DOCUMENT RESUME

ED 337 922 EC 300 664

TITLE	Infant Mortality Review: Project Abstracts, Meeting Proceedings, and Product Information.
INSTITUTION	National Center for Education in Maternal and Child Health, Washington, DC.
SPONS AGENCY	Health Resources and Services Administration (DHHS/PHS), Rockville, MD. Bureau of Maternal and Child Health and Resources Development.
PUB DATE	91
CONTRACT	MCU-117007
NOTE	57p.
AVAILABLE FROM	National Maternal and Child Health Clearinghouse, 38th and R Streets, N.W., Washington, DC 20057 (single copies free).
PUB TYPE	Collected Works - Conference Proceedings (021) -- Reference Materials - Directories/Catalogs (132) -- Guides - Non-Classroom Use (055)
EDRS PRICE	MF01/PC03 Plus Postage.
DESCRIPTORS	*Case Records; Child Health; Congenital Impairments; *Data Analysis; Disease Incidence; Federal Programs; Health Promotion; *Infant Mortality; *Infants; Intervention; *Mortality Rate; Perinatal Influences; Premature Infants; *Prevention; Public Policy; Recordkeeping; Records (Forms); Special Health Problems

ABSTRACT

This publication includes proceedings from a fall 1989 meeting attended by representatives of projects funded by the Maternal and Child Health Bureau of the U.S. Public Health Service as part of its infant mortality reduction initiative. It also contains abstracts describing the funded projects and a list of products available to others interested in implementing infant mortality review. The proceedings section offers summaries of presentations and discussion concerning the Infant Mortality Review Team, record abstraction, parent interviews, data analysis and utilization, and institutionalizing infant mortality review. Twelve projects are described, including projects in Alaska, Arkansas, Connecticut, District of Columbia, Indiana, Kansas, Massachusetts, New York, South Carolina, and Utah. Each project abstract describes the target infant mortality problem, goals and objectives, methodology, and evaluation. Product information is supplied for infant mortality review interview forms, manuals, record abstraction forms, a slide set, and a bibliography. (JDD)

EC 300664

Infant Mortality Review

Project Abstracts, Meeting Proceedings, and Product Information

Supported by the
Maternal and Child Health Bureau

National Center for Education in Maternal and Child Health
Washington, D.C.

Cite as
National Center for Education in Maternal and Child Health. (1991). *Infant Mortality Review: Project Abstracts, Meeting Proceedings, and Product Information.* Washington, DC: National Center for Education in Maternal and Child Health.

The National Center for Education in Maternal and Child Health (NCEMCH) provides information services, educational materials, and technical assistance to organizations, agencies, and individuals with maternal and child health interests. The Center was established in 1982 at Georgetown University within the Department of Obstetrics and Gynecology. NCEMCH is funded primarily by the U.S. Department of Health and Human Services through its Maternal and Child Health Bureau (formerly known as the Office of Maternal and Child Health).

Produced and published by:
National Center for Education in Maternal and Child Health
(NCEMCH)
38th and R Streets, N.W.
Washington, DC 20057
(202) 625-8400

Single copies of this publication are available at no cost from:
National Maternal and Child Health Clearinghouse
(NMCHC)
38th and R Streets, N.W.
Washington, DC 20057
(202) 625-8410 or (703) 821-8955 ext 254

This publication has been produced by the National Center for Education in Maternal and Child Health under its cooperative agreement (MCU-117007) with the Maternal and Child Health Bureau, Health Resources and Services Administration, Public Health Service, U.S. Department of Health and Human Services.

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Preface

Infant mortality review is a major component of the Federal Maternal and Child Health Bureau's (MCHB) infant mortality reduction initiative. With the advent of a slowdown in the rate of decline in infant mortality, MCHB implemented the program in 1984 as a means of improving and refining our data base and understanding of adverse pregnancy and infant health events at the State and local level.

Infant mortality as a national issue preceded Title V of the Social Security Act. Legislation creating the Children's Bureau, ancestor of the current Federal Maternal and Child Health Program, charged the bureau with investigating and reporting "upon all matters pertaining to the welfare of children and child life among all classes of our people and shall especially investigate the question of infant mortality and the birth rate . . . ." The Children's Bureau began the first of many studies of infant mortality in 1913 in Johnstown, Pennsylvania. The information gained helped to inform the public about the many remediable conditions that contributed to infant mortality. The Federal Maternal and Child Health Program, in partnership with States and many other public and private organizations, has continued to address the issue of infant mortality through studies, education, and the development and implementation of services to improve the health of mothers and children.

Under the current Infant Mortality Review program, MCHB funds two methodological approaches to infant mortality review. One is a hospital-based medical record review designed to apply a specific conceptual model to analysis of infant mortality. That model analyzes differences in risk status or in access to effective intervention or both. The second is a community-based case study of fetal and infant deaths to identify socioeconomic, public health, behavioral, administrative, educational, environmental, and systems factors connected with death events. Both approaches are testing methods of aggregating and interpreting data about fetal and infant deaths in a way that provides useful information for policy decisions.

Projects funded by the bureau have met annually since 1988 to share information and discuss common concerns. This publication includes proceedings from the meeting held in fall 1989, abstracts describing the funded projects, and a list of products that are available to others interested in implementing infant mortality review. This publication also includes abstracts of four projects funded since the 1989 meeting. Future efforts will include further development of background and technical assistance materials for those interested in implementing infant mortality review, a more formal involvement of the private sector through a national grant to the American College of Obstetricians and Gynecologists, and assisting States that wish to institutionalize infant mortality review, making it a part of ongoing problem-solving efforts.

Project Abstracts

Alaska Infant Mortality Review Project
State of Alaska Department of Health and Social Services
Section of Maternal, Child and Family Health
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MCHIP
MCJ-026040
10/01/90-09/30/92
Project Director:
Rita A. Schmidt

PROBLEM: Alaska's infant mortality rate remains above the national rate, primarily because of the State's high postneonatal mortality rate, which is 44 percent above the U.S. rate. Alaska's Native infant mortality exceeds white infant mortality in the State by over 50 percent. This gap is greatest among the postneonatal age group (77 percent), despite the fact that the white rate is itself 22 percent higher than the national average. Marked regional differences exist within the State for neonatal as well as postneonatal mortality.

GOALS AND OBJECTIVES: Alaska's multidisciplinary infant mortality review committee of health and social services professionals from State, Federal (Indian Health Service), and local agencies as well as private practice will facilitate the reduction of Alaska's infant mortality rate through an integrated review process which will provide prevention and response information to health professionals and to the public. Additionally, the findings and recommendations of this review process could result in resource reallocation and changes in program design.

Outcome objectives of the review process are to reduce the rates of infant mortality in Alaska to 9.5 infant deaths per 1,000 live births by 1995, including no more than 4.0 postneonatal deaths per 1,000 live births; and to ensure that by 1995 all of Alaska's 8 MCH regions have an infant mortality rate less than 75 percent greater than that of the region with the lowest infant mortality rate, have a neonatal mortality rate less than 100 percent greater than that of the region with the lowest neonatal mortality rate, and have a postneonatal mortality rate less than 50 percent greater than that of the region with the lowest postneonatal mortality.

METHODOLOGY: Alaska's existing Maternal and Infant Mortality Review (MIMR) Committee will collect medical, socioeconomic, and environmental data on each of the State's non-Native infant deaths (approximately 80 to 120 cases per year). Questionnaires will be sent to attending physicians and local public health nurses, and families will be interviewed by a medically oriented social worker. Hospitals will be asked to submit medical records. A physician on contract will review the records for completeness; when the case file is complete, the case will be assigned to a quarterly Case Review Group (CRG) consisting of three physicians and one nurse or social worker (all members of the MIMR Committee), who will reach a determination of factors which may have affected the death and make recommendations for preventing mortality under similar circumstances in the future. The full committee will meet quarterly to review and compile the analyses and recommendations of the Case Review Group as well as to decide any issues of policy or procedure which may arise on a frequent basis during the early years of this project. Case findings and recommendations will be made available annually or semiannually to groups of medical professionals and to the public through presentations by members of the committee and through the publication of reports and the issuance of press releases.

A data base consisting of vital records (birth and death certificate) information on each case plus coded questionnaire responses will be established on a Wang minicomputer. The data base will include data on all infant deaths, including those of Native infants, which are currently reviewed by Indian Health Service staff using similar procedures and questionnaires.

EVALUATION: The data base system will be set up to track progress on the review of each case, which will be entered into the system when a batch of matched birth and death certificates becomes available monthly.

Numbers of reviews will be tallied at the end of each year. Recommendations will be compiled. Simple statistics will be generated from the completed records on an annual and cumulative basis in order to detect trends which may not be obvious from the individual case reviews.

Outcomes will be monitored by the Bureau of Vital Statistics, which computes annual infant mortality rates. These rates will also be computed for each of the State's eight MCH regions in order to monitor regional progress.

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MCHIP
MCJ-056027
10/01/89-09/30/91
Project Director(s):
Deborah Bryant, M.D.
Susan Patton, R.N., B.S.N.

PROBLEM: Progress over the past 15 years in reducing Arkansas's infant mortality rate has been concentrated almost entirely in the area of neonatal medicine. Physicians and hospitals have made considerable progress in improving the survival rates of high-risk newborns in this critical 28-day period. The percentage of births in Arkansas that are low birthweight, however, has remained relatively stable. This has had a great impact on infant mortality.

The capital of Arkansas, Little Rock, is located in the State's most populous county, Pulaski. All of the State's tertiary level perinatal and neonatal services are concentrated here. The population's socioeconomic status is above the State average, and the physician to population ratio (1 physician to 299 people) is higher than the State average (1 physician to 802 people). Yet, the neonatal and postneonatal mortality rates and the percentage of low birthweight births in Pulaski County are higher than the State average. Data currently available through vital statistics do not explain this contradiction.

GOALS AND OBJECTIVES: The goals of the project include development of an infant mortality review model in Pulaski County that will be utilized as part of a needs assessment, program planning, implementation, and evaluation process directed toward coordinating perinatal care and reducing infant mortality rates in Pulaski County. It is also intended that perinatal care providers in other Arkansas counties will utilize the review process to improve the availability and content of risk-appropriate maternal and infant care in Arkansas.

METHODOLOGY: Birthweight and infant mortality depend upon a number of variables, many of them outside the influence of the existing medical care system. There is a need to understand these variables if continued progress is to be made. Therefore, this project will be a process aimed at identifying and examining the factors which contribute to infant deaths in Pulaski County through the systematic evaluation of individual cases. It will not be limited to traditional case reviews or medical audits, but will have a broader scope which includes descriptions of public policies and assistance programs, accessibility of appropriate services, cultural beliefs concerning health care, and personal knowledge and motivation.

EVALUATION: Quantitative and qualitative data will be used to evaluate the project progress and outcomes in three areas:

1. Recommendations that are in the form of activities and strategies aimed at improving the health of mothers and babies;
2. Implementation of the recommendations; and
3. Birth outcomes measured by percentage of infants born at low birthweight, infant death rates, adolescent pregnancy rates, and prenatal care utilization.

Infant Mortality in Hartford, Connecticut: A Community-Centered Review

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MCHIP
MCJ-096011
10/01/88–09/30/91
Project Director:
Georgine Burke, Ph.D.

PROBLEM: This project responds to the high rate of infant mortality in the capital city of Hartford, Connecticut. Three times the State infant mortality rate (IMR) in several neighborhoods, Hartford's high IMR is concentrated primarily among the city's predominantly black and Hispanic populations, of whom nearly 60 percent fall below the Federal poverty level. This disparity is ironic since Hartford, the fourth poorest city nationwide, is situated in the State with the highest per capita income in the country. Hartford's high IMR poignantly demonstrates problems in the availability, accessibility, and appropriateness of prenatal education and medical services.

Infant mortality has declined steadily over the past decade in both Connecticut and the United States in general. The statewide infant mortality rate has been below the national rate over this entire 10-year period, falling to an all-time low of 9.0 deaths per 1,000 live births in 1986. Yet this apparent improvement has not been shared by all. In Hartford, as in other Connecticut cities, high infant mortality remains a persistent problem. During the years 1984–86, the citywide infant mortality rate was 18.0 per 1,000, compared to 9.7 per 1,000 for the entire State. The nonwhite rate, 24.3 per 1,000, greatly exceeded the white rate of 13.0 per 1,000, and is more than double the Surgeon General's 1990 goal that no subgroup of the population should have an IMR greater than 12.0 per 1,000. Thus, the bulk of the continued mortality is found in the nonwhite (primarily black and Hispanic) communities that comprise the majority of Hartford's population.

Low birthweight is a major determinant of infant mortality, especially during the neonatal period, and particularly among those groups characterized by socioeconomic disadvantage. For the years 1984–86, 6.6 percent of Connecticut births were below 2,500 grams, with the rate for whites (which includes those for whom race was reported as unknown) significantly higher than the 1990 objective of 5.0 percent. Among nonwhite births, the percentage of low birthweight (LBW) births does not seem to be changing; it remains high at both the State (12.3 percent) and city (14.6 percent) levels. In the Hispanic population in Hartford, 11.7 percent of all births are known to result in LBW infants.

The rate of births to adolescents is consistently much higher in Hartford than in the rest of the State. The city's proportion of adolescent births was 22.9 percent in 1984–86, more than double Connecticut's statewide rate of 9.1 percent. Adolescents in the cities are giving birth to many more infants than their counterparts in the suburban areas, and the city of Hartford has the highest number of adolescent births of any city in Connecticut. This reflects the fact that childbearing in the adolescent years is generally more prevalent among nonwhite ethnic groups. The citywide rate for whites (22.7 percent) reflects the high pregnancy rates of adolescent Hispanics when compared to the statewide rate for white adolescents (7.1 percent). These figures closely resemble the citywide rate for nonwhite adolescents, which is 23.2 percent.

