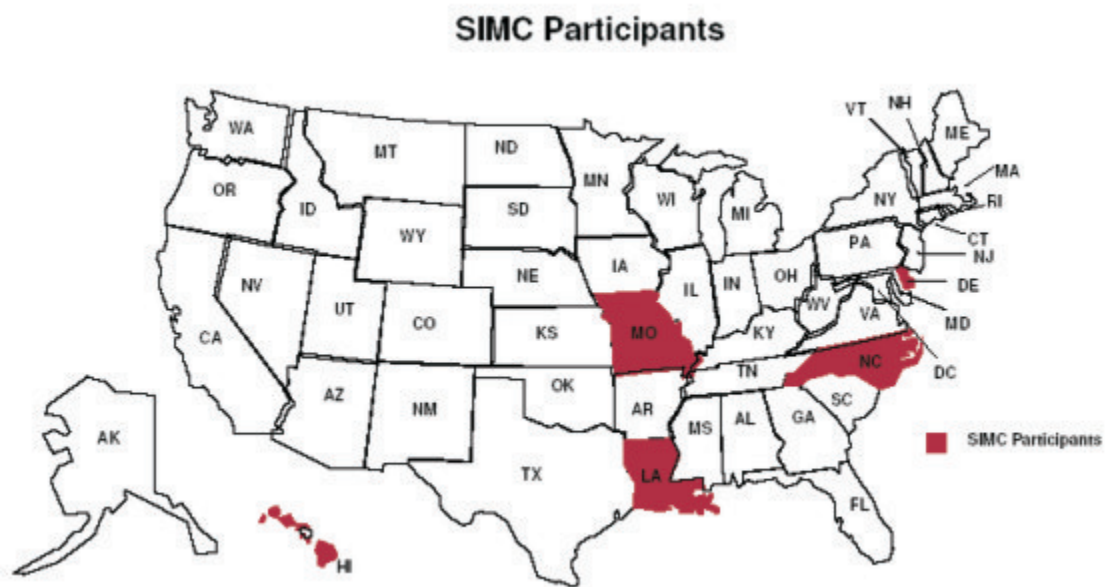


Investigating Troubling Trends: A Report of the AMCHP/CDC State Infant Mortality Collaborative

September 2007



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Executive Summary

2002 IMR Increase Follows Declining Infant Health Indicators

In 2002 the nation experienced the first significant rise in the infant mortality rate (IMR) since 1958—a 1.8 percent increase from the previous year. Although the rate has since inched back downward—from 7.0 infant deaths per 1,000 live births in 2002 to 6.8 in 2005¹—the anomalous jump drew attention to troubling, underlying trends, including rising rates of prematurity as well as low and very low birthweights—important risk factors for infant death.

Given the downward turn in key infant health indicators and stubbornly persistent racial and ethnic disparities in infant mortality rates, in 2004 the Association of Maternal and Child Health Programs (AMCHP) launched the State Infant Mortality Collaborative (SIMC), building on a history of federally-funded efforts to reduce U.S. IMRs. The Centers for Disease Control and Prevention (CDC), Division of Reproductive Health and the March of Dimes Birth Defects Foundation supported the project.

From a pool of applicants with either unusually high, stagnant or increasing IMRs, AMCHP chose five states to participate in the collaborative. Multidisciplinary public health teams from these states—Delaware, Hawaii, Louisiana, Missouri and North Carolina—convened several times over three years to explore possible factors that might be driving adverse infant mortality trends on the state level.

This AMCHP initiative had a strong state-based orientation: the goal was to support individual states as they investigated and made plans to address the infant mortality problem in their jurisdictions as they deemed feasible and appropriate. The SIMC focused on the application of maternal and child health (MCH) epidemiology to discern the underlying factors responsible for excess infant mortality and therefore opportunities for intervention.

Among the problems states encountered during the project were: inadequate analytical resources including human expertise and data systems; high staff turnover; statistically insignificant findings due to low numbers; political pressure to begin program planning prematurely; and, challenging socioeconomic problems accompanying high IMRs.

Promising Project Outcomes

Despite these problems, SIMC participation focused attention and resources on infant mortality in the five participating states. Delaware leveraged its participation in the initiative to build data capacity via acquisition of a CDC MCH epidemiologist assignee and a CDC grant to implement the Pregnancy Risk Assessment Monitoring System (PRAMS), a new birth certificate question to collect information on the use of assisted reproductive technology, a new partnership between the Delaware Department of Justice and Division of Public Health to implement a fetal and infant mortality review program, and a nascent effort to link hospital discharge data with vital records.

Hawai'i expanded its data resources and mapped out a new research agenda that includes post-neonatal health, pre-pregnancy body mass index, weight gain and stress during pregnancy, perinatal infections, periodontal disease, life course/ weathering theories, and birth interval/spacing.

Louisiana discovered significant differences in infant survival rates at Level III versus lower level healthcare facilities and successfully pushed for a regulatory mandate requiring facilities that offer Level III neonatal care to also offer Level III obstetrical care, thus aligning high-level services for women and children. In addition to exploring new ways to analyze PRAMS data on the regional level, the Louisiana team made plans to use PRAMS to examine preconception vitamin use, body mass index and folic acid use. The state MCH epidemiology team is working to link vital records, discharge data for the state's major delivery hospitals, and Medicaid claims data. Among other things, new

data linkages will allow state epidemiologists to examine the impact of hospital transfers on neonatal outcomes.

Missouri analyzed data from the state's infertility prevention program and found a disproportionate prevalence of sexually transmitted diseases among African-American women, a group that is also disproportionately at risk for a number of socioeconomic disadvantages. A series of 18 focus groups across the state generated data used to make the case for several new programs addressing risk factors for infant mortality, including "Back to Sleep" and smoking cessation training programs for providers, a pilot PRAMS program, and an outreach campaign promoting safe infant sleep practices, breastfeeding and folic acid use in the St. Louis area.

North Carolina analyses documented a 67 percent increase in the under 500 gram birthweight category between 1990 and 2005, increasing disparity between the birth outcomes for African-American and white infants (exacerbated by increasing maternal age), a link between "unplanned" pregnancy and low birthweight for white infants and a significant cluster of infant deaths in 13 of the state's 100 counties. State focus groups identified personal, economic and social barriers that hinder the adoption of new health practices among North Carolina women. Just two of the programs ensuing from the SIMC project are: 1) an effort to increase availability of a medication that decreases the risk of preterm birth, and, 2) a statewide perinatal quality care collaborative that to collect data from North Carolina's 26 neonatal intensive care units and set quality benchmarks.

Federal-State Collaboration: Essential to Reversing Adverse Trends

Despite the five teams' progress engaging stakeholders, exploring analytical approaches and, in some cases, jumpstarting new infant health initiatives, the state teams found few, if any, definitive answers. While increasing rates of prematurity and black-white health inequities persist across the U.S., the SIMC demonstrated that underlying issues are complex and may vary across states. Even interventions known to be effective—such as regionalized systems of perinatal care, comprehensive data systems, expanding pre-conception use of folic acid, and promoting safe infant sleep practices—likely need to be implemented differently in different states.

The project confirmed the importance of fully implementing known best practices. It emphasized the value of innovative, non-traditional data analyses and data linkages—informed by program practice—when traditional approaches fail to define the problem. It made clear the need for broad ownership of the public health problems associated with infant mortality and for creative thinking to address them. And it highlighted the critical importance of program evaluation to assure accountability by documenting the relative success or failure of proposed solutions. Ultimately the SIMC demonstrated that state and community issues must be woven into the national infant mortality picture to fully understand national trends. To achieve such a comprehensive picture, states need additional federal assistance

to elucidate and address local problems. Absent a joint federal-state effort, it is unlikely the U.S. will reverse prevailing infant health trends.

Lessons Learned

- There are no easy answers. Seek multiple solutions.
- Broad-based, long term partnerships—involving public health officials, policymakers, community members, healthcare providers, payers and others—are a crucial starting point for infant mortality reduction initiatives.
- Realistic, short-term goals, appropriate use of partners, and ongoing feedback will help to keep partners engaged.
- Infant mortality is inextricably tied to women's health and to broader socioeconomic problems. Infant health advocates should not neglect the larger context in which infant mortality occurs.
- Data analyses should be planned with translation in mind to assure broad dissemination and ownership of findings.
- Data analysis should be supported with conceptual models developed with input from public health program managers.
- Analyses should progress from the simple to the complex and non-traditional, with increasingly sophisticated data linkages, new data sources and increasing time horizons.
- All programmatic efforts should undergo rigorous evaluation to assure accountability.

The MCH Role

The Association of Maternal and Child Health Programs (AMCHP) represents public health leaders and others working to improve the health and well-being of women, children, youth and families, including those with special health care needs. AMCHP members come from the highest levels of state government and include directors of MCH programs. Collectively, state MCH programs support more than 60 percent of all deliveries in the United States and serve more than 33 million women, infants, children and youth each year, including almost 2.5 million pregnant women and 3.9 million infants less than one year of age.¹¹ State MCH programs play an important leadership role in health care communities to promote healthy birth outcomes and develop and implement policies and programs to support the delivery of services to women before, during and after pregnancy. The MCH community also serves as a source of information and education for consumers and providers; promotes family-centered, community-based care that incorporates the needs, perspectives and active participation of affected populations in health programs and policies; and, supports coordinated systems of care by building partnerships.

The prevention of excess infant mortality is a paramount goal for all MCH programs in the United States. It is also an integral component of the nation's health objectives for the year 2010. Indeed, the two overarching 2010 health goals are to increase quality and years of healthy life and to eliminate health disparities—both pertinent to the nation's infant mortality experience.¹² The 2010 target for infant deaths within the first year of life is 4.5, roughly a 33 percent decrease from the preliminary rate of 6.8 in 2005.¹²

Background

In 2002 the nation experienced the first significant rise in the IMR since 1958—a 1.8 percent hike from the previous year.^{2,3} With just over four million U.S. births per year, a 1.8 percent increase in mortality translates to almost 500 additional infant deaths nationwide. Inasmuch as IMR is considered a proxy measure of overall societal well-being, the seemingly small increase was of great public health significance. Although the rate has since inched back downward—from 6.97 in 2002 to 6.79 in 2004—the anomalous jump drew attention to troubling, underlying trends.⁴

Between 2000 and 2005, the percentage of babies born preterm (at less than 37 weeks gestation) rose 9 percent and the percentage of those born with low birthweights (weighing less than 2,500 grams) rose 8 percent.⁵ Of concern, during this same six-year period health authorities documented a 5 percent increase in the number of babies born very preterm (at less than 32 weeks gestation) and a 4 percent increase in the number born with very low birthweights (less than 1500 grams)—important risk factors for infant death.⁵

Among the factors that may contribute to the increasing delivery of preterm and underweight infants in the United States are the increasing proportion of births to older women, increased use of assisted reproductive technology (ART), increasing delivery of multiple births, changing obstetrical practices including greater use of preterm caesarian sections, maternal morbidity, and socioeconomic factors, such as poverty and lack of health insurance.

