILLINOIS

Recommendation: Create a comprehensive dataset to enable a more systematic approach to understanding prematurity in Illinois.

Background

Currently, data to examine the distribution and determinants of premature birth in Illinois are available in multiple, disparate datasets housed in several state agencies. Each dataset has its own data collection processes and was designed for a distinct purpose or program. Some data elements in a particular data system are redundant with those available in another system, while other data elements are uniquely available in only one system. Moreover, data systems with prematurity-related data vary in terms of the records they include, the timeliness of the data extraction/analysis processes, and the reporting capabilities of the system. Some of the data systems include only those women who have delivered a preterm infant, some include only women whose deliveries were paid for by Medicaid, some include a sample of all women giving birth in Illinois, and some include all women giving birth in Illinois.

The fragmentation of the available data makes it difficult to implement a focused, analytic strategy and, subsequently, a targeted set of interventions with measured outcomes. The relevant data sources need to be reconciled and linked as appropriate in order to fully describe and analyze prematurity in Illinois with the goal of designing and implementing effective programs and policies. The table below illustrates the range of data sources with prematurity-related data in Illinois, including examples of the particular contributions of each. The listing in the table is not exhaustive, but shows the major sources of available, but underutilized data.

Examples of Data Sources with Information about Premature Births in Illinois

Data Source	Inclusion	Certain Unique Elements	Agency Home
Perinatal Mortality Review database	Perinatal deaths	Clinical assessment of preventability	IDPH
PRAMS	Probability sample of all births, with oversampling of low birthweight infants	Prenatal care provider discussions, barriers to prenatal care, pregnancy intendedness	IDPH
Birth Certificate	All resident births	Prenatal care initiation and visits	IDPH
Infant Death Certificate	All infant deaths	Cause of death	IDPH
Hospital Discharge Data	All hospital births	Diagnostic and other clinical information during hospital stay, hospital cost information	IDPH

Medicaid Claims	All births covered by Medicaid	Diagnostic and other clinical information during prenatal period, prenatal care cost information	IDHFS
Cornerstone	Participants in state programs	Information about participation in WIC, family case management, and high risk infant follow-up	IDHS

Rationale

Creation of a comprehensive dataset will enable a more systematic approach to understanding prematurity in Illinois. For example, rates of prematurity for all deliveries in Illinois and for multiple subpopulations, as well as consideration of various combinations of other factors, will be possible. Geographic analysis, analysis by Regional Perinatal Center, and time trend analysis would be possible with a comprehensive dataset. In addition, such a dataset would permit flexible and timely responses to quality improvement issues as they arise. The goal of this effort is to examine the data for Illinois as a whole, by geography, and also by Regional Perinatal Network in order to identify possible prevention and intervention strategies, including improvements in the quality of care. Illinois delivery hospitals are organized by 10 Regional Perinatal Networks. Further information on the Regionalization of Perinatal Networks is discussed in Recommendation VI.

A systematic approach to examining and documenting the patterns of prematurity in Illinois provides the opportunity to ask and answer relevant questions, leading to better targeting of programs, increases in cost-effectiveness, and improvement in both health care provided and public awareness.

Required Actions

- Convene Perinatal Data Task Force with representation from IDPH, IDHFS and IDHS, along with key maternal and child health research, academic, and epidemiological stakeholders to create a comprehensive dataset.
- Design a dataset useful for tracking birth events, perinatal morbidity and mortality trends, and hospital discharge outcomes. Tailor data set to enable identification of perinatal patterns, outcomes, and costs for the development of population-based, quality improvement initiatives.
- Create a database (Public Health Node) to allow clinical and community-based providers to access the data in real time/or quickly thereafter.
- Link population datasets to clinical data information systems to create a comprehensive system that captures data on infant outcomes and maternal health before, during, and after pregnancy; use validated, consistent performance measures to ensure uniform, comparable data as recommended by TIOP III (March of Dimes, 2011).
- Provide adequate human resources including maternal and child health epidemiologists and data analysts to increase capacity, utility, and efficiency of data collection and analysis. Enhance current maternal and child health epidemiology skills and workforce capacity. Evaluate existing sources of data for quality, representativeness, and

timeliness and provide resources to make appropriate improvements.

VIII. ELIMINATE ELECTIVE (NON-MEDICALLY INDICATED) DELIVERIES BEFORE 39 WEEKS GESTATIONAL AGE

<u>Recommendation:</u> Provide resources to ensure Regional Perinatal Centers and all network hospitals implement a "hard stop" policy to eliminate elective, early term deliveries. Provide necessary provider education to implement the change process and to monitor progress through ongoing data collection and rapid return of data reports. Implement statewide consumer awareness campaign directed to women of child-bearing age consistent with the message that "healthy babies are worth the wait."

Background

Elective deliveries between 37 and 39 weeks gestation have been increasing in the last 15 years, and account for more than 17.5 percent of live births in the U.S. (Davidoff, 1992). Rates of C-section deliveries, which entail increased risk to the mother, have risen to more than 27 percent (Lawrence, 2012). In 1982, ACOG went on record stating non-medically indicated deliveries should not occur before 39 completed weeks gestation. It has been well documented that babies born between 37 and 39 weeks have increased risk of respiratory, feeding, developmental, and neurological problems. Babies born electively before 39 weeks gestation spend more time in NICU, have longer hospital stays, and are more likely to be readmitted to the hospital, driving up medical costs. Because these non-medically indicated deliveries are generally performed for convenience reasons, they are entirely preventable. In Illinois, the March of Dimes, the Illinois Maternal Child Health Coalition, Quality Quest of Illinois, and the Midwest Business Group on Health, the Illinois departments of Public Health and Healthcare and Family Services, and the Regional Perinatal Centers have begun to make progress in eliminating this unnecessary practice. More decisive actions need to be taken including implementing a consistent mechanism for tracking and sustaining change in eliminating elective, early term deliveries.

Rationale

While changing physician practice and reducing consumer demand for elective deliveries is not easy, a number of quality improvement initiatives, including the March of Dimes Big 5 Quality Improvement project in Illinois and four other states, have demonstrated elective deliveries can be dramatically reduced. Implementation of a statewide quality improvement project, involving both providers and consumers, is relatively inexpensive, doable, and can demonstrate results within 12 months.

Coupling reimbursement reforms with quality improvement strategies can be an added incentive to providers. The Illinois General Assembly has begun to address this issue through Public Act 097-0689 (aka the SMART Act) and Illinois SB 2840. This act stipulates that as of July 1, 2012 IDHFS will pay for cesarean sections at the normal vaginal delivery rate unless a cesarean section is determined as medically necessary. The DRG codes related to cesarean section may be subject to utilization review prior to payment.

Potential Cost Savings: New York State Medicaid Program estimated a reduction of 2 percent in NICU stays related to avoiding induction or cesarean section without medical indications (NMI) for an approximate savings of $5 million per year (based on an average cost of $18,400 for a NICU stay) (New York State Department of Health, 2011). The Ohio Perinatal Quality Collaborative used quality improvement methods to reduce NMI deliveries in 20 maternity hospitals while avoiding 500 NICU admissions for an estimated savings of $11 million annually (Association of Maternal and Child Health Programs, 2012).

