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ABSTRACT In Part I, "Extent of Knowledge and Implications for Social Work Intervention," the following conference papers are presented: (1) "Unintended Pregnancy and Infant Mortality, Strategies and Interventions" (Alfred W. Brann, Jr.); (2) "Implications for Social Work Intervention in Biopsychosocial Factors Associated with Infant Mortality and Morbidity" (Frank B. Raymond, III); (3) "Social Work Program Efforts in Reducing Infant Mortality and Morbidity" (Gardenia B. Ruff); (4) "Theoretical Base for Social Work Intervention" (Kristine Siefert); (5) "Follow-Up of High-Risk Infants" (Eugene Perrotta); and (6) "High-Risk Infants and Child Maltreatment" (Dorothy C. Howze). Part II, "Cultural Barriers," consists of the following: (1) "Cultural Factors Associated with High-Risk Pregnancy Outcome: A Black Perspective" (Barbara S. Cambridge); (2) "Ethnic and Cultural Factors Associated with High-Risk Maternity Outcomes: A Hispanic (Mexican-American) Perspective" (Ricardo Arguijo Martinez); (3) "Ethnic and Cultural Factors Associated with High-Risk Maternity Outcomes in Southeast Asian Refugees" (Lucy Towbin); and (4) "Brief Overview of the Maternal and Child Health System, Oklahoma Area Indian Health Service" (Pamela Turner Hunt). "Care of the Handicapped Child in the Home" (M. Patricia West) and "Building Early Intervention Initiatives" (Anita Farel) are presented in Part III, "Handicapped Child." Part IV, "Bioethical Issues," consists of: (1) "The 'Baby Doe' Rule and the Care of Severely Handicapped Newborns: A Critique" (John C. Moskop); (2) "Bioethics Related to Maternal and Child Health: The Social Work Role in Technological Times" (Mary O. Holden); (3) "Parent's Rights vs. the Child's Rights for Care" (Dorothy Bon); and (4) "Critical Issues in Working with Terminally Ill Adolescents, Young Adults, and Their Families" (Patricia Wood Lavis). Part V, "Advocacy," consists of: (1) "Strategies and Organization for Advocacy" (Dana Hughes); (2) "Examples of Advocacy the State Level" (Doris J. Haar); (3) "Every Number Has a Name" dith K. Barber); and (4) "Healthy Children Initiative of Tennessee" (Lerlie M. Cleveland). (KM)

Infant Mortality, Morbidity, and Childhood Handicapping Conditions: Psychosocial Factors

Based on Proceedings of a Bi-Regional Conference

June 2-5, 1985

Sponsored By
The Department of Maternal and Child Health
School of Public Health
The University of North Carolina at Chapel Hill

and

Division of Maternal and Child Health
Bureau of Health Care Delivery and Assistance
Health Resources and Services Administration
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Foreword

This publication is dedicated to the fiftieth anniversary of the passage of the Social Security Act in 1935. Title V of the Act established, through grants to the States, the Maternal and Child Health and Crippled Children's Services to promote the health of mothers and children and provide comprehensive health care for handicapped children. Administered by the United States Children's Bureau at that time, Dr. Martha Eliot was appointed as its first director. She recognized the importance of social work services in dealing with social and emotional problems associated with issues in maternal and child health. Miss Edith Baker was appointed in 1935 as the Chief of Medical Social Services, thus establishing for the first time a specific administrative unit for a federal public health social work program. Under the subsequent leadership of Miss Virginia Insley and currently Mrs. Juanita Evans, the social work staff of the Division of Maternal and Child Health, (which currently administers Title V) have continuously given attention to the development of social work practice in public health.

The presentation of this Conference, "Infant Mortality, Morbidity, and Childhood Handicapping Conditions: Biopsychosocial Factors," for public health social workers in Regions IV and VI, is an example of the Division's interest in improving the knowledge and skills of social workers in public health. The inclusion of other disciplines among the participants illustrates the Division's concern that a multidisciplinary approach always be used in regard to intervention in maternal and child health problems.

We are grateful to the Division of Maternal and Child Health, Bureau of Health Care and Delivery Assistance, Health Resources and Services Administration, Department of Health and Human Services for the support of this conference through Grant MCJ009056. We appreciate the guidance and contribution of the Planning Committee to the success of the Conference. Particular gratitude is expressed to the Regional Social Work Consultants affiliated with the Division of Maternal and Child Health: Ethel Davenport in Region IV, Atlanta, Georgia and Stephen Finstein in Region VI, Dallas, Texas. Juanita Evans, Chief, Public Health Social Work, Division of Maternal and Child Health, was especially helpful with recommendations regarding organization of the Conference and speakers. Kathleen Bishop, Public Health Social Work Consultant in the Habilitative Services Branch, and Robert Arrindell, Social Work Consultant in the Genetic Services Branch, also contributed to the planning of the program. The expertise of the staff of the Office of Continuing Education, Division of Community Health Services, University of North Carolina School of Public Health, who participated in the planning of the Conference and in its implementation, was very valuable.

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Introduction

Betty C. Glasscock, M.S.S.W.
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Two major objectives of the Surgeon General's efforts in promoting health and preventing disease for the nation are to reduce, by 1990, the infant mortality rate to no more than nine deaths per 1,000 live births and to diminish the incidence of low birthweight babies to no more than 5% of all live births.[1] The association between poor socioeconomic conditions and emotional stress with the incidence of low birthweight and infant mortality has been documented.[2,3] Public health social workers, therefore, have a significant role to play in intervening in these socioeconomic factors and thereby contribute to the achievement of the Surgeon General's objectives.

In order to define the issues for public health social workers and other disciplines employed in Maternal and Child Health and related programs in Regions IV and VI, a conference was held June 2-5, 1985 in Atlanta, Georgia on the subject of "Infant Mortality, Morbidity, and Childhood Handicapping Conditions: Biopsychosocial Factors." It was the first of three annual conferences to be conducted by the Department of Maternal and Child Health, School of Public Health, University of North Carolina at Chapel Hill through a grant (MCJ009056) awarded by the Division of Maternal and Child Health, Bureau of Health Care and Delivery Assistance, Department of Health and Human Services. This first conference emphasized the biopsychosocial factors associated with infant mortality and morbidity. The second conference will focus on interventive strategies. The third conference will emphasize administration of social work programs in maternal and child health agencies. This Introduction summarizes the content presented at the first conference. Selected papers delivered at the conference are published in this volume.

It is important to conduct this series of conferences for public health personnel employed in the Southeastern and Southwestern parts of the United States. The 13 states which compose Regions IV and VI[4] have infant mortality rates higher than the national average which in 1980 was 12.6. In that same year the highest rate in the two regions was 17.0 in Mississippi. The differential rate by race was also higher than the national average rates of 11.0 for whites and 21.4 for blacks. The states which had the highest infant mortality rates for whites were North Carolina and Oklahoma with rates of 12.1. The highest rate for blacks was 23.7 in Mississippi.[5]

In 1983 the Southern Governors' Conference established a Southern Regional Task Force to develop a concerted effort to decrease the rates of low birthweight and infant mortality in these states. Dr. Alfred Brann, a member of the Task Force, gave the keynote address at the conference. He presented the problems of infant mortality and morbidity and made a series of observations relating to the Carter Health Center initiative. He discussed the inequality of access to medical care according to a woman's race, level of education, and income. The concept of distributive justice was introduced as a way to assure all women equal access to prenatal care and, thus, reduce the incidence of low birthweight and the rate of infant mortality.

The discussant, Dr. Frank B. Raymond, Dean of the University of South Carolina College of Social Work and Chairman of the Governor's Task Force on Perinatal Health, gave an overview of the low birthweight problem, the impact of block grants, the cuts in funding, and reduced services. He challenged public health social workers to return to their true heritage and advocate for the people whom they serve.

An example of a social work program in a state health department developing a plan to intervene in infant mortality and morbidity was presented by Gardenia Ruff from the South Carolina Department of Health and Environmental Control. The Division of Maternal and Child Health has applied the Health Analysis and Planning for Preventive Services (HAPPS) Management System developed by the Centers for Disease Control. Mrs. Ruff described the activities of the social work program in applying this model. These activities were described at two administrative levels (state and district/county) in the Maternal and Child Health and Crippled Children Services programs. They included: program planning and policy development, consultation, and direct services. The key factors in this five-year plan are the redirecting of social work services and the evaluation of those efforts in terms of psychosocial outcomes to determine effectiveness of services in reducing infant mortality and morbidity.

The discussant of Mrs. Ruff's paper, Kristine Siefert, directed attention to the relationship between social work and public health and the theoretical base for social work practice in public health settings. Siefert applied the classic causal model (interaction of host/agent and environment) to the problems of infant mortality and morbidity. The epidemiologic analysis was as follows: host-the vulnerable mother; agent-stressful life events and conditions; environment-social deprivation. In conclusion, she presented a provocative history of the contributions social work has made to public health, particularly in the field of maternal and child health.

Specific issues related to maternity and newborn care were explored further in workshops. Topics included: preconceptional intervention in family planning, prevention of low birthweight through maternity care, intervention in biopsychosocial factors affecting the premature newborn, follow-up of high-risk infants, and intervention through a statewide program in genetics.

Ethnic minority groups are at high risk for complications of pregnancy, primarily because a large proportion have low incomes and experience barriers to access to medical care. Differences in cultural values and health practices create distance between patients and health providers. A panel discussion described the health beliefs and the problems in securing medical care experienced by five ethnic groups, i.e. Black Americans, Hispanics, Haitians, Asian immigrants, and Native Americans.

Barbara Cambridge warned against the tendency of "lumpology," i.e., overgeneralization by health professionals when they consider the cultural values and attitudes of black American women. There are a multiplicity of values and attitudes and each woman should be considered as an individual.

She discussed three factors considered significant in influencing the black woman's attitudes toward the utilization of prenatal care: (1) significant others, (2) religion, and (3) stress-producing agents (stressors).

Ricardo A. Martinez shared insights into the Hispanic culture in health care. The health beliefs of the culture included the role of folk medicine and folk healing in the delivery of health care. The traditional role of the father as sole decision-maker and, thus, determiner of who and how health care is to be accessed and utilized is another important factor to be considered.

In describing the massive migration of the Haitian population into Florida during the last five to six years, Frances McGrath brought an acute awareness of the multiplicity of very complex problems encountered in providing services. The services of a tri-lingual paraprofessional has proved invaluable to their program at the Mailman Center. Lucy Towbin described her experiences as the supervisor of a Southeast Asian (Laos, Cambodia, Viet Nam) refugee resettlement program. She emphasized the need for recognizing the stress of resettling in a new country and the trauma experienced by many of the "boat people," e.g., women raped by pirates while enroute. The lack of traditional family support systems and the language and belief systems pose significant barriers.

Pamela Turner Hunt gave historical data on the Indian Health Service legislation as well as statistical data relating to current health care problems of 87 tribes. Alcohol and diabetes account for 95% of deaths, either directly or indirectly. Seventy percent of the population live below the poverty level, a major consideration in planning health care services.

High-risk infants are more likely to experience abuse by their families, probably because of the stress of the required special care and the infant's immature development delaying his ability to respond to parents' interaction as a normal baby would. Dr. Dorothy Howze described the research she and colleagues in the Department of Maternal and Child Health, University of North Carolina School of Public Health, are undertaking. They will follow infants enrolled in the North Carolina high-risk infant tracking system to determine the incidence of child abuse among this population. Using the ecological model, they will test the hypothesis that it is the degree to which the parent is able to cope with stress which determines whether he or she becomes abusive or not.

