



REDUCING INFANT MORTALITY IN DELAWARE



The Task Force Report

MAY 2005

Governor Ruth Ann Minner
The Tatnall Building
Dover, DE 19901

Dear Governor Minner:

We are pleased to provide the final report of the Infant Mortality Task Force. We thank you for the opportunity to serve our state on this very important task force and acknowledge with deep gratitude the contributions of the many Delawareans who worked tirelessly to develop this report.

We are confident that task force recommendations provide a course of action to reduce the high infant mortality rate in Delaware. If adequately funded, many barriers that result in reduced access to perinatal care among minority populations will be removed. In addition, a successor entity to the Perinatal Board, the Delaware Healthy Mother and Infant Consortium, will be empowered to provide guidance to maternal and infant health systems that impact birth outcomes. We also anticipate collateral benefits that positively affect the mortality and morbidity rates from several leading causes of death.

There was wide agreement among task force members that implementation of these recommendations would improve birth outcomes and maternal health care. Many of the recommended actions have been implemented in other states with considerable success. A short list of anticipated results follows:

1. An increase in the number of high-risk women and infants with health insurance.

Access to health insurance is a critical component of assuring healthy birth outcomes for women and children. A lack of health insurance often means late or no entry into prenatal care for women, which can lead to a host of pregnancy complications and delayed diagnosis of treatable conditions.

2. Expanded access to prenatal care through targeted outreach and interventions.

The timing and quality of prenatal care that a woman receives during her pregnancy has a critical impact on the infant's health and survival. Late or no entry into prenatal care is associated with adverse pregnancy outcomes such as increased risk of low birth weight, premature birth, neonatal mortality and maternal mortality.

3. Enhanced data collection and surveillance around maternal and infant health.

Information is vital in making informed decisions about resource allocation and targeting interventions to populations at highest risk. Delaware lags behind other states in data collection that provides key information, such as a Fetal Infant Mortality Review (FIMR) (*see Glossary*), a Perinatal Risk Assessment Monitoring System (PRAMS) (*see Glossary*) and the ability to link databases which separately contain important information but together increase our knowledge even more.

4. Improved prevention and management of chronic diseases among pregnant women.

Preconceptional and prenatal care provides an opportunity to identify and manage chronic and acute medical conditions that can negatively affect birth outcomes.

5. Improved prevention and early detection of birth defects and genetic disorders.

Birth defects are the leading cause of infant mortality. Prevention and early intervention for birth defects and disabilities can have a profound positive effect on a child's health.

6. Expanded access to comprehensive reproductive health and family planning services for the uninsured and underinsured.

Unwanted and closely spaced pregnancies result in more adverse birth outcomes. Three dollars are saved on pregnancy medical costs for every public dollar spent for family planning. Savings and long-term benefits are particularly advantageous in the prevention of teen pregnancy.

7. Implementation of a statewide educational campaign and cultural competence curriculum for providers.

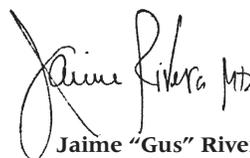
Finding the resources to implement these recommendations will not be without difficulty. Because of the adverse impact of tobacco use on the health of girls, women and their unborn children, the task force supports an increase in cigarette excise tax. Each penny of increased tax yields nearly one million dollars in revenue. The task force recommends that part of the excise tax be used to fund the recommendations in this report.

We thank you for leadership on this very important issue and for the privilege of serving the people of Delaware in this role. We thank you, most of all, on behalf of the many mothers and babies in Delaware whose lives will be bettered when these recommendations are implemented.

Sincerely,



Alvin Snyder, MSW
Co-Chair



Jaime "Gus" Rivera, MD, FAAP
Co-Chair

INFANT MORTALITY BACKGROUND



Why is infant mortality important?

Since mothers and infants are among the most vulnerable members of society, infant mortality is a measure of a population's health. In addition, disparities in infant mortality by race/ethnicity and socioeconomic status are an important measure of the inequalities in a society.

Despite great national wealth, the U.S. ranks 27th among industrialized countries in infant mortality.

COUNTRY	IMR*	COUNTRY	IMR*	COUNTRY	IMR*
1. Singapore	2.5	10. Italy	4.5	19. Denmark	5.3
2. Hong Kong	3.0	11. France	4.6	20. Israel	5.4
3. Japan	3.2	12. Austria	4.8	21. Portugal	5.5
4. Sweden	3.4	13. Belgium	4.8	22. England and Wales	5.6
5. Finland	3.8	14. Switzerland	4.9	23. Scotland	5.7
6. Norway	3.8	15. Northern Ireland	5.1	24. Ireland	6.2
7. Spain	3.9	16. Netherlands	5.1	25. Greece	6.1
8. Czech Republic	4.1	17. Australia	5.2	26. New Zealand	6.3
9. Germany	4.4	18. Canada	5.3	27. United States	6.9

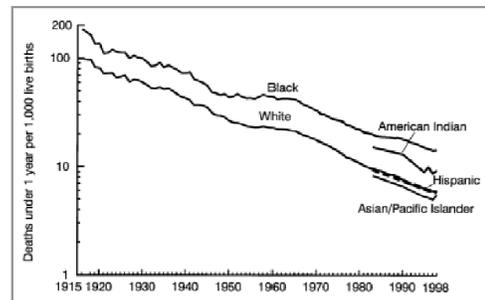
Infant Mortality Rate: Selected Countries, 2000

Source: National Center for Health Statistics, Health, United States, 2004 with Chartbook on Trends in the Health of Americans.

*Number of infant deaths per 1000 live births.

Racial and economic disparities contribute to the problem.

Some have argued that this poor ranking is a reflection of the long-standing disparity between black and white populations, with the infant mortality rate (IMR) among black Americans consistently twice that of white Americans. Others cite the wide inequalities between the wealthiest and poorest segments of our society. While social and racial disparities disproportionately contribute to the mediocre U.S. ranking, higher rates of low birth weight and preterm birth in the U.S. are noted among all groups of infants.

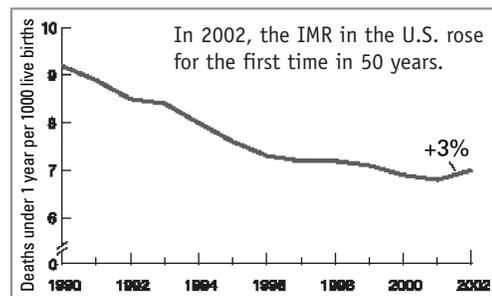


IMR by Race and Hispanic Ethnicity: United States, 1915-1998

Source: Annual summary of vital statistics: trends in the health of Americans during the 20th century. Pediatrics. 2000

Infant mortality is on the rise in the U.S.

An increase in infant mortality occurred after a consistent decline and a period of relative complacency about the progress made in addressing the causes of adverse pregnancy outcomes. New developments in the care of high-risk pregnancies and sick newborns, as well as the prevention of infant death from specific causes such as sudden infant death syndrome (SIDS), had until recently enabled a steady decline in IMR despite increasing trends of low and very low birth weight infants. The 2002 increase in IMR has launched a new national review of causes.



Infant Mortality Rates for the United States, 1990-2002

Source: Explaining the 2001-2002 infant mortality increase: data from the linked birth/infant death data set. National vital statistics reports, 2005

THE SITUATION IN DELAWARE



▶ A task force was charged with examining the issue in Delaware.

As part of this renewed focus, Governor Ruth Ann Minner appointed the Infant Mortality Task Force (IMTF) in 2004 to identify risk factors and implement practices to prevent infant mortality and reverse recent IMR increases in the state. In addition, Delaware was selected to participate in the State Infant Mortality Collaborative (SIMC), convened by the Centers for Disease Control and Prevention, the Association of Maternal and Child Health Programs, and the March of Dimes. This collaborative investigated the specific determinants of infant mortality increases in several states with high IMRs.

▶ How big is the problem in Delaware?

Despite its location on the East Coast among states of relative affluence, Delaware resembles the poorer Southern states in its pattern of infant mortality. For the most recent period (1998-2002), the IMR in Delaware was above 9 deaths per 1000 births. In the most recent state comparisons compiled by the Delaware Health Statistics Center and based on National Center for Health Statistics data, Delaware ranked sixth worst in the nation.

Delaware has the sixth worst infant mortality rate in the nation.

STATE	IMR (PER 1000)	LOW BIRTH WEIGHT (%)
38. New Jersey	6.3	8.0
22. Pennsylvania	7.3	7.9
14. Maryland	8.0	8.9
6. Delaware	9.1	9.0
5. South Carolina	9.3	9.7
4. Louisiana	9.5	10.3
3. Alabama	9.6	9.6
2. Mississippi	10.4	10.6
1. District of Columbia	12.3	12.3
U.S. TOTAL	7.0	7.6

*Ranking of Five-Year Average Percentages of Infant Mortality and Low Birth Weight Births for the U.S., 50 States and District of Columbia, 1998-2002
Source: National Center for Health Statistics and Delaware Health Statistics Center.*

KEY DEFINITIONS

Fetal death—Defined in Delaware as a fetus of at least 350 grams or, in the absence of weight, 20 weeks' gestation, born without a heartbeat, spontaneous respirations or purposeful movement.

