

**MN Task Force on Prematurity**

# **Current State of Prematurity in Minnesota**

**Report to the MN Legislature**

**November 2011**

## **Introduction**

The Minnesota Legislature established the Minnesota Task Force on Prematurity in 2011. Legislative language in 2011, 1<sup>st</sup> Special Session 9, Article 2 (27) directs the Commissioner of Health to convene a Task Force on Prematurity. The Task Force on Prematurity is directed to evaluate and make recommendations on methods for reducing prematurity and improving premature infant health care in the state. The legislation states that by November 30, 2011, the task force must submit a report on the current state of prematurity in Minnesota to the chairs of the legislative policy committees on health and human services. This report provides the current state of prematurity in Minnesota.

**Respectfully submitted by:**  
MN Task Force on Prematurity

**Date:** November 30, 2011

## CHAPTER 9--H.F.No. 25, Article 2

### Sec. 27. MINNESOTA TASK FORCE ON PREMATURITY.

Subdivision 1. Establishment. The Minnesota Task Force on Prematurity is established to evaluate and make recommendations on methods for reducing prematurity and improving premature infant health care in the state.

Subd. 2. Membership; meetings; staff. (a) The task force shall be composed of at least the following members, who serve at the pleasure of their appointing authority:

- (1) 15 representatives of the Minnesota Prematurity Coalition including, but not limited to, health care providers who treat pregnant women or neonates, organizations focused on preterm births, early childhood education and development professionals, and families affected by prematurity;
- (2) one representative appointed by the commissioner of human services;
- (3) two representatives appointed by the commissioner of health;
- (4) one representative appointed by the commissioner of education;
- (5) two members of the house of representatives, one appointed by the speaker of the house and one appointed by the minority leader; and
- (6) two members of the senate, appointed according to the rules of the senate.

(b) Members of the task force serve without compensation or payment of expenses.

(c) The commissioner of health must convene the first meeting of the Minnesota Task Force on Prematurity by July 31, 2011. The task force must continue to meet at least quarterly. Staffing and technical assistance shall be provided by the Minnesota Perinatal Coalition.

Subd. 3. Duties. The task force must report the current state of prematurity in Minnesota and develop recommendations on strategies for reducing prematurity and improving premature infant health care in the state by considering the following:

- (1) standards of care for premature infants born less than 37 weeks gestational age, including recommendations to improve hospital discharge and follow-up care procedures;
- (2) coordination of information among appropriate professional and advocacy organizations on measures to improve health care for infants born prematurely;
- (3) identification and centralization of available resources to improve access and awareness for caregivers of premature infants;
- (4) development and dissemination of evidence-based practices through networking and educational opportunities;
- (5) a review of relevant evidence-based research regarding the causes and effects of premature births in Minnesota;
- (6) a review of relevant evidence-based research regarding premature infant health care, including methods for improving quality of and access to care for premature infants;
- (7) a review of the potential improvements in health status related to the use of health care homes to provide and coordinate pregnancy-related services; and
- (8) identification of gaps in public reporting measures and possible effects of these measures on prematurity rates.

Subd. 4. Report; expiration. (a) By November 30, 2011, the task force must submit a report on the current state of prematurity in Minnesota to the chairs of the legislative policy committees on health and human services.

(b) By January 15, 2013, the task force must report its final recommendations, including any draft legislation necessary for implementation, to the chairs of the legislative policy committees on health and human services.

(c) This task force expires on January 31, 2013, or upon submission of the final report required in paragraph (b), whichever is earlier.

## Background

Premature birth is a serious health problem. Premature babies are at an increased risk for newborn health complications, such as breathing problems, and even death. Most premature babies require care in a newborn intensive care unit (NICU), which have multidisciplinary medical teams (including neonatologists, neonatal nurses, pediatric physical and occupational therapy, pediatric nutritionists, and pharmacologists with pediatric expertise, along with additional specialists) and specialized equipment that can deal with the multiple problems faced by premature infants.

### Cost of Prematurity

Premature 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 there was a 40% rate of symptoms of significant depression. The financial costs 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.<sup>1</sup> Nearly two-thirds of the societal cost was accounted for by medical care. 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 (CP), mental retardation (MR), vision impairment (VI), and hearing loss (HL) 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).”p.399<sup>2</sup> Using these averaged additional costs per infant, **the price Minnesota paid to care for the 7,200 infants born too soon in the state in 2011 amounted to \$371.5 million, for just the first year of life.**

The direct health care costs to employers for a premature 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.<sup>3</sup> The cost to employers for maternal health care, including prenatal care, delivery and postpartum care, increases 75% with a diagnosis of prematurity. Of significant note, in Minnesota, 38% of all births are paid for by public programs accounting for almost 28,500 deliveries.