The Hartford infant mortality review will target for study those fetal and neonatal deaths which occurred among the 1989 birth cohort of city residents. Between the years 1984 and 1986, the number of births averaged 2,864 per year, with 41 percent to blacks and 59 percent to all others (including Hispanics) over the 3-year period. There were 77 infant deaths in 1986; of these, 44 percent were fetal deaths and 35 percent were neonatal deaths.

GOALS AND OBJECTIVES: The Hartford infant mortality review will:

1. Introduce to the infant mortality review process in Hartford a systems approach to the understanding of infant death, incorporating findings from medical review with the insights and experiences of families who have suffered the loss of an infant;
2. Increase sensitivity in the clinical and human service communities to the sociocultural and environmental factors affecting infant death among inner-city families, as well as to culturally appropriate measures for improving communication, compliance, and followup;
3. Improve the intake and pregnancy tracking records of clinical treatment facilities and community-based prevention programs targeted at low-income, inner-city women in Hartford;
4. Ensure that policy and program recommendations emanating from the review are implemented at the State and local levels; and
5. Provide a project model for community-based review of infant mortality which can be duplicated in other urban areas of the State.

METHODOLOGY: The purposes of the Hartford infant mortality review are to: (1) Identify factors contributing to fetal and neonatal mortality which can be prevented by changes in prenatal and perinatal behaviors and changes in policy and programs, particularly those policies which influence access to medical care; (2) develop policy recommendations to limit or eliminate these problems; and (3) initiate efforts to implement the recommended changes. In order to accomplish these tasks, we will organize the Case Review Work Group (CRWG) to assemble and review specific sets of data (indicated below). Assembled cases and preliminary conclusions will be presented to an expert health panel designated as the Infant Mortality Review (IMR) Team.

The review sample will include the following:

1. The 1989 birth cohort of Hartford residents;
2. The first 50 cases of fetal or neonatal death that occurred in this cohort; and
3. Fifty controls—that is, healthy newborns matched according to ethnicity, maternal age, and neighborhood.

Data collection procedures will entail the following:

1. Indepth, structured, qualitative interviews with each mother in both case and control samples, conducted approximately 3 months after the death of the infant;
2. Medical records audit, including hospital and clinic records of cases and controls; and
3. Interviews with 25 community leaders and local social service and medical providers concerning perceived problems related to perinatal behavior and care.

Finally, the infant mortality review will employ a two-stage review process which will include:

1. Individual review of each death, rather than statistical summary of sample data;
2. First-stage case review by an obstetrician, neonatologist, nutritionist, and social scientist;
3. Case summary presented to the IMR team, whose membership consists of health providers and community and governmental representatives; and
4. Steering committee efforts to:
    a. Identify avoidable factors associated with fetal and neonatal death;
    b. Make policy and program recommendations based on case findings;
    c. Design intervention strategies; and
    d. Begin to implement recommendations in their respective service, program, and policy arenas.

EVALUATION: The project evaluation includes both in-house tracking of activities and an independent, process-oriented evaluation; each parallels, to an extent, the other's activities. Tracking will document all project activities, and will monitor the degree to which project activities are consistent with project goals and objectives; assess the completion of specific project tasks; determine participant experience and involvement with the project; and identify problem areas in project functioning.

A similar independent appraisal will be carried out by an evaluator who will, in addition, analyze success in improving medical and program records, and assess the effectiveness of presentations of project findings for increasing understanding among providers about sociocultural, behavioral and environmental, and health delivery/access factors associated with fetal and neonatal mortality.

EXPERIENCE TO DATE: Since October 1, 1988, the Hartford infant mortality review has hired an investigator and coinvestigator and two interviewers, developed two data collection instruments (a medical records audit and a home interview), obtained participation of all CRWG and IMR team members, trained the field interviewers to contact mothers and administer the instrument, finalized procedures for identifying cases and locating mothers, and begun interviewing mothers whose infants died in January and February 1989.

The IMR team has been structured to include representation of all groups in the city working on the issue of infant mortality, especially those individuals with the authority to implement the committee's recommendations. The IMR team membership represents all prenatal clinics and inpatient facilities in Hartford, as well as the city and State health departments, and includes private physicians, community-based organizations, members of local perinatal risk reduction efforts (such as the Hartford Action Plan on Infant Health, the Hispanic Health Council's Comadrona Program, and the March of Dimes), and university-based experts in MCH epidemiology and nutrition. The first group meeting was held in January 1989 to discuss methodology for the project. During the period since October 1988, both investigators have spent considerable time not only in obtaining the commitment of the IMR team and CRWG members, but in securing the critically important support of other hospital and clinic personnel, such as labor and delivery nurses and bereavement counselors, without whose cooperation we would not be able to obtain names of fetal death cases or control mothers. Access to city vital statistics is facilitated by our historically close working relationship with the director of the Hartford Health Department.

The current salient problem in meeting the data collection/case review objectives relates to finding cases once they are identified. There are three factors contributing to the problem: (1) Addresses listed on the death certificates may be unreliable or inaccurate for women who are homeless or have some other reason to fabricate an address; (2) the Hartford population is highly mobile, a situation accentuated by the high cost of housing in the area and frequent movement of Puerto Ricans between Connecticut and Puerto Rico; and (3) for fetal deaths where vital records are not available, we often do not have a maternal address. We are taking a number of steps to address these problems. Women who have moved to a new address can be traced through the post office if they have left a forwarding address. For those women whose addresses are inaccurate, we have obtained the cooperation of all area homeless shelters and have begun to approach local funeral homes to provide information that may help in identifying their actual location.

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MCHIP
MCJ-117013
06/01/90-05/31/93
Project Director:
Louise M. Wulff, Sc.D.

PROBLEM: Although the infant mortality rate for all races has declined in recent years, the rate of decline has slowed considerably. The disparity between the infant mortality rates for black and white infants continues. Major regional and community variations in infant mortality rates also continue. In addition to infant deaths, there are nearly 30,000 stillbirths (fetal deaths at greater than 20 weeks' gestation) which occur each year with little or no attention paid to cause or prevention.

Only a few of the activities under way to combat infant mortality address the need to identify more clearly the specific community patterns and underlying causes (medical, behavioral, and/or socioeconomic) of perinatal and infant mortality. Additionally, the problems of perinatal and infant mortality are complicated, and solving them will require the cooperative activities of many sectors in the health and human services arena.

A national effort is required to provide guidance and stimulate the growth of local activities for the purposes of (1) identifying the causes of perinatal and infant mortality in each community, (2) seeking remedy of those causes, and (3) targeting resources where the greatest benefit can be realized. Physician participation and leadership in these efforts at all levels are critical if meaningful change is to take place. Any activity must also involve other health and social science professions in a cooperative effort, however, since nonmedical factors related to infant mortality often deserve serious consideration.

GOALS AND OBJECTIVES: ACOG proposes to develop and implement a national program of perinatal and infant mortality review as a key force in improving the perinatal and infant mortality rates. The ultimate goal of the project is to reduce stillborn and infant losses. The project intends to accomplish this though the establishment of a national, multidisciplinary committee whose purpose will be to study current and past perinatal and infant review activities, establish optimum methods to conduct perinatal and infant mortality reviews, and stimulate the development of perinatal and infant mortality review committees locally. The National Infant Mortality Review Project will be structured in such a way as to engage the medical community, in cooperation with other health professionals, to look systematically at the cases of perinatal and infant mortality in their respective communities so that causes can be identified, remedies instituted, and public policy influenced to target resources to areas of greatest need.

METHODOLOGY: The project will establish a National Perinatal and Infant Mortality Review Committee, composed of the major medical specialties and other health professions which can effect change relating to infant mortality. This committee will have the responsibility of overseeing: (1) The development of a clearinghouse of current activities and literature in perinatal and infant mortality review; (2) the provision of guidelines for the implementation of perinatal and infant review activities, including revising, expanding, and publishing the draft infant mortality review manual originally prepared in 1988 by the Office of Maternal and Child Health; (3) the development of feedback loops and professional education plans for the professional groups involved, community agencies, and local, State, and national policymakers; and (4) the development of local and State perinatal and infant mortality review committees.

The project will develop and provide the technical assistance required for the implementation of perinatal and infant mortality review committees at the local and State levels.

The project will seek funding for, develop, and evaluate 20 demonstration community perinatal and infant mortality review committees.

EVALUATION: A timeline for the project has been prepared and includes specific deliverable items and milestones to be used to evaluate the project. Each objective and activity will be reported by the project director to the ACOG Executive Director and to the national committee. Appropriate reports will also be submitted to the Maternal and Child Health Bureau.

Infant Mortality Case Review

Indiana State Board of Health
Bureau of Family Health Services
1330 West Michigan Street
Indianapolis, IN 46206
(317) 633-0844

MCHIP
MCJ-186028
10/01/89–09/30/91
Project Director:
Nancy Jewell

PROBLEM: Indiana has the 13th highest infant mortality rate in the United States. In 1986, Indianapolis in Marion County had the highest black infant mortality rate of any large U.S. city with a significant black population (26.2 deaths per 1,000 live births). Based on a 3-year average (1985–87), Marion County had the highest low birthweight rate of any county in the State. The Indiana State Board of Health 1984–86 Birth/Death Cohort Study for Indiana reveals nearly a sevenfold disparity between the infant mortality rate of infants born to black adolescents with inadequate prenatal care and that of infants born to white women 20 years of age or older with postsecondary education and adequate prenatal care.

GOALS AND OBJECTIVES: The project goals are to:

1. Reduce the infant mortality and low birthweight rates in Marion County through the efforts of the Mayor's Task Force on Infant Mortality Oversight Committee; and
2. Demonstrate a community-based, multidisciplinary review model that effectively identifies multiple factors which contribute to fetal, neonatal, and postneonatal mortality in high-risk areas and serves as a working model for other communities.

The primary objective of the project is to create the Infant Mortality Review Committee, composed of professionals from multiple disciplines who will study fetal and infant deaths in Marion County.

METHODOLOGY: The Maternal and Child Health Division of the Indiana State Board of Health's Bureau of Family Health Services, Marion County Department of Public Welfare, Marion County Health Department, Wishard Memorial Hospital, Methodist Hospital, and other key organizations will target 65 census tracts in Marion County with a 7-year average (1980–87) infant mortality rate greater than or equal to 13.2 deaths per 1,000 live births. Case studies will be performed on each fetal, neonatal, and postneonatal death occurring to residents of these census tracts in 1990–91 until a minimum of 50 deaths have been investigated through the systematic evaluation of individual cases to identify and examine the factors which contribute to fetal and infant deaths. Family interviews, as well as medical record reviews, will be an integral part of the review. The aggregate of these individual studies will be evaluated based on demographic characteristics and the most frequently occurring contributing factors.

EVALUATION: The effectiveness of the recommendations generated by the Infant Mortality Review Committee and the success of the Task Force on Infant Mortality will depend upon the following factors:

1. Completeness and accuracy of data abstracted from records and family interviews (missing data will be documented and explained as to reason for incompleteness);
2. Identification of trends and patterns in cases studied which indicate significant contributing factors;

3. Recommendations with measurable short-term and long-term outcomes offered by the Infant Mortality Review Committee; and
4. Flexibility and willingness of community agencies and government bodies to work cooperatively toward common goals.

EXPERIENCE TO DATE: It is anticipated that the projected deadline for completing this project will be met.

The following activities have taken place:

1. Project coordinators with experience in nursing, research, and counseling have been hired;
2. Orientation of the interviewers and abstractors took place on April 7, 1990, and their work began on April 15, 1990.
3. The advisory committee and work group members have been identified.

Infant Mortality Review
Kansas City, Kansas-Wyandotte County
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MCHIP
MCJ-206038
10/01/90-09/30/92
Project Director:
Darrel D. Newkirk, M.D., M.P.H.

PROBLEM: In Wyandotte County, Kansas, the number of infants who die before their first birthday continues to hover above both the United States and Kansas rates. In 1988, Wyandotte County had an infant mortality rate of 13.6 per 1,000 live births, compared to the U.S. rate of 9.9 and the Kansas State rate of 7.9. In the same year, .7.7 black babies died per 1,000 live births, compared to 11.3 white babies. The black infant mortality rate has averaged 65 percent higher than the white infant mortality rate over the last 10 years.

Factors contributing to poor pregnancy outcomes directly related to infant mortality continue to be worse for Wyandotte County than the averages for the United States and Kansas. These include the percentage of low birthweight births, premature deliveries, and adolescent pregnancies, and the percentage of women who do not receive adequate prenatal care. Socioeconomic factors perceived to contribute to the infant mortality rate of the county are the number of women with a low level of education, the percentage of the population living below the poverty level, and the number of single parent families in the county.

Numerous initiatives have been instituted to facilitate the accessibility of prenatal and infant care for the county's residents. Programs have been implemented to impact upon and subsequently reduce the number of infant deaths. The overall rate of infant mortality has declined over the last 10 years, but at a very slow rate. The number of black infant deaths, however, has not declined in comparison to the number of white deaths. The problem of infant and fetal deaths, as well as the continued endless burden of medical costs, poor quality of health, and additional family stress due to complications associated with infant mortality, need to be addressed at a local level on an individual basis.

GOALS AND OBJECTIVES: The goal of this project is to design a process for the identification and examination of the factors contributing to fetal and infant deaths through systematic evaluation of individual cases. Recommendations and interventions can be established to enhance a healthy start in life for all infants. A community-based Infant Mortality Review (IMR) Team and Case Review Work Group (CRWG) will be formed. A systematic approach with standardized abstracting forms and a common methodology for examining factors contributing to fetal and infant deaths will be developed. The data collection process, including reviewing 95 percent of all infant and fetal deaths among Wyandotte County residents, will be implemented. Recommendations will be developed by the IMR team based on the findings. The framework for distribution and utilization of the summary report with recommendations for creative changes in existing health care delivery systems will be designed.

METHODOLOGY: The Infant Mortality Review Team will be created to implement the IMR as well as to coordinate the individual case reviews and establish relationships with relevant community groups and organizations. The Case Review Work Group will be established to perform the individual reviews and make preliminary recommendations. The Implementation Task Force (ITF) will be selected to implement the recommendations of the IMR Team.