Required Actions

- Provide resources to Regional Perinatal Centers and all network hospitals to implement a "hard stop" policy to eliminate elective early term deliveries. Provide necessary education to providers to implement change processes, and to monitor progress through ongoing data collection and rapid return of data reports.
- Urge hospitals having difficulty implementing the change in policy and practice to participate in collaborative efforts, such as the MOD Quality Improvement Service Package or Quality Quest's Healthy Babies, Healthy Moms initiative.
- Require all hospitals to have a "hard stop" policy in place, a quality improvement process underway, and an ongoing quality indicator reflecting the percentage of elective, early-term deliveries reported to IDPH. Collect relevant data on the birth certificate so population-based progress can be measured and monitored over time.
- Engage the IDHFS to develop reimbursement incentives coupled with quality improvement activities to eliminate non- medically necessary deliveries among the Medicaid population.
- Conduct statewide, consumer awareness campaign using age-linguistic/cultural and literacy- appropriate information and tools ("Healthy Babies are Worth the Wait®").

IX. IDENTIFY MEDICAID-ELIGIBLE WOMEN AT RISK OF ADVERSE PREGNANCY OUTCOMES (e.g., women who have had prior preterm birth, perinatal loss, low birthweight infant, baby with birth defect, or present with multiple gestations). PROVIDE ENHANCED PRENATAL CARE THAT LINKS THESE WOMEN TO A MEDICAL HOME, CARE COORDINATOR, AND PRENATAL EDUCATION.

<u>Recommendation:</u> Create and implement a risk-assessment system for identifying early in pregnancy Medicaid-eligible women who are at risk for preterm birth. Provide coordinated, enhanced prenatal care with a maternity medical home provider and intensive care management. Integrate clinical care with nutritional counseling; social support; referrals to appropriate community resources; psychosocial counseling; and coordinated links to WIC, smoking cessation, substance abuse, or other relevant programs that may reduce risk.

Background

Illinois has made progress toward providing greater access to prenatal care for all low income women through the IDHFS Moms and Babies program. In addition, for the past 10 consecutive years, infants born to Medicaid-eligible pregnant women who participated in both the IDHS

Special Supplemental Nutrition Program for Women, Infants and Children (WIC) and Family Case Management (FCM) programs have had better pregnancy outcomes (lower preterm birth rates) than those who have not (IDHS, 2011). IDHS WIC and FCM serve more than 44 percent of all infants born in Illinois and more than 80 percent of Medicaid-eligible. These programs have saved lives and reduced costs.

In addition to the six federally funded Healthy Start programs in Illinois, the IDHS has supplemented WIC and FCM with programs targeted to women who are at greater risk for delivering a preterm baby through Targeted Intensive Prenatal Case Management, and the pilot project, Healthy Births for Healthy Communities, which focused on outreach. The funds for these programs had some matching federal dollars, although with recent budget reductions, funding has been significantly reduced. These more intensive interventions have demonstrated some promise of improved outcomes, but the case management programs often operate independently from the provision of clinical prenatal care. Coordination and communication between the clinical provider and case manager are often minimal which creates gaps and fragmentation of care.

In light of the need to reduce costs while improving pregnancy outcomes, IDHS is currently leading the effort, along with stakeholders across the state, to re-design the FCM program. The new design proposes to focus on pregnant Medicaid-eligible women at risk of adverse pregnancy outcomes, incorporate an evidence-based risk assessment, and strengthen communication between the pregnant woman's medical provider and case manager to link the patient with the broader health and social service system. Based on evidence from other states that have implemented similar integrated medical home partnership models, it is anticipated that women participating will have more comprehensive care and improved pregnancy outcomes.

Of note, the Center for Medicare and Medicaid Innovation released a request for proposal in the spring of 2012 for a Strong Start for Mothers and Newborns Grant to demonstrate the effectiveness of both the Maternity Home model of care and group prenatal care (CenteringPregnancy®) among other models. A consortium of Illinois organizations led by the Illinois Public Health Association, the University Of Illinois College Of Nursing and School of Public Health, and the Illinois Maternal and Child Health Coalition applied for the grant in August to test these models in communities with a high incidence of prematurity. A decision on whether the groups are to receive the grant is expected in October.

A Maternity Care Home model is an evidence-based model of enhanced prenatal care that engages a patient care coordinator who:

> *"guides patients through and around barriers in the complex healthcare system to help ensure timely diagnosis and treatment. The goals for a patient care coordinator are (to) eliminate barriers to care….and include a range of medical and social support services….to help link patients and families to services that optimize outcomes articulated in a patient-centered care plan. Care Coordination may address the social, developmental, educational, and financial needs of patients and family" (*West Virginia Health Improvement Institute).

Other states have successfully implemented pregnancy medical home models targeted toward women at risk of adverse pregnancy outcomes. North Carolina has implemented such a model incorporating physician incentives, expectations for reducing non-medically-indicated cesarean sections, eliminating elective early-term deliveries, and providing progesterone commonly known as 17p (17 alpha hydroxyprogesterone caproate) , to all women at risk of preterm delivery. While initial funds came from the state budget, it is anticipated that North Carolina will save more than $1 million in the first year, and is projected to save $9 million in the second year (Seattle Times, 2012).

According to IDPH, 2,615 of 171,077 babies born in Illinois in 2009 were to women who had a previous preterm or small-for-gestational-age infant (1.5%). Almost 5 percent, or 793 of 17,109 preterm births in 2009, had mothers with a prior preterm or small for gestational age infant. Through aggressive outreach to identify these women at risk early in pregnancy, link them with a pregnancy medical home and a care manager to provide support, education, and coordination with needed community resources, reductions in subsequent preterm births could be achieved.

Rationale

Given that preterm birth has multiple causes – both medical and social-environmental – implementation of an evidence-based strategy that addresses multiple risk factors in a coordinated way, while actively engaging the pregnant woman in her care, has great promise for pregnant Medicaid-eligible women. Furthermore, such strategies, when implemented by culturally-competent providers, may help reduce disparities in pregnancy outcomes. The IDHFS can realize significant cost savings while improving birth outcomes, if some of these recommendations contribute to healthier pregnancy outcomes.

Required Actions

- Implement a pregnancy medical home model for Medicaid-eligible women utilizing lessons learned from other states that have implemented such a model through coordinated efforts between IDHS and IDHFS. Incorporate the pregnancy medical home concept in IDHFS managed care contracts. Adjust reimbursement policies to compensate for the high-risk coordination required in the management of pregnant women at risk of adverse pregnancy outcomes.
- Implement an intensive outreach and case-finding plan to identify women at risk of preterm birth. Consider using community health workers, contacts in places of worship, block clubs, pre-school programs, and community organizations to connect pregnant women to pregnancy medical home.
- Utilize an incentivized screening process within a maternity medical home model to identify Medicaid-funded women at risk of adverse pregnancy outcomes. Promote comprehensive, coordinated prenatal care using a model that encompasses medical, social, and mental health services and/or referral. Promote family-centered care that is attuned to different cultures and ethnicities, and engages the patient in partnership with care providers. Coordinate efforts with IDHS, Title V, WIC programs, and IDHFS. Provide funds for start-up costs, recognizing that the program will eventually pay for itself and result in Medicaid savings when expected outcomes are achieved.