Very low birthweight infants are more likely to have handicapping conditions than those of normal weight. Advances in technology are enabling these children to be cared for at home. Children with genetic diseases, such as cystic fibrosis, are living to adulthood. Parents are in need of help in dealing with the problems of providing care to chronically ill children. Patricia West from the Colorado State Department of Health gave a presentation on the care of the handicapped child in the home. Her focus was on family-centered care for the chronically ill child, a more broad-based perspective. A new family assessment tool and a family "Bill of Rights" are being developed in a new project underway in Colorado. The assessment tool will facilitate the prioritizing of families who are in need of social work services. Ms. West emphasized the necessity of creating a balance between family needs and patient needs in developing psychosocial assessments and intervention plans.

A series of workshops on family-centered care of handicapped children followed Ms. West's speech. They considered the topics of developing community networks of services for families-at-risk, the contribution of parent support groups, care of the ventilator-dependent child at home, building early intervention initiatives, and collaboration of health and education services on behalf of handicapped children.

The ability of medical technology to keep alive seriously ill children with no potential for living outside a tertiary hospital has raised questions about the ethics of society prolonging such lives. Dr. John Moskop, a bioethicist, discussed the major bioethical issues of maternal and child health care, including the legal history of the "Baby Doe" case and the right of the parents to request that life supports be withdrawn from a seriously ill infant. He discussed other issues regarding prenatal diagnosis, abortion, and surrogate parenting. Mary Holden responded with the implications this had for social workers in counseling with parents.

Workshops permitted participants to discuss a range of ethical issues in detail. These included: parents' rights versus the child's rights for care, social work counseling regarding genetic abnormalities, ethical decisions for chronically ill children when professionals and parents disagree, and ethics and the terminally ill adolescent, as well as an opportunity to discuss the "Baby Doe" case in more detail.

The problems of high-risk pregnancies and chronically ill children require changes in the systems of health care delivery and the provision of supportive social welfare services in the United States. The concluding session of the conference contained a speech on "Strategies and Organization for Advocacy" by Dana Hughes of the Children's Defense Fund which described approaches social workers could use in bringing about improvements in these systems. Doris Haar from Louisiana described her efforts in getting clinics for children with spina bifida established throughout the state. The effort in Mississippi to secure state funding for payment of health care for low-income mothers and children who are not eligible for Medicaid was described by Judith Barber. Lerlie Cleveland presented the advocacy efforts of the people involved in the comprehensive child health program in Tennessee.

The content of this first conference presented the basic facts about the problem of low birthweight in the United States and two federal regions. Innovativeness and creativity were displayed in the description of programs developed to intervene in biopsychosocial factors associated with infant mortality and morbidity, and childhood handicapping conditions. Just as the low birthweight infant has had to survive long hospitalization, complex procedures and home care programs, so the public health social worker has had to survive budget cuts, limited service programs, and redirection of programs. The next conference in the series will be on "Social Work Interventions in Infant Mortality, Morbidity, and Childhood Handicapping Conditions." It will be held in Dallas, Texas, May 14-17, 1986. It will facilitate public health social workers being even more creative in new approaches to intervention.

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Part I

Extent of Knowledge and Implications for Social Work Intervention

Unintended Pregnancy and Infant Mortality, Strategies and Interventions

Alfred W. Brann, Jr., M.D.

Everyone in a society uses whatever perinatal health care system exists at least once in their life. One measure of the sophistication of any society has been the thoroughness and detail with which it understands and then deals with its reproductive health care needs. The goal for reproductive health should be that all pregnancies be intended and cared for so that the children and their parents experience a minimum mortality along with the lowest incidence of morbidity, including such things as cerebral palsy, mental retardation, or birth defects.

Currently, there exists a large and unacceptable gap between "what is" and "what could be" in infant mortality and unintended pregnancy. The problem can be described in three simple statements:

1. There are too many unintended pregnancies.
2. There are too many deaths to normal birthweight infants.
3. There are too many low birthweight infants being born.

This long-standing gap is an indication that our society has yet to deal effectively with what should be our greatest concern: our reproductive health and the raising of healthy children.

The gap exists at all levels of our society, but it is concentrated in women who have one or more of the following characteristics:

1. Women who are adolescent
2. Women who are black
3. Women who are educationally and/or economically disadvantaged

The medical knowledge and technology currently exists to significantly reduce this gap. Our nation needs to generate a public policy that clearly articulates the goal that every child born in the United States should be intended and as healthy as possible. From both a humanitarian and economic perspective, to achieve a reduction in the gap, not only must access to current medical technologies be improved but, as importantly, the underlying economic and social disadvantage of some of our citizens, particularly minorities and women, must be addressed.

The intimate interrelationship between high rates of infant mortality and unintended births and economic/social disadvantage is not a unique phenomenon to our country. It is a world-wide phenomenon. This latter problem lies within the larger area of what might be called distributive justice, an area which is clearly outside medical solutions for closing the gap. If the economic and social parts of the equation for closing the gap are not addressed, the use of the medical role in solving a broader social dilemma will simply become increasingly expensive. For example, the cost is approximately $15,000 for a surviving very low birthweight infant (an infant weighing less than 1500 grams or 3.5 pounds at birth) who could possibly have been prevented from having been born early by a more comprehensive reproductive health care policy for all citizens. The total cost of a full-term healthy infant (an infant weighing equal to or greater than 2500 grams or 5.5 pounds) would be only approximately $2100.

This paper will present portions of a report dealing with unintended pregnancy and infant mortality prepared for the Carter Center of Emory University by the World Health Organization's Collaborative Center for Perinatal Care and Health Service Research, a continuing collaborative effort between Emory University School of Medicine, the Department of Human Resources for the State of Georgia, and the Centers for Disease Control. In preparing the report for the Carter Center, the W.H.O. Collaborating Center was asked to complete five tasks. These were to:

1. Analyze current data describing the current incidence of infant mortality and unintended pregnancy, and its impact on society
2. Identify subpopulations who are at increased risk for experiencing adverse reproductive outcomes
3. Describe presently available interventions which are efficacious, if universally applied, in reducing infant mortality and unintended pregnancy
4. Make recommendations for closing the gap between "what is" and "what could be"

Data, on which most of this report is based, comes from reports from the Allen Guttmacher Institute, the 1980 mortality data of the National Center for Health Statistics, and data from matched birth/death certificate linkage from the states of California, Georgia, Massachusetts, Michigan, Missouri, New York, North Carolina, South Carolina, and Tennessee, representing a third of the births of the country.

Unintended Pregnancy

More than half (55%) of all pregnancies in the United States are unintended. An unintended pregnancy can be defined as either a mistimed pregnancy or an unwanted pregnancy. Four of every ten of our nation's young women become pregnant during their teen years, 80% of them unintentionally, when they should be completing high school and preparing for independent roles as adults. Early teenage childbearing usually terminates education, leaving the young woman unemployable and dependent on public welfare and public sources of medical care. Because of her age and lack of experience, she also lacks adequate parenting skills. The woman and her children are often confined to poverty for the rest of their lives with all the accompanying problems—preventable by prevention of untimely early pregnancy.

Women experiencing unintended births tend to have similar characteristics to women who experience an infant death. Hence, reductions in unintended births could lead to a reduction in the infant mortality rate.

Interventions

There presently exist interventions which, if applied more widely, could prevent each year 2.2 million unintended pregnancies (65% of the 3.3 million unintended pregnancies in 1980). Reductions in the number of unintended pregnancies could also lead to more than an 8% reduction in the infant mortality rate.

Assumption of personal responsibility and planning of their reproductive careers by both men and women are the basic tenets of a public policy to reduce unintended pregnancy.

Infant Mortality

The gap in infant mortality is caused primarily by two factors: (1) an excess of low birthweight infants and (2) an excess of postneonatal (one month to one year of age) deaths of normal birthweight infants.

The effect on infant mortality of excessive low birthweight and postneonatal mortality among babies of normal birthweight can be described as follows. White, non-adolescent upper-class women have the lowest infant mortality (6.0 deaths per 1000 live births) because they have low rates of both low birthweight and postneonatal mortality among normal birthweight babies.

Infants of black women are almost four times more likely to be of low birthweight than those in the "best" standard population (infants of white women 20 years of age or older, with 13 years or more education, and who sought early prenatal care). The increased risk is 1.3 for white infants. Adolescent and educationally disadvantaged women in both white and black populations are more likely to have low birthweight infants. These differences in the rate of low birthweight infants are indications of the socioeconomic gap that exists in our society.

The gap is largest in the postneonatal rate and is present for both white and black infants. Infants of white adolescent mothers are six times more likely to die in the postneonatal period than a "best" white standard population. The increased risk is eightfold for black infants of adolescent mothers. Substantial gaps in postneonatal mortality also exist for black and white infants born to nonadolescent women with 12 years or less of education. Black normal birthweight infants are six times more likely to die in the neonatal period, white infants 3.5 times more likely, than the "best" standard.

Interventions for Infant Mortalities

There presently exist interventions which if applied more widely could prevent each year:

- —50,000 low birthweight infants and 4,000 infant deaths associated with low birthweight

—7,500 postneonatal deaths between one month and one year of age (60% of the 13,000 postneonatal deaths in 1980)

Recommendations:

It is recommended that a public policy be generated to insure that the following attainable reductions be reached by the year 2000:

1. A reduction in unintended pregnancies by 65%
2. A reduction of the low birthweight rate by 20%
3. A reduction of postneonatal infant mortality by 60%

Current medical knowledge and technology could permit these reductions by the year 2000 if there is equal access to care, if there is appropriate utilization of care, and if there is assumption of personal responsibility and planning of reproductive careers by both men and women.

Leaders from many areas of our society, including public education, media, community groups, organized medicine, and government must make a concentrated effort if these achievable reductions are to be met. Specific interventions to accomplish the above recommendations are listed below.

1. Public education and information dissemination at the local level, i.e., schools, community groups, and churches to:
   - —Teach our children to plan their reproductive careers and to understand the benefits of delaying childbirth to the post teenage years
   - —Promote the value of prenatal care and parenting skills
2. Legislation to:
   - —Ensure access to family planning, prenatal care (including prenatal diagnosis) for all women
   - —Ensure access to acute and preventive care, including genetic diagnosis and counseling, for all infants
3. Accurate and timely information from the public health sector to monitor regional progress toward these goals
4. Creative strategies to:
   - —Prevent cost-containment efforts and threat of malpractice from limiting access to quality care
   - —Improve the standard of education and standard of living
   - —Provide incentives for women—especially young women—to assume active roles in those activities that make life in our society productive and rewarding
   - —Maintain access to abortion for women who desire to use it

This paper will close with two quotations which, when juxtaposed, seem very appropriate. One deals with the issue of data and the other with the issue of feelings. These quotes from two different times and two very different places are relevant to the issue discussed in this paper. The first, by H. G. Wells:

> Human history becomes more and more
> a race between education and catastrophe.

The second, by the Chilean poet Gabriela Mistral, a Nobel Laureate in literature:

> The child cannot wait. Many things we need
> can wait, but he cannot...To him we cannot
> say 'tomorrow,' his name is 'today.'

The medical knowledge and technology, created through our complex educational system, currently exists to meet the goals projected here by the year 2000.

Implications for Social Work Intervention in Biopsychosocial Factors Associated with Infant Mortality and Morbidity

Frank B. Raymond, III, D.S.W.

The high rates of infant morbidity and mortality experienced in this country, particularly in the South, demand that social workers explore ways they can contribute to the reduction of these problems. The United States has one of the highest rates of infant mortality among developed countries. Among all countries listed by the United Nations, the United States ranks 16th in terms of infant mortality rate. While the western and New England states tend to have lower rates than states in the South and East, no state has an infant mortality rate as low as that of Sweden or Japan.[1]

Given this country's poor standing relative to infant health, social workers can appropriately ask themselves what roles they can play in ameliorating the problems of infant morbidity and mortality. It is likely that infant morbidity and mortality rates can never be reduced significantly unless the associated biopsychosocial factors can be addressed. Social workers are uniquely qualified to deal with many of these biopsychosocial factors. In order for social workers to understand the roles they can perform, they must be knowledgeable of the believed etiology of infant morbidity and mortality. This knowledge of causes will focus attention upon those biopsychosocial variables which can, indeed, be influenced through social work.