Despite gains made during the latter part of the 20th Century, the U.S. has failed to keep pace with other countries. In 1960, 11 nations recorded IMRs lower than the U.S. rate, but in 2003, 27 did so, including the Czech Republic and Singapore.⁶ The lowest IMR in the world in 2003 was just 2.3 infant deaths per 1,000 live births (in Hong Kong), compared to 6.9 in the United States at the same time. Even with the possibility of underreporting of infant deaths in some countries, it is unlikely that the magnitude of underreporting is so extreme and widespread as to significantly impact the international ranking of the U.S.⁷

Given the mediocre U.S. infant mortality experience relative to other nations, the flattening and increases in key infant health indicators in recent years and persistent racial and ethnic disparities in infant mortality rates, in 2004 AMCHP launched the SIMC with support from the CDC and the March of Dimes.

From 13 eligible states and eight state applicants, AMCHP chose five states with either unusually high, stagnant or increasing IMRs to participate in the project. Multidisciplinary public health teams from these five states—Delaware, Hawaii, Louisiana, Missouri and North Carolina—convened several times over three years to explore possible factors that might be driving adverse infant mortality trends on the state level.

The launch of the SIMC project represents one of many federally-funded effort to address infant mortality as a specific topic. Broadly speaking, infant mortality reduction has been described as one of the greatest public health achievements of the 20th Century.⁸ The founding of the federal Children's Bureau in 1913 and the establishment of federally supported state maternal and child health programs under Title V of the Social Security Act in 1935 were both important steps toward improving the health and well-being of women, infants and children in America. But a targeted focus on infant mortality per se did not begin until just before President Lyndon Johnson's War on Poverty. The Maternal and Child Health and Mental Retardation Planning Act of 1963 funded new Title V Maternity and Infant Care (MIC) demonstration projects targeting high-risk mothers in low-income communities. A hallmark of the MIC projects was implementation of the nascent concept of *comprehensive prenatal care*, including medical care, health education and nutrition and social services. This model—now supplemented with care coordination and home visits—has become the standard for publicly supported prenatal care clinics in the U.S.⁹

Another important development in infant mortality reduction was an effort in the mid-1970s to assure linkages among hospitals so that mothers and newborns received the appropriate level of care, an important consideration since medical advances at the time significantly improved survival rates of pre-term and very low birthweight (VLBW) infants if they were treated in a hospital offering access to neonatologists and neonatal intensive care units (NICUs). The federal Maternal and Child Health Bureau's (MCHB's) improved pregnancy outcome (IPO) program enabled select state Title V agencies to coordinate comprehensive prenatal care and to set up a regionalized system of tertiary or Level III hospitals with advanced neonatal services.

This effort was followed by the Healthy Futures/Healthy Generations Program (1988-1993), a joint (IPO) project of MCHB and the Robert Wood Johnson Foundation that attempted to reduce infant mortality in southern states—those with the highest rates in the nation—by improving perinatal systems of care. As with previous IPOs, a major focus was local decision-

Table 1: Infant Mortality Initiatives

- Pregnancy Risk Assessment Monitoring System (PRAMS) a surveillance project of the CDC and state health departments established in 1987 to collect state-specific data for planning and assessing health programs and documenting maternal experiences that may contribute to adverse maternal and infant health outcomes;
- National Fetal and Infant Mortality Review program established in 1990 as a collaboration between MCHB and the American College of Obstetricians and Gynecologists to jumpstart and support local efforts to investigate fetal and infant deaths and make recommendations for community change, if appropriate;
- Healthy Start established in 1991 to provide resources to community consortia overseeing projects to reduce infant that generally encompass health, social and economic services for high-risk pregnant women, infants and children.
- Peristat a March of Dimes data system access to national, state, county and city maternal and infant health data.

making to address local problems. In fact, with the prodding of the Southern Governors Association and its Southern Regional Task Force on Infant Mortality, several southern states created state infant mortality commissions. Several other federal initiatives began around the same time the Healthy Futures/Healthy Generations Program was established (see table 1).

The SIMC shares its state-based focus with many of these previous initiatives. The SIMC goal was to support individual states as they investigated and made plans to address the infant mortality problem in their jurisdictions as they deemed feasible and appropriate. Although not providing direct funding to states, the SIMC's unique contribution was the heightened application of MCH epidemiology to discern the underlying factors responsible for excess infant mortality and therefore opportunities for intervention.

Most of the state teams used the Perinatal Periods of Risk (PPOR) model, an analytical approach that uses birthweight, gestational age and time of death to establish a framework to sort out the complex reasons for infant deaths.¹⁰ The first phase PPOR analysis identifies the populations with high excess infant mortality, while the second phase explains *why* the excess deaths occurred.

AMCHP had two core partners that contributed to the SIMC: the CDC, represented by staff from the National Center for

Chronic Disease Prevention and Health Promotion, National Center for Birth Defects and Developmental Disabilities and National Center for Health Statistics, and the National March of Dimes Birth Defects Foundation. These organizations contributed funding and expert advisors from the earliest stages of the project. CDC and March of Dimes staff helped design the collaborative process, define the criteria for state participation and select the five state teams. They also made substantial contributions to the scientific components of the project throughout its three years.

The SIMC teams were supported by more than 30 national experts and partner organizations, including MCHB; National Institute of Child Health and Development; CityMatCH; National Association of City and County Health Officials; and, a number of state public health agencies, Medicaid agencies, and individual health care providers and researchers.

In addition to this report summarizing the experiences of the state teams and overall lessons learned, the project will produce an infant mortality “toolkit.” This web-based resource will highlight useful data sources for a state infant mortality assessment and provide a framework to assist states in selecting and defining appropriate indicators and selecting and utilizing methodological and statistical approaches to analyze data and interpret findings.

SIMC Team Projects

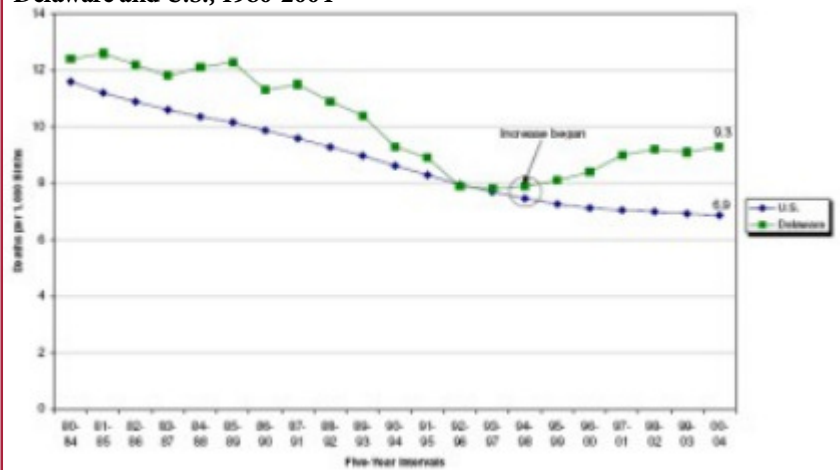
Delaware

Delaware ranks 49th in size among all states. It is made up of three counties—New Castle, Kent, and Sussex. Most of the state outside of New Castle County and Dover in Kent County is rural. Kent County, because of its population size, has been precluded from the benefit of federal designations necessary for eligibility into many federal programs. Kent County has had the lowest access rate to prenatal care in Delaware. Overall, health services in rural parts of the state are more limited in comparison to northern New Castle County. In 2003, Delaware's total population was about 792,495 people. The state averages about 11,000 births per year.

Infant Mortality Experience: Over a three-year period, Delaware's IMR climbed from about even with the national rate to become the highest in the country in 2002. In 2005, the rate remained considerably higher than the national average at 9.4 (see figure 1). Increasing infant mortality has been coupled with significant disparities between African-American and white residents. Black women are 2.55 times more likely to have late or no prenatal care, 2.08 times more likely to deliver a low birthweight (LBW) infant and 2.75 times more likely to suffer the death of an infant younger than 12 months compared with white women.

Before joining the SIMC, state officials conducted a preliminary analysis comparing two time periods: 1994-1996, when Delaware's IMR was 7.1, with 1999-2001, after the IMR had increased 24 percent to 8.8. The analysis revealed that maternal risk factors for infant mortality appeared to be non-traditional; that is, higher educational attainment, private insurance, prenatal care beginning in the first trimester, age greater than 29 years and residence in New Castle County outside Wilmington (a relatively affluent part of the state).

Figure 1: Five-year Average Infant Mortality Rates for Delaware and U.S., 1980-2004



Building on this analysis, the state's epidemic intelligence officer worked with staff from CDC's Division of Reproductive Health to study Delaware's linked birth-death certificate database. They found that a rising rate of multiple births contributed little to the trend, and that infant mortality had increased among singletons as well as twins and triplets. Likely explanations were:

- a rising rate of low- and very-low-birthweight infants—attributable for about a third of the increase in IMR between 1994-1996 and 1999-2001 and for much of the African American-white disparity in infant mortality in the state; and,
- a 33 percent increase in birthweight-specific mortality for infants weighing less than 1,500 grams—attributable for about two-thirds of the increase.

When the VLBW infants were broken down into plurality subgroups, researchers found that singletons had a 14 percent increase in mortality, twins had a 96 percent increase and triplets-plus had more than a 450 percent increase.

Additional analyses revealed that there are likely two major components to the increase in infant mortality in Delaware. The birthweight distribution issue is largely in the less than 500 gram population and primarily affects African Americans. The increasing birthweight-specific mortality occurs primarily in 500-999 gram infants and affects both African Americans and whites.

Researchers also found that the proportion of infant deaths in the early neonatal period (days 0 to 6 of life) increased from 52 percent to 62 percent between the time periods under study, while simultaneously decreasing in the late neonatal and post neonatal periods (days 7 to 27 and days 28 to 364 of life, respectively). Within the early neonatal group, the increase was entirely explained by an increase in deaths during the first day of life, suggesting that babies were being born sicker.

Perhaps the best evidence to support the “sicker baby” hypothesis came from independent research conducted by a neonatologist at Christiana Care Health Center, where more than half of all Delaware deliveries occur. The research showed that the score for neonatal physiology calculated on the first day of life for 1,400 VLBW infants had increased, indicating more illness, between the 1996-1999 and 2000-2003 cohorts.

Various hypotheses were suggested to explain the possibility of sicker babies:

- maternal or other risk factors unrelated to the care infants receive after birth;
- changes in obstetric practice that have resulted in either postponed fetal deaths (but with resultant neonatal deaths) or in truly worse obstetric outcomes;
- changes in reporting and/or classification of late fetal deaths as neonatal deaths; and,
- factors related to infertility treatments, including ART.¹³

Assets and Challenges: Delaware began the project “resource poor” in terms of its capabilities for data analysis. The state has no medical school and no graduate school of public health. It also lost the epidemic intelligence officer who performed the

initial analysis and faced a physical and philosophical separation between the state MCH program and the vital statistics department where most of the analytical work took place. However, project participants “pressed into service” staff from the state's vital statistics center.