- Implement ACOG recommended prenatal care guidelines, including patient education and referrals to appropriate community resources developed through the Children's Health Insurance Program Reauthorization Act (CHIPRA) Child Health Quality Demonstration grant.
- Incentivize providers who adhere to evidence-based, standard- of- care practices for obstetrically at risk patients. Such practices may include, but are not limited to:

    - Identification of women with prior preterm birth and treat with 17P. Following ACOG Guidelines, provide weekly, intramuscular, 17-OH progesterone (17-P) for all women with singleton gestations with a prior spontaneous preterm birth regardless of cervical length. Research suggests that prophylactic use of weekly intramuscular progesterone between 16 weeks and 36 weeks in women who have experienced a prior preterm birth has resulted in 10 percent to 40 percent reduction of PTB in multiple controlled trials (Meis, Dombrowski, Moawad, et al., 2003 and ACOG, 2008). It is estimated, if all eligible women in the U.S. were treated with 17P, approximately 10,000 spontaneous PTBs would be prevented annually, reducing the U.S. PTB rate by approximately 2 percent.

      Estimated savings: Universal, appropriate use of 17P in women with prior PTB is estimated to reduce initial medical costs in the U.S. by more than $505 million, with an annual net savings of $452 million (Petrini, Callaghan, Klebanoff, et al., 2005). According to an analysis of the cost savings associated with 17P treatment regime, reduction in neonatal hospitalization is projected to save $3,800 per woman treated and save $7,500 in medical costs of children in the first 15 years of life. The savings generated far outweigh the costs of treatment (Bailit and Votruba, 2007).

    - Identification of women with singleton pregnancies and short cervical length and treat with vaginal progesterone gel in accordance with current ACOG guidelines. A number of studies have suggested the benefits of using progesterone gel for women with short cervical length to reduce the risk of preterm birth, which in some cases has reduced the risk by up to 50 percent (Cahill, Odibo, Caughey, et al., 2010 and Romero, Nicolaides, Conde-Agudelo, et al., 2011). The **potential cost savings** with this treatment is estimated to be $19 million for every 100,000 pregnant women screened (Werner et al., 2011).

    - Recognition and treatment of asymptomatic bacteruria via early urine cultures.

    - Provision of obstetric provider and consumer education regarding signs and symptoms of preterm labor so that it may be diagnosed and appropriate therapy provided, including transport to the appropriate level care facility for possible delivery and administration of antenatal corticosteroids when possible.

- Collaborate with consumer-friendly organizations, such as the March of Dimes and the Illinois Maternal and Child Health Coalition, to create and to implement a consumer education campaign focused on signs and symptoms of preterm labor. Use information and tools compatible with the culture, practices, and preferred language of the

consumers; consider use of social media, texting, and other communication modalities for women.

- Since only 58 percent of Medicaid women are seen for postpartum care, incentivize providers and hospitals to ensure new mothers have a postpartum visit appointment and a plan for outreach if mother does not show for appointment. Incentivize hospitals to provide discharge planning that links new mom with medical home for ongoing interconception care, family planning, including appropriate pregnancy spacing, treatment of chronic medical conditions, and reinforcement of healthy lifestyles. Link mother with family support and/or early intervention programs to enhance parent-infant attachment and provide anticipatory guidance to foster infant growth and development.

X. INCREASE NUMBER OF SITES AND ENHANCE IMPLEMENTATION OF CENTERINGPREGNANCY® GROUP MODEL OF PRENATAL CARE IN COMMUNITIES WHERE INCIDENCE OF ADVERSE PREGNANCY OUTCOMES IS HIGH

<u>Recommendation:</u> Pursue sources of funding to increase the capacity of current CenteringPregnancy® sites that have been approved by Centering Healthcare Institute (CHI), and expand number of sites to additional Illinois communities where incidence of adverse pregnancy outcomes is high. Consider augmenting content of CenteringPregnancy® groups for women at risk of preterm delivery, such as women with gestational diabetes or hypertension. Monitor outcomes of pregnancies of women participating in this group model of care and compare with outcomes of comparable women in traditional care.

Background

CenteringPregnancy® (CP) is a group model of prenatal care that brings together 8 to 12 pregnant women entering prenatal care in the same gestational period for health assessment, education, and support provided by a health clinician trained in pre-and postnatal care. In Illinois, there are 12 CHI certified sites, including federally qualified health centers, nurse-midwifery practices, and university-affiliated public health departments, which have been delivering prenatal care with this model for the past four years. In an evaluation conducted by the Illinois Chapter of the March of Dimes of CP sites funded through community grants, prematurity rates among women who participated were 50 percent lower than the Illinois rates (Illinois March of Dimes, 2011). A randomized control trial of the CP model found group care participants received higher quality of prenatal care, had fewer preterm births, were more likely to initiate breastfeeding, and had better prenatal knowledge than those participating in typical prenatal care (Ickovics, Kershaw, Wesdahl, et al., 2007). CP is listed among the Agency for Healthcare Research and Quality Innovations Exchange as an innovative strategy with strong evidence for success on improving birth outcomes and provider efficiency. As many women who have had positive pregnancy outcomes through CP are women of color, this model may be particularly useful in reducing pregnancy outcome disparities.

Rationale

CP has been a successfully implemented and evaluated model in Illinois in which participants have had positive, healthy pregnancy outcomes. The model has the potential to both improve quality of care and increase efficiency in the delivery of care. One study suggested group prenatal care increased productivity by as much as 30 percent and reduced appointment wait times by about two-thirds (Bronson and Maxwell, 2004), while simultaneously achieving high level of patient satisfaction. The Strong Start Initiative through Centers for Medicare and Medicaid Services has identified CP as a promising model to improve prenatal care and reduce costs, as has the March of Dimes. While the model is primarily designed for women who are not medically high risk, modifications of the model are currently being explored. Some sites have successfully augmented the care with maternal fetal medicine consultation and additional prenatal visits for women medically at risk for adverse pregnancy outcomes.

Required Actions:

- Identify sites in Illinois communities where there are high rates of prematurity and low birth weight that are amendable to either expanding or initiating the CP model of prenatal care.
- Seek funding from public and private resources and partnerships, such as Strong Start to enhance delivery of current sites and add new sites.
- Ensure that site approval from CHI is obtained for each site in order to maintain fidelity to the model.
- Collect process and outcome data to monitor care and review outcomes.
- Partner with academic institution(s) (i.e., University of Illinois at Chicago that has been an active CP partner) to conduct research on the efficacy of the CP model over time and with varied populations, including augmented care for populations obstetrically at risk
- Provide opportunities for ongoing training for CP providers. Review Medicaid reimbursement policies to incentivize providers and to adequately reimburse providers for group prenatal care delivery with enhanced education.

XI. PRECONCEPTION, WELL-WOMAN AND INTERCONCEPTION CARE STRATEGIES

Recommendation: Provide well-woman preventive care for uninsured and underinsured women, and expand availability, access to, quality of, and utilization of a medical home for care during the pre and interconception periods.