Infant mortality rate (IMR)—The number of infant deaths under 1 year of age per 1000 live births.

Neonatal mortality rate (NMR)—The number of infant deaths under 28 days of age per 1000 live births.

Postneonatal mortality rate (PNMR)—The number of infant deaths between 28 days and 11 months of age per 1000 live births.

Perinatal mortality rate—The number of fetal deaths and infant deaths within seven days of birth per 1000 live births plus late fetal deaths.

Birth-weight-specific mortality rate—The number of infant deaths per 1000 live births in a given birth weight range.

Low birth weight (LBW)—Births less than 2500 grams.

Very low birth weight (VLBW)—Births less than 1500 grams.

Extremely low birth weight (ELBW)—Births less than 1000 grams.

IN MORE PRECISE TERMS, THE INFANT MORTALITY RATE (IMR) IS THE PRODUCT OF THE:

- Birth weight distribution of the population
- Risk of low birth weight babies of dying

This report focuses on strategies to improve the health and survival of infants. Recent IMR increases may also have partially arisen from shifts in the reporting of fetal deaths. Live births and/or more aggressive management of pregnancies (such that fetuses that might have previously died in utero are now being delivered alive and die within the first few days of life) may have impacted the reporting. Both of these artifactual explanations for increasing IMRs should be explored but do not alter the need to improve the conditions that underlie poor perinatal health outcomes.

➡ Racial, ethnic and geographic disparities also affect outcomes.

Racial, ethnic and geographic disparities in Delaware reflect those of the nation. The IMR among blacks in Delaware was 16.7 in 1998-2002, compared to 6.9 for whites and 6.3 for Hispanics. The population of the City of Wilmington, which has more black Americans and low-income residents compared to the state, has the highest IMR (13.5). The suburban areas of New Castle County (8.3) and Kent (9.9) and Sussex (8.3) counties have lower IMRs, but all are higher than the national average.

Delaware's IMR has increased 17.9 percent, from 7.8 in 1993-1997 to 9.2 in 1998-2002. This increase was reflected in both the black and white populations, whose infant mortality rates increased 13.6 percent and 23.2 percent, respectively. An analysis comparing the IMR in the 1994-1996 time period with 1998-2000 found that one-third of the increase was due to the birth of a greater number of extremely low birth weight (ELBW) black babies. Two-thirds of the increased IMR was due to a higher risk of death among VLBW babies in both black and white infants.

The infant mortality rate for blacks is more than twice that of whites and Hispanics.

CITY OR COUNTY	IMR (PER 1000)
Wilmington	13.5
Kent County	9.9
New Castle County	9.2
Sussex County	8.3

Annual Infant Mortality Rates by Area in Delaware 1998-2002(averages)

STATISTICS SUGGEST WOMEN HAVE UNADDRESSED HEALTH PROBLEMS EITHER BEFORE OR DURING PREGNANCY THAT RESULT IN SICK BABIES.

Each year, among the approximately 10,600 (1992-2002 year average) Delaware births, there are about 90 infant deaths. More than 70 percent of these occur in the neonatal period (the first month of life). The remainder occur during the postneonatal period, from one month to the end of the first year of life. This suggests that most causes of infant death arise from maternal health factors, before or during pregnancy, that result in less healthy infants.

Compared to the nation, Delaware's increase in IMR began earlier, in the mid to late 1990s. About one-third of the rise was due to increases in low and very low birth weight (VLBW) infants. Two-thirds was due to an increase in the risk of mortality among VLBW infants. The increased IMR among VLBW infants occurred mostly among conventionally low-risk women who were married, 30 years of age or older, living in suburban New Castle County, and receiving early prenatal care. This suggests that assisted reproductive technologies (ART) and other fertility issues associated with delayed childbearing are a factor.

WHAT CAUSES INFANT MORTALITY?



The Infant Mortality Rate (IMR) is a public health indicator of a complex societal problem. Numerous frameworks have been used to help understand the multiple determinants of infant mortality in a society and to identify interventions to reduce infant mortality. While the root social causes of infant mortality—persistent poverty, pervasive and subtle racism, and the chronic stresses associated with them—may not be easy to address, it is still possible to understand the risks of infant death by examining the biological pathways through which these societal forces act.

▶ Infant mortality is understood as the product of two major chains of events that begin with:

- A sequence of socioeconomic and biological forces on the mother's health that influence the outcome of her pregnancy.
- The adverse outcome of this sequence of events is usually the delivery of a premature, low birth weight or sick neonate.

▶ The second component of infant mortality is:

- The likelihood that the infant will survive given their health status at birth. (This latter component often reflects the medical care provided to high-risk pregnant women and their small, sick neonates.)

Maternal risk factors that contribute to poor pregnancy outcomes.

There are several factors that can increase the risk of an adverse pregnancy outcome and maternal complication.

- **Maternal age:**

The risk of an adverse pregnancy outcome increases at either end of the maternal age spectrum. Although adolescent pregnancy has been long recognized as a risk for poor outcomes, the rates of teen pregnancy and birth have declined dramatically in the last decade. In contrast, many women are now delaying pregnancy into their later 30s and 40s, resulting in high-risk pregnancies among older mothers.

- **Chronic illness:**

Chronic conditions, such as hypertension and other cardiovascular diseases, preexisting or gestational diabetes, and asthma and other chronic lung conditions, increase the risk of an adverse pregnancy outcome and maternal complications. Older mothers and black women may be at particular risk of such conditions.

- **Nutrition:**

Both under- and over-nutrition may place pregnant women at increased risk of an adverse pregnancy outcome. Low folate levels in the preconceptional period and very early pregnancy are now recognized as a risk factor for neural tube defect among infants. The levels of obesity in the U.S. population are rising dramatically and place mothers at additional risk.

- **Infection:**

Sexually transmitted infections, cervical and uterine infection, and asymptomatic bacterial vaginosis are now all recognized as increasing the risk of preterm delivery and may be important factors in explaining higher preterm birth rates.

- **Stress:**

Chronic and persistent stress associated with poverty and racial discrimination are now thought to be an important cause of adverse pregnancy outcome. Stress may have both direct and indirect effects on birth outcomes through biological and behavioral pathways.

- **Unwanted pregnancy:**

Unwanted and mistimed pregnancies are at higher risk of resulting in a preterm or LBW newborn. Women who have unwanted pregnancies are more likely to be malnourished, abuse substances, and delay prenatal care.

- **Smoking and other drug use:**

Smoking, heavy alcohol consumption, and the use of illicit substances all increase risk of adverse perinatal outcomes. Of these, smoking is most common and may carry added risk for newborn health problems with secondhand exposure after birth.

- **Prenatal care:**

Women who receive no prenatal care or who initiate prenatal care late in pregnancy are at increased risk of an adverse pregnancy outcome. High-quality, comprehensive prenatal care may have some role in recognizing risks during pregnancy and addressing these through preventive interventions.

Infant risk factors that contribute to birth-weight-specific mortality.

There are many factors that decrease the likelihood of infant survival.

- **Immaturity:**

The best predictor of infant survival is the infant's size at birth. Birth weight is a product of the gestational age at delivery and the fetal growth rate. In the U.S. and other developed countries, preterm delivery is the leading component of Low Birth Weight (LBW). About 70 percent of LBW, and virtually all Very Low Birth Weight (VLBW) babies, are born prematurely (less than 37 weeks' gestation). The majority of the recent national increase in Infant Mortality Rate (IMR) can be attributed to an increasing number of preterm, VLBW infants.

- **Multiple births:**

Twins and multiple births are more often delivered at earlier gestational ages than single births, resulting in a greater risk of mortality. Multiple births have increased substantially in recent years due to increasing use of assisted reproductive technology (ART). Women who use ART and other fertility treatments have greater rates of preterm birth and LBW, among both multiple and single births.

- **Congenital anomalies:**

Congenital malformations, deformations and chromosomal abnormalities are the leading cause of infant death in the U.S. Of these, neural tube defect is known to be preventable through preconceptional and prenatal folate supplementation. However, prevention is generally difficult since the causes of approximately 70 percent of defects are not known. Universal neonatal screening is performed for several rare abnormalities that can be fatal if not detected and treated promptly.

- **SIDS:**

While the exact causes of SIDS are unknown, the American Academy of Pediatrics' campaign to change infant sleep positions from the stomach to the back corresponded with substantial declines in SIDS-related death rates.

- **Respiratory distress syndrome:**

Preterm infants frequently experience respiratory distress because of incomplete lung maturation. Deaths due to respiratory distress syndrome decreased substantially after widespread use of medical treatments including surfactant and prenatal steroids. Despite medical progress, it remains among the leading causes of infant mortality

WHAT WE CAN DO



Strategies to reduce infant mortality rates.

In practical terms, infant mortality can be addressed by focusing on critical periods in the health of women and their infants and adopting a series of interventions that target specific risks. Because the factors that underlie infant death are multiple and complex, there is no single “magic bullet” to reduce infant mortality. It is important to note that while most interventions focus on women, we must also recognize the critical role of male partners in supporting the health of women and their infants. Further, the focus on the biological and medical pathways should not be interpreted as relieving society of the need to address underlying social inequalities. Finally, reducing infant mortality requires a “life course” approach to the health of women.