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 are also at an increased risk for conditions such as Attention Deficit-Hyperactivity Disorder (ADHD), Sudden Unexpected Infant Death (SUID) and

<sup>1</sup> Institute of Medicine. *Preterm Birth: Causes, Consequences, and Prevention*. National Academy Press, Washington D.C., 2006.

<sup>2</sup> Institute of Medicine. *Preterm Birth: Causes, Consequences, and Prevention*. National Academy Press, Washington D.C., 2006.

<sup>3</sup> Institute of Medicine. *Preterm Birth: Causes, Consequences, and Prevention*. National Academy Press, Washington D.C., 2006.

re-hospitalizations. Two recent studies suggest that premature babies may be at increased risk of symptoms associated with autism (social, behavioral and speech problems)<sup>4</sup>. Studies have shown that babies born very prematurely may be at increased risk of certain adult health problems, such as diabetes, high blood pressure and heart disease.<sup>5</sup> Compounding the physical, cognitive, and mental health risks of preterm births, studies have also shown that 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.<sup>6,7,8</sup> This appears to be particularly true for infants with prolonged stays in NICUs, or whose caregivers were unable to spend significant time with them during their hospitalizations<sup>9,10</sup>. Additionally, infants who are discharged from NICUs while still needing intensive care services (such as those who need monitoring for apnea or who receive feedings via enteral tubes) are at increased risk of abuse or neglect.

The ongoing health issues as these infants grow through the pediatric years into adulthood compounds the health, financial, personal, family, and societal impacts of premature birth. Preterm birth has been associated with lower attainment of educational level, income, and 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<sup>11</sup>. In a *New England Journal of Medicine* article entitled “Long-term Medical and Social Consequences of Preterm Birth” internationally known researcher Dag Moster, MD, PhD states:

“However, 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.”

Most pregnancies last approximately 40 weeks. Babies born between 37 and 42 completed weeks of pregnancy are called full term. Babies born before 37 completed weeks of pregnancy are called premature. More than 70 percent of premature babies are born between 34 and 36 weeks gestation. These are called late-preterm births. Late-preterm babies account for most of the increase in the premature birth rate in this country. A 2008 study found that cesarean sections (c-

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<sup>4</sup> Schendel, D., and Bhasin, T.K. Birth Weight and Gestational Age Characteristics of Children with Autism, Including a Comparison with Other Developmental Disabilities. *Pediatrics*, volume 121, number 6, June 2008, pages 1155-1164.

<sup>5</sup> Hovi, P., et al. Glucose Regulations in Young Adults with Very Low Birthweight. *New England Journal of Medicine*, volume 356, number 20, May 17, 2007, pages 2053-2063.

<sup>6</sup> 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*, 61(4): 629-635

<sup>7</sup> 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*, 108(1): 142-151

<sup>8</sup> Fullar, S. A. (2008). Babies at double jeopardy: Medically fragile infants and child neglect. *Zero to Three*, 28(6): 25-32.

<sup>9</sup> Carroll, D. M., Doria, A. S., & Paul, B. S. (2007). Clinical-radiological features of fractures in premature infants – a review. *Journal of Perinatal Medicine*, 35(5): 366-375.

<sup>10</sup> Lynch, M. A. & Roberts, J. (1977). Predicting child abuse: Signs of bonding failure in the maternity hospital. *British Medical Journal*, 1: 624-626.

<sup>11</sup> Fullar, S. A. (2008). Babies at double jeopardy: Medically fragile infants and child neglect. *Zero to Three*, 28(6): 25-32.

sections) account for nearly all of the increase in U.S. singleton premature births, and this group had the largest increase in c-section deliveries.<sup>12</sup> About 12 percent of premature babies 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.<sup>13</sup> 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.

### **Causes of Premature Births**

Most premature births are caused by spontaneous preterm labor, either by itself or following spontaneous premature rupture of the membranes (PROM). With PROM, the sac inside the uterus that holds the baby breaks too soon. Preterm labor is labor that begins before 37 completed weeks of pregnancy. The causes of preterm labor and PROM are not fully understood. In about half of all cases of premature birth, providers cannot determine why a woman delivered prematurely. Many of those that are known are amendable to medical and public health interventions that subsequently can reduce the rates of premature births.

The latest research suggests that many cases are triggered by the body's natural response to certain infections, including those involving amniotic fluid and fetal membranes. Other maternal health conditions that may contribute to premature birth include diabetes, heart disease, infection (such as urinary tract infection or infection of the amniotic membrane), kidney disease, poor nutrition, preeclampsia, placental disorders (such as placenta previa or abruption), periodontal disease, and the use of tobacco, cocaine, or amphetamines. Under Minnesota Statutes 626.5562, physicians must report instances of prenatal use of controlled substances by women under their care to the Department of Health. According to these physician reports, prenatal drug use occurred in one out of every sixty-five live births in Minnesota in 2007.