Background

Preconception care encompasses care a woman gets before she becomes pregnant and interconception care is care that a woman receives in between pregnancies. Both preconception and interconception care can promote a woman's health and well-being along with enhancing her chance of having a healthy pregnancy when and if she chooses to have a baby. Given that

half of all pregnancies are unplanned, preconception care is critical to enhancing the likelihood of a healthy pregnancy outcome (Custer, Waller, and Vernon, 2008). Because a woman's reproductive years may span four decades, it is important this care be ongoing and includes both screening and risk-reduction activities. Among the recommendations made by the U.S. Centers for Disease Control and Prevention (CDC) to optimize a woman's health throughout her childbearing years are:

- Individual responsibility across the lifespan (development of reproductive life plan).
- Consumer awareness, including the use of age, linguistic, cultural, and literacy appropriate information and tools.
- Preventive visits to a medical home.
- Interventions for identified risks (both social and medical).
- Intensive interconception interventions/care to women with previous adverse pregnancy outcomes, including treatment for chronic health conditions, such as diabetes, heart disease, hypertension, obesity, and other conditions.
- Preconception checkups.
- Health insurance coverage with easy enrollment.
- Public health programs and strategies, including use of social media.
- Research on preconception evidence-based practices.
- Community-wide public health monitoring and surveillance of preconception health (CDC, 2006).

Pre and interconception interventions include access to contraception, if desired, adequate spacing of pregnancies, sexually transmitted infections screening and treatment, including HIV screening and counseling, consumption of folic acid to reduce the chance of neural tube defects, chronic disease management, and behavioral risk factor reduction.

Rationale

Funding relatively low-cost preventive care can go a long way in saving dollars and lives down the road. Public expenditures for family planning care not only help women to achieve their childbearing goals, but they also save public dollars. According to the Guttmacher Institute, for every $1 spent on family planning, $3.74 is saved. Additionally, these services helped to prevent more than 1.9 million unintended pregnancies (Guttmacher Institute, 2012). Every preterm birth averted saves not only the anguish associated with prematurity, but also a significant amount of costs in the first year of the baby's life.

Required Action

- Expand health insurance coverage for low-income women beyond pregnancy to at least one year postpartum. (Currently, the eligibility of most women on Medicaid ends at 60 days post partum.) On average, fewer than 18 percent of women who delivered in 2009 were enrolled in Medicaid during the nine months following delivery (IDHFS, 2011).
- Ensure women are connected to primary care; medical home provider, if not the same as the maternity medical home; and that there is a clear mechanism for communication between maternity medical home and primary care medical home providers.

- Provide incentives to medical home providers to incorporate risk assessment, clinical interventions for chronic medical problems, health promotion and education, referrals for psychosocial interventions as indicated for depression, anxiety, stress-reduction, family violence, smoking cessation, and/or substance abuse; reproductive life planning, and strengthening family and social support (Lu and Kotelchuck et al., 2006).
- Utilize a team approach in medical home to reach uninsured or underinsured women through utilization of public health nurse or care manager and community health outreach workers who can meet clients where they are (e.g., in home, in community locations).
- Integrate IDHS care management with family–centered medical home to foster effective communication between provider and care manager to create a comprehensive care plan including psychosocial, behavioral, and environmental supports.
- Provide ongoing training to IDHS care managers and to IDHFS medical providers to remain current in best practices, quality improvement strategies, and cultural competence. Provide ongoing technical support and monitoring of outcomes
- Incorporate consumer education, including use of age, linguistic, cultural, and literacy-appropriate information and tools; consider use of social media, texting, and other communication modalities for women to encourage healthy pre and interconception health behaviors.
- Require messaging about interconception health be provided to all women enrolled in IDHS Care Coordination program.

XII. ENHANCE REGIONAL PERINATAL SYSTEM TO ENSURE HIGH QUALITY CARE STANDARDS ARE CONSISTENTLY APPLIED IN ALL DELIVERING HOSPITALS AND PREGNANT WOMEN DELIVER THEIR BABIES AT "THE RIGHT PLACE AND THE RIGHT TIME."

Recommendation: Provide additional support, personnel, resources, and expertise to develop, implement, and monitor perinatal quality improvement initiatives through the development of a Perinatal Quality Collaborative working in tandem with the Regional Perinatal System. Assess current perinatal system functioning to ensure pregnant women deliver at the right place at the right time and consistent, high quality perinatal care is provided to mothers and babies.

Background

Evidence supports the regionalization model of perinatal care as the most effective way of organizing neonatal and perinatal services and in increasing survival rates of neonates (Rochefort and Lamothe, 2011). The goals of perinatal regionalization are to assure access to appropriate care, provide outreach education to network hospitals, and assess the care provided at each institution. Illinois has been a pioneer in perinatal regionalization and has had a regionalized perinatal system in place since 1984. Perinatal networks of hospitals were established to facilitate the transport and care of high-risk pregnant women and sick infants to the appropriate level of hospital care. To date, mechanisms for transport have been orderly and

streamlined. Outreach education has been highly successful in staff development and bringing current practice updates to network hospitals.

In 1990, the Illinois Administrative Regionalized Perinatal Health Care Code (Rule 640) was amended to better define levels of care provided by hospital, and many hospitals upgraded the level of care they provided. This allowed the regionalized perinatal system to embrace and to expand quality improvement initiatives that impact the care of pregnant women and infants statewide. The Regional Perinatal Centers have successfully taken on quality improvement initiatives, most recently a postpartum hemorrhage management program that has had an impact on reducing maternal deaths from postpartum hemorrhage. With additional resources, other statewide quality improvement initiatives focused on the prevention of prematurity and improving the health of mothers and newborns could be undertaken. In the long run, such initiatives would not only improve quality, but reduce costs associated with preterm birth.

Unfortunately, due to state budget cuts and dwindling resources, only one quality improvement initiative can be undertaken at a time by the perinatal centers, and then only in a limited way. Several states, including California, New York, Ohio, Florida, and North Carolina, have been successful in creating funded Perinatal Quality Collaboratives that include hospitals, academic institutions, specialty groups (American Academy of Pediatrics; ACOG; Association of Women's Health, Obstetric Neonatal Nurses; etc.), state maternal child health agencies, payers (in some cases), and community organizations to apply quality improvement science to maternal and infant health. Such collaboratives provide the opportunity to partner with multiple sectors to rapidly disseminate evidence-based practices and protocols across the entire perinatal system, implement change processes, collect accurate and timely data, and provide feedback to improve care. The Ohio Perinatal Quality Collaborative was successful in working with 20 maternity hospitals in a quality improvement initiative to eliminate elective early term deliveries, and at a cost savings of approximately $11 million.

Rationale

As indicated in the National Quality Forums Perinatal Care Report in 2008,

> *"Mortality and morbidity associated with pregnancy and childbirth are substantial and to a large extent are preventable through the provision of high-quality perinatal care. Poor quality care provided during the third trimester, labor and delivery, and the postpartum period translates into unnecessary complications, prolonged lengths of stay, costly neonatal intensive care unit admissions, and anxiety and suffering for patients and families"* (National Quality Form, 2009).