TO REDUCE INFANT MORTALITY RATES, WE MUST:

- Target risks during specific stages in women’s lives
- Involve partners and husbands in education and support tactics
- Continue to address social issues that contribute to the problem
- Adopt a “life course” approach to women’s health based on specific life stages

PRECONCEPTION

Healthy “girlhood” is a key to healthy pregnancy and motherhood. Improving the reproductive health of a population must first involve assuring the health of girls and young women who will become mothers. Investing in the health of women must continue into adulthood and the peak childbearing ages to promote the delivery of healthy infants. Among the key elements of such a strategy are:

- Promoting the healthy development of young girls and adolescents to be active, well-nourished and well-educated about their bodies and their sexuality, so that they can make responsible choices.
- Improving access to primary and preventive care for girls and women of all ages to promote the health of mothers, which includes screening and treating preexisting infections and conditions, and the counseling to prevent them.
- Contraceptive counseling and access to family planning services to reduce unwanted, mistimed and closely spaced pregnancies, especially among high-risk populations (e.g., teens and older women).
- Health education and policies that discourage smoking and drug use and promote physical activity and good nutrition to improve behavioral and physical health prior to pregnancy.

PRENATAL

High-quality comprehensive prenatal care has the potential to identify and address maternal risks, resulting in both healthier mothers and infants. Ideally many of the preexisting risks addressed during prenatal care should be prevented or treated prior to pregnancy, but the prenatal period is still an important time to address these and other complications that may arise during pregnancy. The following are critical components of comprehensive, high-quality prenatal care.

- Promote early entry and continued use of quality prenatal care with a full array of enabling and psychosocial services.
- Screen and treat reproductive tract infections and monitor preexisting conditions.
- Continue counseling to encourage healthy life style and good nutrition, including adequate folate and iron intake.
- Educate women about the early signs of pregnancy-related problems.
- Assure management of high-risk pregnancies in maternal-fetal medicine units within regionalized systems of care.

NEONATAL AND POSTNEONATAL

Over the last 50 years, the major improvements in Infant Mortality Rate (IMR) in the U.S. have resulted from successful reduction in postneonatal deaths that are not birth-weight-dependent and, more recently, from innovations that have dramatically improved birth-weight-specific survival. Neonatal intensive care units play a crucial role in providing the care and therapies necessary to sustain premature and otherwise fragile newborns. Other strategies include:

- Improve access to risk-appropriate care via regionalized perinatal systems to assure that neonates are born in or transported to facilities with the highest level of care needed to assure their survival.
- Educate parents about placing infants to sleep on their backs to prevent SIDS and about the importance of reducing secondhand exposure to smoke.
- Conduct Fetal and Infant Mortality Reviews (FIMRs), which bring together clinicians, public health officials and policy makers to examine causes of infant death and learn about preventable strategies to reduce the risk of perinatal death.

INTERNATAL (BETWEEN BIRTHS)

There are unique opportunities to improve the health of the additional pregnancies among women who have suffered an adverse pregnancy outcome (preterm, low birth weight, fetal or infant death). These internatal interventions are important because an adverse pregnancy outcome is the highest risk factor for a second adverse pregnancy outcome.

- Address any known risk factors present in the previous pregnancy and ensure closer clinical monitoring of subsequent pregnancies.
- Continue contraceptive counseling and family planning services to prevent unwanted and closely spaced pregnancies, especially among high-risk populations.

EFFORTS TO MAKE CHANGE HAPPEN



Even a cursory review of this information would suggest that the causes, and therefore the prevention, of infant mortality are complex. Delaware is fortunate to be one of five states participating in a two-year project to evaluate our high infant mortality rates more closely. This State Infant Mortality Collaborative (SIMC) is a joint venture of the Centers for Disease Control and Prevention, the Association of Maternal and Child Health Programs, the March of Dimes, and the five participating states. SIMC has helped Delaware create a framework for hypotheses that would explain high IMRs, and is also producing a "toolkit" for all states. Both products can be used to explore the underlying dynamics that drive our IMR.

Delaware's experience over the last decade proves that a system for ongoing monitoring of the levels of infant death and of the determinants of low birth weight and infant mortality are needed to inform clinicians, public health practitioners and policy makers of changing patterns and risk factors. A surveillance system must include timely and complete vital statistics reports (birth certificates, death certificates, fetal death certificates and certificate linkage), surveys (PRAMS and others), investigations (FIMR, child death reviews), continuous quality of assessment of clinical practices, and the ability to carry out epidemiological analyses.

▶ TO EFFECT CHANGE WE SHOULD:

- Have a system to monitor infant deaths and their causes
- Evaluate and investigate trends
- Accurately and continuously collect statistics and conduct surveys
- Perform quality assessments of clinical practices
- Inform clinicians and others of changing patterns and risks.
- Train and educate staff

▶ RECOMMENDATIONS OF THE DELAWARE INFANT MORTALITY TASK FORCE

What is measured gets done. The Task Force has accordingly set the very specific goal of reducing infant and perinatal mortality rate in Delaware to 4.5 deaths per 1000 live births by the year 2010. In order to track progress toward this goal and monitor all contributing factors to infant mortality, historic and current perinatal mortality rates will be included in the Delaware Vital Statistics Annual Report, beginning with 2003 data.

INFANT MORTALITY TASK FORCE **RECOMMENDATIONS**



Recommendation **1**

Conduct a comprehensive review of every fetal and infant death in Delaware.

The Fetal Infant Mortality Review (FIMR) process begins when a fetal or infant death is identified. FIMR staff collect data about the death and the services the woman and her family receive from a variety of sources such as the death certificate, the physician and medical records. FIMR staff also interview the parents and review records related to home visits, WIC and additional social services. The findings are used to develop a community action plan so that services delivered fill the identified needs.

Action Steps	Start Date	Intended Impact	Agencies Responsible
1. Complete the FIMR pilot now underway by the Division of Public Health (DPH) and Nemours Health and Prevention Services and document lessons learned.	2005	Identify the broad range of IM risk factors to implement preventive measures.	Division of Public Health & Child Death Review Board. Nemours Health and Prevention to complete current FIMR pilot.
2. Revise the Child Death Near Death and Stillborn Commission (CDNDSC) legislation (31 Del. Laws, c. 320-324) to (1) expand authority to investigate stillbirths occurring after 20 weeks' gestation instead of the current 27 weeks; (2) specifically state that the CDNDSC has the authority and flexibility needed to implement FIMR; and (3) acknowledge the role of public health assessment and interventions as a component of the CDNDSC and FIMR processes. These changes will assure that CDNDSC can implement FIMR consistent with national models.			
3. Secure funding for the CDNDSC and develop memorandums of understanding with DPH as needed.			
4. Establish infrastructure under CDNDSC in collaboration with DPH to operate FIMR. This includes oversight, coordination training, issuing contracts, building partnerships, and establishing an advisory committee, case review teams and community action groups.			
5. Initiate FIMR case reviews in 2005.			

Recommendation **2**

Create a monitoring system to increase understanding of the risks faced by pregnant mothers in Delaware.

Pregnancy Risk Assessment Monitoring System (PRAMS) can provide data that will give us a more complete understanding of issues affecting women before, during and after pregnancy. This understanding will contribute to improved delivery of care and improved programs to reduce infant mortality.

Action Steps	Start Date	Intended Impact	Agencies Responsible
1. Work with CDC to determine if methodology preferred in Delaware can be fully or partially funded.	2005	Provide data for planning and assessing health programs.	Division of Public Health & Centers for Disease Control
2. Design questionnaire and protocol for data collection and analysis. Establish advisory group.			
3. Implement survey.			
4. Over an extended time, capture data to evaluate race and county trends related to pregnancy.			

Recommendation **3**

Establish the Delaware Healthy Mother and Infant Consortium (DHMIC) as successor to the current Perinatal Board.

Current systems of healthcare need effective oversight. The Delaware Healthy Mother and Infant Consortium (DHMIC) will help ensure the effective implementation of the recommendations set forth by the Infant Mortality Task Force (IMTF). Consortium mandates should include reviewing and analyzing evaluations and reports and making appropriate recommendations. The Consortium should be established in Delaware Code and report to the governor.

Action Steps	Start Date	Intended Impact	Agencies Responsible
1. Authorize establishment through legislation of a successor entity to the Perinatal Board. This new entity, the Delaware Healthy Mother and Infant Consortium (DHMIC), will be charged with coordinating Delaware's efforts to reduce infant mortality and improve the health of pregnant women and their infants.	2005	The Successor Entity will become an effective oversight and accountability mechanism to ensure all system components are working well and that the recommendations of the IMTF are implemented.	Governor & General Assembly
2. The Consortium's priorities and advocacy agenda will be guided by the recommendations of the Infant Mortality Task Force (IMTF). The Consortium will oversee implementation of the current and future recommendations and develop an annual report to the Governor and Legislature.			
3. The Consortium will meet with the Secretary of Health and Social Services twice a year to present progress and make recommendations.			
4. The Consortium will meet with the governor once a year to present an annual report on progress of implementing the recommendations of the IMTF.			
5. Establish membership and leaders of the Consortium and its committees via gubernatorial appointment. Members will be recruited from the IMTF and Perinatal Board as well as the community and will be comprised of 15 members.			
6. The General Assembly will authorize resources for ongoing administrative support to the Consortium via the Division of Public Health.			
7. The Consortium will develop a strategic plan to carry out its mission and implement the recommendations of the IMTF. It will provide guidance to Delaware's maternal and infant health care systems and related services that impact birth outcomes.			
8. Establish a transition committee appointed by the chairs of the IMTF and the Perinatal Board that will function until the Consortium is operational. The transition committee will (1) assure that essential and urgent work of both groups continue without interruption; and (2) establish committees, by-laws, membership, and other structure and function necessary to assure success of the Coalition.			