The project plan includes the development and implementation of a system for notification of fetal and infant deaths as well as the necessary releases required to obtain records and assure confidentiality.

Abstraction forms for the collection of standardized data and a system for the evaluation of identified factors will be developed. Reports will be standardized to those collected by the State and national reporting systems. A systematic reporting structure will be incorporated to notify all participating health care providers, support agencies, and community resource systems of pertinent findings.

EVALUATION: The objectives will be measured by completion and success of implementation of the recommendations of IMR, the number of cases reviewed, and documented changes directly attributed to IMR. Data for quarterly and annual evaluations of the project objective will be collected through standardized abstracting forms, minutes of meetings, and progress reports. Reports of the data will be made available on a timely basis to all participating agencies or organizations and to all appropriate State and Federal agencies by request.

The IMR process, designed for the identification and examination of the factors contributing to fetal and infant deaths, will be included in the final summary report with recommendations and interventions to enhance a healthy start in life for all infants.

A list of members of the Infant Mortality Review Team and the Case Review Work Group will be documented in the minutes of all meetings. A systematic approach with standardized abstracting forms and a common methodology for examining factors will be developed and assembled in a procedure manual. Data will be abstracted and individual reports will be reviewed on 90 percent of all infant and fetal deaths in Wyandotte County. Reports will be made of all recommendations based on the project findings. A summary report will be designed for distribution.

Case-by-Case: Boston's Infant Mortality Review Project

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MCHIP
MCJ-256026
10/01/89-09/30/91
Project Director:
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PROBLEM: At the most basic level, infant mortality represents a tragedy of enormous proportions: The death of a child at the outset of life. In more global terms, it is a measure of a society's humanity and the quality of services that a society provides its population. Deaths of infants in the first year and the known correlates of being born too small, too soon, are not random or equally distributed events. There are significant regional differences, and often cities with large black populations have worse rates of low birthweight (LBW), prematurity, and infant mortality. Moreover, there is a persisting and, in some cities, growing racial disparity in the rates of low birthweight and infant mortality; black infants are twice as likely to die in the first year of life as are white infants in the United States.

In Boston, with our wealth of clinical knowledge, state-of-the-art perinatal technology, and perinatal and pediatric health resources, we are struggling to understand how to better optimize the chances that all of our children will survive their first year and have healthy, full, and productive lives. In 1988, 136 babies born to Boston residents died before reaching their first birthday. In 1987, 9.3 percent of all resident babies born were less than 2,500 grams (the highest LBW rate in the Commonwealth), and the infant mortality rate (IMR) was 11.9 deaths per 1,000 live births. In 1969, a black infant was 1.4 times more likely to die in the first year than a white infant; by 1987, this disparity had grown to 2.8 (the 1987 black IMR was 20.1 per 1,000, compared to 7.2 for whites). There has been a persistent erosion in the adequacy of prenatal care services. In 1987, only 67 percent of all pregnant women received adequate care (56 percent of all black women and 77 percent of all white women). Within Boston, four neighborhoods in the shadows of the best "medicine" supposedly available to women and children account for 59 percent of all resident births and 75 percent of all infant deaths.

GOALS AND OBJECTIVES: The goals of the Case-by-Case Infant Mortality Review Project are twofold:

1. To develop, implement, and evaluate a process whereby selected individual deaths to infants in the first year of life can be evaluated systematically to identify contributing factors which are amenable to program and policy changes, particularly at the local level; and
2. To develop, implement, and evaluate a process whereby key community leaders and health care and social service professionals can translate infant mortality review information into successful, action-oriented strategies toward the elimination of racial disparities in infant mortality and other adverse health risks and outcomes in Boston.

We realistically expect to achieve process objectives, not health outcome objectives, through this project. These include the completed review of the medical records of all infant deaths, and family interviews and panel review of a select subset of these deaths. We will document and assess the Boston model for conducting infant mortality review, and produce a detailed plan for reducing infant mortality and associated racial disparities in Boston which has the approval of the City and State Commissioners of Health and reflects the will of the Boston community.

METHODOLOGY: The Boston Department of Health and Hospitals (BDHH) proposes to design, implement, and evaluate a comprehensive, community-based infant mortality review process which adapts the methods suggested in the Federal Office of Maternal and Child Health's *Infant Mortality Review Manual* to fit our city's context. Over the 2-year project period, we plan to conduct a detailed medical record review of all infant deaths within the study period (approximately 18 months).

We are able to be timely in the selection of cases due to the unique BDHH Infant Death Surveillance System (IDSS) through which all Boston resident death certificates are automated shortly after issue by the BDHH Office of Health Statistics and Research. Types of data to be collected systematically on each sampled case by trained abstractors include birth and death certificates, and abstracted information of records from five possible sites of care: Prenatal site(s), hospital of delivery, pediatric primary care site (if discharged postpartum), emergency room, and hospital where pronounced dead (if different). This will provide a comprehensive, clinically oriented data base on all cases. More indepth analysis will be conducted on a subset of these deaths, selected on the basis of their policy relevance. Each year a minimum of 30 cases will be "flagged" for the collection of information on the social context of the death through interviews with family members and, in some instances, social service providers. These cases will then be presented to the Case Review Work Group (CRWG), consisting of clinical and social providers. This group will identify contributing factors amenable to prevention through policy or program changes, draw out implications for public health policy, and summarize cases and their findings for presentation to a larger, more broadly based Infant Mortality Review (IMR) team. The IMR team will make final policy recommendations and propose implementation strategies to the city and State departments of health.

Massachusetts Infant Mortality Action Strategy

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MCHIP
MCJ-256039
10/01/90-09/30/92
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PROBLEM: Although the Massachusetts infant mortality rate declined 23 percent from 1980 to 1988, the Commonwealth continues to confront local "epidemics" of infant mortality. Geographic variations in infant mortality rates persist throughout the State. Several cities regularly show infant mortality rates (IMRs) more than 50 percent above the State average. In 1988, the mortality rate for black infants was 142.2 percent higher than the white IMR, a gap which has widened since 1980. Of particular concern is the impression that for some groups excessive infant mortality is a chronic problem. Implementation of the Automated Vital Statistics System and the rapid publication of community-specific vital statistics have improved the Massachusetts Department of Public Health's (MDPH's) ability to characterize infant mortality. These strategies have provided important general background information, but they do not examine the specific social contexts in which the deaths occur nor can they reveal barriers to care or other systemic problems. MDPH must develop a more comprehensive and timely strategy for investigating inequalities in birth outcomes and for implementing specific programmatic solutions to reduce medical and nonmedical risk factors for poor birth outcomes.

GOALS AND OBJECTIVES: The goals of the infant mortality review process to be developed by the Massachusetts Infant Mortality Action Strategy (MIMAS) are to:

1. Develop a model for the rapid investigation of infant mortality in communities or population subgroups with excessive IMRs;
2. Pilot the model in an area with an excessive IMR;
3. Based on the review's findings, develop local action plans with the pilot community which identify specific program and policy actions to reduce infant mortality and which can be implemented at the State and local levels; and
4. Produce materials which can be used by other State Health Departments.

METHODOLOGY:

1. Developing the model for rapid investigation: Existing infant medical audit and infant mortality review procedures are limited by their focus on medical records as the major source of data for their evaluations. We will integrate three sources of information: (1) Data collected from women who gave birth in the target community; (2) a structural analysis of the care delivery system through a provider survey and key informant interviews; and (3) a review of hospital and prenatal care records. MIMAS will mobilize the participation of the pilot community in the design, analysis, and action plan development phases. With MIMAS project staff, the Community Action Board (CAB) will adapt data collection instruments to meet community needs, assess responses using the analytic matrix developed for MIMAS, and recommend specific program changes.
2. Piloting the model: The city of Lawrence has been selected for piloting based on its high IMR, race/ethnic composition, community size, and concerns about access to care.
3. Developing local action plans: With the direction provided by the problem specification, recommendations will be solicited from the community. Key informants will include local

health care and social service providers and local government officials. The discussions will concentrate on solutions to problems identified by the CAB and project staff from the data collection phase and on risk factors that are amenable to program intervention. Focus groups of high-risk women will be formed to solicit specific ideas about the risks and unmet needs previously identified. Project staff and the CAB will review the feedback from the focus groups and key informant interviews and develop an action plan for State and local program implementation.

4. Producing materials: Training manuals, data collection instruments, evaluation forms, and a bibliography will be developed to adapt this approach for use in other communities throughout Massachusetts and in other States. Emphasis will be on the practical implementation of MIMAS and suggestions for modification of the process to meet the needs of many potential users.

EVALUATION: Three directions for evaluation will be pursued. First, the data collection and analysis strategies will be assessed to determine the information which was valuable, the marginal utility of the various components of data collection, and the time and costs of data collection and analysis. Second, the process of working with the CAB in all phases of this project will be examined to ascertain whether this is an appropriate model for local/State collaboration, whether this process yielded specific program and policy recommendations, and, if so, whether they could be implemented. Third, we will monitor the impact of MIMAS in the pilot community for 5 years by following infant mortality and its antecedents, such as low birthweight and inadequate access to prenatal care.

Multistate Infant Mortality Review Project
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Training
MCJ-102
07/01/86-06/30/91
Project Director:
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PROBLEM: Infant mortality patterns have emerged as an important concern for local communities, public agencies, and policymakers. Consequently, there is a growing need for methods that can provide empirical insight regarding the causes of local elevations in infant mortality and directions for remedial action.

Despite common influences, there is considerable variation in the causes of elevated infant mortality rates. This implies that local analysis is indeed often necessary. Moreover, there is a specific need for analytic methods that are expressly directed toward questions of policy. This requires that data collection and analysis address systemic determinants of risk status and health care utilization.

To be useful to local communities and agencies, analytic methods must maximize efficiency and minimize expense. Any proposed methodology must be flexible and sensitive to local concerns. Therefore, data collection and analysis must be based upon standard methodologies so that unnecessary duplication of effort is avoided. It must also be comprehensive enough to include issues likely to be of intensely local concern.

GOALS AND OBJECTIVES: The Multistate Infant Mortality Review Project (MSIMRP) is a collaborative effort to develop a basic analytic system that can assess policy-related problems in local patterns of infant mortality. MSIMRP is not designed to be a "study" of infant mortality; rather, it represents an attempt to design and implement an integrated methodology to analyze clinical information in a format that directly facilitates local efforts to reduce infant mortality. Because MSIMRP is concerned with issues of policy, a central project objective is to organize the collection, analysis, and presentation of data on infant mortality in a framework that is useful in both the clinical and political arenas.

The primary objectives of the Multistate Infant Mortality Review Project are to:

1. Provide an experiential base for the development of methodologies which address policy-based determinants of local infant mortality patterns;
2. Assess the comparability of data sources (e.g., vital statistics and medical records) regarding the determinants of local infant mortality patterns;
3. Examine the causes of regional and social disparities in infant mortality; and
4. Develop training and methodological materials to help facilitate broader national efforts to assess local infant mortality patterns.

METHODOLOGY: The methods developed by MSIMRP represent an attempt to provide critical information for policy deliberation and, at the same time, respect the resource constraints which generally exist at local levels. Therefore, the MSIMRP methodology should not be viewed as in any way excluding other more extensive or refined analytic strategies. To the contrary, the MSIMRP methods are expressly presented as a basic empirical foundation upon which other methodologies can be developed and pursued.

Analytic design and sampling: The analytic structure combines several epidemiologic approaches, but generally conforms to a linked cohort and case-control design. This design requires that information on cases and noncases be collected. All analyzed data were retrospective in nature and available from recorded sources. Data on three analytic groups were collected: (1) All infant deaths; (2) all very low birthweight (VLBW) births (less than 1,500 grams); and (3) a random sample of non-VLBW surviving controls. This sampling framework permits the analysis of factors associated with VLBW and neonatal and infant death. It also allows for the assessment of the distribution of prenatal and preconceptual factors in pregnancies ending in live births.

Data sources: The universe of data is defined from two data sources—vital statistics files and hospital-based medical records.

Vital statistics files. Vital statistics files used by MSIMRP included birth certificate files and linked birth and infant death files. These files were obtained from the appropriate State agencies. Vital statistics files were utilized for two purposes: (1) To provide basic trend information, and (2) for case identification. Year-to-year trends in various components of the infant mortality rate were calculated using vital statistics files. In addition, cases of infant death and VLBW births, and samples of all births, were identified through the analysis of vital statistics. Analyses were confined to all births and infant deaths among residents of the selected geographic areas. Births and infant deaths occurring in the study area but to nonresidents were excluded from the analyses.

Hospital medical records. The primary data source was the hospital medical record. Information was abstracted from the maternal and infant medical records at the hospital of birth, the hospital of death, and all hospitals from which the mother or infant was transferred to the birth or death hospital. A standard abstracting form was utilized for all medical records and was applied by specially trained nurses with significant clinical experience. Data for all autopsies performed were obtained. A 10 percent blinded reabstraction was conducted to ensure the reliability of audited data.

Statistical considerations: A variety of statistical procedures have been used in the production of analytic findings. Tabulations and multivariate models have been performed using SAS data sets and procedures. Data manipulation and rate calculations have been performed in the spreadsheet environments Excel and Lotus 1-2-3. Chi-square testing in stratified analyses was conducted using SAS, Epistat, and EpiInfo software.

Site locations: In order to gain experience in diverse settings, MSIMRP has been active in both rural and urban sites in five areas of the United States:

1. City of Boston, 1980–85;
2. State of Maine, 1984–85;
3. City of St. Louis, 1985–86;
4. County of San Diego, 1985; and
5. Districts 4 and 8, Mississippi, 1984–85.

EXPERIENCE TO DATE: The data collection phase of this project was completed in April 1990. MSIMRP received permission to collect data from all 142 candidate hospitals providing care to women and/or infants across all 5 sites. Records for all but 6 percent of the candidate cases were identified and abstracted. Although considerable differences in record keeping were documented across sites, a core group of critical variables was identified as being generally available from medical records.