The project was also boosted by strong political support within the state, stemming from Delaware's singularly high IMR in 2002. In 2004, the state governor declared infant mortality to be one of three priority health issues and signed an executive order establishing the Delaware Infant Mortality Task Force, charged with developing evidence-based recommendations to reduce the state IMR. Key task force members, including its two co-chairs, were part of the state's SIMC team.

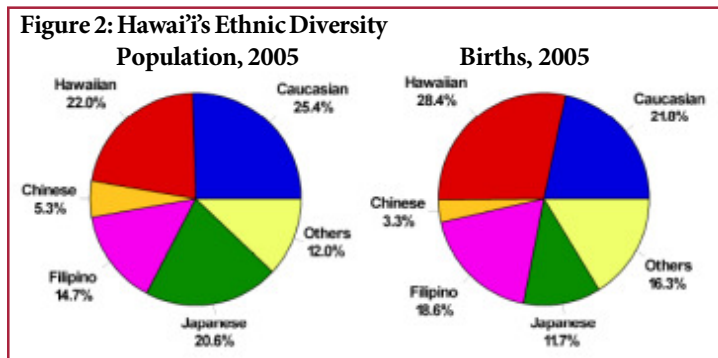
Involvement in the SIMC was also an asset, as it helped to create political space for research into the causes of Delaware's high IMR. Paul Silverman, the lead researcher on the project and the director of the Center for Health Information Management & Disease Prevention in Delaware's Division of Public Health, said, “Research is not something governors like to fund. There is a political need to *do something*, rather than study the issue. I was grateful for SIMC.”

SIMC Project: Perhaps the main benefit of the SIMC project for the Delaware team was a consequent focus on building data capacity. With assistance from CDC researchers, team members explored the various hypotheses for the high and rising IMR. Said Silverman, “When we entered into SIMC, a lot of people felt that ART was what was going on here. We didn't really rule it out, but we changed the framework; there's really a lot more to this.” The team also explored the possibility that reporting changes were influencing the IMR, but never reached the point of reviewing hospital records during the project period.

In 2005, the state acquired a CDC MCH epidemiologist assignee. In 2006, it received a CDC grant to implement the agency's PRAMS for ongoing collection of state-specific, population-based data on maternal attitudes and experiences before, during and shortly after pregnancy. That same year, the Delaware Department of Justice and Division of Public Health began a joint venture to implement a fetal and infant mortality review program, building on the state's child death review process. Beginning Jan. 1, 2006, the state birth certificate includes a question about ART usage.

Phase II of the analysis—which will take place post-SIMC—will include a review of hospital records at Christiana Care Health Center to marry discharge data with vital records and development of a detailed research agenda. “We understand better the nuances in the data and how they differ by race,” said Silverman, “but we still don't understand completely what's driving the data.” He noted that much of the team's energies were diverted by the political expediency of “fielding visible, street-level programs” to address the problem.

Outcomes and Next Steps: The governor's task force issued its report in May 2005. Recommendations included measures to:



Johns Hopkins University which is examining the problem of increasing numbers of VLBW babies.

Hawai'i

Overview: Hawai'i is situated almost in the center of the Pacific Ocean and is one of the most isolated yet populous places on Earth. The state is composed of seven populated islands located in four major counties (the lowest civil subdivision in the state): Hawai'i, Maui, O'ahu and Kaua'i. Approximately 71 percent of the state population resides in the city and county of Honolulu on the island of O'ahu and about three quarters of all births occur here. Only 10 percent of the state's total land area is classified as urban. The majority of tertiary health care facilities, specialty and subspecialty services are located in the Honolulu metropolitan area. Consequently, neighbor island and rural O'ahu residents often must travel to Honolulu for these services. Inter-island passenger travel is entirely by air; a situation that creates a financial barrier for neighbor island residents. Geographic access is further limited because public transportation is inadequate in all areas of the state except for the city of Honolulu. Access to emergency care on neighbor islands often requires the use of helicopters or fixed-wing aircraft.

Hawai'i's population is ethnically heterogeneous, with no single ethnic majority. (see figure 2) Among the significant ethnic groups represented on the island are Native Hawaiian, Chinese, Filipino, Japanese, Korean and Caucasian. A substantial portion of births are to parents of different ancestry. Because of this ethnic diversity—and ongoing immigration from Asia and the Pacific—a number of people speak English as a second language. Ironically, an especially robust economy—with an unemployment rate of just 2.5 percent—has resulted in a rising rate of homelessness as housing costs increase. The total state population is 1,245,000 people, with about 18,000 births per year.

Infant Mortality Experience: After a general downward trend in the state's infant mortality rate between 1980 and 1996, it jumped 15 percent in 1997 from 5.3 to 6.1. It continued to rise for the next three years: by 8 percent in 1998, 5 percent in 1999 and 10 percent in 2000, ultimately reaching 7.6. (see figure 3) Although prior to 2000, these increases were not statistically significant, it was the first time in over 20 years that the IMR increased for three years in a row.

Because health authorities suspected ethnic disparities in the IMR, they evaluated all 2,996 infant deaths that occurred in the state from 1980 to 2000. Yearly infant mortality rates and three-year moving averages were calculated and log-linear regression was used to estimate temporal trends for seven predominant ethnic groups, as defined by self-report.

Results showed that infants born to African American and Hawaiian mothers suffered the highest mortality rates throughout the 20-year period under study. In contrast, infants born to Chinese mothers experienced the greatest relative decline in mortality, going from the position of third highest in 1980 to the lowest in the state by 1990. Furthermore, the gap

increase access to and quality of preconception care, prenatal care and family planning services; improve neonatal transport, especially in rural areas; and, boost infant mortality-related research and consumer education. The governor established the Delaware Healthy Mother and Infant Consortium to implement these recommendations with funding of \$1 million in fiscal year 2006 and \$3 million in fiscal year 2007. Consortium members include state legislators, public health practitioners, non-profit organizations and senior staff within the Delaware Division of Public Health—many of them SIMC team members.

New programs resulting from task force recommendations include:

- a center for excellence in MCH and epidemiology within the Division of Public Health with three new, full-time staff;
- a comprehensive family practice team model program to increase access to supplemental services, such as mental health and nutrition services, for high-risk pregnant women; and,
- a preconception care program for women of childbearing age with a history of poor birth outcomes or who meet other eligibility criteria.

The state—through the center for excellence in MCH and epidemiology—will also carry out continued data analysis. Among the studies that are planned are a multi-site prospective cohort study of women from the first prenatal visit to two years post partum, a review of standards of delivery care, a multi-site study of the preconception care expansion in Delaware, and linkage of maternal and infant data for infants with adverse birth outcomes born between 1989 and 2003 part of a registry for improved birth outcomes. Silverman said, "This is more than just an infant mortality problem. It's a child health and healthy mother's problem." Data collection will reach out into those other areas.

While the resources to implement many of these activities came as a result of the governor's task force recommendations, Silverman said that the task force was able to "detail with much more specificity the epidemiologic needs" as a result of participation in the SIMC project.

State staff are now recruiting research fellows from nearby universities and from the Council of State and Territorial Epidemiologists. They are pursuing funding for a state Healthy Start program and have established relationships with a number of new partners, including the University of Delaware and The

between Chinese mothers and mothers of other ethnic heritage continued to widen from 1990-2000.

In 1999, to qualify for a Healthy Start grant, Title V program staff analyzed disparities in infant mortality by geographic area and ethnicity. They found a dramatic increase in the mortality rates among infants born to Hawaiian/part Hawaiian and Filipino women in Hawai'i county—to 10.9 and 13.0 respectively.

In the late 1990s, increases in neonatal mortality across the state contributed more to the rising overall IMR than increases in post-neonatal mortality. In 1998, however, the post-neonatal mortality rate (5.8) surpassed the neonatal rate (4.9) in Hawai'i County. This turnabout was due to striking increases in the post-neonatal mortality rate for infants of Hawaiian/part Hawaiian women (4.9) and Filipino women (9.7).

Additional analyses, based on the Perinatal Periods of Risk (PPOR) model, revealed that birthweight distribution accounts for approximately 93 percent of the excess fetio-infant mortality in the state, which occurs mostly in the 500-749 gram group.

Assets and Challenges: Hawai'i has historically experienced IMRs at or below national health objectives, and the sudden upturn in infant deaths mobilized health advocates even before the SIMC project began. Two state “perinatal summits” and a “prematurity summit” between March 2003 and July 2004 brought together clinical providers and community and public health leaders to examine infant death data and discuss strategies to address the rising incidence of LBW and preterm births.

The state is, however, handicapped by a problem of low numbers, related to Hawai'i's small population size, small number of annual births and relatively low IMR. For example, Hawai'i's IMR for infants of Filipino women in 1998—13.0 deaths per 1,000 live births—is based on 4 infant deaths. With such tiny numbers, a few health events translate into proportionately large changes in population data. The result is a high level of variability in geographic, ethnic and maternal trends and a diminution in the statistical power of data analyses. Finally,

apart from linked birth and infant death files, Hawai'i has no linked, population-based data systems.

SIMC Project: With support from national and state experts, the Hawai'i team conducted a number of statistical analyses:

- trend analysis examining demographic characteristics, complication of labor/delivery, medical risk factors, obstetric procedures, acute problems of newborns, congenital anomalies and concurrent illnesses or conditions;
- small area analysis—a technique to measure utilization of healthcare resources within a defined geographic area;
- examinations based on the fetal infant mortality review (FIMR) model - Hawai'i has no established FIMR;
- population comparisons looking for ethnic-specific differences that might reveal risk indicators for all groups and potential protective factors among Chinese families; and,
- PPOR analysis.

Among the data sources utilized were: vital statistics records; Hawai'i PRAMS, which began stratifying its sample by ethnicity beginning with the 2004 birth cohort; child death review reports; birth defects monitoring systems; hospital discharge data; neonatal intensive care unit information; extractions from medical chart reviews; and, data from the Malama A Ho'opili Pono (Caring for Mothers and Children in the Right Way) Healthy Start project based in Hawai'i County.

Outcomes and Next Steps: The SIMC project generated more questions than answers. Despite an intensive period of study, the Hawai'i team found no significant differences in population characteristics, patterns of immigrant health status, lifestyle and health behaviors or community environment. Indeed, during the project period, the state IMR *declined* slightly, as did the unintended and teen birth rates, leading investigators to conclude that the problem of infant mortality in Hawai'i is multifaceted.