HEATHER PRICE

“All you had to do was read Victoria’s chart to see how sick she was. She had 16 specialists and was undergoing five different therapies. At the end, she needed 24 hour care. State assistance said she wasn’t sick enough to qualify.”

Victoria Price was born at 28 weeks and weighed two pounds and ten ounces. She spent six weeks and five days in Christiana Care’s Neonatal Intensive Care Unit. At six months, she developed a mild case of reflux which—just days later—became vomiting accompanied by a persistent, inconsolable scream. She stopped eating and her condition was classified as “failure to thrive” in April of 2001. An exam showed no neurological problems. She began feeding through a tube. A month later she began to lose muscle function. Her mother searched for and created a special team that consisted of physicians, occupational, physical and speech therapists. Her condition continued to deteriorate. Victoria died at 22 months of age. Her mother will graduate this May with a degree to provide physical therapy to infants and children.

Recommendation **4**

Create the Center for Excellence in Maternal and Child Health and Epidemiology within the Division of Public Health.

The Center for Excellence in Maternal and Child Health and Epidemiology will provide staff dedicated exclusively to generating and properly analyzing additional data on maternal and child health. The work of this unit will help accurately monitor progress toward reducing infant mortality and eliminating racial and ethnic disparities in birth outcomes.

Action Steps	Start Date	Intended Impact	Agencies Responsible
1. Give the Division of Public Health (DPH) the resources to create this Center for Excellence so that three positions are funded (Management Analyst III, Statistician, Epidemiologist).	2005	Provide dedicated staff to properly analyze and report Delaware’s infant mortality data and address the health issues of women and children.	Division of Public Health, Office of the Governor & General Assembly
2. Hire and train personnel.			
3. Provide resources to ensure that Center staff are solely devoted to maternal and child health data projects, investigations, and service delivery.			
4. DPH’s Office for Women’s Health, Office of Adolescent Health and Maternal and Child Health will form the Center of Excellence in Maternal and Child Health.			

Recommendation **5**

Improve access to care for populations disproportionately impacted by infant mortality.

Some populations have significant barriers to timely care. Unless access to care is improved, these communities are likely to become the source of the next wave of poor birth outcomes.

Action Steps	Start Date	Intended Impact	Agencies Responsible
1. Identify and remove barriers to timely enrollment in Medicaid for women of childbearing age.	2005	Reduce and ultimately eliminate disparities in infant mortality rates.	Delaware Health and Social Services
2. Provide access to care for pregnant women currently eligible for only emergency services.			

Recommendation **6**

Provide access to preconception care for all women of childbearing age with history of poor birth outcomes.

Women who have had a previous poor birth outcome are at extremely high risk when they have another pregnancy unless there is intervention. The best way to quickly reduce the Infant Mortality Rate (IMR) is represented by addressing the needs of this group of women.

Action Steps	Start Date	Intended Impact	Agencies Responsible
1. Build a registry of all women with a history of poor birth outcomes.	2006	Reduce the risk of poor birth outcomes for women at highest risk.	Delaware Healthy Mother and Infant Consortium & Delaware Health and Social Services
2. Provide access to preconception care for all Medicaid-eligible women who have had a poor birth outcome in the past two years.			
3. Work with employers, especially of low wage earners, to encourage access to preconception care.			

Recommendation **7**

Require that insurers cover services included in standards of care for preconception, prenatal and interconception care.

It is important that care be available and that the cost is covered by the provider.

Action Steps	Start Date	Intended Impact	Agencies Responsible
1. Establish standards of care for preconception health in collaboration with providers, medical society, and the American College of Obstetrics and Gynecology. Ensure that insurance carriers cover all services related to preconception health.	2006	Expanded access to health care.	Delaware Healthy Mother and Infant Consortium & Division of Public Health

Recommendation

Implement a comprehensive (holistic) Family Practice Team Model to provide continuous comprehensive care and comprehensive case management services to pregnant women and their infants up to two years post partum. Services will include comprehensive case management, trained resource mothers, outreach workers, nurses, social workers and nutritionists.

Disparities in access, particularly among low-income and minority populations, are a major contributing factor in infant mortality. Community-based interventions have been successful in enrolling women with high-risk adverse pregnancy outcomes who otherwise are unlikely to receive basic care. The holistic family practice model is such a community-based intervention.

PRAMS and FIMR data, as well as information developed as result of recommendations of the Data Committee of the IMTF to identify causes of disparities, will allow the Delaware Healthy Mother and Infant Consortium to paint a clear picture of what needs to be done to eliminate disparities.

Action Steps	Start Date	Intended Impact	Agencies Responsible
1. Ensure all Medicaid-eligible pregnant women have access to this level of care.	2005	Improve poor pregnancy outcomes and reduce costs associated with high-risk births by (1) improving access to comprehensive medical care and health care services; (2) encouraging good nutrition and healthy life styles; and (3) reducing use of harmful substances. Additional benefits include: 1. Better identification and stratification by risk of high-risk pregnancies. 2. Better health care for infants and children. 3. Increased pregnancy intervals. 4. Decreased deaths. 5. Case management for those with previous adverse outcomes. 6. Strategies focused on those with increased risks.	Delaware Healthy Mother and Infant Consortium & Division of Public Health
2. Identify pregnant women and mothers at risk for poor birth outcomes early and provide appropriate screening, counseling, education and access to health care.			
3. Coordinate with existing smoking cessation efforts to target cessation programs to pregnant women			
4. Assess the adequacy of current screening for smoking and substance abuse in pregnant women and close any gaps.			
5. Assess the capacity to provide smoking cessation and drug treatment programs for pregnant women and close gaps.			
6. Work with insurers to create programs to provide interventions to pregnant women addicted to drugs or tobacco.			
7. Consider street-based programs to identify at-risk women in areas of high infant mortality.			

Action Steps	Start Date	Intended Impact	Agencies Responsible
8. Build a more comprehensive system of prenatal care through partnership with non-profit agencies, state agencies and communities to address root causes of IM disparity in Delaware.	2005		Delaware's Healthy Mother and Infant Consortium & Division of Public Health
9. Conduct an in-depth assessment (incl. PRAMS, FIMR and focus groups) of the geographic pockets of high IM in DE, including identification of community-specific risk factors for poor birth outcomes.			
10. Amend the Medicaid Managed Care contract to require the Medicaid vendor and the state's Medicaid program to implement a Best Clinical and Administrative Practices Model aimed at improving identification, stratification by risk, outreach and intervention to all Medicaid pregnancies, particularly those at high risk for poor birth outcomes. Vendor and state's Medicaid program will provide quarterly data for all pregnancy outcomes in the Medicaid program to the Consortium.			
11. Require every insurer in Delaware to participate in a process similar to that above and report pregnancy outcomes to the Delaware Healthy Mother and Infant Consortium.			
12. Expand home visiting programs to meet the needs of all women and infants who are at high risk for poor birth outcomes and include geographic areas of high infant mortality.			
13. Evaluate the system of home visiting services to identify effectiveness, best practices and areas that need improvement.			
14. Study the cost benefit of providing health care and case management services to high-risk women in high IM areas using a mobile van.			



CRYSTAL HANDY

“I feel there just aren’t many number-one doctors in Sussex County. People don’t know what the risks are. They have to be educated. Mothers need to know what they could be facing.”

Crystal Handy’s son was born at 25 weeks. He weighed three pounds and 15 ounces and lived 65 days. Crystal had chronic hypertension and was not aware that it was a pregnancy risk. There was stress in the household. She was smoking. Crystal lives with the guilt that she could have done something to help her baby. When she became pregnant with her daughter—who is now two—she was worried the entire time that she would lose her. She still hasn’t recovered from the emotional toll the experience took on her.



Implement Federal Standards for Culturally and Linguistically Appropriate Services (CLAS).

Increasing cultural and linguistic diversity in Delaware requires the implementation of standards to assure equal access to care and improves patient participation in clinical decision-making.

Action Steps	Start Date	Intended Impact	Agencies Responsible
1. Ensure that patients/consumers receive effective, understandable and respectful care from all providers. Health care services should be provided in a manner compatible with consumers' cultural health beliefs, practices and preferred language.	2005	1. Eliminate language and cultural barriers to health care. 2. Improve provider/patient communication and relationship. 3. Reduce the risk of provider error due to poor communication. 4. Reduce cost of care due to extra tests ordered to help with diagnosis in the presence of language and cultural barriers.	Delaware Healthy Mother and Infant Consortium & providers
2. Implement strategies to recruit, retain and promote a diverse staff and leadership that represent demographic characteristics of their service area.			
3. Ensure that staff at all levels and across all disciplines receive ongoing training in culturally and linguistically appropriate service delivery.			
4. Offer prompt and comprehensive language assistance services, including bilingual staff and interpreter services, at no cost to patients/consumers with limited English proficiency.			
5. Inform patients of their rights to receive language assistance services orally and in writing, using their preferred language.			
6. Assure the competence of language assistance services. Family and friends should not be used to provide interpretation except on request by the patient/consumer.			
7. Make available easily understood materials and signage in the languages of the commonly encountered groups and/or groups represented in the service area.			