The study populations for the five sites were:

	VLBW Survivors	Infant Deaths	Controls
Boston	481	579	872
Mississippi	161	163	391
Maine	195	271	574
San Diego	222	333	666
St. Louis	323	267	534

Preliminary analyses have focused upon the distribution of underlying maternal conditions prior to conception, particularly chronic medical conditions and behaviors such as smoking and drug use, prenatal conditions, and conditions associated with elevated VLBW births. Analyses are also currently being conducted focusing on birthweight- and risk-specific differences in mortality in the neonatal and postneonatal periods. Preliminary findings suggest that the impact of differential access to prenatal care is influenced by differential risk distribution in the populations. The causes of racial disparities in VLBW rates appear to be similar across sites, and differential access to tertiary services may play a potentially large role in shaping regional differences in mortality.

Prospective products of MSIMRP are suggested analytic designs, data collection processes, confidentiality protection mechanisms, personnel training materials, analytic methodologies and software, and options for presentation.

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MCHIP
MCJ-366012
10/01/88–09/30/91
Project Director:
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PROBLEM: In 1987, the infant mortality rate for New York City was 13.1 per 1,000 live births, reflecting the first increase observed in 14 years. The rate of 13.3 per 1,000 for 1988 represented another increase of 1.5 percent, and early projections for 1989 suggest that this devastating trend will continue. Paralleling these data are statistics that reveal alarming increases in the rates of low birthweight births (less than 2,500 grams) and very low birthweight births (less than 1,500 grams), preterm deliveries (less than 37 weeks) and early preterm deliveries (less than 34 weeks), prenatal substance abuse, and perinatal HIV antibodies and AIDS.

All of these serious public health problems are even more prevalent in the inner-city regions where the poor, medically indigent and minority women of highest risk are concentrated. The South Bronx is one such area, and the southernmost health district of Mott Haven continues to report infant death rates that are 45 percent higher than those for New York City (which reports rates 30 percent higher than the national average of 10.4 deaths per 1,000 live births). These statistics are reflected in the unacceptably high U.S. infant mortality rate, which places this country in last place among the 20 developed nations of the world. When the continuing disparity of about 2 to 1 between black and white infant mortality rates is considered, the United States falls to 25th place.

To reverse this devastating status, a new perspective is needed. The high-risk, inner city community of Mott Haven represents a geographically defined area suitable for an intensive analysis of the factors associated with excessive deaths among American babies.

The existence of a New York City Department of Health (NYCDOH) comprehensive case management program for pregnant women and infants in the same health district ensures the necessary followup of these high-risk families during and after participation in the infant mortality review project. The fact that New York City has the only urban-based vital statistics in the United States enhances complete case ascertainment and a timely evaluation of the project.

GOALS AND OBJECTIVES: The primary goal of the project is to implement a comprehensive, community-based infant mortality review process in Mott Haven utilizing a systems approach. The process will examine factors contributing to fetal and infant deaths. Multiple data sources will be used to obtain psychosocial, behavioral, demographic, lifestyle, educational, environmental, historical, obstetrical, medical, familial, administrative, financial, public health, community, and systems factors associated with each death. The infant mortality review will be designed to enhance many other State and local efforts both planned and under way to improve maternal and infant health throughout New York City and State.

The data obtained from this dynamic process will reflect public policies and assistance programs, accessibility of appropriate health and social services, cultural beliefs concerning health care, parental knowledge and motivation, risk assessment, patient management, and provider practices.

Results will be widely distributed in a timely manner for effective planning and implementation. An implementation task force will facilitate these efforts.

Each review will focus on what should happen according to community standards, what different people believe is happening, what different people say is happening, and what really is happening. The degree to which some factors can be prevented or mediated, the frequency with which problems occur, and all contributing factors will be identified. Based on the infant mortality review findings, specific recommendations will be made for strategies and interventions to prevent infant and fetal deaths.

METHODOLOGY: This is a prospective, descriptive study whereby the infant mortality review process is applied to each fetal and infant death that occurs between January 1989 and September 1990 to Mott Haven residents. In addition, for the subset of fetal and neonatal deaths occurring between July 1989 and September 1990 to women delivering at Lincoln Hospital and residing in Mott Haven, two living control infants matched for race and birthweight will be selected to further define important contributing factors. This will result in an ancillary, matched, multiple control design study. Data will be collected utilizing the family interview (usually conducted with the mother), abstracted medical records on the mother and infant, autopsy records, and community services information.

Based on an average of 40 infant deaths and 30 fetal deaths of greater than 20 weeks' gestation annually, approximately 70 losses will be reviewed each project year for a total of 140 during the 2-year grant period. Data for an additional 168 control infants will be reviewed as part of the matched design for the cases born at Lincoln Hospital, resulting in a projected final sample of approximately 350.

EVALUATION: The large volume of descriptive, clinical, socioeconomic, lifestyle, and health systems data collected will be organized to facilitate development of recommendations by the Infant Mortality Review Team. This will be done by identifying specific causes of death, trends or patterns for access to and utilization of health care delivery systems, problems encountered, and questions needing resolution.

Causes of death will be classified by a meaningful preventability algorithm that takes into account interrelated nonclinical factors and is sensitive to reactions of the medical community to such a determination. A major focus of the analysis will be the identification of contributing factors which will be classified as community factors, patient and/or parent factors, health care facility factors, and physician/provider factors.

Analyses will proceed from simple to complex utilizing appropriate univariate, bivariate, and multivariate techniques. Descriptive population data will include tables of the distribution of fetal, neonatal, and postneonatal deaths by birthweight, race, age of death, cause of death, contributing factors, and maternal age, education, parity, and payment source.

Vital statistics data from the Bronx, New York City, New York State, and the United States will be used for comparison. The multiple control matched subset study on all cases delivered at Lincoln Hospital will also be analyzed, utilizing matched pair techniques.

EXPERIENCE TO DATE: Most of the objectives related to year 1 as stated in the original application will be met by the end of the first project year. Several unexpected problems resulted in initial delays for specific activities, however, while the more long-range goal to catalyze a statewide infant mortality review process has been expedited.

Project objectives that have been met to date include the following:

1. All baseline data for the Mott Haven health district, the Bronx, and New York City from 1980 to 1987 and provisional data from 1988 have been analyzed;
2. Meetings have been held with representatives from each collaborating agency and group (i.e., New York State Department of Health, Lincoln Hospital Department of Obstetrics and Gynecology, Lincoln Hospital Social Services, Lincoln Hospital Bereavement Group, Lincoln Hospital Prenatal Care Providers, Bronx Perinatal Consortium, the Program to Reduce Obstetrical Problems and Prematurity (PROPP), Albert Einstein College of Medicine Department of Obstetrics and Gynecology, Bronx Obstetrical Society, the Medical Health Resources Administration SIDS Counseling and Information Services, NYCDOH Public Health Nurses, and the Perinatal Nurse Network);

3. The Case Review Work Group has been created;
4. The Infant Mortality Review Team has been selected and met as a full group in July 1989;
5. Consent forms, letters to request participation, and background information on the project have been developed, piloted, and translated into Spanish;
6. The interview schedule and medical records abstraction forms have been developed and piloted;
7 Case identification systems have been established and tested;
8. Data management procedures have been developed and refined;
9. All computer programs to support screen entry of each study instrument have been completed as scheduled;
10. Medical records and autopsy reports have been requested on all 1989 infant deaths reported in Mott Haven to date;
11. The medical records abstraction process has begun;
12. Interviewers have been hired and trained;
13. The family interview process has begun;
14. An abstract on the infant mortality review process was accepted for presentation at the October 1989 American Public Health Association meeting; and
15. The New York State Department of Health has held two meetings to start a pilot of a seven-county infant mortality review with a focus on providing needed services to the affected families.

The accelerated expansion of the infant mortality review process to seven counties in upstate New York reflects the substantial impact of this SPRANS initiative on maternal and child health programs in New York State. Continued close collaboration between the New York City and New York State Departments of Health will promote the best chance of defining meaningful strategies to prevent the excessive and escalating rate of infant deaths observed against the background of rampant substance abuse and the AIDS epidemic.

Fetal and Infant Mortality Review: Understanding Our Problem
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MCHIP
MCJ-456010
10/01/88-09/30/91
Project Director(s):
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PROBLEM: Over the past decade, except for the years 1980 and 1986, South Carolina has had the highest State infant mortality rate (IMR) in the Nation. South Carolina has also been identified during the late 1970s and early 1980s as one of seven States with a significantly slower decline in its IMR than the Nation as a whole. At its present rate of decline, South Carolina will continue to have one of the highest State infant mortality rates and will only reach 11.4 infant deaths per 1,000 live births by the year 1990, which does not approach the Surgeon General's 1990 objective of 9.0.

South Carolina's poor ranking and poor rate of decline in infant mortality persist in spite of several major State, regional, and national initiatives to reduce infant mortality, and in spite of efforts to increase community and business awareness through the Southern Governors' Association.

GOALS AND OBJECTIVES: The goal of this project is to improve the survival rate of infants in South Carolina so that the State infant mortality rate is at least equal to the rate for the Nation. By analyzing health care financing, systems, and service delivery problems, the project seeks to achieve a better understanding of the medical, social, health service, and environmental factors which contribute to infant mortality both locally and statewide. State and local strategies will then be developed to address identified problem areas.

The primary objective for the project is that, by October 1990, a medical record review will be completed on 20 percent of all South Carolina fetal and infant deaths by local review groups. At least 7 of 15 health districts will participate in this effort.

METHODOLOGY: In pursuit of our goal, the project will:

1. Complete the *Fetal and Infant Death Review Handbook for South Carolina* to provide consistent, step-by-step guidelines for conducting local reviews and assuring confidentiality;
2. Develop a statewide technical support network to facilitate the local review process and enhance consistency and comparability among local area review teams;
3. Implement fetal and infant death reviews that are broad in scope and magnitude in three local health districts (Catawba, Waccamaw, and Appalachia II); and
4. Establish a mechanism for implementing recommendations made by the local area review teams at both the local and State levels.

EVALUATION: The project evaluation will be twofold:

1. The percent of all fetal and infant deaths reviewed will be assessed both during each project year and at the end of each project year. At each quarter, each funded district will be surveyed as to the number of deaths which have been reviewed during that quarter, and that number will be compared to the number of deaths reported on the quarterly fetal and infant death reports. At the end of each project year, we will count the number of death review forms included on the data files which are submitted to the project administrator by each funded district. In addition, we will survey the number of deaths reviewed by those districts not receiving funding.

2. All districts will be surveyed semiannually as to their status in regard to participating in fetal and infant death reviews. This will provide a crude measure of the spread of the ability to conduct reviews in other districts.

EXPERIENCE TO DATE: The *Fetal and Infant Mortality Review Handbook for South Carolina* was completed and sent to the district health directors in February 1989. The South Carolina Medical Association (SCMA) endorses the concept of fetal and infant mortality reviews (FIMRs), but would not endorse the process or handbook until they could be assured that the review discussions and findings would be held confidential, and that there would be no monetary liability by members of the review committees. In January 1989, legislation that would provide confidentiality and liability protection for FIMRs as specified by SCMA was introduced into the 1989 South Carolina Legislative Session. The legislation passed the House and the Senate in May 1989, and was ratified and signed into law by the Governor in June 1989. Because of delays related to SCMA input and the local autonomy of members of State specialty boards, the South Carolina Hospital Association, County Departments of Social Services, and South Carolina medical examiners and coroners, we decided not to seek their support at the State level. Local FIMRs are encouraged to obtain local support from members of these groups.

A statewide technical support network is being developed. A common data management system to enable districts to summarize their own quarterly vital statistics data using EpiInfo or dBase software was developed in December 1987. A list of ICD-9 codes for all causes of South Carolina fetal and infant deaths for 1987 and 1988 was provided to the districts with provisional 1987 and 1988 data. Project consultants were assigned to each grant district in November 1988. A list of appropriate project consultants was compiled in January 1989. FIMR agreements with the three grant districts and five other districts who applied for surplus funding were written, and a district contact person was identified for each district in February 1989. The EpiInfo output of quarterly vital statistics was revised, based on district input, and 1-page summary forms were added in April 1989. Drafts of data collection tools for "never discharged" and "post discharge' deaths and home interviews were distributed to nine districts in May 1989. These were adapted from nationally tested tools with input from three of the grant districts. An FIMR training workshop was held in May 1989 with 8 districts and 34 individuals participating. An FIMR notebook, containing all of the information and tools developed to date for the FIMR process, was given to each district at this workshop.

The status of implementing the death review process is listed below.

	Current Status (10/88–6/89)		Expected Status in 6 Months
Type of Review	Districts	FIMRs	Districts
No Reviews	6	0	2
Vital Statistics Only	3	all	3
Health Department Record Only	4	89	3
Full Review	2	9	7
Home Interview	4	39	5

Six districts are now actively using FIMRs. Four districts are in the process of implementing reviews. A total of 98 South Carolina fetal and infant deaths have been reviewed by a local area committee since October 1, 1988. This represents approximately 10 percent of the fetal and infant deaths that occurred during this time. As a result of these reviews, several local health department policies and procedures have already been revised or added to eliminate breakdowns in health care systems. The State has announced that it is committed to the FIMR process and that it plans to continue the process beyond the grant period, including support of the project administrator position.

Materials produced to date and contained in the *South Carolina Fetal and Infant Mortality Notebook* are:

1. *Fetal and Infant Mortality Review Grant Fact Sheet*;
2. *Fetal and Infant Mortality Review Handbook*;
3. *Confidentiality and Access To Records*;
4. FIMR Quarterly Reports;
5. *Guide to Using Quarterly Reports*;
6. Documentation for the Quarterly FIMR Reports Using EpiInfo Software;
7. Sample Summary Tools with State Provisional 1988 Percentages:
   a. Fetal Deaths—19__, _____Health District;
   b. Neonatal Deaths—19__, _____Health District;
   c. Postneonatal Deaths—19__, _____Health District; and
   d. Infant Deaths—19__, _____Health District;
8. Sample Record Abstraction Forms;
9. Medical Record Audit Form for Fetal and Infant "Never Discharged" Deaths;
10. Medical Record Audit Form for Infant "Post Discharge" Deaths;
11. Sample Home Interview Questionnaire for Fetal and Infant Deaths; and
12. Suggestions for Writing Local Area FIMR Protocols.