Primary Causes of Infant Morbidity and Mortality

It is known that infant morbidity and mortality is directly associated with low birthweight. Low birthweight infants (those weighing less than 2,500 grams) are 40 times more likely to die before the age of one month and 20 times more likely to die before the age of one year. Two-thirds of all infants who die weighed less than 2,500 grams.[2] It is obvious from these data that if the rate of low birthweight can be reduced, a significant impact on the morbidity and mortality rates of infants can be made.

In addition to understanding the relationship between low birthweight and infant morbidity and mortality, the factors that are associated with low birthweight are known. This paper will review those factors.

First, black newborns are more than twice as likely as white infants to weigh less than 2,500 grams. In 1981 the race-specific low birthweight rates among live births in the United States were 12.5% for blacks and 5.7% for whites. These differences cannot be attributed directly to maternal age or education. Although twice as many black births are to teenagers, when black and white mothers are compared by age, blacks are at a higher risk of low birth rate in every age group. Also, although black mothers as a group have less education than whites, when blacks and whites are compared by education level blacks still have a higher risk of low birthweight. Other variables that have been studied have also failed to account for the differential between white and black birthweights. It appears from the research that the cumulative effects over time of black poverty and lower socioeconomic status have played a definite role in these racial differences.[3]

A second demographic factor associated with low birthweight is age. Teenage mothers and those over 35 years of age have higher rates of low birthweight than mothers in their twenties and early thirties. Young motherhood, however, does not appear an independent risk factor for low birthweight. Teenage mothers are also more likely to be black, of low socioeconomic status, smaller, less educated, and later reporting for prenatal care than other mothers.[4]

Third, socioeconomic status, when measured in terms of social class, income, education, or census tract, is associated with preterm delivery and intrauterine growth retardation. Again, there may be other associated factors such as smoking, low maternal weight gain, obstetric complications, and inadequate accessibility to prenatal care.[5]

Education is a fourth factor associated with low birthweight. Risks decline significantly among mothers with at least 12 years of education. This relationship exists regardless of maternal age and race. Since the educational attainment of mothers has increased during the past 10 to 15 years, while the gap in low birthweights among mothers of different levels of education has not closed, the poorly educated may be an increasingly high-risk group.[6]

A final demographic factor associated with low birthweight is the marital status of the mother. Women who are unmarried are consistently at higher risk of bearing low birthweight children than those who are married. Given the dramatic increase in childbearing among unmarried women in recent years, the significance of this risk factor is particularly noteworthy.[7]

In addition to the demographic variables associated with low birthweight there are known behavioral and environmental risks. For example, smoking is directly related to low birthweight. Smoking during pregnancy is associated with a reduction in birthweight ranging from 150 to 250 grams. This relationship has existed for at least 20 years, in spite of the "improvements" in cigarettes claimed by the tobacco manufacturers.[8]

Also, alcohol use has been shown to be associated with low birthweight. Pregnant women who drink heavily are at risk of delivering a baby with fetal alcohol syndrome, characterized by intrauterine growth retardation and other complications. Although the effect of moderate alcohol use is less clear, it does appear to be associated to some degree with fetal development to the extent that the Surgeon General of the United States has recommended that pregnant women do not drink alcoholic beverages.[9]

It is also known that maternal nutrition is directly associated with infant birthweight. Because maternal nutrition is associated with other variables such as socioeconomic status and education, it is difficult to assess the full impact of this factor. The research suggests, however, that inadequate nutrition before and during pregnancy reduces fetal weight gain, thus increasing the risk of intrauterine growth retardation.[10]

In addition to the demographic, behavioral, and environmental factors associated with low birthweight, there are, of course, medical and obstetric risks for low birthweight. These include hypertension/preeclampsia, diabetes, obstetric history of low birthweight, multiple pregnancies, and infections. While these factors are outside the scope of this paper they must also be addressed by the appropriate professionals in order for low birthweight rates and infant morbidity and mortality rates to be reduced.

Although the relationships between some of these biopsychosocial variables and low birthweight are not altogether clear, there is enough knowledge to enable one to reduce low birthweight rates through impacting these factors. It has been demonstrated that these rates can be improved through programs that address those demographic, environmental, and behavioral variables examined above. Yet, although society knows how to reduce the rates of low birthweight and, consequently, the rates of infant morbidity and mortality, evidence suggests that little progress has been made in this regard.

Changes in Infant Mortality Rates

While the data indicate that the United States has experienced a declining infant mortality rate during the last two decades, the rate of decline has now abruptly slowed and, in some areas, the trend appears to have reversed. In 1979 the U.S. Public Health Service established a national goal of nine infant deaths per 1,000 live births by the year 1990. In early 1984 a government official testified in Congress that the goal could be met, given the steady decline that has been experienced. In December of 1984, however, the same official, upon reviewing provisional data for 1983 and the first nine months of 1984, acknowledged that the rate of decline had slowed and that the goal would not be reached by 1990.[11] Research conducted by the Children's Defense Fund found that between 1981 and 1982, 20 states showed increased death rates for some or all infant populations. Furthermore, the data indicated that the gap between white and black infant mortality rates appeared to be widening.[12]

Recent federal policies may have exacerbated the problem of infant mortality for certain segments of our society. For example, because of recent cuts in the federal Aid to Families With Dependent Children (AFDC) program, states have been forced to limit mothers and children who can qualify for Medicaid. which is the largest federal health program for mothers and children. Federal cuts in Maternal and Child Health Block Grants have led states to reduce services offered in maternal and child health clinics or to reduce the number of people who are eligible for care. Additionally, the Childhood Immunizations Program has been underfunded in recent years.[13]

As a result of these federal initiatives, over two-thirds of the states have shown an increased precentage of women receiving late or no prenatal care, compared to 1981. For non-white women there has been an increase in the percentage receiving late or no prenatal care in over three-fourths of the states since 1981.[14] Furthermore, a number of states have shown increased death rates for some or all infant populations since 1981, undoubtedly a result of the reduction in AFDC funding and cutbacks in Medicaid.

If the present federal policies continue, the number of children living in poverty will continue to grow; the number of mothers and children receiving Medicaid benefits will steadily decrease; and more and more hospitals and physicians will refuse to treat poor women and children. This trend must be reversed. Humanitarian reasons demand a reversal. Moreover, practical arguments for the cost-effectiveness of providing adequate material and health care resources to mothers and their children justify the need for reversing this trend. For example, in a study done for the Office of Technology Assessment, Peter Budetti estimated the average cost of neonatal intensive care in 1978 to be $13,616 per patient, while the cost of routine prenatal care was judged to be about $350 per patient. Calculations based on these figures reveal that a comprehensive prenatal program for all low income women would save the Federal Government $360 million per year in outlays for neonatal intensive care and rehospitalization of low birthweight babies.[15]

One positive action at the federal level was the 1984 passage by Congress of the Child Health Assurance Program (CHAP). This legislation requires all states to provide medical services to first time pregnant women living in families below the income level used to determine eligibility for the Aid to Families With Dependent Children program, including those in two-parent families. This will significantly increase the number of women eligible for Medicaid funding. Many more initiatives of this type are needed to turn back the recent deleterious policy developments affecting mothers and children.

Social Work Roles

There are a number of roles social workers can perform in reversing this trend through addressing those biopsychosocial factors which contribute to low birthweight, infant morbidity, and infant mortality. These roles are not necessarily new to the profession, but involve the directing of social workers' unique knowledge and skills towards the amelioration of these problems.

Several of the roles which social workers can perform involve advocacy, at both the macro and micro levels. At the macro level social workers must advocate for such things as a decent standard of living for everyone, adequate nutrition for all mothers and children, and sufficient medical coverage for all members of society. These advocacy efforts can be performed within agencies by social workers seeking the development and implementation of appropriate policies. Social workers can also advocate through formal organizations such as the National Association of Social Workers, perinatal associations, etc. Finally, social workers can lobby as individuals for legislation which is needed to respond to the health and welfare needs of mothers and children.

Social workers engaged in micro practice can also be involved in lobbying activities. The dichotomy which professionals sometimes believe exists between micro practice and macro practice is fallacious; any social worker engages in both types of practice at one time or another. Social workers who engage in direct practice can also advocate within their agencies for needed changes related to program scope, program focus, service accessibility, service continuity, program comprehensiveness, agency methodology, etc. Social workers in agencies providing either direct or indirect services to mothers and children need to be vigilant as to these issues.

Professionally trained social workers are equipped with the knowledge and skills to enable them to advocate at the community level for programs and services related to maternal and child health. For instance, social workers can use their professional skills to motivate, mobilize, and organize citizens groups for action. They can involve themselves in community social planning efforts to address unmet needs of mothers and children and to develop more comprehensive, interrelated services. They can challenge the community to ensure accessiblity of existing programs and to develop new programs where the need exists.

Those social workers who provide services to mothers and children have a responsibility to make certain that the program has an adequate public information component. For example, the agency should publicize the needs of healthy mothers and babies, the risk factors associated with low birthweight, the availability of programs and services for mothers and children, etc. Obviously this can be done through the news media or existing public information services within the agency.

In order to ensure effective and efficient perinatal programs, however, social workers in these agencies should go beyond pubic information efforts and engage in other outreach endeavors. High-risk groups should be identified. Attempts must be made to educate them as to their health care needs and to link them to appropriate services.

Another role of social workers in perinatal agencies involves the development and implementation of family planning services where possible. Research has shown that family planning does make a difference in reducing the rate of low birthweight and, consequently, the infant mortality rate. The decrease in the low birthweight rate results from a reduction of births to high-risk women, especially teenagers, an increase in the interval between births, and a reduction of unwanted pregnancies.[16] Unfortunately, many agencies serving women and children provide treatment or, at best, secondary prevention programs. Family planning is primary prevention at its best.

Social workers in any agency which provides services to women and children must also be vigilant in providing early identification and counseling to high-risk cases in their own case loads. Although social workers may know the high-risk factors to look for, under the pressure of providing other services they sometimes fail to identify those women who need special services. Certainly reducing the risk before conception offers more protection to the client than subsequent counseling. For example, social workers can educate women as to the importance of nutrition before and during pregnancy, the need for treatment of chronic illnesses such as hypertension and diabetes, and the importance of reducing smoking and alcohol consumption during pregnancy. In performing these roles social workers should, of course, work with other health care delivery professionals.

In providing services to women and children social workers must recognize the value of relating to the experiences, beliefs, and attitudes of women during pregnancy if they are to be successful in their service delivery. Social workers are uniquely trained to recognize the influence of cultural values and beliefs in all human behavior. Such values, beliefs, and prior experiences undoubtedly affect the health care practices of pregnant women, including their utilization of health care resources. Likewise, the fears, conflicts, and emotional problems experienced by expectant mothers influence both directly and indirectly their health care behaviors.

Social workers who provide services in perinatal agencies must also ensure the involvement of significant others in the services that are provided. Services directed at maternal and infant health enhancement are most successful when they include the mother's support system. These "significant others" may be the woman's spouse, boyfriend, mother, other relative, or friend. Often these others give erroneous, if well-meaning, advice to the mother, undoing the potential success of the social worker. It is crucial, therefore, that these persons be involved in both preventive and treatment programs.

Finally, social workers in agencies which provide services to women and children must ensure that mothers receive appropriate information on parenting. Such parenting information may include educating women as to the nutritional needs of mothers and children, emphasizing the importance of health clinic visits, and helping them learn to handle the stresses associated with motherhood. Parenting information should also include educating women regarding the behavior of newborns, emphasizing the importance of "baby-proofing" the house, and making mothers aware of other community resources such as day care.