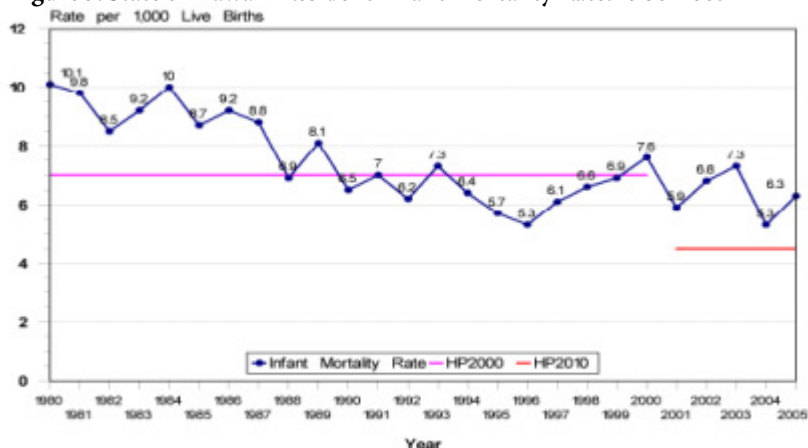
Loretta Fuddy, the SIMC team leader and chief of the Hawai'i Family Health Services Division, said “There's no simple answer. It's not an access issue; it's not a change in reporting.”

Thanks to the partnerships formed as a result of the initiative, the Family Health Services Division now has access to additional data sources. Moving forward, the team plans to focus on support services for high risk populations, enhanced preconception care and additional scientific studies to examine a host of issues:

- post-neonatal health, including hospital and emergency room visits during the first year of life;
- pre-pregnancy body mass index;
- weight gain and stress during pregnancy;
- perinatal infections;
- periodontal disease because Medicaid enrollees have access only to emergency oral care;
- life course/weathering theories; and,
- birth interval/spacing.

Said Fuddy, “We identified a need to develop our skills in collection and analysis of qualitative data.

Figure 3: State of Hawai'i Resident Infant Mortality Rate: 1980-2005



Source: Hawaii State, Department of Health, Office of Health Status Monitoring
*Provisional data

It's multifactorial and may require a higher level of research and into new areas that we had not previously anticipated."

The team concluded that effectively addressing the problem of infant mortality will require asking the right questions, accessing quantitative and qualitative information, and advocating for larger system involvement.

Louisiana

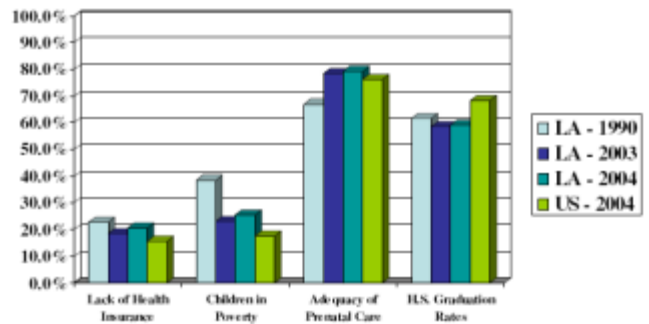
Louisiana has two main racial groups, with whites comprising 64 percent of the population and African Americans about 33 percent. Although nearly 73 percent of the population lives in an urban area, geographically Louisiana is predominantly rural. Only 17 of the state's 64 parishes have at least 70 percent of their population classified as urban; six of those parishes are in the greater New Orleans metropolitan area. In 2004, Louisiana had the 4th highest child poverty rate in the U.S., the third highest rate of uninsured residents and the seventh highest rate of high-school drop-outs. (see figure 4)

Louisiana has a unique history of a comprehensive, publicly-financed health care system to serve its large proportion of poor citizens. Almost 70 percent Louisiana deliveries are covered by Medicaid. However, the figure should probably be higher since most impoverished residents deliver at state hospitals, and many don't apply for Medicaid. In the past, Louisiana has relied heavily on its regional, state-supported hospital system and large network of publicly funded clinics to provide preventive and primary health care to pregnant women, infants and others. Louisiana health authorities have placed great emphasis on prenatal care and have achieved rates of early entry and adequacy of prenatal care that are higher than national averages. Although the state has experienced substantial budget shortages that have impacted the services provided through its Department of Health and Hospitals, recent expansions of the state Medicaid program have lessened the need for direct services through the public health units.

Louisiana's residents and physical infrastructure took a tremendous blow from hurricanes Katrina and Rita in 2005. Overall, more than three million people were impacted and more than 1,300 lost their lives. The population in New Orleans was reduced from 450,000 to about 185,000. The state's pre-existing health and infrastructure problems, coupled with the post-hurricane provider exodus, population shifts and extensive damage to the healthcare system, create huge challenges for the state health care delivery system. Louisiana's healthcare industry still functions at no more than 50 percent of its former capacity, with 6,000 fewer trained medical professionals. The state has a population of 4.5 million people and about 65,000 births per year.

Infant Mortality Experience: Louisiana had one of the five highest IMRs in the U.S. each year from 1998 to 2002. In 2004, the state ranked 49th nationally in infant mortality and had a 15.6 percent rate of preterm delivery, surpassed only by Mississippi and Alabama.

Figure 4: Louisiana Health Indicators, United Health Foundation: 2004 Edition



Louisiana Rankings 2004: Lack of Health Insurance (48th), Children in Poverty (47th), Adequacy of Prenatal Care (19th), High School Graduation Rates (44th), Overall 50th

Infant mortality rates for New Orleans have risen in recent years, exceeding the already high statewide rates. From 1998 to 2002, IMRs were 9.1, 9.2, 8.9¹⁴, 9.8 and 10.2 for Louisiana and 6.1, 8.7, 7.0, 10.5 and 12.6 for New Orleans.

The 2000 IMR, 8.9, was underreported due to uncounted deaths among infants weighing less than 500 grams at birth. MCH epidemiologists noticed that original state vital records reports showed a 53 percent death rate among infants weighing less than 500 grams—a rate implausibly lower than the 90 percent death rate for this group nationally. They therefore adjusted the number of deaths upward to achieve a 90 percent mortality rate among these extremely tiny infants. The adjusted overall IMR for 2000 is 9.8.

The rising IMR has effected both of the state's major racial groups, although worsening rates among whites have led to slightly decreasing African-American-white disparities. From 1998 to 2002 white IMRs rose from 5.8 to 6.9 statewide and from 2.3 to 5.3 for New Orleans, and African American IMRs rose from 14.0 to 15.0 statewide and from 7.1 to 14.5 in New Orleans. Other African American subpopulations, such as those in Jefferson Parish, the north shore of Lake Pontchartrain and Lake Charles, suffer even greater disparities in infant mortality compared to whites.

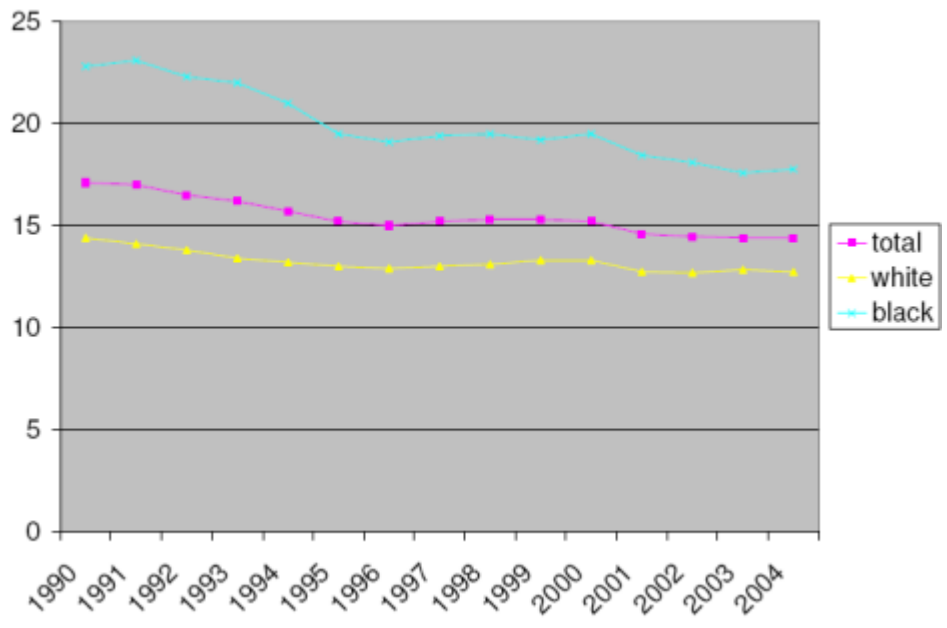
Roughly 65 percent of infant deaths in Louisiana from 1998 to 2002 occurred during the first 28 days of life in the neonatal period, with little fluctuation from year to year. Birthweight-specific mortality rates, however, rose for both LBW and VLBW infants for both African Americans and whites. During this time, rates rose substantially higher for VLBW live births in all three race categories: 168.6 to 186.9 for all races; 173.4 to 187.1 for white infants; and, 169.5 to 189.7 for African American infants.

The leading causes of neonatal death from 2000 to 2002 were conditions originating in the perinatal period, responsible for 72 percent of deaths and primarily related to prematurity; complications of pregnancy, labor and delivery; and respiratory distress or other respiratory conditions. Congenital malformations, deformations and chromosomal abnormalities accounted for about 22 percent of neonatal deaths with little to

no disparity between African American and white infants. Only a very small proportion of Louisiana births are multiple births, but between 10 percent and 20 percent are VLBW in any given year.

A study using the 1998-2002 Louisiana linked live birth and infant death files examined variations in maternal and newborn characteristics. Low education, unmarried status, preterm birth and LBW/VLBW were all significantly associated with increased infant mortality for both whites and African Americans. The study also found that the neonatal mortality rates were significantly higher in Level I and Level II hospitals (181.8) than in Level III and Level III-R hospitals (111.5).

Figure 5: Louisiana Resident Birthrates



Using PRAMS data, state researchers determined that smoking in pregnancy, inadequate weight gain during pregnancy, lack of counseling during prenatal care and low income status are all risk factors for LBW and VLBW births in Louisiana.

Assets and Challenges: Staff within in the Louisiana MCH program—including an assigned CDC MCH epidemiologist and eight state MCH-dedicated epidemiologists, three at a doctoral level—comprise an important state resource for infant mortality investigations. The MCH program also has a strong relationship with the Tulane School of Public Health and the Louisiana State University Department of Pediatrics. The state benefits from an extensive system of databases and data linkages involving vital records, Louisiana PRAMS, Medicaid, WIC, the birth defects surveillance program, the newborn screening and lead surveillance programs, youth risk behavior surveys, and the sexually transmitted disease and HIV programs.

Through the MCH program in recent years, the state has implemented a maternal weight gain campaign, a SIDS reduction program, and the Fetal and Infant Mortality Reduction Initiative (FIMRI). The FIMRI has two components: fetal and infant mortality reviews and a nurse-family partnership home visiting program. The home visiting program provides nursing support for eligible pregnant mothers and follow-up services for up to two years post partum.