Infant Mortality Review to
Decrease Perinatal Mortality
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MCHIP
MCJ-496013
10/01/88-06/30/91
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PROBLEM: In the 1970s, Utah had the lowest infant mortality rate (IMR) in the United States. At one time, the State's IMR compared favorably to even that of the Scandinavian countries, which historically have had the best rates in the world. In recent years, however, Utah's decline in infant mortality has not kept pace with that of either the Scandinavian countries or other States. During the late 1970s, the State attempted to keep pace with programs such as the M & I Program, the newborn and maternal special care units at the University of Utah, and a high-risk transport system. Unfortunately, limited funds prevented the implementation of the State perinatal health care plan and a statewide system of public prenatal care. In February 1987, State funds were appropriated for prenatal care. In the summer of 1987, a statewide multidisciplinary committee was appointed to write a State perinatal health care plan. As part of the statewide needs assessment, the committee has proposed producing geographic, birthweight-specific infant/neonatal and fetal mortality tables, followed by mortality case review studies in sites with the highest perinatal mortality. The case reviews would enable the State to target specific contributing factors and to develop the quality assurance portion of the State perinatal health care plan.

GOALS AND OBJECTIVES: The goal of this project is to decrease perinatal mortality both statewide and in specific high perinatal mortality sites. The project will conduct perinatal case reviews in two urban and two rural/frontier high perinatal mortality sites. One hundred cases will be reviewed in each of the urban sites and 50 in each of the rural sites. At least one factor contributing to perinatal mortality will be identified at each site and targeted for action through the State Perinatal Health Care Plan, the State Title V agency, and/or the local health department. Two years after project completion, programs addressing contributing factors and a quality assurance plan of the State Perinatal Health Care Plan will be in place.

METHODOLOGY: To identify pockets of high perinatal mortality in Utah, birthweight-specific perinatal mortality tables by hospital in urban areas and by county or health district in rural/frontier areas will be calculated for three time periods, 1979–81, 1982–84, and 1985–87.

The State Perinatal Health Planning Committee will serve as an infant mortality review committee. The Rural Prenatal Care and Consultation Team will serve as the working case review committee. The working committee will be augmented by those State Perinatal Health Planning Committee members with expertise in case review and by key local officials. A registered nurse with perinatal health expertise will coordinate the reviews, which will occur over a 2-year period.

The project will use the descriptive format described in the Office of Maternal and Child Health's *Infant Mortality Review Manual*. Infants weighing less than 500 grams and infants born to out-of-state residents will not be included. Equal numbers of fetal and neonatal deaths will be reviewed. The study period will be from 1985 to 1987. The State Perinatal Health Planning Committee will target contributing factors for action in its written plan. The case review format will be maintained as part of the section on quality assurance. The State Title V program, the University of Utah, and the Intermountain Health Care Corporation will either develop programs to address the contributing factors or assist local communities and local health departments with such programs. By targeting programs to address contributing factors, the Utah project hopes to decrease low birthweight and perinatal mortality in the high mortality sites and statewide.

EVALUATION: Tracking activities include:

1. Reviewing all process objectives and making certain they are all complete, except the perinatal case review sites scheduled for year 2;
2. Repeating the demographic study and community resource evaluation in the two areas where the Perinatal Infant Mortality Case Review was completed, looking for any improvement in resources; and
3. Developing and implementing a questionnaire to determine how the case reviews were received by the two sites reviewed.

EXPERIENCE TO DATE: A registered nurse with experience in perinatal health in Region VIII and an M.P.H. degree has now been hired. The project has completed the 3-year, birthweight-specific mortality table for each urban hospital and each rural health district. The four case review sites have been selected. It is anticipated that audit forms and a confidentiality policy will be ready so that case reviews at the first rural site can begin and be completed by the end of the first grant year. It is further anticipated that information from the 3-year mortality tables will allow the State's Title V agency to target efforts toward the sites with high mortality rates in at least two of its current programs, the MCH funded prenatal clinic and the Prenatal Initiative/Baby Your Baby Program.

Meeting Proceedings: OMCH Infant Mortality Review Meeting

A Potpourri of Process Issues

Nancy Haliburton, R.N., M.A., Discussion Leader
Deputy Chief, Maternal and Infant Health Branch
Maternal and Child Health Bureau
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Utilization of the Infant Mortality Review Team

Nancy Haliburton began the session by reminding the participants of the differences in scope and function between the Infant Mortality Review (IMR) Team and the Case Review Work Group (CRWG) The IMR team is a larger group than the CRWG, and its responsibilities are to develop final recommendations and oversee implementation of those recommendations.

Several projects mentioned that because the IMR team is structured to include people who have the authority to implement the final recommendations and since these people usually have hectic schedules, it can be difficult to get IMR team members together for a meeting. Strategies that projects have found useful to alleviate this problem include: Sending members a meeting agenda and asking them to add topics they are interested in addressing; asking members to designate another person from their organization to attend if they themselves are not able to; sending case summaries to members before the meeting; and assigning team members responsibility for presenting a case to the whole group.

Projects have taken different approaches to presenting the collected data to the IMR team. The Connecticut project reported that the Case Review Work Group reviews the cases first, and that this group is responsible for ensuring that the case summaries presented to the IMR team are accurate. The CRWG spends about 15 to 20 minutes evaluating and summarizing each case. The next step is to assign each case to an IMR team member. That member is then responsible for presenting the case to the whole IMR team. The presenter receives all of the case materials, and the rest of the IMR team members receive a 2½-page case summary. This summary usually contains a one-page summary of the medical record and a 1½-page summary of the home interview. It is felt that if the summary was any longer, the IMR team members might not have the time to read it. Although project members feel that reading separate summaries of the medical record and home interview information may not be the best way to review a case, the information is presented this way because the IMR team members generally want to look first at the medical records and then review the home interview data for additional information. The other reason the Connecticut project separates the medical record and home interview information is to show how an opinion formed on the basis of the medical record may be changed by looking at the home interview data. At first, in order to avoid influencing the IMR team's decisions, the IMR team members were given the case information and allowed to draw their own conclusions. Project members may change this procedure, however, because they do not feel that the IMR team members work with the data often enough to be able to readily discern patterns. In the future, the preliminary conclusion of the Case Review Work Group may be presented to IMR team.

In South Carolina, the Case Review Work Group first reviews each case and decides which deaths were the most preventable (i.e., cases that indicate where changes, such as filling gaps in services, would be useful), and these cases are then presented to the IMR team. CRWGs in each of the nine participating health districts consist of two to four people who generally meet on a monthly basis. The IMR teams in each district usually meet every 6 months, although one meets quarterly.

In New York, individual cases have not been presented to the IMR team because the large number of cases make that approach impractical and providers responsible for the care of an individual case might be on the IMR team. Cases are instead, presented in clusters based on the topic (such as substance abuse) which is the focus of a particular meeting. The IMR team is presented with the number of cases in the topic-specific group which had particular factors (such as homelessness or teenage parenting) associated with it. The Case Review Work Group does, however, review each individual case.

The Utah project has not started its review yet, but anticipates that the cases will be readily known to the IMR team members. They feel therefore that it is important to stress to IMR team members that the infant mortality review will not just be a review of the quality of care, but will be an examination of gaps in service and other issues as well.

The Connecticut project reports that it has not had a problem with cases being known to the IMR team members because they work with three separate institutions, and case identification is difficult across institutions.

It was mentioned that one of the original reasons for the IMR team was to disseminate and implement the recommendations for change which the infant mortality review generates. It was stressed that it is critical for the IMR team to delineate specific recommendations, followup on their implementation, and evaluate the effectiveness of the implemented recommendations. Some felt that although the IMR team needs to take ownership of the recommendations and expand them, the recommendations may be generated largely by project members instead of the IMR team.

The difficulty some projects have had in getting the IMR team to recognize the broader, social implications of the infant mortality review was discussed. Some felt that if the IMR team were truly multidisciplinary, a broad range of issues would be addressed.

Changes made due to the infant mortality review were discussed. The point was made that it is difficult to identify every change brought about by the review, since IMR team members may change a policy or procedure at their own institution without necessarily informing the IMR team or project members The Connecticut project mentioned that it had recognized a need for educating women about preterm labor, and is currently looking into ways of doing so. The New York project said that as a result of its infant mortality review infant transport was being reviewed citywide, and that the bereavement committees in three institutions had been reinstated. The South Carolina project mentioned that the infant mortality review was useful in getting people to consider factors influencing infant mortality, such as gaps in service, which are outside the medical model.

Record Abstraction

The difficulty of obtaining records from private physicians was discussed. The New York project said that because it is associated with the New York City Health Department and sends letters to the physicians on Health Department letterhead, it may have fewer difficulties in obtaining records. Some physicians send copies of the records to the New York project in response to the letter, while others say they do not have the facilities to make copies but allow project members to come to their offices to examine the records. Record abstraction has also been made more difficult for the New York project by patients who used false names and/or Medicaid numbers, and by infants who have been treated in many different emergency rooms. It was mentioned that the latter problem could be ameliorated by using information from the home interview to help determine when and where the infant received care.

The Connecticut project observed that the thoroughness of the medical records varies from hospital to hospital, and it has have gotten better quality data from non-computerized systems than from computerized systems.

Standard prenatal care forms were discussed as a way to assure common data elements and to make data abstraction easier. It was reported that Louisiana has developed a standard prenatal care form for the state, and that the American College of Obstetricians and Gynecologists has just produced a standard prenatal care record as well.

Training of Abstractors

The South Carolina project's approach to training abstractors is to have a project staff member abstract sample records with personnel in each participating health district; it is a one-on-one, informal training process.

The Harvard University study reported that the training of abstractors was not formalized at first, but over the course of the project a formal, structured, 1½-day training program has been developed. The project has produced a videotape of one of these training sessions, and is putting together a second training videotape.

AIDS

The New York project wondered how others were dealing with HIV data. They report that although there is 100 percent anonymous newborn screening in New York State, it is not helpful to the project because the results are not available by case. They have therefore had to apply for a separate grant in order to determine the seroprevalence rate among fetal and infant deaths in New York City. They are finding a large disparity between the number of pediatric AIDS cases and the seroprevalence rate of newborns.

Locating Mothers

A participant asked what success the projects had in locating mothers. The New York project reported that before it tries to locate the mother, it first obtains all of the information possible about the case from the mother's prenatal care and delivery records and other medical sources. So far about half of the mothers have been located, and 10 percent of them have refused to be interviewed. The project has linked these women with case-management services, and it is hoped that this positive link may make them more willing to become part of the project.

The Parent Interview

Georgine Burke, Ph.D., Discussion Leader
Research Associate for Maternal and Child Health
Hispanic Health Council, Connecticut

Usefulness and Appropriateness of the Parent Interview

Georgine Burke began the discussion by asking participants what they expect to learn from the parent interview that cannot be learned from the medical records. She feels this is an important question since the home interview is expensive and labor intensive. Participants said that they felt the family interview could give them information that was missing on the medical forms (especially information on prenatal care); more information about substance abuse; insights into the social dimensions behind socioeconomic factors, such as level of education; information on ethnocultural considerations; and insights into family dynamics, the role of the father, and the economic situation of the woman and its bearing on prenatal care and health. It was also pointed out that the medical records frequently describe a patient as "non-compliant" or "difficult," and that the family interview allows the woman to present her interpretation of her interactions with health professionals, as well as to discuss other things that were going on in her life at that time that may have influenced her to behave in a "difficult" manner.

The issue of when the parent interview is and is not necessary was discussed. It was pointed out that most health agencies do not have the same personnel or financial resources that the grant projects have, and therefore it is critical to decide under what conditions the parent interview is required. It was suggested that the parent interview may not be an appropriate first step for a community that has little information about their infant mortality situation; it may be too detailed and specific a tool for an initial analysis. Once a general picture of infant mortality in the community is obtained from other data—such as medical records and vital statistics—a more focused analysis that includes parent interviews can be designed.

The Connecticut project said that in its case, the rationale for including the interview component was that Hartford had already been studied extensively, so there was a lot of aggregate data available. The project members felt that they had good information on infant mortality's precursors, and they wanted to examine these factors in greater depth. They feel that the parent interviews helped identify points for intervention in a very specific way.

It was felt that the projects which are using parent interviews have an obligation to check whether the overall project recommendations would have been different if only medical records had been examined.

It was proposed that focus groups might be a less expensive way to get the same kind of information that the parent interview provides. Participants reported on focus groups that had been conducted in the District of Columbia, Arkansas, and Boston which yielded valuable insights into women's perceptions of prenatal care and barriers to obtaining care.

Although many felt that a skillfully conducted focus group could be informative, it was mentioned that focus groups have some difficulties of their own, including the danger of sample bias and the need to provide supplemental services for participants, such as day care and transportation.

Structure of the Parent Interview

The question of whether or not it is appropriate to give incentives to parents who participate in the home interview was discussed. The Connecticut project reported that it had considered giving money to parents who agreed to be interviewed, but decided not to do this because of concern about how parents might feel about being paid to talk about their infant's death. The interviewer does bring a small gift, however, such as a flower arrangement. The Boston IMR Project said it had been decided to pay focus group members for their time, as it was felt that they were doing valuable work for the project.

The Connecticut project discussed the development of its parent interview instrume and then described the structure of the final interview form. The project members reported that they began by talking to women who had lost infants 1 to 2 years previously, and they refined their questions with each interview. It was learned that it is important to spend the first part of the interview trying to make the woman comfortable with talking to the researchers by inquiring after her well-being and asking her whether she had any mementos of her infant. It took approximately six months for the development of the instrument, which was then pre-tested on volunteers who were identified for the project by bereavement nurses.