Research shows that prenatal care including a comprehensive drug maintenance and therapy program is beneficial for pregnant women and their babies. Newborns exposed to opiates during pregnancy typically require treatment for withdrawal symptoms and prolonged hospital stays. Illicit drug use during pregnancy is associated with low birth weight, developmental deficits affecting behavior and cognitive impairment involving attention, language, speech and learning skills, as well as SIDS. These are lifelong deficits and cannot be measured in simple monetary terms.<sup>14</sup>

Any woman can give birth prematurely, but some women are at greater risk than others. Researchers have identified some risk factors, but providers still can't predict which women will deliver prematurely. The three groups of women at greatest risk for premature birth are: (1) women who have had a previous premature birth; (2) women who are pregnant with twins, triplets or more; and (3) women with certain uterine or cervical abnormalities.

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<sup>12</sup> Bettegowda, V.R., et al. The Relationship Between Cesarean Delivery and Gestational Age Among U.S. Singleton Births. *Clinics in Perinatology*, volume 35, 2008, pages 309-323.

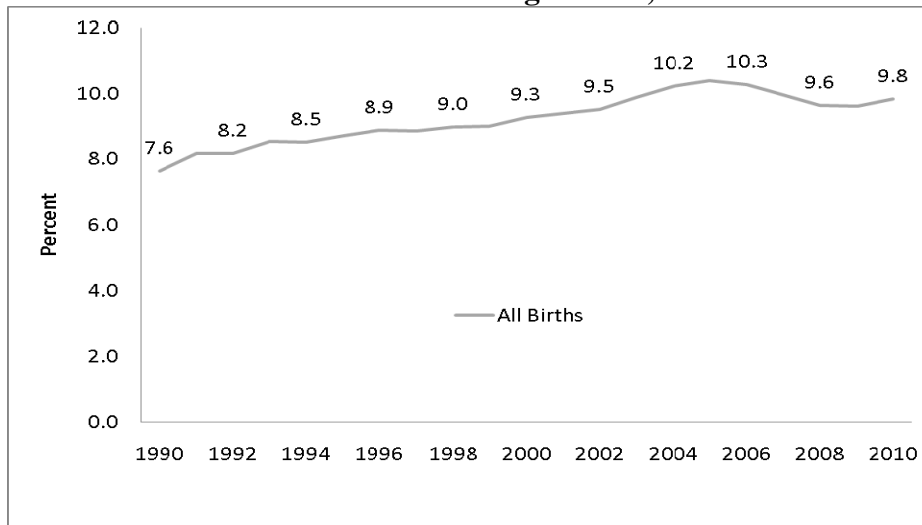
<sup>13</sup> Martin, J.A., et al. Births: Final Data for 2006. *National Vital Statistics Reports*, volume 57, number 7, January 7, 2008.

<sup>14</sup> Minnesota Department of Health, November 2011.

### Premature Birth in Minnesota

Between 1990 and 2010, the rate of infants born prematurely in Minnesota increased nearly 28%. The trend hit its peak in 2005 and declined until 2009 with the largest decline occurring in babies born between 34 and 36 weeks gestation. In 1990 the actual number of infants born prematurely in Minnesota was 4,678. In 2005 that number jumped to 6,558 and declined slightly to the 2010 number of 6,130.

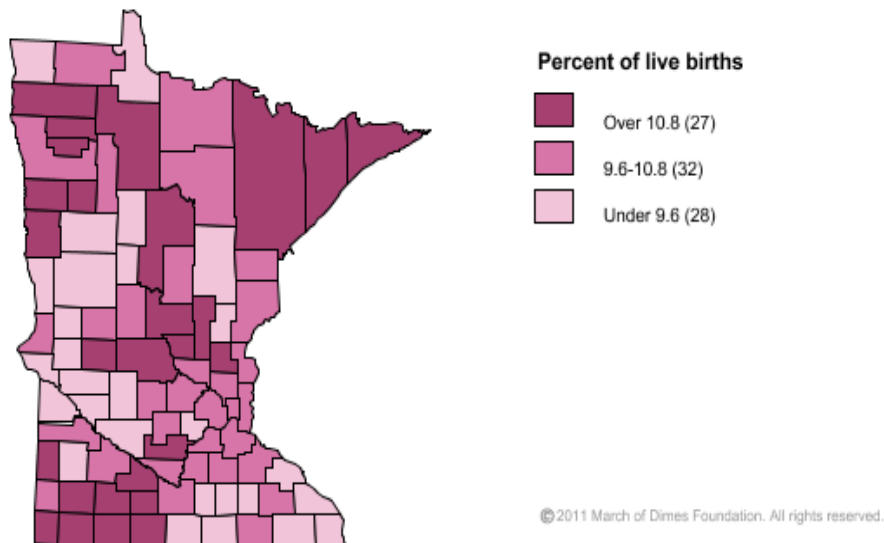
**Percent of births born before 37 weeks gestation, Minnesota 1990-2010**



Source: Minnesota Department of Health, Center for Health Statistics. November 2011

In Minnesota, the overall rate of babies born prematurely is 9.8%. However, counties within Minnesota have preterm birth rates that range from 6.4% in Swift County to 15.4% in Lake County.