Of all the challenges facing the state, the biggest is the continued impact of hurricanes Katrina and Rita, including a devastated healthcare infrastructure and an influx of more than 100,000 undocumented and non-English speaking workers and their families who have little access to healthcare or to bilingual services of any kind. Undocumented, pregnant women have minimal access to high-risk pregnancy care and no access to planned caesarian sections. Although Medicaid pays for emergency deliveries, emergency room visits without deliveries are cost

prohibitive to undocumented women, and the public health medical center offers no care for this population. Other challenges include poor access to preventive care for women prior to pregnancy and underreporting of infant deaths, particularly for infants weighing less than 750 grams.

SIMC Project: Project analyses explored:

- breastfeeding trends;
- unintended pregnancy;
- STDs during pregnancy, an important issue since Louisiana is among the top five ranking states for prevalence of gonorrhea, chlamydia and syphilis during pregnancy;
- pregnancy outcomes among WIC enrollees;
- associations among VLBW, prematurity and the level of the delivery hospital;
- birth spacing;
- maternal mortality;
- regional differences in perinatal experiences documented through Louisiana PRAMS; and,
- PPOR.

Outcomes and Next Steps: As with other initiative participants, not all of the team's analyses yielded definitive findings. Over a year and a half period, the Louisiana team explored methods to produce regional estimates of PRAMS data, using a regression-assisted estimation technique. MCH epidemiologists concluded that this approach is not appropriate for data analysis at the regional level, as it yields over-inflated standard errors that preclude meaningful interpretation of the data. Despite this disappointment, the team learned valuable lessons, and the state will continue to explore other analytical strategies as resources permit.

Some analysis, however, did generate useful information. The team found that the survival rate for VLBW infants is 88 percent in Level III facilities compared to 84 percent in lower level

facilities. It was also able to demonstrate that WIC enrollees have a higher rate of LBW deliveries than non-enrollees, and that STDs and shorter between-birth intervals correlate with adverse pregnancy outcomes.

One result of this new information is a regulatory mandate published in February 2007—and championed by the state’s perinatal commission—requiring facilities that offer Level III neonatal care to also offer Level III obstetrical care, thus aligning high-level services for women and children.

In addition to exploring new ways to analyze PRAMS data on the regional level, the team is planning to use PRAMS to examine preconception vitamin use, body mass index and folic acid use. The MCH epidemiology team is working to complete additional data linkages, including a linkage among vital records, discharge data for the state’s major delivery hospitals and Medicaid claims data. The team plans to explore the impact of hospital transfers on neonatal outcomes. Previously inaccessible data on transfers will become available once the linkage of vital records and hospital discharge data is complete.

Two new interventions are now being implemented in Louisiana. The first is a screening and referral protocol to help providers address a number of maternal risk factors and to improve risk factor surveillance generally. Pilot data from private obstetrical practices and WIC clinics in the Baton Rouge area show that 31 percent of infants born in the area are exposed to alcohol, tobacco or illicit drugs; 17 percent of pregnant women suffer from depression; and, just over 5 percent of pregnant women are victims of domestic violence. The screening tool is being adapted for statewide use. The second initiative, “Take Charge,” expands Medicaid coverage for family planning services to 200 percent of the federal poverty level.

Overall, the Louisiana team reported that few conditions and few interventions are well-supported by an evidence base, either state-wide or nationally. MCH epidemiology analyses will provide ongoing guidance for future program planning.

Additional resources and publications are posted on the websites of the Louisiana Maternal and Child Health Program (<http://www.dhh.louisiana.gov/offices/?ID=267>) and the Partners for Healthy Babies Program (<http://www.1800251BABY.org>).

Missouri

Missouri has both Midwestern and Southern cultural influences, reflecting its history as a border state between the two regions. St. Louis and Kansas City are the two largest metropolitan areas, followed by Jefferson City which has a population of about 40,000. In recent years, St. Louis has suffered from unusually high infant mortality, high teen pregnancy rates, elevated high school dropout rates and elevated STD rates, including the highest rate of gonorrhea in the country. More than a quarter of all African American deliveries in Missouri occur in St. Louis City. The state’s population decentralized during the 1990s, with people and jobs moving beyond the major metropolitan areas.

With this shift came an increase in the capital and operation costs for utility and transportation infrastructure, a septic seepage problem in the Ozark lakes that now threatens the area’s \$1.6 billion tourist industry and increasing isolation of low-income and minority Missourians in inner city areas. In 2003, the state population was 5.7 million, with about 77,000 annual births. About 44 percent of these births are covered by Medicaid. An estimated 85 percent of Missouri residents are white and 11 percent African American.

Infant Mortality Experience: Missouri’s IMR has been persistently higher than the national rate, though slightly declining or stagnant through the 1990s. In 2002, it jumped 15 percent to 8.5; up from 7.4 the previous year. African American infants have consistently fared worse than other resident infants. In 2002, for example, the African American IMR was 17.1, roughly double the state IMR and more than double the rate for white infants. (see figure 6)

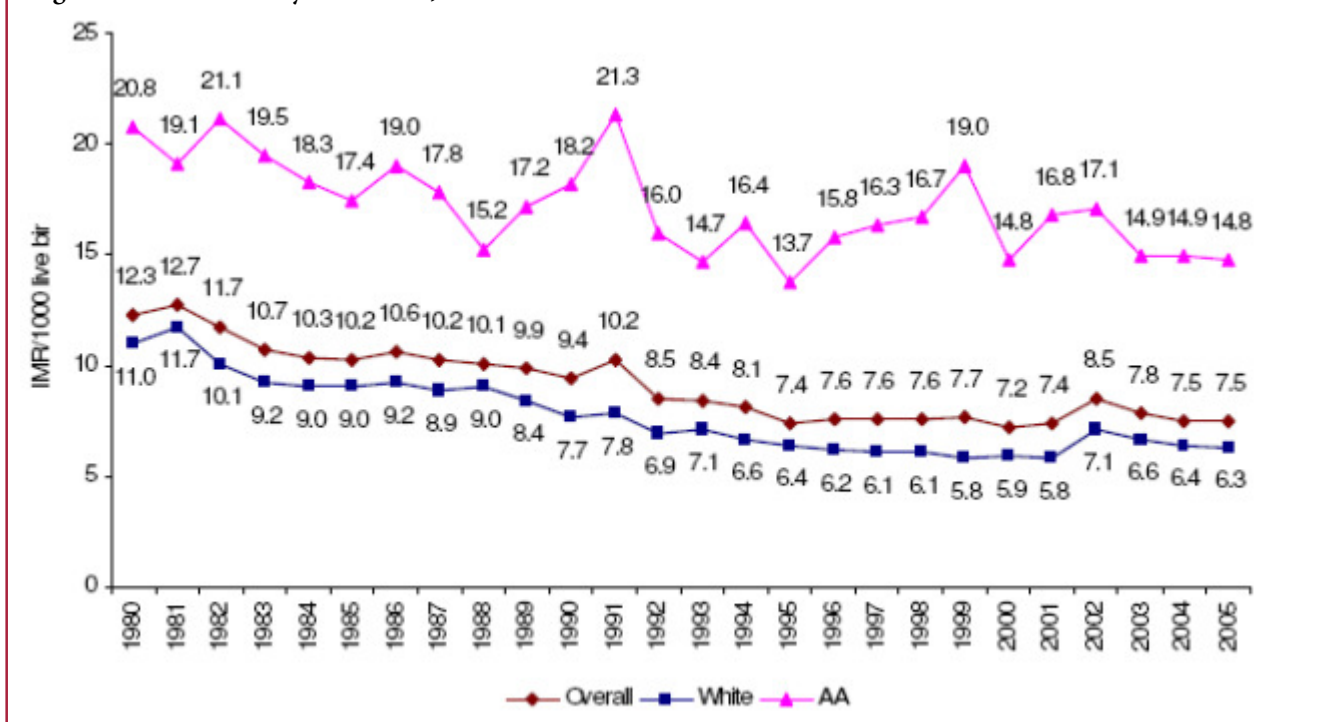
Contributing to the high IMR are high levels of maternal smoking, premature births and LBW, as well as low levels of prenatal care. Notably, the rate of smoking among pregnant women in Missouri was 18.1 percent in 2002 - 19.4 percent for white births and 12.9 percent for African American births - compared to 11.4 percent nationally. Rates of preterm birth in 2005 were 11.9 percent overall, 18.5 percent for African American infants and 10.7 percent for white infants. The SIDS rate in Missouri increased for the first time in five years from 0.8 in 2001 to 0.9 in 2002, with the African American SIDS rate at 1.9 versus 0.8 for white infants.

A Phase I PPOR analysis showed that causes of excess fetal/infant death and consequent opportunities for intervention vary according to the race of the mother. The greatest excess infant death among white mothers is attributable to maternal health/prematurity and infant health, while for African American mothers the greatest excess infant death is attributable solely to maternal health/prematurity.

Assets and Challenges: Missouri has a robust data system. In addition to state vital statistics, the SIMC team had access to the Missouri Information for Community Assessment (MICA) database, a web-based tool developed by the Missouri Department of Health and Senior Services that is a rich source of information on a variety of maternal and infant health indicators such as maternal smoking, maternal weight change, intendedness of pregnancy and prenatal care usage. The major challenge facing the team was staff turnover, unfortunately a problem not uncommon in state health agencies.

SIMC Project: Health disparities were an important focus for the Missouri team. One effort involved identifying pregnant women from the Missouri Infertility Prevention Program (MIPP) and linking them with 2000-2003 STD and birth/death files. The MIPP tests all participants for chlamydia and gonorrhea, providing the most appropriate control group since both positive and negative results are reported for all participants. MIPP screens those women at highest risk for infection based on developed screening criteria: all women aged 24 and younger

Figure 6: Infant mortality in Missouri, 1980-2005



and women aged 25 and older presenting with clinical signs and/or having known contact with an infected individual. Screening and testing are performed in family planning and STD clinics statewide, plus other enrolled sites serving high-risk populations.

Eighteen focus groups across the state to learn how Missouri parents—primarily low-income African American individuals—make decisions regarding infant care, particularly infant feeding and sleeping practices constituted the second effort. Altogether, 126 people participated in the focus groups; about 44 percent from the St. Louis area, 52 percent African American, 75 percent under age 30 and just over 50 percent reporting incomes of less than \$10,000 per year.

Outcomes and Next Steps: MIPP data analyses revealed a high incidence of STDs, particularly gonorrhea and chlamydia. Overall, 8.1 percent of pregnant women enrolled in MIPP tested positive for chlamydia, with a disproportionate amount of disease occurring among African American women.