Conclusion

The various roles that social workers can perform in responding to the problems of infant morbidity and mortality, ranging from advocacy efforts to direct services to clients, suggest that these problems are not just medical in nature but must be responded to from a broader perspective. Undoubtedly, the only way infant morbidity and mortality rates can be reduced significantly is through efforts directed toward the biopsychosocial factors. While tremendous progress has been made in medical technology to improve the health of women and children, too little has been achieved in the biopsychosocial areas.

Not only is it more effective to respond to the problems of infant morbidity and mortality through addressing the biopsychosocial factors, it is also more efficient. The medical technology we have developed to keep low birthweight infants alive has proven highly successful, but it is also terribly expensive. It is much more effective and less costly to provide preventive programs and services which address the nonmedical aspects of infant morbidity and mortality. To "medicalize" these problems, which are largely nonmedical in etiology, is a mistake.

This paper has demonstrated how social workers can be significant agents in responding to the biopsychosocial factors associated with infant morbidity and mortality. By virtue of their special professional training, social workers are uniquely qualified for these roles. If social workers make the commitment to carry out these roles, they will thereby make an important contribution to the amelioration of these problems which affect some of the most helpless members of society.

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Social Work Program Efforts in Reducing Infant Mortality and Morbidity

Gardenia B. Ruff, M.S.W.

Introduction

Infant mortality rates in both the United States and the South are excessively high despite the technological advances which have been made to address the problem. These advances have been based largely on a medical model and other strategies to improve prenatal, intrapartum, postpartum, and infant care. However, given the factors known to be associated with infant mortality and morbidity—socioeconomic status, age, education, nutrition, lack of access to care, etc.—it is obvious that infant mortality and morbidity are also influenced by social factors which must be considered in improving perinatal health.

We have seen a reduction in infant mortality rates but not to the extent desired. In 1982, the infant mortality rate in South Carolina was 16.1 deaths per 1,000 live births which was the highest in the nation.[1] In 1983, the infant mortality rate was 15.0 deaths per 1,000 live births, and we experienced a further decline in 1984 with an infant mortality rate of 14.7.[2] This decline in the infant mortality rates is encouraging; however, the fact that the rate has not declined as fast as expected has precipitated a closer examination of associated social risk factors by maternal and child health professionals and the development of preventive strategies within Maternal and Child Health programs to impact the health problems.

This paper will describe the efforts of public health social workers within the South Carolina Department of Health and Environmental Control to reduce infant morbidity and mortality in the state. This description does not include any specific project or research design. Social work activities at two administrative levels (state and district/county) in the Maternity, Child Health, and Crippled Children's programs will be described. These activities include: program planning and policy development, consultation, and direct services. The foci of social work efforts at all levels are an orientation to prevention and an orientation to populations.

Program Planning and Policy Development

Maternal and Child Health (MCH) programs have traditionally been unable to demonstrate clearly how the expenditure of funds and effort affect the health status of the MCH population. The South Carolina Department of Health and Environmental Control's MCH Program, until 1984, was a typical example of this problem. It had the ability to measure activity but recognized the inability to demonstrate how that activity affects the health status of the MCH population. The Program had excellent resources—personnel, funding, and statistical data compilation—though it lacked real, usable information, and the utilization of a logical method by which to target resources and bring about the greatest positive impact.

During 1983, the state social work consultants were involved in the Bureau of Maternal and Child Health's development of a State MCH Five Year Plan which outlined specific health outcome objectives to be achieved by 1990. The Plan was implemented July 1984 and is based on the Centers for Disease Control Health Analysis and Planning for Preventive Services (HAPPS) management system.[3] This system focuses on management as a process in which people, technology, and other resources are organized and directed toward the solution of a problem. This was a new planning process for the Maternity, Child Health, Crippled Children's, and Family Planning programs as the focus was on health status problems, rather than various program elements. The Bureau adapted and implemented the HAPPS model to address priority health status problems in the South Carolina Maternal and Child Health populations.

The MCH Five Year Plan includes six problem areas: perinatal mortality, readiness for first grade (health problems of preschool children), immunizations, school-age child (health problems), dental, and post-neonatal mortality. Each problem includes a five-year outcome objective, a three-year impact objective, and a one-year process objective with specific activities to achieve each stated objective.

The process required a careful problem analysis to establish the determinants and contributing factors to each of the identified health problems. The determinants are defined as the direct causes and/or risk factors which, based on scientific evidence, are thought to influence directly the level of a health problem. The contributing factors are defined as those factors that either directly or indirectly influence the level of a determinant. The implementation plan is a response to each of the three parts of the problem analysis: health problem, determinants, and contributing factors. The development of an appropriate intervention strategy leads to activities or a work plan which describes exactly how program resources will be utilized.

The state Five Year Plan became a blueprint from which local district plans were developed to achieve their "fair share" of the improvement of each health problem. In developing the Plan, an assessment was made relative to the availability of past, present, and future resources, i.e., funds, personnel, time, materials, and facilities. From this assessment, process objectives were defined as "expected" and "desired." The "expected" objectives were to be addressed by every district and the "desired" objectives were optional, based on available resources. The major task of the districts was to go through each problem analysis, assume responsibility for "expected" process objectives, and to develop the activities that were specific to the way they desired to reach the "expected" objectives.

The social work consultants' involvement in this process assured that this Plan would include a psychosocial perspective in addressing identified health problems of the MCH population. The MCH programs' use of the model also required that MCH social work activities become more focused to achieve the health status process objectives.

In essence, there was a need to direct social work resources within the programs more specifically toward the solution of the health problem. This process was initially met with some resistance by the local social work staff. It was perceived to be in conflict with our traditional delivery of social work services by focusing primarily on the psychosocial problems presented by various patients enrolled in the programs rather than focusing on program goals and objectives relative to specific population groups. However, staff were assured that the intent was not to compromise social work activities for program goals and objectives. This was an effort to provide for more sound planning of social work activities.

Recommendations for social work activities were developed relative to process objectives included in the Plan for three of the six problem areas (perinatal mortality, post-neonatal mortality, and readiness for first grade). The following provides examples of process objectives for perinatal mortality and social work activities:

Process Objectives	**Social Work Activity**
1. By June 30, 1985, 90% of the Special Supplemental Food Program for Women, Infants, and Children (WIC) prenatals will have an interconceptional period of one year.	100% of WIC prenatals served by Social Work will have had their post-partum contraceptive plans assessed relative to noted strengths/weaknesses during the social work intervention.
2. During Fiscal Year 1985, 95% of WIC prenatals will have their risk determined and a plan of care developed.	100% of high-risk maternity patients sponsored by the Department of Health and Environmental Control (DHEC) perinatal program will have a psychosocial assessment and a plan of care developed.

Consultation

We are all aware of the value of consultation in enlarging and extending social work services. Social work consultation is provided at both the state and local levels in all of the MCH programs. The social work consultants on the state level provide both program and professional consultation relative to addressing the social and emotional needs of specific population groups. At the local level, direct service social workers also provide consultation and education to other members of the health team and agencies involved in the patient's care.

In addition to providing consultation as described above, the Maternal Child Health Social Work Consultant on the state level, participates on a

Hospital Perinatal Capabilities Consultant Review Team. The purpose of this team is to assist in establishing a state perinatal network of regionalized care through a review of hospitals' perinatal capabilities. This is also an effort to decrease the number of infants born in hospitals with capabilities inappropriate to the mother's and infant's risk status. The lack of an organized regional system for perinatal care and inappropriate care provided at the delivery of the infant are determinants of infant mortality in South Carolina.

Hospitals across the state with delivery services greater than 500 deliveries are assessed relative to their obstetric, delivery, and newborn services. The team consists of an obstetrician, neonatologist, an obstetric and a neonatal care nurse, a social worker, and a hospital administrator. This is an external review team which includes consultants who are employed outside of the region of the hospital which is being reviewed.

In addition to a review of the medical services provided, the hospital's capabilities relative to addressing psychosocial aspects of care are also assessed. The Social Work Consultant assesses perinatal social work services as follows: (1) availability of hospital social work services to obstetric and newborn patients, (2) types of referrals to social work, (3) scope of social work service delivery, and other aspects of psychosocial care which promote social and emotional health.

During the reviews it has been noted that the hospitals usually have a very small social service department in which minimal social work services, if any, are provided to the perinatal patient population. Priority referrals to the social worker are usually non-existent. The Social Work Consultant addresses these issues through recommendations to increase social work availability, to establish priority groups for social work referrals, to increase the scope of services, and to provide coordination of services. An important aspect of the hospital social worker's role in providing services to perinatal patients is establishing linkages to health care and other community resources. The hospital social worker is in a unique position to facilitate linkages and patients' access to needed services especially since, in many instances, there may not have been any patient contact with health care providers prior to the hospital admission.

The Social Work Consultant's participation on the Perinatal Capabilities Consultant Review Team is viewed as an integral component in the state's development of the regionalized system of care and the promotion of appropriate social work services in reducing infant mortality and morbidity.

Another effort in which the Family Planning Program Social Work Consultant has been involved is the Preconceptional Intervention Project (PIP) which addresses health promotion prior to conception. In the perinatal problem analysis of the Five Year Plan, poor preconceptional health status, i.e., preconceptual maternal factors related to infant mortality, was defined as a determinant of perinatal mortality. The Project seeks to promote optimal preconceptional health status through risk screening to identify health conditions and other behaviors which should be changed or improved prior to pregnancy.

Other activities have included the development of "Guidelines for Maternal and Child Health Patient Referrals to Social Work" which includes MCH priority patient groups and psychosocial risk criteria. Priorities have been established according to risk categories relative to the amount of staff time available. The establishment of priority groups facilitates referrals and screening for individuals at special risk to permit early social work intervention.

Although the guidelines were developed at the state level, districts are encouraged to further refine criteria in terms of geographic and/or county specificity. In other words, within a district, there may be different criteria for each county based on the major social and emotional health problems of the population served.

Priority patient groups within the Maternity Program are: high-risk program maternity patients and teenagers, 17 and under. The priority groups in Child Health include: infants/children, ages 0-2 and infants/children of adolescent parents.

In the Crippled Children's Program, the social work psychosocial assessment was established as one of the three core services to be provided to each child as he or she enters the program. The other core services are the nursing assessment and the pediatric evaluation. As a core service, a standard was developed which states that each child in the program shall receive a comprehensive psychosocial assessment within 45 days of the initial clinic appointment and/or the initiation of service(s). The program's priority group relative to the above includes ages 0-6.

Direct Services

Social Workers at the district and county levels provide services within the parameters of state and district program plan(s), standards, and policies. Direct service activities include psychosocial assessments and an appropriate plan of care for all high-risk maternity patients; teenagers, 17 and under; and Crippled Children's Program patients, ages 0-6. Social workers also provide follow-up of patients discharged from newborn intensive care units and social work services to high priority infants. High priority infants are babies born with any one of six risk factors that are statistically associated with infant death. Several of the risk factors associated with early infant death are social factors—mothers under 18, single mothers, and mothers with low educational attainment. Coordination of care with both the health team and other community agencies is a strong component in social work service delivery.

Conclusion

The above social work activities do not reflect our total efforts in reducing perinatal health problems. These activities are highlighted to describe our efforts in redirecting social work services in the Maternal and Child Health programs. Our challenge now is to evaluate these efforts, not only in terms of health-problem outcomes but also in terms of psychosocial outcomes, to determine the effectiveness of our services in reducing infant mortality and morbidity.

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Theoretical Base for Social Work Intervention

Kristine Siefert Ph.D.