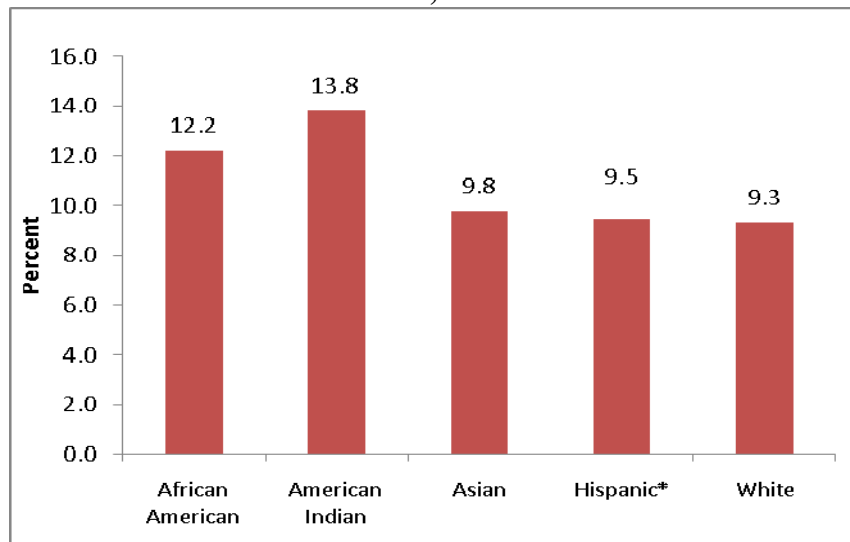
**Preterm Birth: Minnesota 2005-2008 Average**



Source: [www.marchofdimes.com/peristats](http://www.marchofdimes.com/peristats). November 2011

In the United States, prematurity/low birth weight is the second leading cause of all infant deaths (during the first year of life) and the leading cause of infant death among black infants. These racial and ethnic health disparities are prominent in Minnesota as well. The graph below illustrates the serious disparities that exist among Minnesota's populations of color in terms of the number of babies born prematurely.

**Premature Births by race/ethnicity of Mother  
Minnesota, 2008-2010**



Source: Minnesota Department of Health, Center for Health Statistics. November 2011  
\*Can be any race

Minnesota 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 in Minnesota.

In a recent analysis conducted by PRAMS, mothers with a premature delivery were more likely to have five or more stressful life events within the previous year before the infant was born (Table 2). Stressful life events were also categorized into emotional stressors, financial stressors, partner-related stressors, and trauma stressors. There was no significant difference between mothers with a premature delivery as compared to mothers with a normal term delivery between the stressful life events categories. Though, for the category *financial stressors* there was a slightly higher prevalence for mothers with a premature delivery (52.4% compared to 46.6%).



**Table 2. Maternal Risk Factor Characteristics: Premature Delivery versus Not Premature Delivery, Minnesota Pregnancy Risk Assessment Monitoring System (2007-2009)**

Risk Factors	Premature Delivery		Not Premature Delivery	
	Percent	95% CI	Percent	95% CI
<b><u>Stressful Life Events</u></b>				
5 or more Stressors <sup>^</sup>	12.7%	(9.3-17.1) <sup>†</sup>	7.9%	(7.1-8.9)
Emotional Stressors	27.4%	(22.4-32.9)	27.6%	(26.2-29.2)
Financial Stressors	52.4%	(46.6-58.1)	46.6%	(44.9-48.3)
Partner-related Stressors	26.0%	(21.2-31.3)	26.4%	(25.0-28.0)
Trauma Stressors	16.0%	(12.3-20.7)	15.9%	(14.8-17.2)
<b><u>Tobacco Use</u></b>				
Smoke 3 months prior to pregnancy	25.0%	(20.3-30.3)	24.3%	(22.9-25.9)
Smoke last 3 months of pregnancy	13.7%	(10.1-18.2)	13.7%	(12.5-14.9)
<b><u>Alcohol Use</u></b>				
Alcohol 3 months prior to pregnancy	63.4%	(57.8-68.8)	65.9%	(64.2-67.5)

<sup>†</sup> Represents <60 respondents; data might not be reliable.