Action Steps	Start Date	Intended Impact	Agencies Responsible
8. Develop, implement and promote a written strategic plan that outlines clear goals, policies, operational plans and management accountability/oversight mechanisms to provide culturally and linguistically appropriate services.	2005		Delaware Healthy Mother and Infant Consortium & providers
9. Conduct organizational self-assessments of CLAS activities and integrate cultural and linguistic competence-related measures into internal audits, performance improvement programs and patient satisfaction assessments, and outcomes-based evaluations.			
10. Ensure that patient demographic data is collected in health records, integrated into the organization's management information systems and periodically updated.			
11. Maintain a current demographic, cultural and epidemiologic profile of the community as well as a needs assessment to accurately plan and implement services that respond to the cultural and linguistic characteristics of the service area.			
12. Develop collaborative partnerships with communities and use a variety of formal and informal mechanisms to facilitate community and patient/consumer involvement in designing and implementing CLAS activities.			
13. Ensure that conflict and grievance resolution processes are culturally and linguistically sensitive and capable of identifying, preventing, and resolving cross-cultural conflicts or complaints by patients/consumers.			
14. Regularly make information available to the public about innovations in implementing the CLAS standards and provide public notice in their communities about the availability of this information.			

Recommendation **10**

Create a cultural competence curriculum for providers.

Cross-cultural education offers promise as a tool to improve health care professionals' ability to provide quality care to diverse populations and thereby reduce health care disparities.

Action Steps	Start Date	Intended Impact	Agencies Responsible
1. Assess current needs and available educational resources.	2005	Increase cultural competence in obstetric care.	Delaware Healthy Mother and Infant Consortium & Division of Public Health
2. Collaborate in a public/private partnership to deliver the educational training.		Improve the quality of care.	
3. Offer education on family planning, including bus cards, billboards and flyers that encourage preventive health care and save lives through planned families and by teens delaying pregnancy.		Reduce Infant Mortality.	
4. Explore how other states have mandated training in cultural competence as a condition of professional licensure. Require documentation of cultural competency to obtain/maintain professional license. Require cultural competence credits as part of CME requirements.			
5. Provide funds to health providers that are equipped to provide culturally competent, comprehensive care for pregnant and post partum clients. Support other providers in building cultural competency.			
6. Offer technical assistance to providers to improve the quality of care to high-risk pregnant women and the level of cultural competence in health care delivery. The curriculum should target providers caring for women, infants and children, and recommend an educational plan for its delivery. Curriculum should cover domestic violence and depression screening as well as appropriate nutrition education.			

Recommendation **11**

Improve comprehensive reproductive health services for all uninsured and underinsured Delawareans up to 650% of poverty.

For every public dollar spent on family planning, three dollars are saved in pregnancy and related health costs.

Action Steps	Start Date	Intended Impact	Agencies Responsible
1. Apply to the Center for Medicaid and Medicare Services for a Section 1115 Medicaid waiver that will expand coverage for family planning services to all uninsured Delawareans (whether or not they have ever participated in the Medicaid program) up to 650% of the federal poverty level (or to the highest income level possible that still complies with CMS budget neutrality requirements).	2005	Reduce infant mortality. Extend interpregnancy birth intervals. Improve identification and treatment of sexually transmitted diseases.	Delaware Health and Social Services
2. Establish standards for accessibility that include bus routes, walking distance, hours of operation, language barrier considerations, appointment and walk-in hours and teen centers or teen-centered hours. Provide immediate access to care, structure the program so that providers can directly enroll eligible clients, based on declaration of income and family size. Assess family planning needs and service sites to assure statewide access especially in targeted high-risk areas.			
3. Allocate state funds to provide free or low-cost family planning services for uninsured and underinsured Delawareans above the waiver income ceiling.			
4. Include sexually transmitted infection screening and treatment in the package of covered services.			
5. Implement an awareness campaign so that uninsured and underinsured Delawareans know about it.			



MELISSA JOHNSON

“We needed someone who understood us. Who could laugh with us, cry with us and know what we’ve been through.”

Amya Johnson was two pounds, four ounces when she was born at 26 weeks.

She was the second premature baby born to Melissa Johnson. Melissa had no medical issues, no history of high blood pressure and was completely healthy.

Amya was born with a heart defect and was not expected to live through the night. She became a medical miracle when a heart surgeon performed surgery to correct the problem. She lived 87 days. Her mother only held her four times. That experience led Melissa to become a counselor for other mothers of premature infants.

Recommendation **12**

Fund an in-depth analysis of programs in Delaware that mitigate infant mortality and create and implement an ongoing process for continuous quality improvement for services and programs developed to eliminate infant mortality.

Programs aimed at reducing infant mortality constitute a significant investment in resources. It is important to evaluate them for effectiveness, continue those that work and discontinue those that don't.

Action Steps	Start Date	Intended Impact	Agencies Responsible
1. Develop a compendium of established and new programs addressing infant mortality including program goals and objectives and program contact information. Include Early Head Start programs in the analysis.	2005	Provide an in-depth evaluation of Delaware programs aimed at reducing infant mortality.	Delaware Healthy Mother and Infant Consortium & Division of Public Health
2. Establish an evaluation methodology that will be used to assess the process, impact and outcome of programs.		Provide technical assistance to programs that ask for it or need it to improve their ability to provide improved birth outcomes.	
3. Prioritize and initiate objective, independent evaluations of programs on an ongoing basis.		Improve birth outcomes.	
4. Analysis should identify and eliminate gaps in services and areas of disparity, implement program outcome evaluations and improve care.			
5. Assist organizations providing programs to at-risk pregnant women, particularly the state's Medicaid program and Medicaid vendors, create and implement continuous quality improvement programs to improve birth outcomes.			
6. Assist organizations implementing Continuous Quality Improvement/Best Clinical Administrative Practices during the perinatal period for all services and programs, both government and private.			
7. Amend the Medicaid managed care contract to require the Medicaid program and its vendors to implement a Center for Health Care Strategies Best Clinical and Administrative Practices model for continuous quality improvement and provide data on a quarterly basis for all pregnancy outcomes within the Medicaid Program to make available through external reporting to the HMI Consortium.			

Action Steps	Start Date	Intended Impact	Agencies Responsible
<p>8. Require the State Medicaid contractor to participate in a statewide outreach and case management effort to mitigate poor birth outcomes as set forth by the Infant Mortality Task Force. DHMIC will present a report to the governor that includes the standards of care and a timeline that outlines the process through which the Council will educate all service components about the standards of care as related to coordination of care.</p>	2005		Delaware Healthy Mother and Infant Consortium & Division of Public Health
<p>9. Implement a statewide awareness campaign to educate all service components about the standards of care, which shall include screenings for emotional, physical and mental health issues. [Provide comprehensive, coordinated, integrated and accessible services statewide aimed at women at risk for poor birth outcomes.]</p>			
<p>10. Develop and implement standards of care for pregnant women and for preconceptional and interconceptional care consistent with 1995 ACOG guidelines.</p>			
<p>11. Require outcome measures of all publicly funded programs. DHMIC will establish guidelines for outcome management systems, recommend outcome measures to use and develop recommendations for the implementation of outcome management systems.</p>			
<p>12. Adopt regulations that would require the measures be used.</p>			
<p>13. Implement a statewide awareness campaign to educate all publicly funded service components about the standardized outcome measures. [Measures should demonstrate the effectiveness of maternal and infant health services.] [Adopt existing IM prevention goals.]</p>			

Recommendation **13**

Create an epidemiological surveillance system to evaluate and investigate trends and factors underlying infant mortality and disparity.

The factors behind the increasing infant mortality rates have changed over time. It is important to be able to monitor these changes and respond in a proactive manner.

Action Steps	Start Date	Intended Impact	Agencies Responsible
1. Determine why Delaware has a high preivable (very premature) birth rate and why it's higher among blacks.	2005	Gain insight into Delaware's infant mortality rate and reason for racial disparity.	Delaware Healthy Mother and Infant Consortium, Division of Public Health & Hospitals
2. Assess the manner in which classification of fetal deaths and live births have changed over time. (Explanation: A change in reporting of fetal deaths so that they are more likely to be counted as live births will increase the infant mortality rate; and may be due to changes in classification and/or medical management of pregnancy, labor and delivery. This assessment may involve reviewing information in hospital maternal and infant mortality records, and/or linking DPH birth, death and hospital discharge databases.)			
3. Investigate the degree to which less healthy pregnant women impact infant mortality rates and explain the racial disparity. (Explanation: Low birth weight and infant death is known to be impacted by the mother's health risks [high blood pressure, interpregnancy interval, poor nutrition, obesity, infection, advanced maternal age, etc.])			
4. Investigate the degree to which perinatal care impacts infant mortality rates and explain the racial disparity. (Explanation: Most of the decrease in infant mortality nationally is attributed to improvement in perinatal care and access to that care. Perinatal care can have an impact in two ways: [1] access to adequate risk assessment, referral, and risk-appropriate care will generally increase the health of the mother and newborn; [2] a trend toward more aggressive management of pregnancy and delivery may result in a live birth at high risk of neonatal death.)			
5. Conduct an in-depth analysis of the impact of malpractice insurance on obstetric care and the availability of OB providers, especially in under-served areas, in Delaware.			