In her paper, "Social Work Program Efforts in Reducing Infant Morbidity and Mortality," Gardenia Ruff makes a number of important points that are useful to consider not only as they relate to the efforts of public health social workers to improve perinatal outcomes in the state of South Carolina, but also as they relate to the practice of public health social work in general. Ruff points out that despite technological advances in medicine, infant mortality rates in this country remain excessively high. She notes that the advances that have been made have been based on a medical model—that is, treatment after a problem occurs. She believes that if infant morbidity and mortality are to be prevented, there must be increased attention to the social factors which are known contributors. She describes a redirection of social work services at all levels of the state health department to focus on prevention and on populations at risk. The activities and, even more significantly, the orientation Ruff describes are central to and definitive of the practice of social work in public health. This paper examines the relationship between social work and public health, and the theoretical base for social work practice in public health settings.[1]

Social Work and Public Health

Social work, with its historical commitment to vulnerable and oppressed populations, its dual focus on person and situation, and its commitment to social action on behalf of the underserved, shares considerable common ground with public health.[2,3,4] Public health has been defined as "a social movement concerned with protecting and promoting the collective health of the community."[5] Public health's unique characteristic is organized community effort; problems are viewed from the community rather than the individual perspective. Public health uses data from epidemiologic studies to identify the need for preventive health services, to set priorities for the rational allocation of scarce resources, and to evaluate the effectiveness of preventive programs. Concepts from public health and epidemiology are useful for health care social workers in identifying populations at risk, in assessing the determinants of that risk, in setting appropriate goals and objectives, in selecting strategies for health promotion and prevention, and in evaluating the outcome of intervention.[6]

The agent-host-environment triad is a classic causal model used in public health to analyze the relationships that exist among the three factors that epidemiologists consider necessary for a disorder to occur: a susceptible host, a disorder stimulating or perpetuating agent, and the physical, biological, and social environment in which the agent and host interact. An unusually potent agent, a hostile environment, or a weakened host can upset the organism's balance from a state of equilibrium to one of disease. However, strengthening the host by general health promotion or by specific protective measures, eliminating the agent, or modifying the environment can prevent this from occurring. This model originated in the study of communicable disease, but, as Lilienfeld[7] notes, comparable relationships exist among noninfectious agents and host and environment. The epidemiologic triad is useful for public health social work practice because it sensitizes social workers to the concept of multiple causality and identifies risk factors that indicate increased vulnerability. This enables workers to provide outreach to populations in need of preventive intervention. In addition, it can be used in assessment to determine where intervention can and should be directed. The more elaborate complex models that have evolved in epidemiology are also important, but this classic approach is of immediate value in providing guidelines for public health social work practice.

To promote increased awareness of risk factors, each of the three components of the agent-host-environment triad should be examined. In public health social work practice, the disorder stimulating or perpetuating agent is often what is referred to as a stressor: a stressful life event or condition, such as a major loss, which can negatively affect the susceptible individual if that person is unsupported by the environment. Various stressful life events can upset the person's ecological balance from health to disease or disorder, depending on the magnitude of the stress and the resources the person has available to buffer its impact. Examples of such life events include divorce or separation, loss of a job, moving, and birth of a child.[8,9] Host factors can be viewed in terms of individuals at high risk because of certain personal attributes, such as infectious disease, nutritional deficiency, chronic illness, or biologic impairment due to genetic disorder.[10] Other host risk factors include maturational or developmental crises: pregnancy or parenthood, for example. Certain personality traits, such as impulsivity, can contribute to an individual's being "crisis-prone."[11] All of these factors increase host vulnerability and place the person at increased risk of a health problem. Public health social workers must anticipate vulnerability in such individuals. They constitute populations-at-risk, and preventive measures and general health promotion efforts should be undertaken to protect their health. In analyzing the environmental factors that promote or have a detrimental effect on health, the well-established relationships between health and economic status, social class, poverty, and racism should be examined.[12 13] Assessment of social support is critical in identifying high-risk individuals and must include assessment not only of the availability of social support but the individual's ability to make use of support and the support actually received.[14 15] Those who need support most may be the least able to make use of available resources; the public health social worker must promote appropriate utilization as well as access.

An example of the application of the agent-host-environment triad to the problem of infant mortality and morbidity illustrates the model's usefulness for public health social work practice.

Factors Associated with Infant Mortality and Morbidity

A number of maternal characteristics are associated with high risk of infant mortality and morbidity; Table 1 lists some major biopsychosocial risk factors. Certain diseases have a detrimental effect on pregnancy, and pregnancy in turn may exacerbate certain maternal conditions. Diabetes mellitus, gestational hypertensive disorders, and sickle-cell disease, for example, are associated with both increased risk of maternal mortality and morbidity and with a high perinatal death rate. Women with a history of reproductive failure or wastage are also at higher risk during subsequent pregnancies. Mothers who have had previous fetal deaths, low birthweight infants, or abortions have far less likelihood of producing an infant who survives than women with more favorable reproductive histories, regardless of age or birth order. Women who have given birth to an infant with a genetic, congenital, or familial disorder are at increased risk of poor pregnancy outcome.[16,17] Adolescent mothers and mothers over 35 years of age, mothers with short pregnancy intervals, and mothers who smoke or abuse drugs or alcohol during pregnancy are also at higher risk. Black mothers are at particularly high risk, for reasons which will be discussed below.

A number of studies have documented the critical role played by the social environment in determining infant mortality and morbidity. Poverty is a major risk factor; research has shown that social deprivation significantly increases the likelihood of low birthweight.[18,19,20,21] Infants of adolescent mothers are at higher risk of both neonatal and post-neonatal mortality, primarily due to low birthweight. A recent study examining the high mortality rates of infants of adolescent mothers suggests that young maternal age is a marker for low socioeconomic status.[22] In addition, investigation of post-neonatal deaths among adolescent mothers found that another contributor related to poverty and lack of education was the adolescent mother's failure to recognize the need for and subsequently use the level of medical care appropriate to her infant's condition.[23]

Many of the factors associated with low socioeconomic status are associated both with race and with preterm birth and low birthweight.[24] The incidence of low birthweight among blacks is twice as high as among whites, and, nationally, black mothers are three times more likely to be under 18 years of age than white mothers. Black mothers are almost seven times more likely than white mothers to be single at the time of the infant's birth. Young maternal age and social deprivation are strongly associated with low birthweight, and the high incidence of low birthweight among blacks is not surprising. High rates of out-of-wedlock births and a high percentage of female-headed families are characteristics of chronic poverty and, as noted above, social deprivation is not only a direct influence on infant mortality and morbidity, but a powerful impediment to access to health services, including preventive care. Moreover, minority status alone, independent of income, inhibits the utilization of preventive care, for segregation and discrimination can produce psychological as well as external barriers to access.[25]

In discussing the consistent association between out-of-wedlock birth and low birthweight and prematurity, Stubblefield[26] suggests that being married may be associated with greater social support and less stress. The effects of psychosocial stress on pregnancy are well-established. There is impressive evidence that psychosocial stressors, or agents, are associated with preterm birth. Some researchers believe that stress is the most important factor in increasing the risk of preterm labor.[27] Newton and his colleagues found, in a study of 132 women admitted to the hospital in spontaneous labor, that women who delivered preterm had experienced significantly more stressful life events during pregnancy. Greater numbers of stressors were associated with greater prematurity and, the lower the social class, the larger the number of major stressful life events. Social class was independent of psychosocial stress, however, and did not alone account for the higher incidence of prematurity.[28] It is likely that social deprivation induces stressful life events and conditions, and that stress then initiates the chain of events that culminates in prematurity.[29]

Psychosocial stress in the perinatal period has also been associated with an increased risk of parenting disorders, including child maltreatment and child homicide. Ten Bensel and Paxson[30] compared abused infants with a control group of infants who had not been abused during the three-year period following their discharge from a special care nursery. Length of hospitalization, maternal-infant separation, infrequent maternal visits, illness in the infant's first year, and maternal illness during pregnancy were studied. Postpartum separation of mother and infant and maternal illness during pregnancy were the only significant differences found between the abusing and control group mothers. This suggests that the stress of illness and separation from the baby following birth may cause or contribute to subsequent maltreatment. Studies of parents who commit neonaticide have consistently observed that the parents are young, predominantly single mothers, and non-psychotic; they are likely to have concealed the pregnancy and to have sought neither prenatal care or care at the time of delivery. Researchers concur that the newborn is killed primarily for social or economic reasons.[31] Neonaticide is the only type of child homicide with a higher rate of occurrence in rural areas; it is suggested that this may be due to the lack of availability or social disapproval of abortion.[32,33]

Figure 1 illustrates an epidemiologic analysis of the problem of infant morbidity and mortality. Using the agent-host-environment triad to analyze the multiple causes of poor pregnancy outcome, the public health social worker can identify major risk factors, assess the extent to which they can be eliminated or changed, and implement appropriate strategies—both short-term and long-range—of preventive intervention at the multiple levels indicated. To effectively address the determinants of infant mortality and, thus, accomplish primary prevention, the public health social worker must engage in the three levels of intervention described by Ruff[34]—program planning and policy development, consultation, and direct service—simultaneously.

Public Health and Social Work

It is clear that public health and epidemiology have much to contribute to the theoretical base for social work interventions. It should be kept in mind, however, that social work in turn has made, and continues to make, major contributions to public health.[35] The first prospective survey was undertaken by the social workers of the U.S. Children's Bureau. As Julia Lathrop described in a 1919 article in the *American Journal of Public Health*, women agents of the Bureau followed infants in eight cities and in several rural areas throughout the first year of life to identify factors associated with infant mortality. Lathrop[36] noted that "so far as the Bureau was aware, the method employed by the Bureau was new." Lathrop also emphasized that the social workers' investigations approached infant mortality as a social issue rather than as a medical problem. The foci of the studies undertaken by the Children's Bureau were the social, economic, civic, and family conditions which were correlated with higher or lower infant mortality rates.[37] The findings of these studies were used to establish the need for federally supported health services for mothers and children. Passage of the Maternity and Infancy Bill, as the legislation Lathrop proposed came to be called, became the first organized goal of women in the United States after obtaining the suffrage.[38] The Children's Bureau enlisted the support of the Women's Joint Congressional Committee, which coordinated lobbying activities for nearly two dozen national women's organizations. The lobby for the bill was described as one of the strongest ever seen in Washington.

The Maternity and Infancy Bill, which emphasized preventive care, was opposed by the American Medical Association as well as by a number of ultra conservative groups. The American Medical Association viewed the bill as an attempt at government control over medicine; the editor of the *Illinois Medical Journal* (1921) referred to the bill as a "menace" and the women of the Children's Bureau as "endocrine perverts" and "derailed menopausics."[39] Senator James Reed (D-Missouri), not only attacked the bill as radical and bolshevistic, but ridiculed the women of the Children's Bureau for being single. Speaking before Congress, he asked,

> Mr. President, when we employ female celibates to instruct mothers how to raise babies they have brought into the earth, do we not indulge in a rare bit of irony? I repeat, I cast no reflection on unmarried ladies. Perhaps some of them are too good to have husbands. But any woman who is too refined to have a husband should not undertake the care of another woman's baby when that other woman wants to take care of it herself. . .We would better reverse the proposition and provide for a committee of mothers to take charge of the old maids and teach them how to acquire a husband and have babies of their own.[40]

Despite such opposition, social workers continued their advocacy, and the Maternity and Infancy Bill became the Sheppard-Towner Act of 1921. Further efforts ultimately resulted in passage of the Title V amendments to the Social Security Act, which provided appropriations for programs to promote the health of mothers and children and prevent mental retardation and infant and maternal mortality. Social work has continued to be an integral force in the development and maintenance of maternal and child health as well as other public health programs. The multiple levels of intervention engaged in by our predecessors, based on methodologically rigorous research establishing the social determinants of health problems and the need for preventive health services to populations-at-risk, provide a useful model for the practice of public health social work today.