<sup>#</sup> Represents <30 respondents; data not reported.

<sup>^</sup> Chi-square p-value < 0.05

*Minnesota Department of Health, Community and Family Health Division, Women and Infants Health Unit  
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### **Minnesota Perinatal Organization and the Minnesota Prematurity Coalition**

Minnesota Perinatal Organization’s mission is to promote the health and well being of childbearing women, infants and families at the broadest social level. This interdisciplinary association was founded in 1974 to bring together individuals and organizations dedicated to improving perinatal health. The Minnesota Perinatal Organization (MPO) and its members share a passion for the health and well being of childbearing women, infants and families. MPO promotes best care practices in health care through education, championing positive changes in practices, programs and policies, and inspiring mentors and role models by networking with healthcare workers throughout the region.

In order to address Minnesota’s issues affecting premature infants, the Minnesota Perinatal Organization has assumed leadership of the Minnesota Prematurity Coalition which specifically focuses on the prevention of prematurity and issues impacting infants born prematurely and their families. The Minnesota Prematurity Coalition brings together community and health organizations, faith-based groups, healthcare providers, and parents to increase quality healthcare access and awareness around premature infant health issues.

Members of the Minnesota Prematurity Coalition serve on the MN Task Force on Prematurity in order to continue addressing preterm birth issues on a statewide level. The membership of MPO

and the MN Prematurity Coalition will allow for the issues of prematurity to be addressed from multiple vantage points ensuring a well-rounded, statewide look at premature birth in Minnesota.

## Current Practices – Prevention Activities

### **Evidence-Based Childbirth Program**

In January 2012 a new MN Department of Human Services policy will go into effect: *Evidence-Based Childbirth Program*. The evidence-based childbirth program promotes the implementation of policies – within hospitals providing services to recipients of Minnesota Health Care Programs – that discourage the use of elective inductions prior to 39 completed weeks gestation. The increasing use of elective inductions has been accompanied by a host of unintended consequences with acute and long-term health implications for mothers and babies. National and Minnesota groups have recommended that elective inductions not occur before 39 weeks gestation.

In Minnesota the Perinatal Practices Advisory Group – a group of Obstetricians, Neonatologists, Clinical Nurse Specialists, Managed Care Administration, MN Department of Health, March of Dimes and MN Department of Human Services – made recommendations to the MN Department of Human Services to help reduce the number of elective inductions that occur before 39 weeks in Minnesota. The new policy is based on strong evidence and is supported by Minnesota legislation. The new requirements effective January 1, 2012 are as follows:

1. The MN Department of Human Services requires all hospitals to report induction of labor data for all births covered by Minnesota Health Care Program.
2. The Minnesota Department of Human Services is asking hospitals to implement policies and processes designed to minimize non-medically necessary inductions prior to 39 completed weeks gestation.

### **General Education to public and providers**

Very little education exists for the public on premature births and their causes. While some messages can be seen in local advertisements or within hospitals; healthcare organizations and providers are not extensively involved in public education around prematurity prevention. Clinics, hospitals and community providers may offer prenatal classes or childbirth preparation classes in the community. The classes provide an opportunity for both education and psychosocial support to a targeted group of expectant parents. In recent years the decline of attendance at these types of classes has decreased the exposure of women and their partners to this crucial information.

Education to providers is found via their professional associations and in the form of conference lectures, articles, webinars and grand rounds. Other sources of information can be local or regional. Perinatal Collaboratives are becoming more informative and engaging as the synergy between evidenced based medicine, public health, and improved public and professional access to higher quality health data begins to shape the discussions and practices in the fields of perinatal and neonatal medicine.

## **Smoking Cessation Programs**

Minnesota is a leader for providing public awareness of the impact of smoking through the QUITPLAN®. Current data from the MN Department of Health demonstrates that for the past several years many risk factors are declining; the number of packs of cigarettes sold, the number of students who have smoked in the last 30 days, the number of adults who are current smokers and the percentage of high school youth exposed to secondhand smoke in the last 30 days. Most healthcare providers and hospitals are required to ask about smoking habits on each visit and offer assistance with documentation in the medical record. According to the March of Dimes Peristats website, in Minnesota in 2010, 16.9% of women of childbearing age (18-44 years) reported smoking. On its' women's reproductive health website, CDC projects that " If all pregnant smokers quit smoking, as many as 5%–8% of preterm infants, and 13%–19% of term low birthweight infants could be born a normal weight. In addition, as many as 23%–34% of infant deaths from SIDS, and 5%–7% of infant deaths from preterm births could be prevented." Source:

<http://www.cdc.gov/reproductivehealth/WomensRH/ChronicDiseaseandReproductiveHealth.htm>