Providing resources for the formation of a Perinatal Quality Collaborative working closely with the Regional Perinatal system in Illinois could ensure pregnant women and their infants receive consistent quality care based on standards and guidelines established by professional organizations, national advisory bodies, and regulatory agencies. Investment in robust informatics systems for all perinatal centers with reports generated in real-time to continuously measure outcomes, provide feedback on clinical care and interventions, and track change processes could go a long way in furthering the understanding of factors contributing to

adverse pregnancy outcomes. Furthermore, Administrative Perinatal Centers need the tools to assess and make adjustments to the regional perinatal system in order to ensure all high-risk pregnant women deliver at the "right place at the right time." Study after study has confirmed pregnant women with high risk pregnancies have better outcomes if born in highly specialized perinatal centers (Lasswell, Barfield, Rochat, Blackman, 2010). This approach saves lives and dollars.

Required Actions

- Provide adequate support, personnel, resources, and expertise to develop a multi-stakeholder Perinatal Quality Collaborative that works closely with the regional perinatal system to implement quality improvement initiatives focused on healthy pregnancy outcomes for mothers and newborns.
- Assess current Regionalized Perinatal System to best determine how it can be re-organized and supported to meet the goals and objectives of the IDPH's Perinatal Program and the increased demand for quality improvement initiatives.

XIII. ADVOCATE FOR INITIATIVES THAT PROMOTE SOCIAL EQUITY AND FOCUS ON REDUCING LONGSTANDING RACIAL AND ETHNIC DISPARITIES IN PREGNANCY OUTCOMES

Recommendation: Raise awareness in the health community of the effects of racism and marginalization on health outcomes. Ensure equal access to culturally sensitive, patient-centered medical homes coupled with social support and linkages to community resources. Collaborate with and build upon efforts across the state to invest in communities, provide job-skills training, adequate housing, access to nutritional food sources, and family-centered support services. Train health care workforce in culturally and linguistically appropriate service delivery. Invest research dollars in determining strategies that are effective in increasing healthy pregnancy outcomes in women of color.

Background and Rationale

Racial and ethnic disparities in pregnancy outcomes and infant mortality are longstanding and persistent. While the reasons for this are complex and multi-faceted, these disparities need to be actively addressed if we want to make progress in improving the health of mothers and babies. Throughout the life span race/ethnicity, poverty and education are interconnected with health and social factors and have a cumulative effect on health (Lynch, and Smith, 2005). Life Course Theory (LCT) offers a framework to view health disparities as rooted in social determinants and social inequity across the life cycle. LCT is a way of looking at health as a complex interplay among biological, behavioral, social, environmental, and structural factors. Birth outcomes are not only influenced by what goes on during the nine months of pregnancy, but also are affected by the entire life course leading up to the pregnancy. Therefore, steps to ameliorate inequities and build resilience among populations at risk must incorporate shifts in personal, social, economic, and environmental factors, along with ensuring access to quality health care. Efforts to reduce disparities in pregnancy outcomes must be purposeful, patient-

focused, and inclusive of linkages between health care providers and community resources for safe housing, food access, behavioral health, job and educational opportunities, and social support.

Required Actions

- Support public health initiatives focused on social determinants of health across the life course.
- Create an interagency and transdisciplinary task force to examine factors that contribute to racial and ethnic disparities in pregnancy outcomes. Review research, practice models, and initiatives that have been successful in other states in improving pregnancy outcomes, particularly among women of color. Make recommendations to fund best-practice programs to improve birth outcomes among specific populations.
- Collaborate with and build upon initiatives across the state to invest in place-based initiatives that provide job-skills training, adequate housing, quality education, access to nutritional food sources, and family-centered support services.
- Incentivize training of providers to create culturally-sensitive, patient-centered medical homes connected to social support and linkages to community resources**.**
- Train health care workforce in culturally and linguistically appropriate service delivery.
- When patient race/ethnicity disparities are identified, determine root causes and intervene appropriately.

Conclusion

With health reform through the Affordable Care Act underway, and a renewed focus nationally and internationally on the impact of preterm birth on families and the associated health care and societal costs, we have an opportunity before us. The ASTHO Challenge to reduce preterm birth by 8 percent by 2014 provides both urgency and incentive to invest Illinois state resources in preventing preterm birth. We can no longer ignore the striking racial and ethnic disparities in pregnancy outcomes among Illinoisans. With more than 21,000 babies born too soon in Illinois at an estimated social- economic burden of $1.09 billion, we are compelled to move to thoughtful, cost-saving solutions.

While prematurity is a complex issue requiring further research to be more fully understood, we know there are biological, behavioral, environmental, social, and systems level factors that play a role in healthy pregnancy outcomes. There are no easy solutions and it will take time and resources to carry out the recommendations in this document. Nevertheless, the recommendations are evidence-based and doable. Through focused efforts, building and strengthening partnerships with state agencies, providers, consumers, and maternal child health organizations, we can make great strides in ensuring every baby has a healthy start. There are no quick fixes, but in this time of economic austerity, we have an opportunity to take a step forward, to engage stakeholders, to pool resources and seek new ones, and to carry out a coordinated statewide plan directed at improving birth outcomes in Illinois.

We can build upon some of the efforts currently taking place in our state – the regionalized perinatal system, quality improvement initiatives eliminating elective early term deliveries, redesign of the IDHS case management system to focus on high risk pregnant women and linkage of prenatal care with IDHS care management and community resources, the IDHFS CHIPRA grant that aims to improve children's health outcomes by reducing pre-term births, and many other dedicated efforts to improve maternal child health.

Illinois cannot afford to delay in intervening to save our most vulnerable citizens. Reducing prematurity rates by even 8 percent (from 12.4% to 11.4%) in the next two years could prevent the anguish of 1,368 families, and save $70.6 million dollars. With the Affordable Care Act, there may be new opportunities to provide a continuum of care, linking preventive, preconception, prenatal, family planning, and well-woman care. It is time to move forward, collaborate with maternal child health stakeholders in Illinois to craft a shared vision, and mobilize resources to implement recommendations described in this document.

References

American Journal of Obstetrics and Gynecology, (2003); 188:419–24. 2. *ACOG Committee Opinion No. 419. Table 1. ... N England Journal of Medicine,* 348:2379–85.

American College of Obstetricians and Gynecologists and Society for Maternal Fetal Medicine. Obstetric Gynecology 2008; 112:963-5.

Association Maternal and Child Health Programs, Compendium (2012, July). *Forging a Comprehensive Initiative to Improve Birth Outcomes and Reduce Infant Mortality*: Policy and Program Options for State Planning, 69.

Bailit, Jennifer L and Votruba, Mark E. (2007). *Medical cost savings associated with 17 alpha-hydroxyprogesterone caproate.* American Journal of Obstetrics & Gynecology., 219e1-7.

Behavioral Risk Factor Surveillance System, Centers for Disease Control and Prevention.

Behrman, RE and Butler AS, Eds. (2006, July). *Committee on Understanding Premature Birth and Assuring Healthy Outcomes, Preterm Birth: Causes, Consequences, and Prevention*. http://www.nap.edu/catalog/11622.html.

Behrman, RE, Butler, AS, Eds. (2006). *Preterm birth: Causes, consequences, and prevention.* National Academy of Sciences, National Academy Press, Washington, D.C. pg. 399.

Bronson DL, Maxwell RA. (2004). *Shared medical appointments: increasing patient access without increasing physician hours.* Cleveland Clinical Journal of Medicine. Vol. 71(5): pg. 369-77.