Table 1

Biopsychosocial Risk Factors Associated with Infant Mortality and Morbidity

1. Chronic illness
2. Infection
3. Nutritional deficiency
4. Previous reproductive failure or wastage
5. Short pregnancy intervals
6. Fifth or greater pregnancy
7. Previous Rh isoimmunization
8. Family history of hereditary disorder
9. Mental retardation
10. Psychiatric disorder
11. Drug or alcohol abuse
12. Heavy smoking
13. Maternal age under 18 or over 35
14. Poverty
15. Less than high school education
16. Member of oppressed or underserved minority group
17. Single mother
18. Accidental or unwanted pregnancy
19. Lack of experience in infant and child care
20. Social isolation
21. Stressful life events or conditions
22. Marital conflict
23. Family conflict
24. Previous history of child abuse or neglect

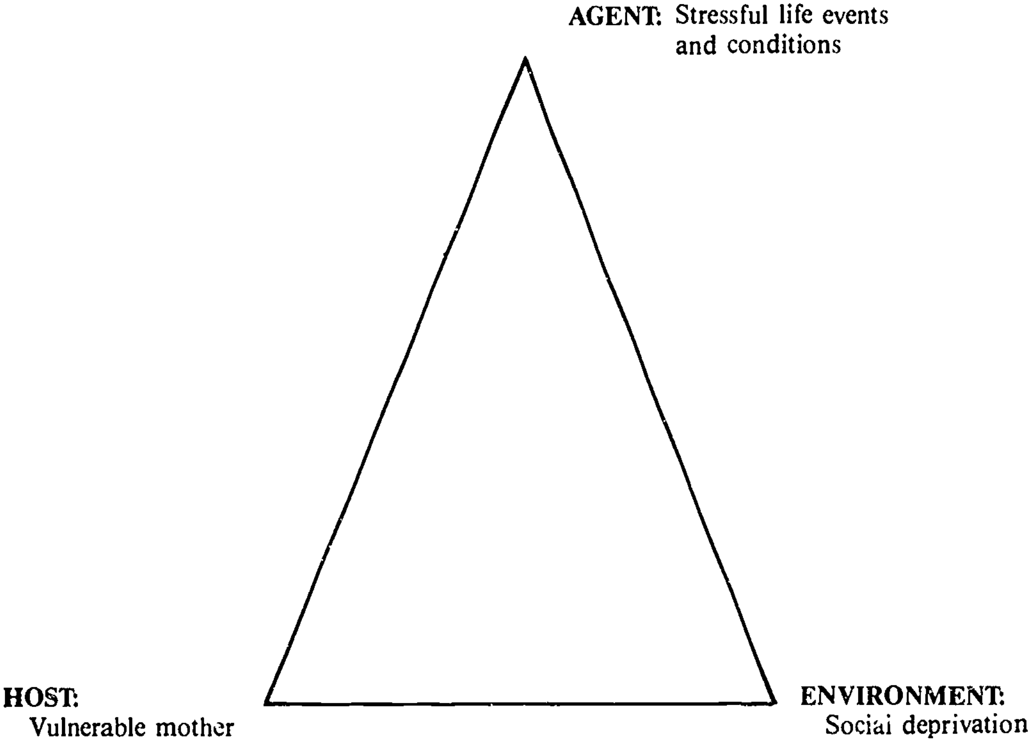

Figure 1: Epidemiologic Analysis of Infant Mortality and Morbidity

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Follow-Up of High-Risk Infants

Eugene Perrotta, M.S.W., M.Ed.

The importance of following vulnerable infants with high-risk conditions is well documented.[1] The extent to which social workers participate in following high-risk infants varies, depending upon a number of factors. Among other things, they must know which children and families are more likely to need assistance during the first three years of life. They must also have a defined approach to follow-up, the tools to facilitate the process, and the time and resources required to do an adequate job. Having a systematic follow-up program will facilitate optimal social work contributions to improving health outcomes among high-risk infants and their families.

The purpose of this presentation is to provide social workers a framework for following infants who are at-risk for disabling or maladaptive conditions. The conceptual approach to be presented is based on the work of Theodore D. Tjossem and Kathryn Barnard and will include some of their basic concepts and applied research. These concepts and the accompanying methods are applicable in community-based settings, such as local health departments and developmental evaluation programs, and, to a limited extent, in institutional settings such as hospitals. The presentation is based on the assumption that social workers have responsibility and competence to help detect infants who need close monitoring during the first three years of life and to determine the resources to meet the needs of infants and their families.

Tjossem suggests that high-risk conditions which have debilitating consequences for infants and their families may be classed in three ways, i.e., according to conditions of established risk, biological risk, or environmental risk.[2] He refers to infants with established risks as "infants whose early appearing aberrant development is related to diagnosed medical disorders of known etiology bearing relatively well-known expectancies for developmental outcome within specified ranges of developmental delay." These might include conditions such as meningitis, seizure disorder, galactasemia, and Down syndrome. Environmental risk ". . .applies to biologically sound infants for whom early life experience, including the maternal and family care, health care opportunities for expression of adaptive behaviors, and patterns of physical and social stimulation are sufficiently limiting to the extent that without corrective intervention they import high probability of delayed development." Examples of environmental risk include low income, unemployment, mother's age under 14, and a drug or alcohol-abusing parent. Biological risk is defined as that condition which. . . "specifies infants presenting a history of prenatal, perinatal, and early development suggestive of biological insult to the developing central nervous system and which either singularly or collectively increases the probability of later appearing aberrant development." Examples of biological risk include respiratory distress syndrome, meconium aspiration syndrome, prematurity and low birthweight. Tjossem's approach to conceptualizing risk status helps to narrow the categories of risk indicators and simplify the process of identifying infants appropriate for varying follow-up activities.

In North Carolina's statewide high-risk infant identification and tracking initiative, the High Priority Infant Program, infants' risk conditions may be classified into three categories based on a different conceptual approach. Group A includes infants in neonatal intensive care units with the following conditions: (1) less than 1500 grams, (2) intracranial hemorrhage, (3) meningitis, (4) seizures, and (5) neurological abnormality due to perinatal asphyxia. In Group B, infants may have any one or more of seventeen biological conditions or "serious environmental, social, or parenting disturbances" (see Appendix A). Infants with Group C conditions may have one or more of any of the conditions in Groups A or B, but have not been identified in the newborn nursery. Infants in the C category may also be visually impaired, hearing impaired, developmentally delayed, or suffering failure to thrive—conditions usually not diagnosed until later in the first year of life after hospital discharge. The major difference between A and B categories versus the C category is that "C' infants are identified post-discharge. This approach to conceptualizing risk status is the basis for a statewide protocol employed by public health nurses, physicians, and developmental evaluation staff in following infants enrolled in North Carolina's High Priority Infant Program.

According to the protocol, infants with Group A conditions are eligible for enhanced follow-along services including more home visits, developmental screening, guidance and counseling, and a standardized follow-up assessment at 12 months of age. Infants with Group B or C conditions may or may not receive these services, depending on the professional judgement of whomever is following the child's progress. The categorization of risk conditions can affect practitioners' decisions about the amount and type of follow-up which they provide to any infant in the Program. Decisions about follow-up services must ultimately be a function of the individual needs of infants and families, regardless of the categorization of their risk conditions.

Tjossem's scheme for classifying high-risk conditions was applied to the framework of the North Carolina High Priority Infant Program in order to understand the distribution and load of cases according to risk status. A preliminary report of the North Carolina Health Services Information System states that among a sample of 1,131 infants enrolled in the program during a three month period, 11% were identified by established risk indicators, 60% by biological indicators, and 29% percent by environmental conditions.[3] Of this same number of infants, 17% were identified in the North Carolina program on the basis of Group A indicators, 77% on the basis of B indicators, and 6% were identified after discharge or through C indicators. Most of the infants in this sample (874) were identified on the basis of prematurity, or birthweight between 1,500 grams and 2,500 grams, and/or some other biological condition. Almost one-third of the infants were identified on the basis of environmental conditions. Most infants have combinations of risk indicators, warranting surveillance for both biological and environmental reasons.

While Tjossem's approach and the High Priority Infant Program help to identify and sort individual and group conditions, social workers need additional information to decide on needs for follow-up.

The basic question remains as to which infants are more vulnerable for maladaptation or disabling conditions. Evidence suggests that the transactional approach most accurately reflects how risk indicators associate with poor developmental and health outcomes.[4] That is, following an infant's progress over time, and considering child, parent, and environmental factors in relation to one another provides the most accurate information for making decisions about services which match the infant's needs.

The work of Kathryn Barnard and her colleagues at the University of Washington[5] provides useful instrumentation for identifying the early signs of factors which are significantly associated with developmental and health problems detectable during follow-up. The parents' sensitivity to their infant's cues or their response to the infant's distress are important indicators of potential problems such as abuse or neglect.[6] Social workers should consider these principles in following high-risk infants whom they serve. Interaction among parent, child, and environmental conditions is believed to be strongly associated with child health and developmental outcomes. Methods of interview and service planning based on these considerations will enhance social work follow-up.

Follow-up by social workers must, therefore, address more than the traditional factors such as socioeconomic status, family history, and eligibility for public assistance. Refined observation of the interactions between infant and parent within their natural environment improves the professional's ability to pinpoint problematic behavior which may need to be changed early before it reaches dysfunctional or critical proportions, as in the case of child abuse or neglect. Barnard suggests observation of certain types of interactional situations between child and caregiver, such as the feeding and teaching situations, to assess strengths and weaknesses. In her training program, Nursing Child Assessment Satellite Training (NCAST), she suggests the use of Sander's "Model of Adaptation" (see Appendix B) as a framework for the parent-child assessment process.[7] This model emphasizes the need to determine the degree and level of reciprocity between child and caregiver within their environmental context. The responsiveness of the caregiver must match the infant's level of functioning. Social workers who employ Barnard's behavioral techniques can provide improved guidance and support to parents about the role their infant's behavior plays in modulating their reciprocal interactions. These interactional patterns in turn provide data for determining if more follow-up is needed.

From this perspective, follow-up becomes more than an occasion to assess how well planned objectives are being met. It is a time to suggest improvements in areas such as handling, feeding, sleep, problem-solving, and play. Social workers can be equipped to address this wide range of parent concerns, as well as refer to other resources.

The extent to which social workers apply these types of methods of follow-up activities with high-risk infants is unclear. Surveying nine neonatal intensive care unit social workers in North Carolina in 1985, Julia Gaskell, a student in the Department of Maternal and Child Health, School of Public Health, University of North Carolina at Chapel Hill, found that respondents had little time for any follow-up at all. Only 10% of those surveyed had any sort of written protocol for follow-up. Gaskell reported that phone follow-up was very limited and done only occasionally to assess how the family was doing. Thirty percent of those social workers surveyed see families in hospitals for follow-ups, apart from the clinic. Factors such as lack of time, geographic inaccessibility, hospital policy, competition with other health professional roles, and high caseloads constrain these social workers' abilities to conduct follow-up.

Social workers in community-based settings may have a greater opportunity to apply the kind of follow-up suggested in this presentation. Surveys similar to the one Gaskell conducted with hospital social workers may yield useful information about the follow-up activity of those in other community-based settings.

In summary, social workers are challenged to develop a conceptual framework for following infants at risk for disabling conditions and maladaptations. Incorporation of advanced methods, which improve assessment during follow-up, can also enhance the service social workers provide. Focus on the environmental conditions and parent-child interaction will yield valuable information when trying to distinguish higher from lower risk infants. Having an effective approach, based on the transactional nature of human development and interaction—not risk categories alone—is suggested to improve follow-up of high-risk infants by social workers.

Appendix A

High Priority Infant Program
Code B
Identified Nursery Conditions

Serious environmental, social, or parenting disturbances:

- —Single parent with problem of family support
- —Parent with incapacitating medical/mental handicap
- —Parent with history of alcohol or drug abuse
- —Mother demonstrates difficulty in maternal/infant interaction
- —No prenatal care (drop-in)
- —Mother 14 years or less

Birthweight 1501-2000 gms. (3 lbs. 5 oz.—4 lbs. 8 oz.)