## **CenteringPregnancy®**

CenteringPregnancy® is a multifaceted model of group care that integrates the three major components of care: health assessment, education, and support, into a unified program within a group setting. Eight to twelve women with similar gestational ages meet together, learning care skills, participating in a facilitated discussion, and developing a support network with other group members. Each CenteringPregnancy group meets for a total of 10 sessions throughout pregnancy and early postpartum. The practitioner, within the group space, completes standard physical health assessments.<sup>15</sup>

Site approval is provided by the *Centering Healthcare Institute* to ensure quality standards are met. Studies have shown that Centering Pregnancy programs reduce preterm birth, increase breastfeeding and improve social support for women.<sup>16</sup> In Minnesota, 3 organizations are approved to facilitate Centering Pregnancy programs: Mayo Clinic, Park Nicollet Nurse Midwives, and Hennepin County Nurse Midwives & affiliated clinics.

## **WIC – Special Supplemental Nutrition Program for Women, Infants and Children**

WIC serves low-income pregnant, postpartum and breastfeeding women, infants and children up to age 5 who are at nutritional risk. WIC provides nutritious foods, nutrition education (including breastfeeding promotion and support), and referrals to health care and social services at no charge. The two major types of nutrition risk that are recognized for WIC eligibility are:

- Medically-based risks such as anemia, underweight, overweight, history of pregnancy complications, or poor pregnancy outcomes.
- Dietary risks, such as failure to meet the dietary guidelines or inappropriate nutrition practices.

<sup>15</sup> Centering Healthcare Institute, [www.centeringhealthcare.org](http://www.centeringhealthcare.org). Retrieved November 1, 2011.

<sup>16</sup> Ickovics, J., Kershaw, T, Westdahl C, Magriples U, Massey Z, Reynolds H, Rising, S. (2007) Group prenatal care and perinatal outcomes: a randomized controlled trial. *Obstetrics and Gynecology*, 110(2), part 1: 330-39.

The Minnesota Department of Health WIC Program received \$104,577,910 from the federal government in FY 2011 and local WIC agencies served 141,598 women and children in FY 2009 and 138,562 in FY 2010.

### **Family Home Visiting**

The Minnesota Family Home Visiting Program positively influences the lives of at-risk pregnant women, primary caregivers, infants and children through its goals to foster healthy beginnings, improve pregnancy outcomes, promote school readiness, prevent child abuse and neglect, reduce juvenile delinquency, promote positive parenting and resiliency in children, and promote family health and economic self-sufficiency for children and families.

Family home visiting programs target women at higher risk for premature birth and low birth weights. These programs may contribute to fewer premature births for family home visiting prenatal clients compared to the rest of the state. Family home visitors (Public Health Nurses, educators, and health workers) provide assessments, education and psychosocial support. Prenatal women are assessed for the presence of risk factors that can lead to poor birth outcomes including screening for depression, domestic violence and chemical use. At-risk pregnancies are closely monitored and education is provided on decreasing risk factors for intrauterine growth restriction such as poor nutrition and tobacco and other substance use. The home visitor provides education on the importance of breastfeeding for infant nutrition and parent-child interaction. Families are connected to needed community resources for preventive health care services (including prenatal care and well child visits), insurance, parenting, mental health needs, chemical dependency issues, employment, housing, education, financial and food.

Minnesota's local public health departments and tribal government family home visiting programs served 27,300 primary caregivers, prenatal clients and children under the age of six during the first half of 2009 representing 80,800 visits. Over 15% of the populations served were prenatal clients, 21% of those prenatal clients were adolescents.

### **Access to Healthcare**

The Institute of Medicine, among others, found that uninsured women forgo or postpone needed care. The reverse is also true – having health insurance improves access to timely medical care, a critical factor for women who are at risk of preterm birth. Early care and treatment of medical conditions (diabetes, hypertension, sexually transmitted diseases, for example) may reduce the risk of preterm birth.<sup>17</sup> According to the U.S. Census Bureau, Current Population Survey, 2009-2011, the percentage of women ages 15-44 with no source of health insurance coverage in Minnesota was 12.1%.

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<sup>17</sup> 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, pgs. 107-139.)

## Current Practices - Premature Infant Healthcare Delivery

Inpatient care for preterm infants in Minnesota is provided in Neonatal Intensive Care Units (also referred to as Level 3 NICUs) and Special Care Nurseries (Level 2 nurseries). Throughout the state, Level 3 NICUs provide advanced life support, mechanical ventilation, and surgical services for the sickest and most preterm infants. Level 2 nurseries are located throughout the urban and suburban areas of the state, delivering moderate acuity care such as non-invasive respiratory support, IV antibiotics, and tube feedings, with the remainder of low acuity care for the “late” preterm infants delivered in newborn nurseries throughout the state.