Cahill AG, Odibo AO, Caughey AB, et al. (2010). *Universal cervical length screening and treatment with vaginal progesterone to prevent preterm birth: a decision and economic analysis.* American Journal of Obstetrics & Gynecology). Vol. 202: pg. 558.

Carke, SL, Frye, DR, Meyers, JA, et al. (2010). *Reduction in elective delivery< 39 week gestation: comparative effectiveness of 3 approaches to change and the impact on neonatal intensive care admission and stillbirth.* American Journal Obstetrics & Gynecology. pg. 203.

Carroll, D. M., Doria, A. S., & Paul, B. S. (2007). *Clinical-radiological features of fractures in premature infants –a review.* Journal of Perinatal Medicine. Vol. 35(5): pg. 366-375.

Centers for Disease Control and Prevention (2006). *Recommendations to improve preconception health and health care.* Morbidity and Mortality Weekly Report. Vol. 55(6): pg.1-23. Retrieved from: http://www.cdc.gov/mmwr/preview/mmwrhtml/rr5506a1.htm.

Collins JW Jr., David RJ, Handler A, Wall S, Andes S. (2004). *Very low birthweight in African American infants: the role of maternal exposure to interpersonal racial discrimination.* American Journal of Public Health. Vol. 94: pg. 2132-8.

Custer M, Waller K, Vernon S, O'Rourke K. (2008). *Unintended pregnancy rates among a US military population.* Paediatric Perinatal Epidemiology; Vol. 22: Pg.195-200.

D'Angelo, D; Williams, L; Morrow, B; Cox, S; Harris, N; Harrison, L; Posner, SF; Richardson Hood, J; and Zapata, L. (December 14, 2007). *Preconception and Interconception Health Status of Women Who Recently Gave Birth to a Live Born Infant*— Pregnancy Risk Assessment Monitoring System (PRAMS), United States, 26 Reporting Area, 2004. Morbidity and Mortality Weekly Report, In Surveillance Summaries; Vol. 56 (SS10): Pg.1-35.

Davidoff MJ, Dias T, Damus K, Russell R, Bettegowda VR, Dolan S, Schwarz RH, Green NS, & Petrini, J. (2006). *Changes in the gestational age distribution among U.S. Singleton Births: Impact on rates of late preterm birth, 1992 to 2002.* Seminars in Perinatalogy. Vol. 6 (30:1): Pg. 8-15.

Fonseca EB, Celik E, Parra, et al. (2007). *Progesterone and the risk of preterm birth among women with a short cervix*. New England Journal of Medicine (2007). Vol. 357: Pg. 462.

Fullar, S. A. (2008). *Babies at double jeopardy: Medically fragile infants and child neglect*. Zero to Three, Vol. 28(6): Pg. 25-32.

Geronimus AT (1996). *Black/white differences in the relationship of maternal age to birthweight: a population-based test of the weathering hypothesis.* Social Science Medicine, Vol. 42: Pg. 589-97.

Guttmacher Institute (2012). *Facts on Publicly Funded Contraceptive Services in the United States.* http://www.guttmacher.org/pubs/fb_contraceptive_serv.html

Hamos, Julie. (2012) *Report to the General Assembly*, Illinois Department of Healthcare and Family Services, Pg.15.

Hamos, Julie. (2012) *Report to the General Assembly*, Illinois Department of Healthcare and Family Services, Pg. 41.

Hassan et al. (2011 July). *Vaginal progesterone reduces the rate of preterm birth in women with a sonographic short cervix: a multicenter, randomized, double-blind, placebo-controlled trial.* Ultrasound Obstetrics & Gynecology, Vol. 38(1): Pg.18-31.

Hovi, P., et al. (May 17, 2007). *Glucose regulations in young adults with very low birthweight.* New England Journal of Medicine, Vol. 356 (20): Pg. 2053-2063.
Hunter, R. S., Kilstrom, N., Kraybill, E. N., &Loda, F. (1978). *Antecedents of child abuse and neglect in premature infants: A prospective study in a Newborn Intensive Care Unit*. Pediatrics, Vol. 61(4): Pg. 629-635

Iannucci TA, Tomich PG, Gianopoulos, JG. (1966). *Etiology and outcome of extremely low-birth-weight infants.* American Journal of Obstetrics & Gynecology; Vol. 174: Pg. 1896-902.

Ickovics J, Kershaw T, Wesdahl C, et al. (2007). *Group prenatal care and perinatal outcomes: a randomized controlled trial.* Obstetrics and Gynecology; Vol. 110(2 Pt 1): Pg. 330-9.

Illinois Department of Human Services, Division of Community Health Prevention, (January 2011). *The family case management program and special supplemental nutrition program for Women, Infants and Children,* Pg. 2.

Illinois Department of Public Health, (2009).

Illinois March of Dimes *Evaluation of CenteringPregnancy*® sites funded by Illinois Chapter. (2011).

Institute of Medicine, *Insuring Health: Health Insurance Is A Family Matter*, Washington, D.C.: National Academies Press, (2002). (See Chapter 6, Health Related Outcomes for Children, Pregnant Women, and Newborns: Pg. 107-139).

Institute of Medicine, (2006). *Preterm Birth: Causes, Consequences, and Prevention.* National Academy Press, Washington D.C.

Institute of Medicine, (2006). *Preterm Birth: Causes, Consequences, and Prevention.* National Academy Press, Washington, D.C.: Pg. 399.

Kiska ZA-F, Palomar L, Lee KA, et al. (2007). *Racial disparity in the frequency of recurrence of preterm birth.* American Journal of Obstetrics and Gynecology: Vol. 196(2): pg. 131.e1-131.e6

Lasswell SM, Barfield WD, Rochat RW, Blackmon L. (2010). *Perinatal regionalization for very low-birth-weight and very preterm infants: a meta-analysis.* Vol. 304(9): Pg. 992-1000.

Lawrence, Hal (May-June 2012). *Why 39 weeks?* ACOG Clinical Review: Vol. (17)3, May-June 2012, Pg. 1.

Lu and Kotelchuck et al. (2006). Maternal Child Health Journal.

Lynch, J. & Smith, Davey. *A life course approach to chronic disease epidemiology.* Annual Review of Public Health: Vol.26: Pg. 1-35.

Lynch, M. A. & Roberts, J. (1977). *Predicting child abuse: Signs of bonding failure in the maternity hospital.* British Medical Journal, Vol. 1: Pg. 624-626.

March of Dimes (2009). *Pregnancy Complications: Depression*. Retrieved from marchofdimes.com/complications_depressionhtm

March of Dimes (December 2010). *Toward Improving the Outcomes of Pregnancy III.*

Martin, J.A., et al. *Births: Final Data for 2006* (January 7, 2008). National Vital Statistics Reports, Vol. 57(7).

Maternal-Fetal Medicine Units Network (2003). [published erratum appears in New England Journal of Medicine, New England Journal of Medicine. Vol. *349*: Pg.1299].

McManemy, J, Cooke, E, Amon, E, Leet, T. (2007). *Recurrence risk for preterm delivery*. American Journal of Obstetrics & Gynecology; Vol. 169: Pg. 576.

Meis PJ, Ernest JM, Moore, ML. (1987). *Causes of low birth weights in public and private patients.* American Journal of Obstetrics & Gynecology; Vol. 156: Pg. 1165-68.