Gestational age of 34 weeks or less

Hyaline membrane disease (RDS—Respiratory Distress Syndrome)

Aspiration pneumonia

Other pneumonia

Recurrent apnea

Bilirubin > 20 mg/dl

Other serious neonatal infection

Persistent fetal circulation

Neural tube defect

Other major birth defect or syndrome

APPENDIX B

From: Barnard, Kathryn, *NCAST-I: Instructor's Manual*
University of Washington, Seattle, Washington, D.C. 1980

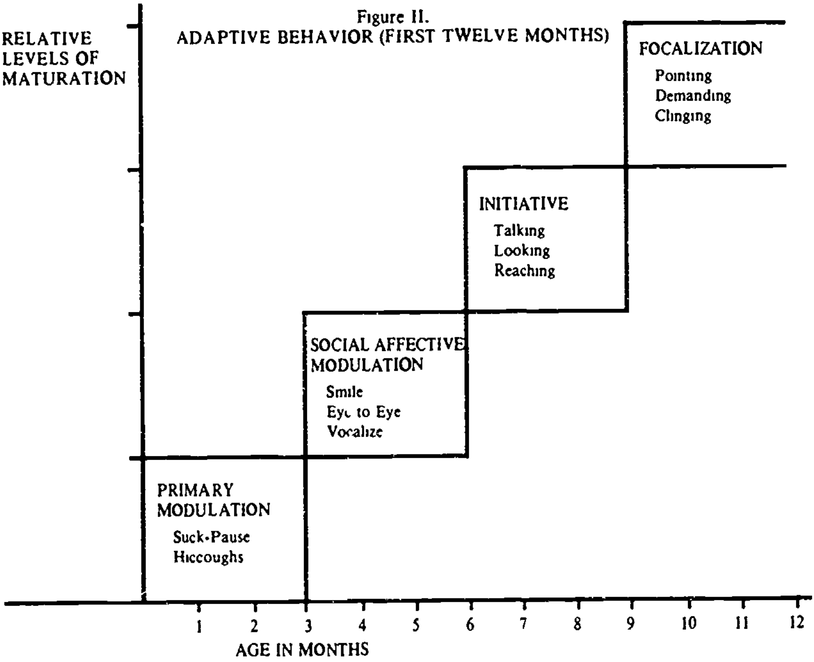
Figure II.
ADAPTIVE BEHAVIOR (FIRST TWELVE MONTHS)

From Sander, Louis W. "Issues in Early Mother Child Interaction" *Journal of American Academy of Child Psychiatry* 1 (1) 141-166, 1962
Adapted and reprinted with permission.

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High-Risk Infants and Child Maltreatment

Dorothy C. Howze, Dr.P.H.

What We Know

Researchers have uncovered a number of physiological characteristics that are associated with child malreatment. Among the characteristics often identified as risk factors are low birthweight, prematurity, chronic illnesses, and handicapping conditions.[1,2,3,4]

One of the most difficult problems in the interpretation of these findings is establishment of cause and effect. While many of the studies examining relationships between the cited factors and child maltreatment assume that child abuse is the effect of the factor under study, this assumption is not entirely defensible. In fact, these findings are somewhat speculative because much of the research documenting the link between child maltreatment and prematurity and other physiological factors lacks the methodological rigor necessary for establishing causality. That is, the majority of these studies are retrospective case-control designs in which "causality" is established by first identifying the effect, i.e., child maltreatment, and then going back to link it with the cause, i.e., the physical characteristics of the child victim. Because of the ex post facto nature of the research, particular aspects of underlying factors that may have precipitated the child maltreatment cannot be isolated. For example, findings derived from ex post facto research indicating that premature and low birthweight infants tend to be victims of child maltreatment are interpreted as indicating that prematurity and low birthweight cause child maltreatment. However, those aspects of prematurity or low birthweight, which might lead to child maltreatment, may not have been examined. For instance, premature infants present numerous caretaking difficulties such as slow development, irritability, and feeding problems. Additionally, they require increased medical attention which often necessitates separation from the mother. Furthermore, circumstances surrounding the birth of a premature or low birthweight infant may affect the acceptance of the child into the family. These circumstances could lead to considerable stress and anxiety within the family. The fact that these factors often accompany prematurity raises particular questions that weaken the interpretations of a causal relationship based on retrospective studies. Some of these questions include the following: does the separation of the infant from the mother immediately following birth disrupt the bonding process and, thus, make it easier for child maltreatment to occur? Do stressful circumstances surrounding the child's birth precipitate the abuse, or are premature infants abused because of factors such as obnoxious behaviors and unattractive physical appearances?

What We Need to Know

Unfortunately these questions will remain unanswered until we can conduct large-scale longitudinal case-control studies which allow us to follow children from birth. Such studies will not only help to untangle the web of cause and effect between the child's physical characteristics and child maltreatment but also help clarify the relationship between the child's characteristics and extrinsic factors that might contribute to child maltreatment. One example of such a research effort is that being conducted by the author and her colleague, Dr. Jonathan Kotch. The aim of that research is to test Garbarino's[5] ecological model of child maltreatment, in a population of high-risk infants (see Figure 1). These infants, who are identified by North Carolina's High Priority Infant Program, possess physical characteristics such as low birthweight, congenital abnormalities, neonatal illnesses, and familial risk factors, such as, young adolescent mothers, poor maternal bonding, and no prenatal care, all of which place these infants at risk of adverse medical and/or developmental outcomes.

The ecological model espoused by Garbarino is a multidimensional paradigm of child maltreatment. It is a model for understanding the complex interactions among factors such as individual, familial, social, and cultural, which affect families.[6] Additionally, the model provides a framework for understanding the relationship among stress, social support systems, and child maltreatment. Finally, it is well-suited for examining a confluence of factors that contribute to child maltreatment. The model not only helps in the analysis of the causative role of each factor, but it also permits examination of their interaction across a logical temporal sequence.

As shown in Figure 1, the model offers a framework for considering available supports and resources in relation to a typology of four levels which are labelled as individual, familial, social, and cultural. By examining each of the four levels, we can proceed to show relationship between these factors, social supports, and stress.

The four levels of factors, as a group, comprise what are termed predisposing factors. Predisposing factors are characteristics that make the individual susceptible to child maltreatment and precede the life events.

1. *Individual* factors are the characteristics that the parent and the child-victim possess as a result of their unique life histories and physical and psychological attributes.[7] In the case of parents, several characteristics have been found to be related to incidents of child maltreatment. Some characteristics which repeatedly appear in the literature are poor self-concept, poor self-esteem,[8] a history of abuse as a child,[9] a lack of parenting skills,[10] and/or a general lack of knowledge about child development.[11] Also included in the category are the special characteristics of the child. As noted earlier, the literature cites prematurity, low birthweight, congenital defects, and chronic illnesses as factors observed in child-victims.

It would be incorrect to conclude that these individual factors are sufficient in and of themselves to cause abuse. Rather, they must be seen in the context of the parent-child relationship which, in turn, is nested in the wider family. Therefore, the next level of the model, that of the family, is observed.

2. *Familial* factors are those involving both the structure and function of the unit.[12] Some of the family structural variables found to be associated with child maltreatment are: single working (female) parent in the home[13] and families with four or more children.[14] Family functioning characteristics include marital instability or violence.[15]
3. Families interact with larger *social* units and these relationships may affect the risk of abuse. Included in this social category are quality of housing, presence of unemployment or underemployment, and formal and informal relationships. Each of these have been found to be related to child maltreatment but, again, none by itself is a sufficient cause.
4. Lastly, there are *cultural* factors. By cultural factors we mean the all-embracing ideological fabric in which the individual, the family, and society are embedded.[16] Most important among these cultural values, for our purpose, are those that favor violence and corporal punishment.

These individual, familial, social, and cultural factors interact with life events and can result in child maltreatment. However, social supports/social networks can act as mediators, in the presence of precipitating factors, and prevent the occurrence of child maltreatment. Social networks consist of the number of friends, relatives, and group memberships the individual has. Social support pertains to whether the individual can rely on the social ties and contacts identified for support or assistance.

In understanding this model, it is important to know that the precipitating factor, life events, is simply the occurrence of objective milestones in the family's life cycle, unburdened of any normative connotations.[17] They are simply things that happen. They need not, in themselves, be good or bad for the person. These events become stressful only when the individual defines the event as such. In other words, a given life event may be perceived as stressful by one person but not the other. Although some of the literature in the field equates life events and stress, the equating of the two factors blurs an important distinction.

As noted earlier, the ecological model will be tested using a group of high-risk infants. The research protocol calls for 1,000 infants at increased risk of adverse health outcomes and an unmatched group of 125 non-high-risk, normal infants in the same hospital to be interviewed soon after birth.

The infants will be followed from birth to one year to determine whether child maltreatment occurs.

High-risk infants reported for abuse will be matched with non-abused high-risk infants. These two groups and the normal non-abused infants will be re-interviewed at one year of age (see Figure 2). Differences in individual, family, social, and cultural factors and differences in life events, stress, and social supports/social networks which distinguish abused, high-priority infants from non-abused high-priority and normal infants will be analyzed. Figure 3 indicates the variables and the instruments that will be used in the study.

While there is an array of variables displayed in Figure 1, not all of the identified familial, social, and cultural factors were selected for examination. Recognizing that no research study can examine all of the factors, we selected the most salient.

It is expected that the results of this research will generate new skills and insights for rational program development with a view toward prevention of child maltreatment and its sequelae. One problem with current efforts on behalf of abusive and neglectful families is that gaps in our knowledge of the causes of the problem hamper the selection of appropriate strategies. Thus, our decision-making regarding effective prevention and intervention programs has been based more on intuition than on sound scientific research.

A finding derived from this research showing that social support and social networks are key elements in minimizing child maltreatment would suggest an intervention that would appeal to many communities. In addressing this problem, agencies could target existing resources toward families at greatest risk. Such a strategy may prove most cost-effective in the long run.

The cost-effectiveness of an intervention strategy is important since for many communities any consideration involving increased resources is an unlikely solution. Most of these communities are stretched to their financial limit and are unable to support new health and welfare programs. While such communities express a concern for families in distress, they are seeking ways of meeting the needs of these families within the limits of existing services and programs.

It is also expected that this proposed research will benefit the statewide effort to identify high-priority infants. If this research demonstrates that lack of social support and/or social networks are key factors in the maltreatment of high-risk infants, then this information can be used to encourage officials to include these factors and other social indicators among the high-priority criteria. Additionally, the program personnel could be encouraged to devote special attention to these children in its monitoring efforts.

In conclusion, despite the fact that presently we do not have sound, empirical research on the causes of child maltreatment, it does seem that there are certain things that we do know and on which we concur. For instance, we know that parenting is adversely affected by: (1) having a low birthweight baby or a baby whose growth and development is slower than normal, (2) lacking the support of friends and neighbors or relatives when a parent is under stress, (3) having a parent unemployed or not having enough money to meet daily basic needs, and (4) not knowing what to expect developmentally from a child. This knowledge base, although too limited to provide definite solutions to the problem of child maltreatment, points to interventions and practices that seem to promote the health and well-being of families and their children, a primary objective of maternal and child health practice.

Acknowledgement

Dr. Jonathan Kotch is principal investigator and Dr. Dorothy Howze is co-investigator of the grant, "Stress and Social Support in High Risk Infants," MCJ-370521-01-0.