In its final form, the Connecticut project reported, the interview is structured to allow the interviewer to spend the first part of the interview informally talking with the woman about the infant and the infant's death, without taking notes, to make the woman feel more comfortable talking to the interviewer. Then the interviewer asks the woman to talk about when she first found out that she was pregnant, and about her experience of the pregnancy, labor and delivery, and the infant's death. Next the woman is asked about lifestyle factors, stress, economic problems, and other events that may have been going on in her life at the time of the pregnancy or the infant's death. Substance abuse is asked about towards the end of the interview, in the hopes that some rapport has been established with the woman which will increase the likelihood of obtaining accurate answers. This two-part approach—an informal discussion followed by a more methodical questioning about the pregnancy, delivery, and infant's death—means that the woman may have to give the same information several times. The researchers stressed that it is important for the interviewers to make it clear that they are paying attention and have not forgotten the woman's previous comments, but that they just need to go over some of the information more than once.

There was some discussion about how to question a woman about the circumstances surrounding the death of her infant without causing or exacerbating feelings of guilt or self-blame about the death. Connecticut project members said that they do not believe that the interview causes the women to blame themselves. They reported making every effort to avoid causing self-blame, since the reason for interviewing the woman is to give her a chance to provide her perspective on the infant's death, not to assign blame. They feel that a lot of the women are ruminating over the cause of the infant's death anyway, and they report that many parents express confusion about the cause of death during the interview. The project has found this to be a difficult situation to deal with since the interviewer—who is not a medical professional—is not in a position to be able to provide information to the parents about the cause of the infant's death. In cases where project staff feel they could be of some help in alleviating concern (for instance, if a woman wrongly feels the death is a result of an amniocentesis), the interviewer will encourage the woman to call her physician to discuss it. However, because many of the mothers feel uncomfortable calling their physician, the project members do not feel that this is a satisfying solution.

The South Carolina project said that in its experience, the woman usually feels a tremendous need to talk about the death. It is felt that many of the women do not mind participating in the project because it gives some meaning to the infant's life: They may feel that their own infant did not die in vain if their participation in the project may help save another infant's life.

The Connecticut project stated that it also found that many women feel a need to talk about the death. The women were approached approximately 3 months after the infant's death, and many said it was a relief to be able to talk about the infant again, since their family and friends thought they should have recovered from the loss by that time.

The way in which the women were approached for the interview was discussed. The Connecticut project reported that it sends a letter to the woman introducing the project and emphasizing that the community wants to work on the infant mortality problem. Then the interviewer calls the woman, asking if she would rather be interviewed in her home or elsewhere, since many of the women do not like to be interviewed in their homes. The procedure is somewhat different if the mother is a minor, in order to protect her confidentiality: The interviewer goes directly to the home instead of sending a letter first, and parental permission must be obtained for the minor to participate in the project.

The South Carolina project reported that its first step in approaching the woman is to send the interviewer directly to the home, without any previous letters or phone calls. The interviewer tells the woman that they have some community resources to refer her to, and asks whether it is a good time to talk with her about them; if it is not, another time is scheduled. The communities with which the project is working are somewhat used to public health nurses and other health and social services personnel working in the neighborhood.

The question of audiotaping the interviews instead of or in addition to the interviewer writing the responses was discussed. Several of the projects felt that taping and transcribing would be too expensive and that the families would resent the taping of the interview.

Projects were asked whether they tried to interview other family members in addition to the mother. The South Carolina project replied that it only interviews the mother, since she is the one with the most information about the pregnancy and the infant. The Connecticut project members said that they would like to interview other family members, but that they do not have the resources to do so; they already spend approximately 10 hours on each completed case. They report that in some cases the father is around during the interview, but in other cases the mother asks that he not be present. It was pointed out that having another person present during the interview might influence the woman's answers.

The Interviewer

Connecticut project members stressed the importance of the interviewers to an infant mortality review's success. They reported that they put a great deal of effort into finding and including in the review women who are likely to be missed in survey studies, so it is important that these women not be put off by an inept interviewer. They feel that the most important thing about their interviewers is that they are from the community in which they are working; therefore, they understand the neighborhood and are linguistically and culturally compatible with the women they are interviewing. Because the format of the Connecticut project's interview is open-ended, the interviewer needs to understand the intent of each question because it may need rephrasing during the interview. Role-playing and practice interviews are part of the training process for interviewers. The project also reported that it is useful for the interviewer to talk to the project coordinator as soon as possible after the interview in order to alleviate any stress that may develop as a result of the interview.

It was asked whether any of the projects had considered a team visit to the homes by a nurse and a social worker. The Connecticut project replied that it had looked more for people with certain personal qualities than for people with degrees, and that a lot of their interviewers are non-professionals.

The New York project reported that its interviewers are professionals who are paid by the hour. The interviewers are public health nurses or others with a background of mental health experience, and some of them are moonlighting from their full-time jobs. Because of the dangerous neighborhoods in which they must work, an escort is sent with each interviewer. The interviewers take note of the environment during the interview, including who else is in the home at the time, and whether the woman seems inebriated. Often the interview is interrupted and the interviewer must return at a later time.

The Connecticut project said that its interviewers are also paid by the hour, in order to encourage time spent on case-finding, and that most of the interviewers have other jobs as well. The interviews can rarely be finished in one session, and so the interviewers must return to complete them at another time.

The projects were asked whether all of their interviewers were women. The Connecticut project and the New York project replied that all of their interviewers are women, although New York reported that the escorts they send with the interviewers are men. The South Carolina project said that they have one man at the present time, but that he may not end up doing any interviews.

The extent to which the interviewer should provide referrals and/or case management services to the families was discussed. The Connecticut project felt that the interviewers could offer some suggestions about referrals and sometimes do a little bit more than that, but that they should not become too involved in the case. It recognized that this is a difficult issue in selecting interviewers.

because interviewers must be empathetic and caring, but not become so involved in the case that they end up guiding the woman's responses. It is felt that since the interviewers come from these problem communities themselves, they may be used to walking that fine line between empathy and over-involvement.

The Boston IMR Project felt that it is possible for the interviewers to do some case management without becoming overly involved. It also reported that since the project staff are acting in their capacity as members of the health department, they have to find a way to combine the functions of interviewing and case management to a greater degree than would a private organization.

Confidentiality Issues

The projects were questioned about whether or not the interviewer knows the cause of the infant's death. The New York project reported that there was a long debate over this issue, but it was finally decided that the interviewer needed to know the cause of death in order to make appropriate referrals and meet other needs the family may have. Many project members argued against this policy, however, because of the potential for interviewer bias. The Connecticut project reported that its interviewers do know the cause of death from the death certificate.

Reporting of child abuse was also discussed. The New York project said that it states in the consent form that any evidence of child abuse and neglect will be reported. Because of the project's case-management backlog, however, they are able to do the assessment of such situations for the child welfare agency and it is possible sometimes for the child to stay with the family with their case-management team's supervision, so word gets around the neighborhood that the project is willing to work with people. The South Carolina project and the Connecticut project reported that they also are required to report evidence of child abuse or neglect.

Ethnic Differences in Concepts of Prenatal Care

The projects were asked whether they found that Hispanics in their study populations had different concepts than blacks or whites about what constitutes appropriate prenatal care. The New York project reported that the concept of prenatal care was different in the Hispanic population, that some Hispanics go to alternative providers, and that in the Bronx, for example, health professionals have trained these alternative providers in basic health information and referral procedures.

The Utah project reported that different concepts of prenatal care are also an issue among Native American populations.

The Connecticut project said that it was difficult to generalize about concepts of prenatal care among the Hispanic population, and pointed out that there is a lot of variation within ethnic groups by class and by level of acculturation. It was felt that there are a lot of barriers between providers and patients, including poor communication and differences in culture, social class, and language, and that although this problem is more common among Hispanics, it also occurs among other ethnic and racial groups.

It was pointed out that migration also affects concepts of prenatal care, because if a woman does not live near her relatives, the family member who may have traditionally been responsible for helping her learn about pregnancy and infant care may not be available to her.

Data Analysis and Utilization

Paul Wise, M.D., Discussion Leader
Senior Research Fellow, Division of Health Policy
Harvard Medical School

Paul Wise began by giving a description of his project's approach to infant mortality review and the model they are using, and then discussed how they are analyzing the data from their project, the use of the expert panel, and the interaction between different components of the infant mortality rate in Boston in the 1970s and 1980s. The following is a summary of Dr. Wise's presentation.

Description of the Model

We feel that infant mortality reviews are hampered by the fact that epidemiology per se does not relate very well to policy. It has been my experience that the end result of many infant mortality reviews is a huge 55 by 55 table, which is hard to interpret. Also, analyses may have interesting, credible findings, but these findings may not necessarily be relevant to policy concerns. What we have tried to do in our project is create a disciplined framework for analysis of infant mortality, and to make the analysis policy-driven. We were interested in the issue of disparity, because maternal and child health policy so frequently deals with disparities—between black and white, rich and poor, one time period and another. Specifically, we wanted to get beyond simple documentation and come to a greater understanding of these disparities.

In our view, the graph of the infant mortality rate for blacks and whites in the United States over the last 20 years holds many clues as to how we should be approaching the analytic process of looking at infant mortality data. Both black and white infant mortality rates have gone down enormously in the last 20 years; nevertheless, the disparity between the black and white rates persists. This implies that the causation of the decline is inherently different than the causation of the disparity; in other words, that the factors that drive the rates down may be inherently different than the factors that drive them apart. Therefore, if you are interested in the causation of the disparity, you will have to address it directly.

How do we address disparity? Consider the following example:

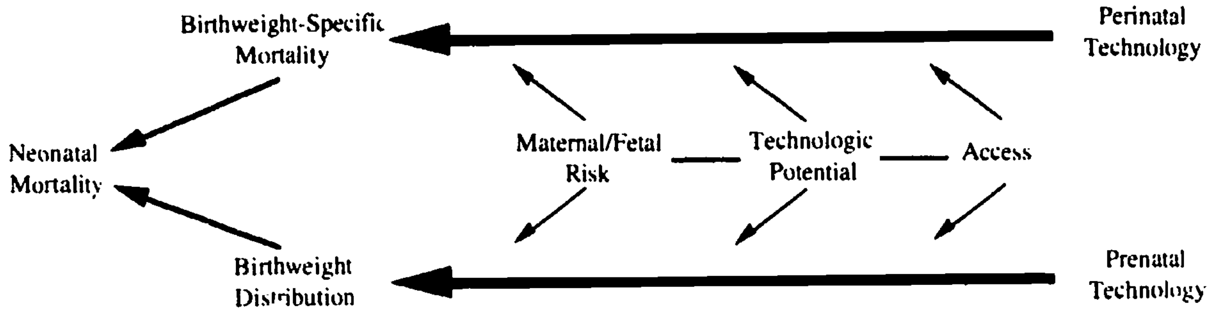
Group	Number Exposed	Mortality Rate
I	97	3%
II	129	27%
III	147	49%

Here we have similar exposure, but disparate outcomes. Why? There could be differences in underlying risk status, i.e., Groups I, II, and III could be different age groups. Or, the risk could be the same, but there could be differences in who got effective intervention. In my view the only mechanisms by which disparity in mortality rates can occur is through differences in risk status or in access to effective intervention, or both. There is not another alternative. The example cited above shows the death rates of women on the Titanic, by passenger class. This is a case of differential access to an effective intervention—the life boats were loaded by deck, i.e., by social class.

How does this example apply to infant mortality? We will start with neonatal mortality. First, we break the neonatal mortality rate into its two components, birthweight-specific mortality (BWSM) and birthweight distribution (BWD). This is pretty much a straight epidemiological approach. The test for us is to transform this epidemiology in a way that relates it to policy.

Empirically, interventions that relate to BWSM tend to be clustered around perinatal interventions or technologies, particularly neonatal intensive care and obstetrical management of high-risk labor and delivery (see figure 1). The word ***technologies*** is used here in the broadest sense of the word to signify not just machines or medical technology but all forms of intervention.

Figure 1. Neonatal Mortality Model



Interventions that relate to BWD tend to be prenatal interventions. Again, the word *intervention* is used in a broad sense to mean social intervention, social support programs, the Special Supplemental Food Program for Women, Infants, and Children (WIC), etc., as well as general medical forms of prenatal care.

But if the relationship between perinatal interventions and BWSM, and prenatal interventions and BWD, were uniform for all social groups, you would not have any disparity in BWSM and BWD and ultimately in neonatal mortality. But we know that there in fact are enormous disparities, and that implies that these relationships are modulated such that we get disparities in BWSM and BWD that ultimately give us the documented differences in neonatal mortality rates.

What are the potential modulating forces? First, there may be differences between the populations that are being compared in maternal-fetal risk status. We know that differences in maternal-fetal risk status can affect BWD: Differences in maternal health status, including hypertension and diabetes; in demographic variables, like maternal age and parity; and in maternal behaviors, like smoking and drug use, can all cause differences in BWD.

This relationship is symmetric; there can be differences in maternal-fetal risk status that affect BWSM, but we are finding that the effect of risk status on BWSM is not powerful empirically. An example in which risk status can affect BWSM is when there are differences between the populations being compared in their predisposition for certain lethal congenital anomalies. Another example of risk status affecting BWSM is when populations have different patterns of carriage of pathogenic organisms like strep: Infants may be born with the same birthweights, but the ones that are exposed to the pathogenic organism are likely to have higher BWSM. Again, the relationship between maternal-fetal risk status and BWSM is not very powerful, but it does exist and we have to be careful about it.

The second potential force modulating the relationship between perinatal interventions and BWSM and between prenatal interventions and BWD is differences in access to these interventions. Clearly, differential access to prenatal interventions is a major contributor to differences in BWD.