Compared to a reference group of African American women ages 30-34, African American women ages 15-19 were 4.2 times more likely to be infected with chlamydia, those ages 20-24 were 2.8 times more likely to be infected, and those ages 25-29 were 1.6 times more likely to be infected. Compared to a reference group of white women ages 30-34, white women ages 15-19 were 3.0 times more likely to be infected with chlamydia, and white women ages 20-24 were 2.2 times more likely to be infected. There was no significant elevated risk among white women ages 25-29.

The high prevalence of STDs among young, African American

women is a concern because 55 percent of all African American births in Missouri occur among women ages 15-24. African-American teenagers, in particular, have the highest rates of STDs in the state and often have other socio-economic risk factors that make them especially vulnerable to adverse pregnancy outcomes.

Focus group findings showed that about 62 percent of participants initiated breastfeeding after the birth of their youngest child and that virtually all women had positive attitudes towards breastfeeding in terms of health benefits, mother-child bonding and convenience. Although cost-savings was mentioned by several women as a benefit of breastfeeding, it was rarely a primary reason behind feeding choices.

Reasons for *not* breastfeeding also included convenience (i.e., not being “tied down”), worries about the quantity and quality of breast milk, embarrassment (especially for the youngest mothers) and frustration with the breastfeeding experience. Overall, it appeared that advice from WIC and other healthcare providers often led only to a decision to breastfeed in the hospital, rather than long-term breastfeeding plans. Decisions to breastfeed for an extended duration were more often rooted in the advice of family members and the mother’s personal decision-making process.

At least half of focus group participants reported that they slept with their infants in bed with them, primarily to be close to them. Safety was the major reason for placing a child in a crib or bassinet.

Almost all participants were aware of expert recommendations to place infants in a supine sleep position. This high level of

awareness, however, did not necessarily translate into action. One theme that emerged—and which was especially salient for African Americans—was concern over choking on vomit if the child was put to sleep on his or her back. Some mothers used a split-the-difference approach and laid their children to sleep on the side, using rolled blankets to support them. Few parents understood the reasoning behind supine sleep advice.

Overall, focus group findings highlight a need to target grandmothers as well as mothers in informational campaigns, especially in the African American community, to squarely address concerns about the supine sleep position and to encourage providers to address the specific worries of parents when devising solutions and offering advice.

Although infant mortality has not been a legislative focus in Missouri—and no legislation resulted from the data generated through the Missouri SIMC project—SIMC data was used to make the case for several new programs addressing risk factors for infant mortality:

- a “Back to Sleep” training program for nursery room nurses, home visiting personnel, healthcare providers, federally qualified health center staff, daycare providers and first responders;
- a pilot Missouri PRAMS program in 2005-2006, which documented, among other things, that almost 55 percent of Missouri women consume no prenatal vitamins before becoming pregnant;
- a \$155,000 outreach campaign promoting “safe sleep,” breastfeeding and folic acid use in the St. Louis area targeting four zip codes associated with high rates of adverse pregnancy outcomes via the use of bus signs, billboards, radio and television advertising, and distribution of educational materials; and,
- a smoking cessation training program for health care providers implemented through a contract with the University of Missouri and funded by the March of Dimes.

North Carolina

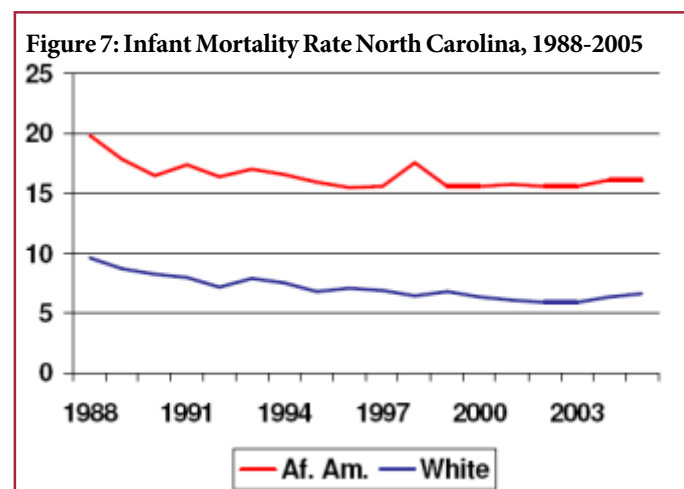
There are 85 county or district health departments and 100 county social services departments providing health and social services for North Carolina’s 100 counties. This decentralized structure poses special challenges for the design and implementation of statewide initiatives. Priority-setting and problem-solving within the Title V program routinely involve use of an extensive network of state-level interagency working groups and the input of public health workers and others at the regional and local levels. Although the use of managed care organizations for service delivery to Medicaid recipients was implemented in a deliberate fashion in the late 1990s, the shift from public to private sector provision of services to the low-income population has had a profound impact on the local public health agencies that have traditionally provided subsidized primary and preventive health services. Due to strong interest from members of the state general assembly and public health leaders, a public health task force was established in mid-2003 to study public health in the state and devise an action plan to

strengthen the public health infrastructure, improve health outcomes and eliminate health disparities. In May 2004, the North Carolina Office of Minority Health released a publication illustrating areas of health disparities, prominently including health insurance coverage rates, sexually transmitted disease rates and IMRs. The total state population is about 8.0 million, with roughly 120,000 births per year. African Americans are the largest racial/ethnic minority group in the state, but the Hispanic/Latino population increased over 300 percent between 1990 and 2000, when it comprised about 5 percent of the population. In 2002, 12.8 percent of live births in the state were among Latinas, compared to only about 2 percent in the early 1990s.

Infant Mortality Experience: Despite years of intensive efforts to combat the problem—and despite improving rates—North Carolina’s IMR remains among the worst in the nation. In both 2004 and 2005, the state IMR was 8.8, compared to 8.6 in 2000 and 10.6 in 1990.

A PPOR analysis conducted in 2004 suggests that the health of women of childbearing age is an important contributor to the IMR. The fetio-infant mortality rate for the 5,591 fetio-infant deaths between 1997-2001 in North Carolina was 9.8 deaths for every 1,000 live births. The rate for African Americans (14.7) was, however, more than double that of whites (6.0). More than a third of the fetio-infant deaths were associated with risks attributable primarily to maternal health. For African American births, almost half of infant deaths are related to maternal health. In recent years, racial disparities have worsened. The ratio of minority to white infant deaths was 1.9 in 1990, 2.3 in 2000, 2.5 in 2004 and 2.3 in 2005.

The downward trend in infant mortality in North Carolina that occurred between the late 1980s and early 1990s was due entirely to improved birthweight-specific survival rather than to a decline in LBW rates, according to studies conducted in the state. (see figure 7) In fact, the percentage of infants born VLBW and very preterm (<32 weeks gestation) has steadily worsened over the past 15 years or more among both multiple births and singletons.



Assets and Challenges: The North Carolina team began the project with support from more than three dozen individual partners and access to a rich collection of data. The team relied heavily on the North Carolina composite linked birth file, also known as the “Baby Love” file since much of it was developed for evaluations of post-1987 Medicaid expansions that were collectively referred to as the Baby Love Program. Data that are linked annually to the live birth file include Medicaid newborn hospitalization records, Medicaid maternal delivery records, Medicaid maternity case management records, child service coordination records, prenatal WIC records, records of prenatal visits at public health clinics, infant death records, a summary of Medicaid newborn costs in the first 60 days of life, and a summary of Medicaid infant costs in the first year of life. An important challenge for the North Carolina team is the state’s long history of racial discrimination and its lingering effects.

SIMC Project: The North Carolina SIMC team had three major goals:

1. To develop a new picture of infant mortality in the state by conducting an ambitious set of data reviews, drawing on linked birth/infant death files, linked “Baby Love” files, North Carolina’s Behavioral Risk Factor Surveillance System and North Carolina PRAMS. Studies included analyses of cause- and birthweight-specific mortality; utilization of prenatal care, care coordination services and risk-appropriate perinatal care; impact of multiple deliveries; trends in gestational age at delivery; changes in key risk factors over time; and, geographic variation in infant mortality.

2. To develop strategies to address infant mortality in the context of women’s health and health disparities, drawing on an examination of maternal risk factors associated with adverse pregnancy outcomes, as well as qualitative data gleaned from 21 focus groups conducted across the state from May through June 2005. The focus groups were conceived as exploratory in nature, but based on the general premise that women’s general health and health practices are key to reducing infant mortality. They focused on two overarching questions:

Table 3: Racial Disparity in Birth Outcomes Increase with Age

Birth Outcome Measures by maternal race and age for NC Residents, 2001-2005			
Age:	15-19	20-34	35+
<i>% Very Low Birthweight (<1500grams)</i>			
African American	3.2	3.6	4.7
White	1.7	1.3	1.6
Ratio	1.9	2.9	2.9
<i>Neonatal Deaths per 1,000 Live Births</i>			
African American	10.7	11.0	12.9
White	6.1	3.8	4.5
Ratio	1.8	2.9	2.9

- Why do women adopt—or not adopt—preventive health behaviors?
- Why do women use—or not use—preventive health services?

Two hundred and four people participated in the focus groups, which were conducted in English. Ninety-five percent of participants were female and most between the ages of 18 and 59 - with 45 percent between 18 and 29. About two thirds (67 percent) were African American, 21 percent Caucasian, 10 percent American Indian, and 6 percent Hispanic/Latina. Three quarters had an annual household income of \$45,000 or less.

3. To solicit the input of other stakeholders and experts to analyze different components of the data, generate hypotheses regarding the factors driving infant mortality in North Carolina and assess how well the state is implementing various promising interventions.

Outcomes and Next Steps: The updated infant mortality picture in North Carolina confirms that the downward trend in the state’s IMR slowed markedly in the mid-1990s. It also shows an increase in 2004, followed by a constant rate in 2005. The state’s death rate for infants less than one day old decreased 21 percent from 1991-1992 to 2001-2003, from 4.7 to 3.7. The fetal death rate decreased 17 percent over this time period, from 8.7 to 7.2. Together, this data suggests real improvement in fetal and early neonatal survival. However, during a similar timeframe—from 1989-1993 to 1999-2002—the percentage of infant deaths occurring in the first hour of life jumped from 26 percent to 29 percent.

As in other states, a steady increase in the proportion of LBW live births—coupled with stagnant mortality rates in each birthweight category in recent years—is a major factor driving the IMR. The percent increase of LBW by weight category ranges from 8 percent to 67 percent from 1990 to 2005, with the greatest increase in the under 500 gram birthweight category. During the period 1989-1993, 15 percent of post-neonatal deaths were to babies weighing less than 1,500 grams at birth. By 1999-2003, this percentage had increased to 22 percent, suggesting that the survival of VLBW babies past the neonatal period may be slowing the decline in the overall post-neonatal mortality rate. Births that were “unwanted,” based on PRAMS data, had

Table 2: Racial Disparities in Health Outcomes Increase with Age

2005 NC BRFSS Survey Results			
Age:	18-24	25-34	35-44
<i>Percent Obese (BMI>=30)</i>			
African-American	21.7	34.0	40.8
White	16.2	21.5	23.7
Ratio	1.34	1.59	1.72
<i>Percent Who Report Their Health as Fair or Poor</i>			
African-American	9.1	9.3	14.8
White	6.6	7.5	9.2
Ratio	1.38	1.23	1.61
<i>Percent With High Blood Pressure</i>			
African-American	11.4	17.3	32.6
White	9.5	10.0	17.6
Ratio	1.20	1.73	1.85

a significantly higher percentage of LBW than all other births overall and for whites, but not for African-Americans.