Recommendation **14**

Create a linked database system to meet data analysis and program assessment goals and improve health care and services provided to the public.

Linking health databases will improve public health by more efficiently and expeditiously meeting health care needs, including preventive and therapeutic services, while maximizing often limited resources.

Action Steps	Start Date	Intended Impact	Agencies Responsible
1. Review similar projects listed on the Public Health Informatics website and those involved with the All Kids Count network. Conduct literature review, make contacts with other state, federal and private agencies to assist with project outline for the creation of an integrated data warehouse. Contact and engage potential stakeholders, including those that control the databases of interest, potential data users, technical personnel, to develop project goals, identify specific databases and determine what data is available. Consider the need for an outside entity to assist with the implementation of formal business plan, such as Public Health Informatics Institute.	2006	Expand the scope of data that can be analyzed in order to better understand Delaware's infant mortality.	Delaware Healthy Mother and Infant Consortium & Division of Public Health
2. Move forward with selection of contractor and communicate recommendations from step above. Employ contractor to create the physical and technical infrastructure necessary to create the integrated Health Data System. This will involve designing the system, purchasing or developing the software, and any necessary hardware.			
3. Establish linked database system incrementally. Communicate with all stakeholders how the system will change what they do and how it can help them. Maintain and update on an ongoing basis.			
4. Begin with a core set of databases that would include vital records, hospital discharge, newborn screening (both blood and hearing), immunization registry and birth defects registry.			



SARA MYERS

“There are little or no home visiting services in Sussex County. I have been there when we have discharged an infant born drug-addicted that was sent home on tincture of opium to manage withdrawal symptoms without any follow-up care. There are not enough nurses to do what we know makes a difference.”

Sara Myers remembers when her job made a difference. Working at a clinic, she remembers when there was pregnancy testing and a nurse practitioner who examined the expectant mothers and followed their progress. There were prenatal education and childbirth classes. After the babies were delivered, there were home visits. People experienced a continuity of care and a level of trust. Since managed care, it's all changed. There are not enough programs and not enough nurses and social workers to go around.

Conduct a statewide education campaign on infant mortality targeted at high-risk populations.

It will take the entire community to reduce infant mortality. The people who are at the highest risk must receive messages and information that help them understand that they are vulnerable. Those at low risk must learn how they can stay that way.

Action Steps	Start Date	Intended Impact	Agencies Responsible
<p>1. Conduct a statewide educational campaign on improving birth outcomes aimed at all women, particularly those at high risk for poor birth outcomes. Apply best practices and outcome measures to the campaign. Coordinate the campaign with other educational efforts aimed at high-risk populations such as those from the Department of Education and the Department of Health and Social Services. Consider making infant mortality the theme for 2006 Women’s Health Expo.</p>	<p>2005</p>	<p>Increase awareness of infant mortality among high-risk populations, increase availability of services to all women, particularly those at high-risk for poor birth outcomes, and provide public education about ways to improve birth outcomes.</p>	<p>Division of Public Health—Center for Maternal and Child Health Epidemiology</p>
<p>2. Create an Education Committee within the Consortium to coordinate all health promotion activities and serve as a clearinghouse for information, data and research on infant mortality. Coordinate education efforts for community and professionals that includes training on domestic violence, safe sleep positions, substance abuse and smoking, preconception health, breast-feeding, birth intervals, adolescent health and stress. Include workplace education.</p>			
<p>3. Campaign should include all avenues to reach populations and be culturally competent. It should address the impact of chronic illness, early prenatal care, smoking, healthy life styles, etc. Collaborate with Delaware Helpline to ensure that the public can be directed to appropriate services and resources in response to educational campaigns.</p>			
<p>4. Promote breast-feeding, increase breast pump availability through insurance coverage and assure availability of low-cost pumps to low-income women.</p>			

Recommendation **16**

Expand the birth defect registry surveillance and make it proactive by broadening monitoring, early intervention and prevention programs.

If we can identify exposures or other factors that may increase the risk of birth defects, information can be provided to women who are planning a pregnancy or who are already pregnant.

Action Steps	Start Date	Intended Impact	Agencies Responsible
1. Review existing legislation authorizing birth defects registry and amend as needed.	2006	Identify causes of birth defects, prevent birth defects and better connect affected children to services.	Delaware Healthy Mother and Infant Consortium & Division of Public Health
2. Establish an advisory committee to oversee birth defects registry operations and assure adequate analysis of data.			
3. Re-implement active case finding to supplement existing passive reporting (birth and death certificates, hospital discharge data). Increase provider education about reporting requirements.			
4. Develop prevention strategies.			
5. Evaluate current or potential software to maintain registry and implement appropriate changes.			
6. Publish annual report and post to web.			
7. Find better ways to connect affected children with services.			

Recommendation

17

Continue to improve the statewide neonatal transport program.

Each newborn infant must be transported to the facility where he or she can receive the highest level of care.

Action Steps	Start Date	Intended Impact	Agencies Responsible
1. Conduct ongoing evaluations of the neonatal transport system.	2005	A complete understanding of issues affecting neonatal transport will result in improved access to care.	Hospitals & Delaware Healthy Mother and Infant Consortium
2. Implement recommendations from these evaluations.			

Recommendation

18

Evaluate environmental risk factors for poor birth outcomes.

Identify, eliminate or mitigate risk factors in the environment.

Action Steps	Start Date	Intended Impact	Agencies Responsible
1. Assess environmental risks for poor birth outcomes in Delaware in collaboration with Department of Natural Resources and Environmental Control.	2006	Determine if environmental risks/conditions are contributing to poor birth outcomes.	Division of Public Health—Center for Maternal and Child Health & Department of Natural Resources and Environmental Control.

Recommendation

19

Promote oral health care, particularly the prevention and treatment of periodontal disease, as a component of comprehensive perinatal programs.

Action Steps	Start Date	Intended Impact	Agencies Responsible
1. Assure that oral health is integrated into education, outreach and access to care programs for perinatal care.	2005	Decrease poor birth outcomes by treating periodontal disease among low-income pregnant women.	Delaware Healthy Mother and Infant Consortium, Division of Public Health, Delaware Dental Society & Delaware Health and Social Services
2. Assess the feasibility and benefits of providing periodontal evaluations and treatment to low-income pregnant women with severe and progressive periodontal disease.		Reduce disparities in access to periodontal care.	
3. Include randomized clinical trials in the proposed state infant mortality research agenda to study the effects of periodontal treatment on pre-term births.		Obtain a better understanding of the extent that poor birth outcomes can be decreased by treating progressive periodontal disease among low-income women.	
4. Educate providers on how to diagnose, treat and refer pregnant women with severe periodontal disease.			

Recommendation

20

Provide an annual report to the governor on current and future factors impacting the availability of obstetrical practitioners. Include recommendations to remedy systems capacity issues.

Adequate access to care starts with the availability of health care providers.

Action Steps	Start Date	Intended Impact	Agencies Responsible
1. Publish a biennial capacity study on the supply and distribution of services to pregnant women, particularly in areas where infant mortality is highest.	2006	Policy makers and program staff will have the data necessary to implement programs to improve access to care.	Delaware Healthy Mother and Infant Consortium & Division of Public Health
2. Annually assess the financial factors that affect the availability of practitioners.		The DHMIC will utilize this report to make recommendations to the governor.	
3. Make recommendations for improvement.			

Paying for the Recommendations

The Infant Mortality Task Force recognizes the critical impact of tobacco use on the health of girls and women, and on the health of babies born to women who have used tobacco. The task force also acknowledges that increasing the cost of tobacco can reduce the number of young people who start smoking. For these reasons, the task force supports recommendations made by the Delaware Advisory Council on Cancer Incidence and Mortality and Tobacco Free Delaware (the Delaware IMPACT Coalition) to increase the cigarette excise tax. Each penny increase in the excise tax would yield more than \$1 million in revenue. The task force recommends that the excise tax be used to fund the recommendations in this report.

Costs of Implementing Recommendations

Reducing infant mortality requires implementing multiple prevention and intervention strategies that address a variety of risk factors. While solutions are expensive, considerable savings in health care spending offset costs. For example, low birth weight (LBW) is a major cause of infant mortality. It is associated with costly medical care and high rates of chronic and disabling illnesses.

Prevention is the most cost-effective approach. In 1985, Institute of Medicine analyses showed that money spent for prenatal care for high-risk women yielded savings on the total cost of caring for LBW infants requiring extensive care; we expect the savings would be even greater today. Eliminating financial barriers to early and comprehensive maternity care, providing adequate service capacity and accessibility, and developing public education and outreach programs are essential elements of a system of care to reduce infant death. These are cost-effective solutions to saving children's lives and enabling healthy life styles for high-risk pregnant women.