Meis PJ, Klebanoff M, Thom E, Dombrowski MP, Sibai B,Moawad AH, et al. (2003) *Prevention of recurrent preterm delivery by 17 alpha-hydroxyprogesterone caproate.* National Institute of Child Health and Human Development.

Mercer, BM, Goldenbert, RL, Moawad, AH, Meis, PJ, Iams, JD, Das, AF, Caritis, SN, Miodovnik, M, Menard, MK, Thumau, GR, Dombrowski, MP, Roberts, JM, Mcnellis, D, *For the National Institute of Child Health Human Development Maternal-Fetal Medicine Units Network.* American Journal of Obstetrics and Gynecology 1999; 151:1216.

Minnesota Task Force on Prematurity. *Current state of prematurity in Minnesota*, Report to the Minnesota Legislature, 2011.

Moster D, Lie RT, & Markestad, T. (2008). New England Journal of Medicine; Vol. 359: Pg. 262-273.

Muglia LJ and Katz, M. (2010). *The enigma of spontaneous preterm birth.* The New England Journal of Medicine, Vol. 362: Pg. 529-35.

National Center for Health Statistics (2009).

National Center for Health Statistics, (Retrieved September 23, 2012). L*inked birth/infant data.*

National Center for Health Statistics, (2009). *Final natality data.*

National Quality Forum (2009). *Perinatal Care, National voluntary consensus standards for perinatal care 2008: A consensus report*, Vol. i-ii.

Petrini J, Callaghan W, Klebanoff M, et al. (2005). *Estimated effect of 17 alpha hydroxyprogesterone caproate on preterm birth in the United States.* Obstetrics & Gynecology, Vol. 105: Pg. 267-72.

New York State Department of Health, 2011, *Redesigning the Medicaid Program*, Medicaid Redesign Team Basic Benefit Redesign Work Group, Final Recommendations.

Rochefort C, Lamothe L. (July 2011). *Forcing the system: A configuration analysis of regionalized neonatal-perinatal health network.* Health Care Management Review, Vol. 36(3): Pg. 241-251.

Romero R, Nicolaides K, Conde-Agudelo A, et al. (2011). *Vaginal progesterone in women with an asymptomatic sonographic short cervix in the mid-trimester decreases preterm delivery and neonatal morbidity: A systematic review and meta-analysis of individual patient data*, American Journal of Obstetrics & Gynecology: DOI: Vol. 10: pg. 1016/j.ajog. 2011. Vol. 12: pg. 3.

Schendel, D., and Bhasin, T.K. (2008). *Birth weight and gestational age characteristics of children with autism, including a comparison with other developmental disabilities*. Pediatrics, Vol. 121(6), Pg. 1155-1164.

Seattle Times, (2012), http:www.bnd.com/2012/02/27v-print/2075786/pregnancy-medical-homes-gain-momentum.html

Shiono PH, Klebanoff MA, Rhoads GG. (1986). *Smoking and drinking during pregnancy: Their effects on preterm birth.* Journal of the American Medical Association: Vol. 255: Pg. 82.

Slattery, MM, Morrison, (2002). *JJ.Preterm delivery*. Lancet, Vol. 360:Pg. 1489.

Strathearn, L., Gray, P. H., O'Callaghan, M. J., & Wood, D. O. (2001). *Childhood neglect and cognitive development in extremely low birth weight infants: A prospective study.* Pediatrics, Vol.108 (1): Pg. 142-15.1

Texas Health and Human Services Commission (October 2010). *Annual savings and performance report for the women's health program* (Austin, Texas: HHS)

Werner et al. (2011 July). *Universal cervical-length screening to prevent preterm birth: a cost-effectiveness analysis.* Ultrasound Obstetrics Gynecology: Vol. 38(1): Pg. 32-7.

West Virginia Health Improvement Institute. Pediatric Care Coordinator Resource Guide. Cross Lanes, West Virginia: Pg. 7-8.

Prematurity Task Force 2012

Glossary of Terms

Access to Care: The ability to receive appropriate health care either by the being able to see a provider (providers present in the community), ability to get to a provider (transportation, hours of clinic operation), or ability to pay for care (presence/absence of insurance or Medicaid/Medicare).

ADHD (Attention Deficit/Hyperactivity Disorder): A chronic condition that affects millions of children and often persists into adulthood. ADHD includes some combination of problems, such as difficulty sustaining attention, hyperactivity and impulsive behavior. Children with ADHD also may struggle with low self-esteem, troubled relationships and poor performance in school

Adverse pregnancy outcome: Health conditions for the woman that develop during the pregnancy/at delivery which can extend into the postpartum period and include maternal death. Pregnancy/birth outcomes for the fetus/infant including fetal death as well as the birth of a low birthweight or preterm infant, an infant with a congenital malformation, and/or infant death.

Antepartum: Occurring before parturition, or childbirth, with reference to the mother.

Apnea: Cessation of breathing for more than 20 seconds or the cessation of breathing for less than 20 seconds if it is accompanied by bradycardia or oxygen (O_2) de-saturation.

Autism: Autism spectrum disorder (ASD) is a range of complex neurodevelopment disorders, characterized by social impairments, communication difficulties, and restricted, repetitive, and stereotyped patterns of behavior. Autistic disorder, sometimes called autism or classical ASD, is the most severe form of ASD, while other conditions along the spectrum include a milder form known as Asperger syndrome, the rare condition called Rett syndrome, and childhood disintegrative disorder and pervasive developmental disorder not otherwise specified (usually referred to as PDD-NOS. Although ASD varies significantly in character and severity, it occurs in all ethnic and socioeconomic groups and affects every age group. Experts estimate that three to six children out of every 1,000 will have ASD. Males are four times more likely to have ASD than females.

Cerebral Palsy: While cerebral palsy is a blanket term commonly referred to as "CP" and described by loss or impairment of motor function, cerebral palsy is actually caused by brain damage. The brain damage is caused by brain injury or abnormal development of the brain that occurs while a child's brain is still developing — before birth, during birth, or immediately after birth.

Cesarean Section: The delivery of a baby through a cut (incision) in the mother's belly and uterus. It is often called a C-section.

DRG (Diagnosis Related Group): Any of the payment categories that are used to classify patients and especially Medicare patients for the purpose of reimbursing hospitals for each case in a given category with a fixed fee regardless of the actual costs incurred.

Disparity: An **i**nequality or difference in some respect between groups of people. Health disparities refer to differing outcomes/end results in health and wellness between different populations.

Family planning: Programs to regulate the number and spacing of children in a family through the practice of contraception or other methods of birth control.

Folic Acid: A B vitamin found in foods like leafy green vegetables and fortified pasta and cereal. Up to 70 percent of neural tube defects, birth defects of the brain and spinal cord can be prevented if women consume folic acid before and during pregnancy. Women of reproductive age should consume 400 mcg of folic acid daily. A healthy diet and a daily multivitamin with 400 micrograms of folic acid are the best ways to get the recommended amount of folic acid.

Full-term: Describes the length of a pregnancy that is between 37-41 weeks.

Infant Mortality Rate (IMR): The number of infants who are born alive, but die before 1 year of age.

Interconception: Refers to the time period between pregnancies.