Between 1989 and 2002 infant death rates declined more among whites than among African Americans and American Indians. Alarming, an historic neonatal survival advantage of LBW African American babies has decreased over time, probably contributing to increasing racial disparities.

Racial disparities in both birth outcomes and women's health measures increase with maternal/female age. (see tables 2 and 3) While the percentage of multiple, live births has increased dramatically over time, it has increased more or less equally among whites and African Americans, therefore impacting racial disparities little, if at all.

Half of the excess infant deaths in North Carolina are clustered in 13 of 100 counties.

Focus group findings revealed that virtually all racial/ethnic groups in North Carolina have a complex and well-rounded concept of health and wellness. However, a major theme that emerged in all focus groups was the inadequacy of health awareness alone to prompt behavior change. Barriers to the adoption of new health practices included personal, economic and societal issues. Women spoke about time constraints, juggling multiple roles, and difficulty navigating a health care system that is not always friendly, affordable or accessible. Self-empowerment—the ability to make informed decisions about health behaviors—was limited for many participants and especially so for younger women, racial minorities, and those of lower socioeconomic status and/or lower educational attainment.¹⁵ A report of focus group findings, *Women's Health: Attitudes and Practices in North Carolina*, can be accessed at <http://nhealthystart.org/index2.htm>.

All of these findings fed into a number of products and initiatives. Of special note, the state's Child Fatality Task Force has included health disparities as part of its scope of work and successfully pushed for legislation to fund two SIMC team recommendations. The first project is a preterm birth prevention initiative in which 17 alpha hydroxyprogesterone caproate—a drug shown to decrease the risk of preterm birth by more than a third among high-risk women—will be made available to all low income pregnant women with a history of preterm birth.¹⁶ The project protocol and marketing materials are posted at <http://www.mPombaby.org/>. (Click on *Health Care Professionals* and then *Progesterone Program*.) The second project is state-wide perinatal quality care collaborative, which will collect data from North Carolina's 26 neonatal intensive care units and set quality benchmarks in a process involving public health authorities, clinical providers and families. A blueprint for the effort was due to the state general assembly in June 2007. The legislation, Senate Bill 1253, Session 2005, can be accessed at <http://www.ncleg.net/Legislation/Legislation.html>.

Other outcomes include:

- state funding to support an expansion of Medicaid income

eligibility up to 185 percent of the federal poverty level through a Family Planning 1115 Medicaid waiver thereby expanding access to family planning services;

- development of several scholarly articles, publications and consumer materials, such as *Racial Disparities in Birth Outcomes Increase With Maternal Age* and *Taking Care of Me*, both available online¹⁷;
- Legislation to increase the number and funding of community-based, minority infant mortality reduction “Healthy Beginnings” projects.¹⁸

Lessons Learned

At the last meeting of the SIMI travel teams, in Atlanta, Ga., in December 2006, participants discussed common challenges and strategies to overcome them. Three overarching themes emerged.

No Easy Answers

First was the elusiveness of easy explanations or solutions for the “astoundingly rising” rates of prematurity that are driving infant mortality. “There is no silver bullet,” said one participant. “The answers are likely to be multifactorial.”

Broad-based, Long-term Partnerships Are Key

The second theme follows from the first; namely the need for broad-based, long-term partnerships to systematically collect and study data and evaluate interventions over time. Such partnerships must necessarily include both those with statistical expertise—to analyze the data—and those with programmatic expertise—to frame and animate the data within a real-world context.

Within the initiative experience, some participants cited a tension between the epidemiologic and programmatic perspectives. While everyone agreed that states' data capacity was substantially enhanced over the course of the three-year project, one participant noted that “there was not a great linkage of the analytic and epi work to the actual interventions that were implemented. We didn't use our programs experiences to go back and say, “These are the analytic issues we need to address.” One of the expert researchers noted that the public health community has not identified the next round of effective interventions after surfactant and safe sleep that can substantially reduce infant mortality. “Without further evidence on better defining the issues and on effective solutions,” he said, “we will continue to struggle to make progress.”

In addition to the usual coalition members—encompassing the medical, public health and social welfare communities—partnership with the broader lay community is essential. Said one of the project's leaders, “As we move to address the social and health issues to address infant mortality, the community must see the larger picture, own the problem and be engaged in the solutions.”

Infant Mortality Inextricably Tied to Women's Health

Finally, it is fair to say that the third theme was one of frustration

at the limited impact of the initiative process itself and the low priority accorded to infant mortality reduction on a national level. “Why hasn’t infant mortality made more of a ripple in society?” asked one state team member, “it’s just not registering.” Said another, “You need energy to care about women, to care about poor women and women of color.”

Among the reasons put forth for infant mortality’s low profile as a political or social issue were the lack of a clear strategy to address the problem or to address the high rates of pre-term birth and racial disparity associated with it; competition from other important health issues; the relatively few people “touched” by infant mortality on a personal level and a societal preference to showcase “miracle” babies as opposed to those whose lives have ended tragically soon.

“You do yourself a disservice if you think infant mortality is the narrow issue,” said one participant. “This is really about the health of women and families.”

There was also recognition of the limited impact any program can make when it is confined to addressing infant mortality in a narrow sense. Infant mortality stems from a complex array of health and social issues and occurs within a larger context than the 40 or so weeks of pregnancy. Inadequate housing, unemployment, domestic violence, discrimination, limited access to basic healthcare and other disadvantages that precede and follow pregnancy all influence maternal and fetal health. “You do yourself a disservice if you think infant mortality is the narrow issue,” said one participant. “This is really about the health of women and families.”

Despite these limitations, the group found value in forging the partnerships, asking the questions, and engaging policymakers and the public in a process to begin to address the issue.

Recommendations

Develop a Partnership Network

Developing an infrastructure for infant mortality reduction efforts is crucial before progressing far with data analysis. A broad-based partnership network offers many advantages. (see table 4) Partners often have access to data that would not otherwise be available or can contribute tangible resources to coalition efforts. Some partners, such as university researchers, bring analytical expertise. When the time comes for data translation, partners can provide credibility and an entrée to policymakers, state agencies, clinical networks, communities, the local media and others.

In addition to building partnerships in the early stages of infant mortality reduction initiatives, SIMC participants stressed the importance of clearly defined coalition management, having “the right champions to lead.” Coalition leaders should give each partner a defined role “so they know why they are at the table,” keep all partners “plugged in” to the status of ongoing work, and “be able to speak with authority about where you are and what you’re doing.” The most rewarding

partnerships are those where every member can contribute to the process in a meaningful way and feel that they are getting something in return.

Using Quantitative, Qualitative Data Effectively

To the extent possible, both quantitative and qualitative data should provide the evidence base for subsequent interventions, program refinements and course corrections. Participants stressed the need to conduct basic surveillance and program evaluation in addition to research to explore the causes of infant mortality. They also suggested a natural progression to more complex types of data analysis and more sophisticated data linkages.

While SIMC participants recommend that coalitions use a variety of experts and “pull them in as far you can,” they also note the singular importance of epidemiological expertise. In general, the state teams preferred the involvement of a designated MCH epidemiologist who was likely to be more familiar with the issues immediately impacting infant mortality and less distracted by other health events, such as avian influenza. University researchers might also be tapped for assistance.

Some teams—such as Louisiana, Hawaii and Delaware—had the assistance of CDC epidemiology assignees; others relied on in-house staff. To the extent practicable, participants recommend cultivating an ongoing relationship with epidemiology staff. “It’s not a once a year thing or a single report thing. It’s lunch, it’s walking down the hall, it’s a continuous process,” said one team member. Having involved epidemiologists and others with data expertise, the next step is to “listen to them when they push for quality data.” That is, don’t plan interventions prematurely.

At the same time, data collection and analysis should occur through a visible, credible process that involves partners to the extent possible and confers broad ownership of findings. “Doing it in a collective way allows for cross-fertilization in learning. Credibility is key.”

Table 4: Suggested Partners for Infant Mortality Reduction Coalitions

- Business groups (“Business is driving quality assurance.”)
- Funders
- Groups with grassroots connections such as fetal and infant mortality review teams, community action teams, and Healthy Start programs
- Community members
- Groups with legislative connections
- March of Dimes
- Novel partners such as housing and justice authorities who can address problems in neighborhoods where clusters of infant deaths have occurred
- Payers such as state Medicaid agency¹⁹
- Professional associations such as American Academy of Pediatrics, American College of Obstetricians and Gynecologists
- Provider groups such as hospitals and provider networks)

Participants suggested several general strategies for data collection and analysis:

- *Assess what data is readily available.* Begin with conventional, simple analyses and move onto more complex, nontraditional analyses. “There are not necessarily clear answers out there, but there are steps you need to go through to rule out causes.”
- *Assure data quality* through the use of standard data definitions and consistent, appropriate data collection methods. When you find problems in the data, work with those who collected it to resolve those problems. “Some of the people collecting data may be in the field and have high turnover. Hence the importance of involving multiple partners and making sure that data is collected in a uniform manner over time.”
- *Support data analysis with conceptual models* developed with input from program managers. “In MCH, we have vital records; there is not necessarily the need to build the research process. We go straight to number crunching. This is not good. Start the process by framing the issue and framing a research process.”
- *Keep expanding data linkages* as the process evolves. Consider linkages with education, oral health, etc. “Data set linkages are important.”
- *Don't neglect program evaluation.* Collect data to gauge the effectiveness and impact of possible solutions and to assure a system of accountability. “If we just do *something* and don't know if it is working, we may be slow in moving to better define the issues or find a better strategy.”

Translating Data to Promote Shared Ownership of Problems, Advocacy for Infant Mortality Reduction

Data can be a powerful tool. In Delaware, the state's national infant mortality ranking captured the governor's attention and prompted legislative action. Often, however, findings are complex, nuanced and require deliberate translation for targeted audiences.

Plan with Data Translation in Mind — Ideally, the study process should be planned and developed with data translation in mind. This may mean driving through neighborhoods with the highest IMRs to understand the context for the data, or learning the state budget and legislative processes to understand the context for data translation to policymakers. “You have to think way down the road,” said one participant. “You can't just show up and expect to have (funding) tomorrow. In 2006, plan for 2009.”