Implementation of task force recommendations should significantly expand services to high-risk pregnant women through public/private partnerships. State funds will be leveraged through community service providers, many of which have been involved in task force committees.

Infant Mortality Task Force Costs

Recommendation	Year 1			
	Annual One-Time	State Funds—FY 06	Federal Funds—FY 06	Total—FY 06
1. Conduct a comprehensive review of every fetal and infant death in Delaware.	\$0	\$157,257	\$0	\$157,257
2. Create a monitoring system to increase understanding of the risks faced by pregnant mothers in Delaware.	\$15,000	\$80,000	\$0	\$80,000
3. Establish the Delaware Healthy Mother and Infant Consortium (DHMIC) as successor to the current Perinatal Board.	\$0	\$50,000	\$0	\$50,000
4. Create the Center for Excellence in Maternal and Child Health and Epidemiology within the Division of Public Health.	\$10,000	\$153,000	\$0	\$153,000
5. Improve access to care for populations disproportionately impacted by infant mortality.	\$0	\$416,102	\$0	\$416,102
6. Provide access to preconception care for all women of childbearing age with history of poor birth outcomes.	\$0	\$852,000	\$852,000	\$1,704,000
7. Require that insurers cover services included in standards of care for preconception, prenatal and interconception care.	\$0	\$0	\$0	\$0
8. Implement a comprehensive (holistic) Family Practice Team Model to provide continuous comprehensive care and comprehensive case management services to pregnant women and their infants up to two years post partum. Services will include comprehensive case management, trained resource mothers, outreach workers, nurses, social workers and nutritionists.	\$50,000	\$1,594,886	\$0	\$1,594,886
9. Implement Federal Standards for Culturally and Linguistically Appropriate Services (CLAS).	\$350,000	\$175,000	\$175,000	\$350,000
10. Create a cultural competence curriculum for providers.	\$200,000	\$100,000	\$0	\$100,000

Bold type indicates costs calculated at ten months.

Year 2			Year 3		
State Funds—FY 07	Federal Funds—FY07	Total—FY 07	State Funds—FY 08	Federal Funds—FY 08	Total—FY 08
\$188,708	\$0	\$188,708	\$188,708	\$0	\$188,708
\$80,000	\$0	\$80,000	\$80,000	\$0	\$80,000
\$50,000	\$0	\$50,000	\$50,000	\$0	\$50,000
\$183,500	\$0	\$183,500	\$183,500	\$0	\$183,500
\$832,205	\$0	\$832,205	\$1,040,256	\$0	\$1,040,256
\$1,704,000	\$1,704,000	\$3,408,000	\$2,130,000	\$2,130,000	\$4,260,000
\$0	\$0	\$0	\$0	\$0	\$0
\$1,863,863	\$1,863,863	\$3,727,726	\$2,329,829	\$2,329,829	\$4,659,657
\$175,000	\$175,000	\$350,000	\$175,000	\$175,000	\$350,000
\$100,000	\$0	\$100,000	\$100,000	\$0	\$100,000

Infant Mortality Task Force Costs (continued)

Recommendation	Year 1			
	Annual One-Time	State Funds—FY 06	Federal Funds—FY 06	Total—FY 06
11. Improve comprehensive reproductive health services for all uninsured and underinsured Delawareans up to 650% of poverty.	\$0	\$150,000	\$1,339,200	\$1,489,200
12. Fund an in-depth analysis of programs in Delaware that mitigate infant mortality and create and implement an ongoing process for continuous quality improvement for services and programs developed to eliminate infant mortality.	\$100,000	\$300,000	\$0	\$100,000
13. Create an epidemiological surveillance system to evaluate and investigate trends and factors underlying infant mortality and disparity.	\$0	\$100,000	\$0	\$100,000
14. Create a linked database system to meet data analysis and program assessment goals and improve health care and services provided to the public.	\$0	\$0	\$0	\$0
15. Conduct a statewide education campaign on infant mortality targeted at high-risk populations.	\$0	\$275,000	\$0	\$275,000
16. Expand the birth defect registry surveillance and make it proactive by broadening monitoring, early intervention and prevention programs.	\$0	\$0	\$0	\$0
17. Continue to improve the statewide neonatal transport program.	\$0	\$0	\$0	\$0
18. Evaluate environmental risk factors for poor birth outcomes.	\$0	\$0	\$0	\$0
19. Promote oral health care, particularly the prevention and treatment of periodontal disease, as a component of comprehensive perinatal programs.	\$0	\$75,000	\$0	\$75,000
20. Provide an annual report to the governor on current and future risk factors impacting the availability of obstetrical practitioners. Include recommendations to remedy systems capacity issues.	\$25,000 (Year 2)	\$0	\$0	\$0
TOTALS	\$750,000	\$4,478,245	\$2,366,200	\$6,844,445

Year 2			Year 3		
State Funds—FY 07	Federal Funds—FY07	Total—FY 07	State Funds—FY 08	Federal Funds—FY 08	Total—FY 08
\$297,600	\$2,678,400	\$2,976,000	\$372,000	\$3,348,000	\$3,720,000
\$100,000	\$0	\$100,000	\$100,000	\$0	\$100,000
\$100,000	\$0	\$100,000	\$100,000	\$0	\$100,000
\$1,500,000	\$0	\$1,500,000	\$0	\$0	\$0
\$275,000	\$0	\$275,000	\$275,000	\$0	\$275,000
\$30,000	\$0	\$30,000	\$30,000	\$0	\$30,000
\$0	\$0	\$0	\$0	\$0	\$0
\$25,000	\$0	\$25,000	\$0	\$0	\$0
\$75,000	\$0	\$75,000	\$75,000	\$0	\$75,000
\$40,000	\$0	\$65,000	\$40,000	\$0	\$40,000
\$7,619,876	\$6,421,263	\$14,066,139	\$7,269,293	\$7,982,829	\$15,252,121

OUR THANKS TO ALL OF THOSE WHO HAVE GIVEN THEIR TIME

...to help us learn how we can reduce infant mortality in Delaware. The task force committee members and chairs have all been volunteers in this effort. This report is the result of the hours, days and months of research, resolve, commitment and knowledge that they brought to the project. In particular, we would like to thank the families of those who have experienced infant deaths. Sharing your stories has given us valuable insight into your loss. It is because of you and the many families like yours that these recommendations have been made.

COMMITTEE MEMBERS

INFANT MORTALITY TASK FORCE

Jaime H. Rivera, MD*
 Alvin Snyder, MSW*
 Steven Berlin, MD
 The Honorable Patricia Blevins,
 State Senator
 Anthony Brazen, DO
 Deborah Chang, MPH
 Garrett Colmorgen, MD
 Janet Cornwell, PhD
 Steven Dowshen, MD
 Katherine Esterly, MD
 Lynne Howard
 Ted Jarrell, Ph.D.
 Catherine Kanefsky
 Sharon Kaplan, BA, MA
 Drew Langloh
 Joseph Letnaunchyn
 Lolita Lopez, CHE
 Wanda Lopez, BS
 Stanley Lynch, MD
 The Honorable Pam Maier,
 State Representative
 Mark Meister
 Brian Olson, MBA
 Sharon Painter
 David Paul, MD
 Julia Pillsbury, DO
 Tonia Ryan
 The Honorable Teresa L. Schooley,
 State Representative
 John Stefano, MD
 Judy Walrath, PhD
 Nancy Wilson, PhD

BEST CLINICAL AND ADMINISTRATIVE PRACTICES COMMITTEE

Deborah Chang, MPH*
 Celeste Anderson, MS
 Marihelen Barrett, RN, MS
 Edwina Bell-Mitchell
 Janet Brown, RN, MSN, NCSN, FNP
 Emma Curtis
 Linda Daniel, RN, MSN, CCM

Sandy Elliot, CNM, MSN
 Penny Gross
 Linda M. Henshaw
 Katherine Kolb, RN, BSN, MS
 Alyson Lang
 Mark Meister
 Mariann Kenville-Moore
 Anthony Oliva
 Julia M. Pillsbury, DO, FAAP, FACOP
 Anthony Policastro, MD
 Joan Powell, MPA
 Mariann Powell, RN
 Meena Ramakrishnan, MD, MPH
 Ami Sebastian-Hauer
 Eva Sowinsky
 Sandy Voss

PREVENTION COMMITTEE

Steven Dowshen, MD*
 Marie A. Allen, MS, CFCS
 Maddy Anderson, RN, HCM, CPUR
 Steve Berlin, MD
 Joyce Breasure
 Deborah P. Brown
 Bernice Edwards
 Michelle Eichinger, MS
 Ellen Feinfeld
 Bob Gambardella, MA
 Cindy R. Genau
 Muriel E. Gilman, MPA
 Helene Gladney, MPA, MHR
 Stella P. Guest
 Robert P. Hall, MDiv, DAPA
 Nancy Hastings, RN, IBCLC
 Sharon J. Kaplan, BA, MA
 Moonyeen Klopfeinstein, MS, RN,
 IBCLC, CCE
 Eduardo Lara-Torre, MD, FACOG
 The Honorable Pam Maier,
 State Representative
 Minerva Marrero
 Maria Matos
 Bess McAneny RN, MSN**
 Kathleen Mosby