Interpregnancy interval: This is the interval between one pregnancy and the next.

LBW (Low birth weight): Refers to infants weighing less than 2,500 grams or 5.5 pounds at the time of their birth.

MCH (Maternal and Child Health): Includes all America's pregnant women, infants, children, adolescents, and their families—including women of reproductive age, fathers, and children with special health care needs.

Morbidity: The rate of incidence of a disease, illness, or condition.

Mortality: The number of deaths in proportion to the population; the death rate

Neural Tube Defect: A congenital defect of the central nervous system, including the spinal cord, skull and brain, resulting from failure of the neural tube to properly close during fetal development. Defects may include absence of the skull, and protrusions of the brain or spinal cord.

Perinatal: Of, relating to, or being the period around childbirth, especially the five months before and one month after birth.

Postpartum: The postpartum period can span anywhere from immediately after the baby is born, to the first year after birth.

Preeclampsia: A condition in pregnancy characterized by abrupt hypertension (a sharp rise in blood pressure); albuminuria (leakage of large amounts of the protein albumin into the urine); and edema (swelling) of the hands, feet, and face. Preeclampsia is the third most common cause of maternal mortality. Fetal mortality is also high because of the high incidence of premature delivery in these cases.

PROM (Premature rupture of membranes): Refers to a patient who is beyond 37 weeks' gestation and has presented with rupture of membranes (ROM) prior to the onset of labor.

Preconception: Generally, referred to as the time before a woman becomes pregnant. This also can mean any time from the first menstruation up until onset of menopause when a woman can become pregnant. Preconception care is different from prenatal care in that it focuses on the health and well-being of a woman before she gets pregnant.

Premature: A baby who is born before 37 completed week's gestation.

Prenatal Care (PNC): Refers to the medical care recommended for women before and during pregnancy. The aim of good prenatal care is to detect any potential problems early, to prevent them if possible (through recommendations on adequate nutrition, exercise, vitamin intake etc.), and to direct the woman to appropriate specialists, hospitals, etc. if necessary.

Preterm labor: When a pregnant woman goes into labor before 37 completed weeks of gestation.

SGA (Small for Gestational Age): A term used to describe newborns below the 10th percentile in height or weight for their estimated gestational age. The gestational age is based upon the date of the mother's last menstrual period.

SIDS (Sudden Infant Death Syndrome): The sudden death of an infant less than 1 year of age that cannot be explained after a thorough investigation is conducted, including a complete autopsy, examination of the death scene, and review of the clinical history. SIDS is a subset of sudden unexpected or unexplained infant death.

Sleep Related Infant Death: Deaths due to suffocation, strangulation, entrapment, wedging, overlay, or undetermined. A sub-set of SUID. These are usually preventable deaths.

STIs (Sexually Transmitted Infections): These include HIV/AIDS, chlamydia, syphilis, herpes, and gonorrhea.

Stressors: An agent, condition, or other stimulus that causes stress.

SUID (Sudden Unexpected or Unexplained Infant Death): Death of an infant that cannot be determined because other factors are involved.

VLBW (Very low birth weight): Refers to infants weighing less than 1,500 grams or 3.3 pounds.

Maternal and Child Health Programs

FCM (Family Case Management): Administered by the Illinois Department of Human Services, FCM helps families with a pregnant woman, infant, or young child to obtain the health care services and other assistance they may need to have a healthy pregnancy and to promote the child's healthy development. The goals of the FCM program are to provide access to primary health care, identify and resolve access barriers, provide health education to all.

Healthy Start: Focuses on improving maternal and child health outcomes by increasing access to and use of health services for women and their families while strengthening local health systems and increasing consumer input into these systems of local care. Healthy Start also focuses on developing and mobilizing strong community coalitions, local and state governments, the private sector, providers, and neighborhood organizations.

Moms and Babies: A program through Illinois's All Kids program for pregnant women and their babies. Moms and Babies pays for both outpatient and inpatient hospital services for women while they are pregnant and for 60 days after the baby is born. It also pays for services to babies for the first year of the baby's life, if the mother is covered by Moms and Babies when the baby is born.

Strong Start for Mothers and Newborns: This initiative is a joint effort between the Centers for Medicare and Medicaid Services (CMS), the Health Resources and Services Administration, and the Administration on Children and Families. The Strong Start initiative supports reducing the risk of significant complications and long-term health problems for both expectant mothers and newborns

TIPS (Targeted Intensive Prenatal Case Management): Enhances the Family Case Management program by providing intensive prenatal case management services to pregnant women determined by assessment to be at high risk for preterm delivery. The Illinois Department of Human Services funds agencies in targeted areas of the state with very high Medicaid expenditures for infants.

WIC: Special Supplemental Nutrition Program for Women, Infants, and Children. WIC is s a Federal assistance program of the Food and Nutrition Service (FNS) of the U.S. Department of Agriculture (USDA) for health care and nutrition of low-income pregnant women, breastfeeding women, and infants and children under the age of 5.

Governmental Agencies or Programs

ASTHO (Association of State and Territorial Health Officers): Through its performance projects ASTHO fosters a culture of quality improvement in state health agencies and systems. ASTHO provides technical and program support to the Public Health Accreditation Board and regularly provides custom technical assistance to states preparing for voluntary national accreditation.

CHIPRA (Children's Health Insurance Program Reauthorization Act): Special enrollment rights for employees and dependents under employer-sponsored group health plans. These CHIPRA enrollment opportunities are required to be offered when an employee or eligible dependent is covered under a Medicaid plan or state children's health insurance program ("CHIP"), and loses eligibility under that plan or when they become eligible under a CHIP or Medicaid plan for premium assistance that could be used toward the cost of an employer plan.

CMMI (Center for Medicare and Medicaid Innovation): U.S. federal agency that administers Medicare, Medicaid, and the State Children's Health Insurance Program.

IDHFS (Illinois Department of Health and Family Services): State agency responsible for administering the Illinois' Medical Assistance Programs under the provisions of the Illinois Public Aid Code, the Illinois Children's Health Insurance Program Act (CHIPRA), Covering All Kids Health Insurance Act, and Titles XIX and XXI of the federal Social Security Act. HFS is responsible for providing health care coverage for adults and children who qualify, and for providing Child Support Enforcement services to help ensure children receive financial support from both parents. IDHFS' policies are implemented with an emphasis on quality service delivery (access to care, evidence-based practice), cost containment strategies (structure and operations), program integrity enhancements, and agency efficiencies (quality measurement improvement).

IDHS (Illinois Department of Human Services): State agency provides services in the areas of health, family support, youth development, substance abuse prevention, and violence prevention and intervention; the Division of Family Health promotes and improves the health status, self-sufficiency, and

integrity of families. Services provided include WIC, Family Case Management, family planning, child care assistance program, and Head Start.

IDPH (Illinois Department of Public Health): State agency works to promote the health of the people of Illinois through the prevention and control of disease and injury. All of this is done through vaccinations to protect children against disease; testing to assure the safety of food, water and drugs; licensing to ensure quality health care in hospitals and nursing homes; investigations to control the outbreak of infectious diseases; collection and evaluation of health statistics to develop prevention and regulatory programs; screening newborns for genetic and metabolic diseases: and programs to meet the special health needs of women, including the Regionalized Perinatal System.