Again, this relationship is symmetric, and differences in access to perinatal interventions can affect BWSM. This is manifested in regionalization for the most part: Regionalization of high-risk pregnancy, labor and delivery, and particularly regionalization of neonatal intensive care. Improved access to prenatal care is critical, but it is important to point out that access to perinatal interventions is also critical to differentiation in neonatal mortality between social groups. This is particularly important now because we are beginning to see the unraveling of regionalized neonatal care and high-risk obstetrical care based on ability to pay. Where that happens, it can have an enormous impact on disparity because 60 to 80 percent of the total decline in the neonatal mortality rate in the United States in the last 20 years has come about from improvements in BWSM. So even small social gradients in access to these perinatal interventions have potentially an enormous impact on creating disparities.

The efficacy of the interventions is another component to this model, and it links risk and access together in a policy analysis. We have termed the efficacy of the intervention its "technologic potential." This component is important because differential access to an intervention wholly without efficacy is not likely to result in disparities in outcome. This implies that efficacy has to play a role in the analysis. The way it generally works in a policy format is that when you have interventions with low efficacy, then differentials in maternal-fetal risk status are going to dominate differentials in outcome. When you have an intervention that is high in efficacy, differentials in access to that intervention are going to dominate disparities in outcome. So for different risks, and therefore for different interventions, the discussion moves back and forth between differential access and differential risk.

We see this interaction working itself out in policy debates. An example of such a debate is the response to advocates' pleas for improved access to prenatal care. Some opponents questioned the cost of improving access, but what was infuriating to the advocates was that some people began to question the efficacy of prenatal care. This questioning of the efficacy of prenatal care was perceived as the biggest threat, because what happens if you question the efficacy of prenatal care? The discussion is shifted away from access discussions, pleas for improved access are undermined, and a higher burden is put on differentials in maternal-fetal risk and maternal behaviors.

Another example of such a policy debate is in the field of AIDS prevention and treatment. When there was a perception that there was no effective intervention, the whole discussion was on defining risk groups and implementing risk reduction. Once there was a perception of an efficacious intervention, mainly AZT, then the discussion shifted and we began to talk about access to this intervention. People were caught extremely flat-footed on the access issue; nobody knew how the intervention was going to be paid for and there was no delivery system in place, because this shift happened so fast that people were not prepared for it.

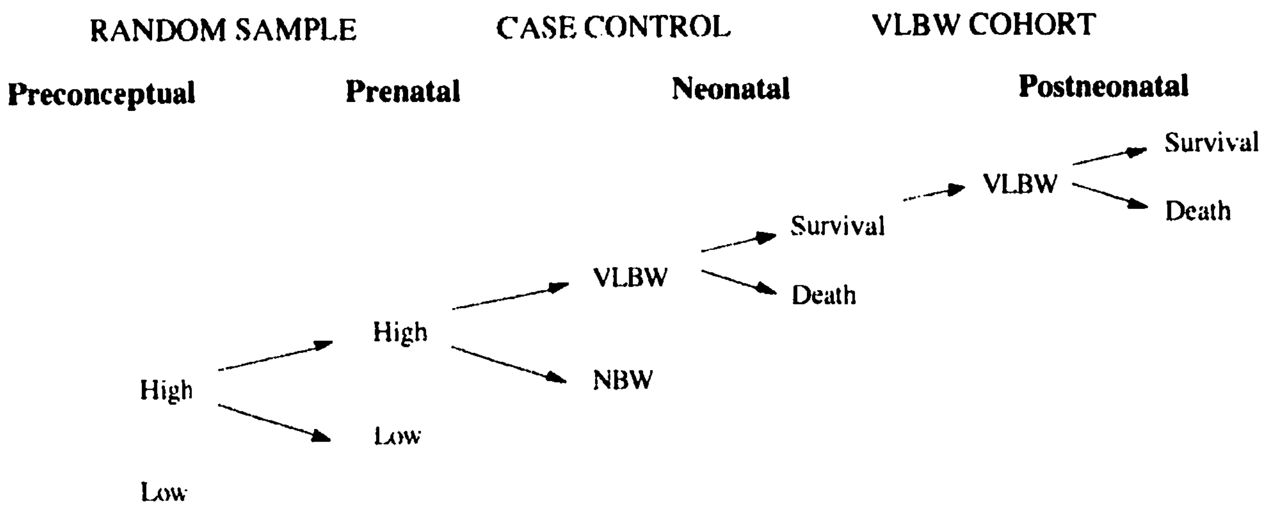
What this model suggests, then, is that there really are only four mechanisms by which disparities in neonatal mortality can occur. You can take this model and map the landscape of differentiation in neonatal mortality rates by examining these four arenas of interaction: Differences in access affecting BWSM, differences in access affecting BWD, differences in maternal-fetal risk affecting BWSM and differences in maternal-fetal risk affecting BWD.

Application of the Model to the Multistate Infant Mortality Review Project

We took this model of neonatal mortality and placed it as a template on the data we collected in our project. The Multistate Infant Mortality Review Project has five sites: The City of Boston, the State of Maine, the City of St. Louis, San Diego County, and two rural east-central health districts in Mississippi. At each of those sites we included all infant deaths, all very low birthweight (VLBW) survivors, and a random sample of all births (which will include a few VLBW births and a few infants who ultimately died, but in general becomes a group of controls). We did a medical record review at each of these sites of the hospital records of the mother and infant. This is a strictly hospital-based medical record review; there are no family interviews or interviews of hospital staff. The purpose here was not to do a study of infant mortality per se, but to gauge the utility of a medical record audit. We were really trying to see how far we could take, in a policy context, the use of hospital-based medical records, because we were interested in putting together a system of analysis that could be used by local health agencies that would not require a lot of money and a long period of time to complete.

We applied the model to the data in the following way. The first question we asked was: Are there differences in risk status between rich and poor in the preconceptual health of women (see figure 2)? We were quite interested in what women's health brings to the discussion of differential infant mortality. It is my strong feeling that policy tends to treat women like baby factories; we are only interested in their health once they are pregnant. In some real way the differential in infant mortality rates in this country is a legacy of the differentials in women's health status. So we begin with trying to document whether a woman's preconceptual health status is high or low risk.

Figure 2. Neonatal Mortality Template



The second question was: What is the prenatal risk status? Is the pregnancy high risk or low risk? And because we are interested in policy implications, we want to know if there is a social gradient to who is high risk and who is low risk.

The third question was: Given risk status in pregnancy, are there differences in pregnancy outcomes? For example, given that a group of women have high-risk pregnancies, is there a social gradient as to who has a good birth outcome and who has a bad birth outcome? A bad birth outcome might be, for example, VLBW or prematurity. Again, we want to know whether this social gradient in who has bad birth outcome and who has good birth outcome is mediated by social differences in utilization of care.

Fourth, given poor birth outcome—VLBW for example—some infants will die, and some will survive the neonatal period. The question was: Given that a group of infants are high-risk neonates, is there a social gradient to which ones live and which ones die, and if so, is this social gradient mediated by utilization? Here we are primarily talking about regionalized neonatal intensive care.

Fifth, for high-risk infants who survive the neonatal period, we wanted to know whether there is a social gradient to which infants live and which die in the postneonatal period, and whether that differentiation in survival is mediated by the utilization of care. That is where we ended, because we are only looking at infant death, but this process actually never ends until you do die. This process of risk differentiation and social stratification of risk-specific outcomes mediated by differences in utilization occurs forever. Although we artificially stop at 1 year, we know that we are seeing children die in the 2nd and 3rd year of life from the same kinds of social causation.

Use of the Expert Panel

How do you decide whether certain conditions are high risk or low risk, and how do you decide what constitutes high and low utilization? In our view, the purpose of the expert panel is to answer these questions. What an expert panel is asked to do, basically, is to answer the following questions for each case they review: First, is there an identified risk in this case, such as substance abuse, young maternal age, or hypertension? If there is a risk, was there much that could be done to ameliorate this risk? In other words, was the technologic potential high or low? Finally, if there was a risk and high technologic potential, did the woman get the appropriate intervention? This is the logic of preventability.

We had a choice in the use of our expert panel. We could have said we want an expert panel to go through all of these cases and differentiate along this cascade of risk, utilization, and outcome. But we felt strongly that expert panels have only limited utility. Our feeling is that expert panels are problematic because of the expense and the fact that it is hard to get them together, which implies that your membership from meeting to meeting is going to change; you may have some people there one time and other people there the next.

So we said we would not use the expert panel to go case by case. What we used the expert panel to do was to give us criteria that we could then use to address the data. In other words, we did not ask them to review 50 records; we asked them to tell us which of the conditions which we may find in the medical records are high risk and which are low risk. For example, is maternal diabetes high risk or low risk? Is maternal age of 19 high risk or low risk? Is hypertension high risk or low risk? Secondly, we asked them to tell us whether, given a certain high-risk condition, there was an effective intervention available to deal with it, and if so, what that intervention is. For example, is substance abuse high risk? The answer is yes. Is there any effective intervention? This causes some discussion. What about severe obesity or smoking? The medical community was not clear that there are effective interventions for these risks. So there was conflict and discussion, but ultimately these questions were resolved. Then we tracked what sentinel utilization markers there are likely to be in the medical record that can help us to determine whether the person got the intervention or not.

There are, of course, problems that arise in asking an expert panel to do this. However, this is exactly what you are asking them to do in going through each case. All we are doing is making the process explicit. You may not like the fact that we classified smoking less than a pack of cigarettes a day as low risk, but at least you know that is how it was classified; it is explicitly stated, not hidden in the proceedings of the expert panel. There is no reason that you cannot change the risk criteria in your own study if you do not agree with ours.

Another advantage of making the risk classification this explicit is that it makes comparisons of infant mortality reviews possible from place to place and from time to time, because the exact criteria that were used is known. This method also allows you to create and examine different scenarios by changing the criteria.

Although the expert panel is not a good way, in our view, to analyze data, it does have an important role in bringing about improvements in policy and public health. It is an activist role, rather than an analytic one. For instance, the expert panel may be one of the few mechanisms for bringing public health, community-based workers together in the same room with clinicians so that they can talk about issues common to both of them. Particularly in the urban areas, there seems to be a schizophrenia between the clinical and public health worlds, and it happens most where the clinical and the public health communities are strong.

Our view is that you need a layered approach, and that the role of an expert panel should be defined by the larger context of infant mortality reduction. But in terms of data collection, the expert panel is often best used in the presence of population-based data that will provide a population-based map of the landscape of infant mortality; the expert panel then becomes a place to refine our understanding of the data and more importantly to provide communication and active response to what the data are telling us. We use this kind of stratification model to pick and choose what type of cases to focus on. For example, the mayor of Boston is interested in the high, high, lows: High risk, high technologic potential, but low utilization cases. That is where policy is affected, and where legislators are most concerned.

Interaction Between Different Components of the Infant Mortality Rate

The interaction between the different components of the infant mortality rate and how that interaction can affect the overall infant mortality rate is illustrated by what happened in Boston in the 1970s and 1980s, but we think it has been happening in a lot of other places as well.

In examining the increase in the infant mortality rate in Boston in the 1980s, we find that what caused this increase was an increase in the VLBW birth rate, an increase in the mortality rate of normal weight infants, and an increase in the postneonatal mortality rate; the VLBW mortality rate, however, stayed about the same. What is worrisome is that the three components that increased are precisely those components of the infant mortality rate that are most heavily tied to social class. What is not generally related to social class is the VLBW mortality rate. The mortality rate of VLBW infants is not generally affected by income as long as income does not determine whether the infant is in a Neonatal Intensive Care Unit or not, and in Boston, basically every infant is born at a tertiary hospital.

When we examine the Boston infant mortality rate in the 1970s, we find that the mortality rate of VLBW babies was dropping very fast, but then began to stabilize in the 1980s. What had happened was that the three components more closely tied to social class (VLBW birth rate, normal birthweight mortality rate, and postneonatal mortality rate) had gone up at different points in the 1970s, but they were overwhelmed by the massive improvements in the VLBW mortality rate. Then in the 1980s, the relative stabilization of the VLBW mortality rate allowed a fuller expression of the other three components. What we then began to see was a more volatile infant mortality rate, and one that was more closely tied to social class effects.

This analysis of the components of the infant mortality rate illustrates how there can be deterioration in the social position of women and children at the same time the infant mortality rate is improving. Even now, most places in the country are still on the steep slope of sharply decreasing VLBW mortality rates because they are still heavily regionalizing. But the places that have had increases in the infant mortality rate as well as a more volatile rate, particularly in the mid-1980s, are precisely those areas that are heavily regionalized and have been heavily regionalized for a long time. The places that are most heavily regionalized are precisely the places you would expect to have problems show up in the infant mortality rate because their VLBW mortality rate reductions will be stabilizing, thus allowing the other three components of the infant mortality rate fuller expression.

The following is a summary of the discussion that followed Dr. Wise's presentation.

The way in which socioeconomic status (SES) fits into the model was discussed. Dr. Wise felt that any model that puts SES in a particular box is incorrect, and the reason he does not identify it specifically in his model is because he feels that it comes into play everywhere—it is the third dimension of the model as a whole.

When asked whether fetal mortality was addressed in this project, Dr. Wise replied that they did not look at fetal deaths, but that component could be added to the basic model by inserting fetal death as an intermediate poor outcome. In other words, the question to be asked would be: Given risk status in pregnancy, is there a social gradient to fetal mortality, and is that social gradient in fetal mortality mediated by differences in utilization of care?

It was pointed out that because of the degree of artifact inherent in obstetrical practices—in deciding whether or not to induce delivery in certain circumstances, for examp. -it would be better to look at perinatal instead of neonatal deaths. Dr. Wise agreed that it is better to look at perinatal deaths, and said that they will be able to do this for some sites, but for other sites it was not possible to get the information needed for such an analysis.

When asked whether the data were treated continuously or dichotomously, Dr. Wise replied that the data were treated dichotomously, and that risk status was divided into three categories: High, moderate, and low. He feels that for policy analysis, however, two categories would really be sufficient, since the functional differences in a policy analysis between high and moderate risks, or between moderate and low risks, are not very large.