### Level 3 NICU:

The highest level of intensive care is delivered in NICUs situated near larger, urban hospitals in Burnsville (1), Duluth (1), Edina (1), Maplewood (1), Minneapolis (3), Robbinsdale (1), Rochester (1), St. Cloud (1) and St. Paul (1). For the sickest and most preterm infants, these units provide the highest level of intensive care, including mechanical ventilation, surgical services, advanced radiological imaging, and access to a wide variety of medical and ancillary specialists. Lengths of hospital stay can typically be weeks to months. This highly specialized care is under the supervision of a neonatologist, a pediatrician with postgraduate training in newborn intensive care. Typically, neonatal nurse practitioners, nursing professionals with advanced training supplement this care.

Hospitals with Level 3 NICUs also have non-medical services available to families during their infants’ stay in the nursery. For example, families may have access to a hospital social worker, private rooms, access to computers, free meal services, lactation consultants, and personnel to help families apply for county assistance.

### Level 2 Special Care Nursery:

The moderately acute preterm infants receive care that is typically less intensive than in Level 3 NICUs, such as non-invasive respiratory support, IV fluids and medications, tube feedings, and cardiorespiratory monitoring. These units are located throughout the urban and suburban areas of Minnesota. Lengths of stay in these units are typically a few weeks. Care is usually managed by a neonatologist or pediatrician, or less often, a family physician. These nurseries are usually staffed by neonatal nurse practitioners as well.

### Level 1 Newborn Nursery:

The mildly ill or “late preterm” infants are typically managed, alongside “well” or term newborns in this setting, available in most hospitals offering maternity services. Typical care includes routine newborn care, but in hospitals lacking Level 2 or 3 nurseries, may offer tube feedings, cardiorespiratory monitoring, or in some sites, IV medications or fluids. Care is typically supervised by a pediatrician or family physician.

In 2011, the Minnesota Prematurity Coalition conducted a survey in which they gathered information from community hospitals to assess the need for resources and information related to the care and discharge of the Late Preterm Infant (34 – 37 weeks gestation) from the hospital

setting. A majority of the hospital staff surveyed indicated that a universal late preterm discharge checklist would be beneficial in the care of late preterm infants.

## **Current Practices - Family and Infant Follow-Up**

Following discharge, preterm infants require specialized care that differs from term infants. Because preterm infants are at increased risk for problems such as respiratory difficulties, i.e. chronic lung disease of prematurity and apnea of prematurity, feeding difficulties and poor weight gain, infection, and cognitive and/or motor delays, it is of utmost importance that access to primary care is maintained. In addition, infants may require follow-up care with medical specialists such as a pulmonologist, neurologist, cardiologist, or gastroenterologist. Regular eye examinations by a pediatric ophthalmologist trained in the eye development of preterm infants are also required. Ancillary services such as audiology, occupational or physical therapy, and speech and language pathology may also be required. Because preterm infants may display signs of apnea of prematurity, or gastroesophageal reflux requiring specialized management, apnea monitors and positioning devices may be required following hospital discharge, managed by an apnea team.

Access to a primary care provider is essential not only to ensure the overall health and well-being of the infant, but to also assess the emotional and physical health of the family, which can be burdened with additional stress of the needs of a preterm infant.

Graduates of Level 3 NICUs with more prolonged or complex courses typically follow up in a specialized NICU follow-up clinic, typically affiliated with the NICU at which care was delivered. Detailed developmental assessments usually begin within months following discharge and continue at regular intervals until preschool age, and enhance the regular developmental assessments conducted in the primary care clinic and early intervention services.

There are several public health, human services and education programs available to support premature infants and their families across the state. Some of these include:

### **Family Home Visiting**

Family home visitors provide assessments, education and psychosocial support for the family with a premature infant. Families receive education on infant care, child growth and development, positive parenting, disease prevention and preventing exposure to environmental hazards. Home visitors provide assessments of both the baby and the caregiver including screenings for depression, assessing health and safety and observing the parent-child interaction. Home visitors connect low-income and other high risk families to community resources for preventive health care services (including medical care and well child visits), insurance, parenting, chemical dependency issues, employment, housing, education, financial and food. Early identification of infants and children not meeting developmental or social-emotional milestones and referring these children to community resources for further assessment and intervention is a critical role played by family home visiting. The close relationship of family home visiting with these early childhood organizations facilitates early intervention and reduces duplication of services.

### **Follow Along Program**

The Minnesota Follow Along Program (FAP) is a free program that provides periodic monitoring and screening of infants and toddlers at risk for health, social and emotional or developmental problems to ensure families receive early identification, assistance, and services. In 2010, the FAP was available in 84 counties and 4 tribal reservations (the FAP is not available in Faribault, Martin, Stearns and Ramsey counties; however these counties may have other developmental screening models available to the children and families in their areas). Some agencies offer the FAP to all families of newborns in the county, while other agencies only have the capacity to serve at-risk children and their families. The FAP is a partnership between state and local public health agencies.