Senee Oates
 Stephen Pearlman
 Maria Picazo
 Mary E. Polk
 Janet Ray
 Noreen Renard
 Barbara Ridge
 Suss Scheppele
 Sandra Shelnut, MSW
 Catherine Short
 Rob Simmons, Dr.Ph, MPH, CHES
 Libby Thomas
 Bernice L. Wilkins
 Beverly Williams
 Linda C. Wolfe, BSN, RN, NCSN

DATA SCIENCE COMMITTEE

David Paul, MD*
 Ted Jarrell, Ph.D.*
 Anthony Brazen III, DO, MBA
 Nancy Colley, RN, MS, APN
 Mary Anne Ebersol, RN, BSN
 Lamar Ekbladh, MD
 Michael Gamer-McCormick, PhD
 James M. Gill, MD, MPH
 Judith Herrman, PhD, RN
 Stephen Thomas Lawless, MD, MBA
 Jim L. Lesko
 Robert Locke, DO, FACOP, FAAP
 The Honorable Teresa L. Schooley,
 State Representative
 John Stefano, MD
 Donald G. Unger, PhD
 Judy Walrath, PhD

SYSTEMS OF CARE COMMITTEE

Drew Langloh*
 Deborah Baley, PhD
 The Honorable Patricia Blevins,
 State Senator
 Maria Matos
 Linda C. Brasel
 Linda Brittingham, MC, LCSW
 Sylvia Brooks, EdD

Suzanne Cohen
 Janet R. Cornwell, PhD
 Susan Ccyk, MED, CRC, CPRP
 David Hack, MD
 April Hickerson
 Eric Jacobson
 Fritz Jonnes
 John W. Land
 Joseph Letnaunchyn
 Bill Love
 Herb Martin
 Bianca Pagan
 Sharon Painter, MS
 Marc Richman, PhD
 Tonia Ryan
 Al Snyder, MSW
 Bridget Wheatly, RN, MS
 Nancy Wilson, PhD

DISPARITIES COMMITTEE

Lolita Lopez, CHE*
 Lynne Howard*
 Donald Berry
 Adrienne Bey, MSW, PhD
 Garrett Colmorgen, MD
 Katherine Esterly, MD
 Alice Goodfellow Davis
 Susan Greenstein, MSS, ACSW
 H. Ward Grover
 Anne Marie Higley
 Jan Hudgins
 Debra Jackson Spence
 Wanda Lopez, BS
 Patricia Lynch, MSN, RNC
 Marcella Martin
 Brian Olson, MBA
 Michele Pray-Griffith
 A. Richardson
 Rhonda Tsoi-A-Fatt
 Hal Wallach
 LaVaida Owens-White, MSN, RN
 Estelle Whitney

The task force and its chairs offer their thanks to the many Division of Public Health staff who worked tirelessly on committees and provided logistical support for the work of the task force and the working group.

DATA COMMITTEE

Paul Silverman, Dr.PH—Subject
 Matter Expert
 Barbara Gladders, MS—Subject
 Matter Expert
 Sarah Myers, RN, BSN—Facilitator
 Vince Checchi, Facilitator

PREVENTION COMMITTEE

Herman Ellis, MD, MPH—Subject
 Matter Expert
 Prue Albright, RN, MSN—Facilitator

SYSTEMS OF CARE COMMITTEE

Kathy Collison, MS—Subject
 Matter Expert
 Dennis Rubino, MSW, MPH—Facilitator

DISPARITIES COMMITTEE

Mawuna Gardesey, MBA—Subject
 Matter Expert
 Loretta Taylor, Facilitator
 Michelle Mathew, BS—Facilitator

BEST CLINICAL AND ADMINISTRATIVE PRACTICES COMMITTEE

Bonnie MacLeod, RN, MSN—Subject
 Matter Expert
 Lois Quinlan, MBA, MT(ASCP)DLM—
 Facilitator
 Anita Muir, MS, RD—Facilitator

WORKING GROUP

Jaime Rivera, MD—Chair
 Alvin Snyder, MSW
 Barbara Jarrell, MBA
 Paul Silverman, Dr.Ph
 Herman Ellis, MD, MPH
 Mawuna Gardesey, MBA
 Leslie Kling, BS
 Jacqueline Chrisman, MD, MPH, MBA
 Prue Albright, RN, MSN
 Jill Rogers, RN, MSN
 Barbara Gladders, MS
 Greg McClure
 Dave Walton
 Heidi Truschel-Light

LOGISTICAL SUPPORT

Mawuna Gardesey, MBA
 Leslie Kling, BS
 Jill Rogers, RN, MSN
 Dave Walton
 Jean Collison
 Peggy Carney
 Barbara Reinert
 Susan Thomas
 Theodore Mermigos, Jr.
 Donna Sharp
 Amanda Yarnal
 Nate McCormack
 Pat Zielen
 Danielle Lawson
 Nathalie Moore
 Wendy Ringler
 Joanne Dell'Aquila
 Ronniere Robinson, BS
 Laura Benton
 Amy Reninger
 Michelle Moore
 Cindy Lee
 Walt Mateja, MPA
 Janet Schulte
 Jean Collison

**Denotes committee chair. **Disagrees with recommendation on family planning*

G L O S S A R Y O F T E R M S

birth defect—A birth defect is any structural or biochemical abnormality, regardless of cause, diagnosed at any time before or after birth, that requires medical or surgical intervention or that interferes with normal growth or development. Birth defects are a leading cause of infant mortality, accounting for more than 20% of all infant deaths. Because the causes of nearly 70% of all birth defects are unknown, there is concern about whether environmental pollutants cause birth defects.

CDNDSC—Child Death, Near Death, Stillbirth Commission.

CLAS—Culturally and Linguistically Appropriate Services.

CMCHE—Center of Excellence in Maternal and Child Health and Epidemiology.

CQI—Continuous Quality Improvement.

DHMI—Delaware Healthy Mother and Infant Consortium.

fetal death—Defined in Delaware as a fetus of at least 350 grams, or in the absence of weight, 20 weeks gestation, born without a heartbeat, spontaneous respirations or purposeful movement.

fetal mortality rate—The number of fetal deaths divided by the number of live births plus fetal deaths, per 1000 live births plus fetal deaths.

FIMR (Fetal and Infant Mortality Review)—A process used by many states and localities to learn more about infant deaths than can be found on birth and death certificates. The FIMR process begins when a fetal or infant death is identified. FIMR staff collect data about the death and the services the woman and her family receive from a variety of sources, such as the death certificate, the physician and hospital records. FIMR staff also interview the parents and review records related to home visits, WIC (Special Supplemental Nutrition Program for Women, Infants and Children) and additional social services. During the course of these interviews, important public health services can be offered to the family. To be successful, the findings of FIMR must be used in a community action plan to make differences in the way services are delivered.

infant mortality rate (IMR)—The number of infant deaths under one year of age per 1000 live births.

low birth weight (LBW)—Births less than 2500 grams.

neonatal mortality rate (NMR)—The number of infant deaths under 28 days of age per 1000 live births.

perinatal mortality rate—The sum of late—more than 28 weeks' gestation—fetal deaths plus infant deaths within 7 days of birth per 1000 live births plus late fetal deaths.

postneonatal mortality rate (PNMR)—The number of infant deaths between 28 days and 11 months of age per 1000 live births.

PRAMS—Pregnancy Risk Assessment Monitoring System is a surveillance project of the Centers for Disease Control and Prevention (CDC) and state health departments collects data on maternal attitudes and experiences before, during and immediately following pregnancy. Research has indicated that maternal behaviors during pregnancy may influence infant birth weight and mortality rates. PRAMS provides data for planning and assessing health programs and for describing maternal experiences that may contribute to maternal and infant health. Delaware ceased receiving funding from CDC for PRAMS in 2001. PRAMS provides data not available from other sources about pregnancy and the first few months after birth and is used to identify women and children at high risk for health problems, to monitor changes in health status and to measure progress toward goals.

very low birth weight (VLBW)—Births less than 1500 grams.

ACKNOWLEDGEMENTS

The Infant Mortality Task Force acknowledges the valuable work of the following outstanding individuals.

The Perinatal Board

The Perinatal Board has worked diligently over the years to reduce the infant mortality rate in our state. Many of the board members served on the task force committees.

Katherine Esterly, MD, <i>Chair</i>	Cathy Kanefsky	Anthony Policastro, MD
Bridget Adams	Bill Kirk, III, JD, MA	Vince Poppiti, JD
The Honorable Patricia Blevins	Joe Letnaunchyn	Marianne Powell, RN, MSN
Garrett Colmorgen, MD	The Honorable Pam Maier	Agnes Richardson, RN, MSN
Carlos Duran, MD	Jane Maroney	Dennis Rubino, MSW, MPH
Jacki Gorum, DSW	Susan Noyes, RN, MS	Judy Walrath, PhD
John Holden	Nancy Oyerly, RN, MS	Sam Waltz, Jr.
Carl Kanefsky	Maria Picazo	

Bernard Guyer, MD, MPH

Dr. Guyer is a Zanvyl Krieger Professor of Children's Health in the Department of Population and Family Health Sciences at Johns Hopkins Bloomberg School of Public Health. He was instrumental in helping us develop a framework for fashioning a set of science-based recommendations to deal with the infant mortality problem in Delaware.