The way in which the interaction between risk and access was dealt with was discussed by using the example of a woman who is a cocaine user. The first question to be answered, Dr. Wise explained, is: Is this a high risk condition? The answer is yes. Next, is there an intervention that exists to treat this condition; i.e., is there a high technologic potential? Again, the answer is yes. The final step is to determine whether or not the woman got this intervention. If the answer is no, the woman is classified as a low utilizer. This woman is, therefore, an example of a high risk, high technologic potential, but low utilization case.

The question of missing data was brought up. Dr. Wise reported that overall, 5 percent of the records were never found and another 5 percent of the records were so poor that they had to be thrown out. He pointed out, however, that the proportion of missing data was different for different groups; a woman with a lot of medical problems at 28 weeks, for example, is likely to have a much better record of her preconceptual and prenatal health. The proportion of missing data also varied from site to site.

It was asked whether a diabetic with tight control would be considered high risk. Dr. Wise replied that such a case would be classified as high risk, high technologic potential, and high utilization, whereas a diabetic with no control would be classified as high risk, high technologic potential, and low utilization. In the first case, the risk is being modulated by utilization. The question is: Is there a social gradient to who is a high utilizer and who is a low utilizer?

It was asked whether there were expert panels at each of the five sites. Dr. Wise reported that there is only one expert panel for the project, so that comparison of the sites would be possible, but that each site has its own advisory committee which is responsible for the generation and implementation of recommendations for that area.

Institutionalizing Infant Mortality Review

Karla Damus, Ph.D., Discussion Leader
Director of Research and Epidemiology
Bureau of Maternal Services and Family Planning
New York City Department of Health

Karla Damus began by describing her experience with institutionalizing infant mortality review in her project, and then outlined several factors she considers important to the process of institutionalization. The following is a summary of Dr. Damus's presentation.

Because I am director of epidemiological research in the maternal bureau of the New York City Health Department, one of my responsibilities is infant and maternal death review for New York City. When we were awarded the grant for this project, we had already identified some regions of the city in which we wanted to intensify the infant mortality review process. We decided to have one level of analysis overall, with more intensified levels of analysis in those areas where our extant data indicated we should be focusing our attention.

We set up a process in which we look at our 30 health districts and we project what we expect the number of deaths to be each month; then, once we get the vital statistics for each month, we compare expected with actual numbers of deaths. We then proceed to act in the districts we find to have an unacceptable variation from the expected number of deaths. We have made different ranges acceptable for different parts of the city, because there might be other issues that would make us want to examine a particular area fairly soon, even though the actual number of deaths was not far from the expected.

In refining the infant mortality review process, we have identified a number of elements that are essential in institutionalizing infant mortality review. First, there must be leadership which believes that infant mortality review is important, and that it is important to look at the process of infant mortality review in a detailed way. This was key for us in New York City because people were already getting some data on infant mortality, so there was no initiative to look at it in a new way. It is important to either get leadership that emphasizes the review process, or be able to provide information to people that clearly establishes that there is a problem with the current situation, so that the status quo is no longer acceptable.

In addition to having the need for infant mortality review identified by people in leadership positions, there must be access to data bases. That requires, of course, a relationship with the local department of health and often the state department of health as well. There are also additional useful data bases that people rarely use, like the Medicaid data base, the WIC data base, and the hospital discharge data base.

These data bases are filled—like all extant data bases—with problems, yet it is incumbent on those who are starting an infant mortality review to examine these sources and determine what can be presented to the provider community, the advocate community, and the client community. This will generate tremendous interest in the issue. It is necessary to do whatever is possible to develop interest in wanting information, because then the difference between the information that is wanted and the information that is available becomes clear.

For example, I was the keynote speaker at the Central Labor Rehabilitation Council for New York City. In my address I discussed infant mortality in the context of the labor force, because that is what interests them. With statistics for the year 2000 from the Maternal and Child Health Bureau and the American Public Health Association, I talked to them about how children are becoming a smaller percentage of our population, but that they are 100 percent of our future, and that therefore we need to start now to help ensure their health and productivity. The interest that was generated was amazing. Requests have come into the health department suggesting different ways of looking at infant death for different parts of the city, and asking for information about how much preterm births cost the work force in New York City.

Another important way to create a need for data from the infant mortality review is to establish some sort of regular report, perhaps to the mayor's or the governor's office, on expected and actual numbers of infant deaths, or something similar. When people with authority get used to seeing this information, they will be sure that the necessary resources are allocated to continue to provide that information. It is very important to indicate on these reports that the funding source is a grant, so people will know that the reports are limited unless another funding source is made available.

Another method that helps us in an urban area is to analyze the distribution of deaths by institution. That way we know to target the institutions that have the greatest numbers, since they are likely to be the most interested in being involved. We do not go to the institutions and tell them that they have the largest numbers of deaths, but we start to talk to them about the problem in order to get them interested and involved. We do this by giving grand rounds, at which some clinicians for the first time really come to understand that someone actually uses the information from all of the birth and death certificates they fill out. It is really a learning experience, and it is important to speak to the residents, the nurses, the clerks, and the other people who fill out these mandated documents and forms. Once informed, the enthusiasm for fulfilling that responsibility increases, so obviously the data bases under review get better.

I always make sure that the institutions' administrators are involved; I always give a little pitch to the administration about how important this type of data is to them, and how much staff time it takes to collect all the data. We try to get them to realize that if they cooperate with us in setting up a system for collecting this data on an institutional level, it will benefit them by increasing their efficiency and the amount of information they can access. We start with small benefits, like electronic birth certificates and computerized labor and delivery logs at specific institutions, to try to get them involved.

Behind all this is the hope that we can inspire these places to have a standard, uniform record-keeping system. Because there will never be any mandated document that will have all the variables needed for a study, there will always be a need to have groups come in and do an external abstraction process. That is expensive, and if the goal is to institutionalize infant mortality review, the strategy from day one should be to set up a mechanism within these institutions so that they have a data base in which everyone can have as much confidence as in the data base set up by having an external team come in and review the records.

Our next step is to try to deal with the institutions' quality assurance and morbidity and mortality committees. These committees are natural places to start to organize interest in the infant mortality review process. Each committee usually has some mechanisms which will allow data that are collected for other purposes to be looked at in a slightly different way with respect to infant death review. It is useful to attend the meetings of these committees and present information that came from the confidential medical piece of the birth and death certificates. This can inspire interest in working with your project, and has really been successful for us.

It became key very early on for us to use some of our resources to provide incentives to institutions. For instance, at one institution we are using part of our support from the city—because we have a lot of in-kind positions on our grant that are paid for by the City of New York—to do tasks such as entering information from the labor and delivery log. This is helpful in many ways to the institution, and it was a small investment given the amount of excitement and involvement in the process which it generated. Otherwise we may have spent a lot more money and time trying to convince people to be part of the infant death review process. But by identifying a need in the institution that would eventually link with the review process, we were able to make the institution happy, and they in turn opened their doors to us, enabling us to spend less and achieve more. That is all part of this philosophy of institutionalizing the process: We realize we will never have the resources to go into each place and replicate it—we do not have 45 times our budget to do this at each institution—and therefore our goal has always been from day one to try to get people to buy into it.

Another element, in addition to getting the institutions involved, is the establishment of an advisory council on reproductive health issues. Depending on your local resources, this council could deal with a wide range of issues or be more focused. Infant mortality review would not necessarily have to be an area of focus initially, but as the council addresses reproductive health issues and maternal and child health, they will address infant mortality, because it is so central to these issues.

This gives you another level of leadership and expertise, and another group which will be demanding the kind of information infant mortality reviews can provide.

I think one of the objectives of this whole project was to try to promote institutionalization of the infant mortality review process. I did not think long enough about these issues in previous grants, so when the grant ended, I would be devastated by the inability to continue the work. So I have become very sensitive to the need to start the minute you get funding support to look for other sources that will be able, when the original funding ends, to pay for the components of the project which are found to be worthwhile. This also requires a strong commitment to evaluation from the beginning.

I would like to open the discussion up to get the thoughts and experiences of other projects.

The following is a summary of the discussion that followed Dr. Damus's presentation.

The question was raised about how to make a particular institution aware of missing or inadequate data in their records. Dr. Damus suggested approaching the issue in a larger context. For instance, if the hospital records on prenatal care are problematic, someone could go to the institution and give a presentation on prenatal care in the area. When the institution's staff see that much of the data on how much prenatal care women received is missing, it can be explained to them that if the records are not filled out properly, there will not be much data to analyze.

The Utah project reported that because Utah is still regionalizing, the tertiary centers were motivated to become involved in the project. Also, the Healthy Mothers, Healthy Babies advocates were important in building grass-roots interest.

The issue of institutional mortality rates and confidentiality was discussed. Dr. Damus reported that her procedure is to give each institution its own data, so that they feel they are getting something back from the project, but to make it clear to them that confidentiality is a major concern. She emphasizes to them that she is turning the data over to them and they are responsible for keeping their own statistics confidential.

Product Information

Product Title: Infant Mortality Review Home Interview Form **Grant #:** MCJ-186028

Description: (1990). This is a home interview questionnaire designed to obtain information about socioeconomic, behavioral, and demographic factors as well as information on utilization of services and risk status which is often unavailable, incomplete, or unreliable on health care records. Questions are designed to clarify provider input and circumstances surrounding a particular death. The form has 196 questions.

Producer:
Indiana State Board of Health, Bureau of Family Health Services, in cooperation with the Department of Pathology of the Indiana University School of Medicine and with Riley Hospital

Source:
Indiana State Board of Health
Bureau of Family Health Services
1330 West Michigan Street
Indianapolis, IN 46206
(317) 633-0844

Price: Contact source for price information.

Product Title: Infant Mortality Review Manual (draft) **Grant #:** N/A

Description: (1988). This 65-page manual provides guidance to professionals who wish to develop a case study approach to infant mortality review. In addition to discussing issues raised by the infant mortality review process, the manual outlines the procedure for preparing for and conducting an infant mortality review. Presentation of review findings and implementation of recommendations are discussed as well. Sample record abstraction and home interview forms are included.

Producer:
U.S. Department of Health and Human Services
Public Health Service
Health Resources and Services Administration
Maternal and Child Health Bureau

Source:
Maternal and Child Health Bureau
Parklawn Building, Room 9-31
5600 Fishers Lane
Rockville, MD 20857
(301) 443-5720

Price: No charge.

Product Title: Infant Mortality Review Parent Interview Form **Grant #:** MCJ-096011

Description: (1989). This 33-page parent interview form, designed to be administered to mothers, contains questions covering the health, lifestyle, and economic factors affecting the parents and their infant. Pregnancy, labor and delivery, and the postpartum period are covered, and questions on substance use and the mother's pregnancy history are included. The interview concludes with an assessment of whether the mother could benefit from participation in a support group. The interview form is available in both Spanish and English versions.

Producer:
Infant Mortality in Hartford:
A Community-Centered Review
Hispanic Health Council

Source:
Hispanic Health Council
Publications Department
96 Cedar Street, Suite 3A
Hartford, CT 06106
(203) 527-0856

Price: $5.00

Product Title: Infant Mortality Review Record Abstraction Forms **Grant #:** MCJ-186028

Description: (1990). This set of professional resource abstraction forms is designed to obtain information on fetal, neonatal, and postneonatal deaths in a complete and accurate manner. The five forms included in this set are: Office or Clinical Prenatal Records, Hospital or Delivery Records, Fetal and Newborn Deaths, Postneonatal Deaths, and Infant Mortality Case Review Death Summary.

Producer:
Indiana State Board of Health, Bureau of Family Health Services, in cooperation with the Department of Pathology of the Indiana University School of Medicine and with Riley Hospital

Source:
Indiana State Board of Health
Bureau of Family Health Services
1330 West Michigan Street
Indianapolis, IN 46206
(317) 633-0844

Price: Contact source for price information.

Product Title: Infant Mortality Review Slide Set **Grant #:** N/A

Description: (1988). This set of 40 slides and the accompanying text (29 pages) outline the case study approach to infant mortality review. The set provides the same information contained in the Infant Mortality Review Manual (draft).

Producer:
U.S. Department of Health and Human Services
Public Health Service
Health Resources and Services Administration
Maternal and Child Health Bureau

Source:
Maternal and Child Health Bureau
Parklawn Building, Room 9-31
5600 Fishers Lane
Rockville, MD 20857
(301) 443-5720

Price: Available for long-term loan at no charge.

Product Title: Perinatal and Infant Mortality Audits, Surveys, and Reviews: A Bibliography (Technical Report Series 89-05) **Grant #:** MCJ-009110

Description: (1989). This 8-page bibliography includes nearly 100 articles published between 1950 and 1989 which deal with perinatal and infant mortality audits, surveys, and reviews. This listing will be updated as new articles are identified for inclusion.

Producer:
HHS Region III Perinatal Consortium
Johns Hopkins University
School of Hygiene and Public Health
Department of Maternal and Child Health

Source:
HHS Region III Perinatal Consortium
Johns Hopkins University
School of Hygiene and Public Health
Department of Maternal and Child Health
624 North Broadway
Baltimore, MD 21205
(301) 455-3754

Price: Single copies available at no charge.

Product Title: South Carolina Fetal and Infant Mortality Review Notebook **Grant #:** MCJ-456010

Description: (1989). This 170-page manual outlines the procedure for establishing fetal and infant death reviews and provides guidelines and options for review design. Included are relevant South Carolina laws and policies on confidentiality, a guide to using quarterly computerized reports of birth and death certificate data, and sample medical abstraction and home interview forms. An outline for writing local area fetal and infant mortality review protocols is also provided.

Producer:
South Carolina Department of Health
and Environmental Control
Bureau of Maternal and Child Health

Source:
South Carolina Department of Health
and Environmental Control
Bureau of Maternal and Child Health
2600 Bull Street
Columbia, SC 29201
(803) 737-4190

Price: Single copies available at no charge.