The FAP provides helpful information to families on an on-going basis about how their child is developing and helps them understand the developmental stages of their child. In addition, families are sent age appropriate activities that encourage parents to interact with their children in a positive manner. If developmental concerns are found, the family is contacted and decisions are made between the professional and the family as to the next steps. Data from the FAP 2010 Annual Report state:

- 32,820 children were active in the FAP during 2010.
- 286 children had birth weights of less than 1500 grams and 1011 were less than 2500 grams.
- 1746 children were less than 36 weeks gestational age.
- Children most likely to fail an ASQ are children with risk factors that include; NICU graduates, suspected hearing loss, atypical or delayed development, gestational age equal to or less than 36 weeks gestation, birth weight less than 2500 grams (5lbs 8.2 ozs), Apgar score six or less at 5 minutes, history of drug and alcohol use during pregnancy and lack of prenatal care (3 or less visits starting in the 2<sup>nd</sup> trimester).

### **Help Me Grow (HMG): Infant and Toddler Intervention Services (birth to 3 years)**

Minnesota's HMG Infant and Toddler Intervention services (Part C) are designed for children birth to three years of age who may be experiencing delays in their development for several reasons, including special health conditions. Minnesota's eligibility guidelines assure that all premature infants born at or below 1500 grams are automatically eligible to receive HMG services. Premature infants born at a weight greater than 1500 grams may be eligible to receive services as well, after an individual developmental evaluation and family assessment. Services are provided at no cost to the family and are designed to meet the unique developmental needs of each child and their family; which may include physical, occupational and speech therapy, as well as service coordination. Child count data from December 2010 state that Minnesota served approximately 5000 children from birth to three years of age in the HMG program.

### **Help Me Grow (HMG): Preschool Special Education (3-5 years)**

Minnesota's HMG Preschool Special Education services (Part B) meet the needs of preschool children (3-5 years of age) who meet state eligibility criteria for developmental delay or disability and are experiencing challenges in their learning and development. A child may be eligible if he/she has a significant delay in development of their ability to learn, speak or play. Services are individually tailored to meet the unique learning needs of each child. Child count

data from December 2010 state that Minnesota served approximately 15,000 children from three to five years of age in the HMG program.

### **General Education (Kindergarten to grade 12)**

Even though the medical information on prematurity is not currently maintained in a child's educational record, many children born prematurely may be eligible to receive special education services up to 21 years of age. Identical to the eligibility information stated above for 3-5 year olds, children and young adults that meet the state criteria for developmental delay or disability and have an identified, educational need, are entitled to receive an education through school, including specialized instruction and related services that prepares the child for further education, employment, and independent living.

Free Appropriate Public Education (FAPE) is an educational right of children with disabilities in the United States that is guaranteed by the Individuals with Disabilities Education Act (IDEA) and the Rehabilitation Act of 1973 (specifically Section 504). Based on IDEA, the U.S. Department of Education – Office of Special Education Programs sets high standards and provides guidance to schools for how special education services are made available to address the individual needs of children with disabilities. Considering not all children are eligible to receive special education services through IDEA, families are also able to request specific accommodations or modifications through the development of a 504 Plan to assure their child has the opportunity perform at the same level as his/her peers (examples of accommodations include, blood sugar monitoring, an extra set of textbooks, a peanut-free lunch environment, home instruction, or a tape recorder or keyboard for taking notes).

### **WIC – Special Supplemental Nutrition Program for Women, Infants and Children**

WIC serves low-income pregnant, postpartum and breastfeeding women, infants and children up to age 5 who are at nutritional risk. For more details of the WIC program, please refer to page 11 of this report.

### **Medical Home**

Medical Home is an approach to primary care where primary providers, families and patients work in partnership to improve quality and value in the health care system, and improve health outcomes for individuals with chronic health conditions and disabilities.

This approach improves the way the individual clinicians and the clinic systems work with and meet the needs of all individuals with chronic, complex health conditions or disabilities using the following tools and strategies:

- Developing trusting relationships with patients/families
- Partnering with and learning from patients and families
- Using a team approach for the care of chronic conditions, which includes planned, proactive visits
- Coordinating care
- Co-managing with patients/families and specialists
- Assisting with transitions
- Providing connections with community organizations
- Is satisfying for patients/families, providers and clinic staff



- Continuously works on quality improvement

Premature infants benefit from the Medical Home model. This model has been established to respond to needs of the premature infant and their family. Integration into the Medical Home model is occurring as the spread of this practice is seen across the state.

## Articles of Interest

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