Be Consistent and “Make it Real” — Prepare to involve epidemiologists past the analytical stage and spend time to assure that “data” and “program” staff have the same understanding of the data and can deliver consistent messages. The message itself should encompass both the financial and emotional costs of infant mortality. “Make it real,” advised one team member. “Talk about the impact even if you don't have solid answers to reduce the rate. There is a societal cost that we need to address.”

Gear Presentations to Professional, Lay Audiences—Potential audiences include a broad range of stakeholders from

parents and community members to clinicians and policymakers. All of these groups must share ownership of the problem to build the political will necessary to gain state resources to begin to address underlying issues. Before engaging a particular group, do some research to “be sure you know what's on their minds and adapt your message, if you can, to bring it in line with their concerns.” Involving partners with credibility with a local audience can help. Said one SIMC participant, “We need to translate our work so that our agendas and their agendas merge.”

While it will undoubtedly be helpful to involve the local media - and to provide them access to the individuals who have generated the data - coalitions may not wish to publicize all of their findings. For example, if hospitals are performing poorly in some areas, it may be more effective to work with hospital officials “behind-the-scenes” to address problems.

Coalition members should not expect all stakeholders to have a ready interest in research findings. It will probably be necessary to go into the community to present the data to key groups “where they are.” “Don't make them come to you,” said one team member.

Incorporate Infant Mortality into Others' Agendas — It will be important to use the information that you generate to “leverage other opportunities to keep the issue in the forefront.” Infant mortality reduction can tie into the March of Dimes prematurity campaign, women's health and reproductive health. “How do we weave what we have into the topic of the day?” asked one participant. The bottom line: Be prepared to work on other people's agendas to advance your own.

Table 5: Next Steps: Avenues for Future Analytical Work

Suggestions for future analytical work stress the need to both broaden the number of data measures and lengthen time horizons.

- *Collect both quantitative and qualitative data.* As one participant noted, “Society looks on women as having made a choice to be poor and single. We have some obligation to tell other stories and create other views.” Another participant suggested using the CDC's PRAMS to solicit not only quantitative information, such as the occurrence of an event, but also qualitative information, such as the perceived quality of care.
- *Consider new data areas,* such as quality-of-care or anything associated with quality assurance, costs associated with adverse pregnancy outcomes and prevalence and cost of longer-term morbidity.
- *Consider “hidden issues,”* such as abortion, family planning, unintended pregnancy and women's health. “Number of deaths cannot be our only hallmark. We need other indicators below that to shape our infant mortality picture.”
- *Develop longitudinal measures* such as linking birth outcomes with school data.
- *Consider inter-state analyses* such as comparing changes in Medicaid reimbursement rates.

Sustainability and Next Steps

The first round of data analysis and program planning will not be the last. Initiative members stressed the need to plan for long-term sustainability of efforts to reduce infant mortality. In North Carolina, advocates worked for eight years to get a Family Planning 1115 Medicaid waiver approved by the Centers for Medicare and Medicaid Services. A Louisiana SIMC team member noted, “Fifteen years ago we decided prenatal adequacy was the key to our woes. Now we have excellent prenatal care adequacy and it hasn’t made a whole lot of difference.” In light of such challenges, persistence and flexibility are key. Said one participant, “Be patient, but be proactive. Don’t be too patient.”

Accountability, Sustainability Linked — At the outset, sustainability will require mechanisms for monitoring and accountability to ascertain that stakeholders are doing what they agree to do. It will also require ongoing program evaluation and the willingness to “shut down programs that don’t work” and to work to institutionalize those that do.

Think Outside-the-Box — The same flexibility applies to research. If simple, conventional analyses fail to yield significant findings, coalition members may need to pursue new, potentially novel avenues of research. (see table 5)

Set Realistic Goals to Keep Partners Engaged — Because major improvements may take years to develop, it is important to set realistic, intermediate goals that may not immediately impact infant mortality, to be proactive in framing success stories such as “kids who lived when they might have died,” and to recognize small successes so that partners can see progress. “People need to feel that they’re accomplishing something,” one participant said. It may be useful to develop an annual report on infant mortality reduction to document successes and remind stakeholders that the issue has not been eliminated. An annual report can also be a means to share best practices in a non-threatening way as well as efforts that are not wholly successful.

Don’t Forget the Big Picture — Throughout the process, it is crucial to keep partners engaged, orient new coalition members adequately and recognize that infant mortality is not an isolated problem. “Be at the table to talk about health care coverage and homelessness and poverty,” said one SIMC participant. “MCH needs to be at the table to talk about these larger issues.”

Conclusions

The SIMC project identified the first group of U.S. states in half a century to see its IMRs flatten or rise and supported five teams of analytical and program staff through a process to discern the underlying factors driving excess infant deaths. Unfortunately, as the national IMR levels off, more and more states will likely struggle with the same problem. As one expert advisor to the project noted, “We went to the early states that stopped [decreasing infant mortality] and the early states whose rates went up. Others will follow.”

Despite progress engaging relevant stakeholders and exploring analytical approaches, the state teams found few definitive answers. Indeed, the problem of stagnant and rising infant mortality is far from resolved and may be an ongoing problem. While increasing rates of prematurity and black-white health inequities persist across the U.S., the SIMC project demonstrated that underlying issues are complex and may vary across states. Even interventions known to be effective—such as regionalized systems of perinatal care, comprehensive data systems, expanding pre-conception use of folic acid and promoting safe infant sleep practices—likely need to be implemented differently in different states. As one SIMC participant said, “We can’t just figure this out at the national level.”

The project confirmed the importance of fully implementing known best practices. It emphasized the value of innovative, non-traditional data analyses and data linkages—informed by program practice—when traditional approaches fail to define the problem. It made clear the need for broad ownership of the public health problems associated with infant mortality and for creative thinking to address them. And it highlighted the critical importance of program evaluation to assure accountability by documenting the relative success or failure of proposed solutions. Ultimately the SIMC project demonstrated that state and community issues must be woven into the national infant mortality picture if we are to fully understand national trends. To achieve such a comprehensive picture, states need additional federal assistance to elucidate and address local problems. Absent a joint national-state effort, it is unlikely the U.S. will reverse prevailing infant health trends.

Endnotes

¹ Throughout this report, all infant mortality rates refer to the number of infant deaths per 1,000 live births.

² Mathews TJ, Menacker F and MacDorman MF. Infant mortality statistics from the 2002 period linked birth/infant death data set. *National Vital Statistics Reports*. 2004;53(10):1-32.

³ Kochanek KD and Martin JA. Supplemental analyses of recent trends in IM. Health E-stats. <http://www.cdc.gov/nchs/products/pubs/pubd/hestats/infantmort/infantmort.htm>

⁴ Provisional 2005 data from the National Vital Statistics System, National Center for Health Statistics, Centers for Disease Control and Prevention.

⁵ National Vital Statistics System, National Center for Health Statistics, Centers for Disease Control and Prevention. Based on final data for 2000-2004 and provisional data for 2005.

⁶ Health, United States, 2006. Based on data from the following sources: Organisation for Economic Cooperation and Development (OECD): OECD Health Data 2005, A Comparative Analysis of 30 Countries, www.oecd.org/els/health/; United Nations: 2000 Demographic Yearbook, United Nations Publication, Sales No. E/F .02.XIII.1, New York, 2002; World Health Organization Statistical Information System (WHOSIS), www3.who.int/whosis/; United States and Puerto Rico: Centers for Disease Control and Prevention, National Center for Health Statistics. *Vital Statistics of the United States*, vol. II mortality part A (selected years). Public Health Service. Washington, DC; Sweden: Statistics Sweden; Costa Rica: Direccion General de Estadisticas y Censos. Elaboracion y estimacion, Centro Centroamericano de Poblacion, Universidad de Costa Rica, <http://ccp.ucr.ac.cr/observa/index1.htm>; Russian Federation: Goskomstat, www.gks.ru/eng/; Israel: Central Bureau Statistics of Israel, www.cbs.gov.il/engindex.htm.

⁷ MacDorman M. "Recent trends in Infant Mortality in the United States." Presentation at the 2007 annual meeting of the Association of Maternal and Child Health Programs. Arlington, Virginia. March 4, 2007.

⁸ Kotelchuck M. Safe Mothers, Healthy Babies: Reproductive Health in the 20th Century. In Ward JW and Warren C (eds). *Silent Victories: The History and Practice of Public Health in Twentieth-Century America*. Oxford University Press, 2007.

⁹ Ibid, Kotelchuck.

¹⁰ CityMatCH, University of Nebraska Medical Center, Centers for Disease Control and Prevention, National March of Dimes Birth Defects Foundation

and the Health Resources and Services Administration, Maternal and Child Health Bureau. Perinatal Periods of Risk Approach. Accessed April 2, 2007 at www.citymatch.org/PPOR.

¹¹ Health Resources and Services Administration, Maternal and Child Health Bureau. Title V Information System. <<https://perfdata.hrsa.gov/mchb/mchreports/Search/search.asp>> Accessed December 28, 2006.

¹² U.S. Department of Health and Human Services. *Healthy People 2010*. 2nd ed. With Understanding and Improving Health and Objectives for Improving Health. 2 vols. Washington, DC: U.S. Government Printing Office, November 2000.

¹³ Although the rising multiple birth rate itself was shown not to be responsible, the infertility treatments might play a role.

¹⁴ The 2000 IMR, 8.9, was underreported due to uncounted deaths among infants weighing less than 500 grams at birth. MCH epidemiologists noticed that original state vital records reports showed a 53 percent death rate among infants weighing less than 500 grams—a rate implausibly lower than the 90 percent death rate for this group nationally. They therefore adjusted the number of deaths upward to achieve a 90 percent mortality rate among these extremely tiny infants. The adjusted overall IMR for 2000 is 9.8.

¹⁵ A report of focus group findings, *Women's Health: Attitudes and Practices in North Carolina*, can be accessed at <http://nchealthystart.org/index2.htm>.

¹⁶ The project protocol and marketing materials are posted at <http://www.mPombaby.org/>. (Click on *Health Care Professionals* and then *Progesterone Program*.)

¹⁷ *Racial Disparities in Birth Outcomes Increase With Maternal Age* available at <http://www.schs.state.nc.us/SCHS/pdf/SB27.pdf>, and *Taking Care of Me*, available at <http://www.nchealthystart.org/catalog/prepregnancy.htm>.

¹⁸ The legislation was rolled into a comprehensive community health disparity reduction package submitted by the North Carolina Minority Health Advisory Council. An allocation of \$2 million per year will allow eight of 45 newly funded community health disparity projects to address infant mortality reduction as part of a preconception/health promotion effort for women of childbearing age. Efforts are underway to add chronic disease prevention/control as a targeted focus of the infant mortality reduction projects.

¹⁹ In Louisiana, for example, demonstrating the correlation between poor oral health and poor birth outcomes led the state Medicaid program to cover dental care for eligible, pregnant women.



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