Figure 1. THE ECOLOGICAL MODEL OF CHILD MALTREATMENT

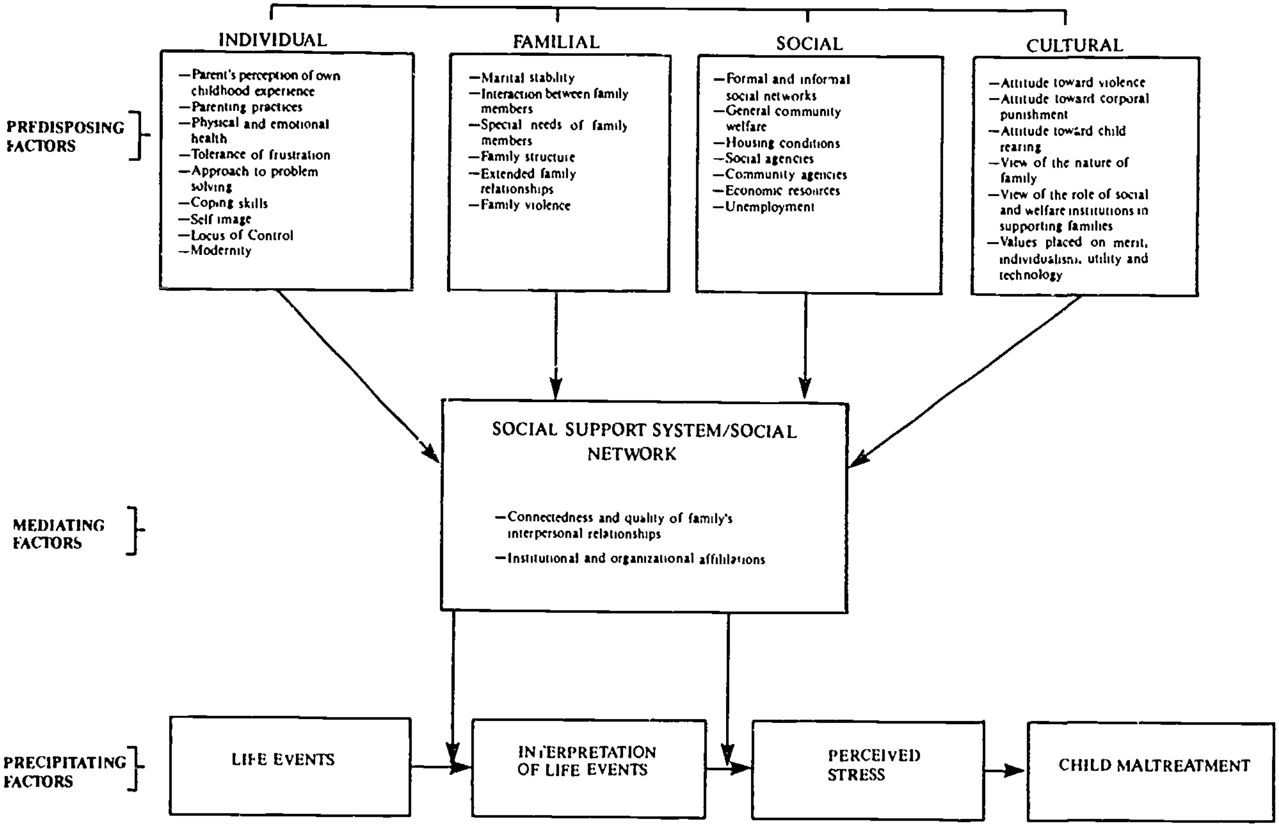
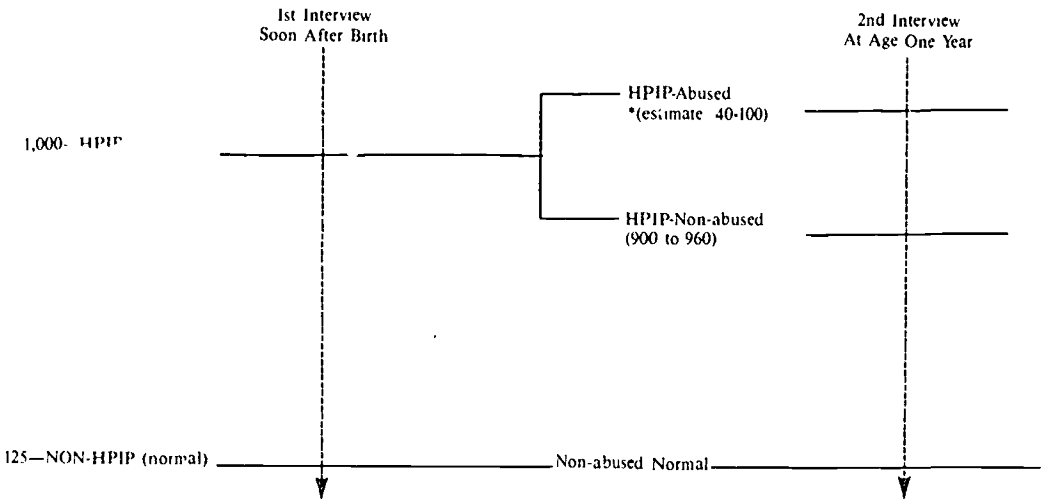


Figure 2

Design for High-Risk Infant Research
Case Control/Prospective Design



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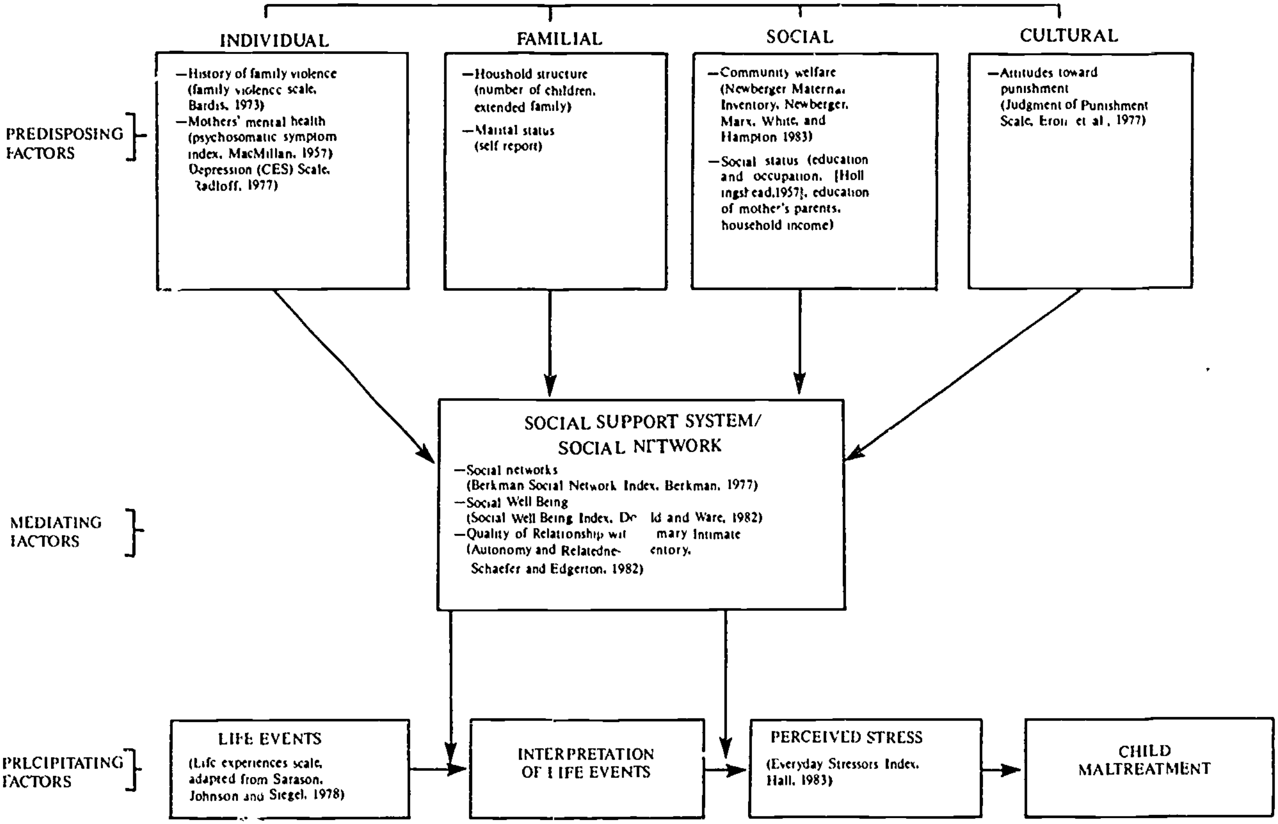
*Based on 3 9/100 confirmed cases (Hunter et al , 1978) for high risk infants, 41 9% rate of confirmation of reported high risk infant cases

FIGURE 3

THE EXAMINATION OF THE ECOLOGICAL MODEL
OF CHILD MALTREATMENT
(variables and measures)



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Part II

Cultural Barriers

Cultural Factors Associated with High-Risk Pregnancy Outcome: a Black Perspective

Barbara S. Cambridge, Ph.D.

Introduction

The interrelationship among the major socio-demographic factors are numerous, and it is often difficult to determine the precise association between individual factors, i.e., age, education, marital status, economic status, and the place of residence or work and their collective influence on an individual's attitude and behavior toward the utilization of health care services. Therefore, any discussion of the influence of culture on attitudes and behavior must be cognizant of this relationship. Kumabe supports this concept when she writes "ethno-cultural" factors must be viewed within the context of their interrelatedness to other social, economic, and demographic characteristics.[1] To illustrate, racism has a profound effect on life styles of black families, and to ignore this factor would relegate our discussion to an exercise in superficiality.

Any discussion of black families as a cultural entity, runs the obvious risk of over-generalization, i.e., "lumpology", abundantly practiced in the literature and in many health care service models. *All black people are not alike.* Black individuals and families represent a multiplicity of life styles, value systems, attitudes, beliefs, and patterns of behavior. A young school-age mother living at home with parents is far more likely to reflect parental attitudes toward health care than an older adolescent living independently.

This presentation will focus on several factors considered significant in influencing the black woman's attitudes toward the utilization of prenatal care. The factors are: (a) significant others, (b) religion, and (c) stress producing agents (stressors.)

Significant Others

Family: It is generally acknowledged that a strong kinship bond exists within the black community. Reliance on family is viewed as a coping strategy used by many black families to survive their social environment.[2] Hill identifies five major and distinctive features of black families: strong kinship bond, strong work orientation, adaptability of family roles, strong achievement orientation, and a strong religious orientation.[3] Billingsley cites three general categories of black families—primary families, extended, and augmented.[4] Martin and Martin further suggest that black families place a high reliance on the support of the extended family.[5] Cambridge, in a survey of attitudes of black urban youth toward their families, reported that 97% of the participants felt that his or her family would be the primary source of help if he or she were in trouble.[6]

Female relationships (mothers, grandmothers, mothers-in-law, and sisters) within a family significantly influence attitudes and behaviors about pregnancy and health care. The degree of influence, however, is significantly related to the age of the pregnant woman, proximity to family, and the amount of contact with family. Old wives' tales and superstitions about pregnancy and childbirth are freely passed on.

Father of the Baby: Sociological research persists in perpetuating the myth that black fathers are carefree, irresponsible, and pathological. Black fathers, like other fathers, carry their fathering roles and responsibilities in many different ways and with varying degrees of satisfaction. However, unlike other fathers, black fathers often find they are unable to fully carry the role of family protector and provider simply because they are black.[7] Hendrix, interviewing young black single fathers, reported that the majority of the fathers were concerned about the welfare of their offspring, but were constantly faced with employment instability, inadequate education, and training.[8]

Another commonly held myth about black fathers is that their physical absence from the home negates their influence and contribution to the family's functioning. This is untrue; the primary factor is not his absence or presence, but the nature of the relationship between the father and mother and, possibly, her family. Many black women, because of previous negative encounters with health care professionals, find it "safer" to conceal the nature of their relationship.

Religion

Religion and religious beliefs have been a major determinant of human behavior since the dawn of history. Several writers have pointed out the role of religion in helping black people cope with societal pressures and stresses (Hill, Martin, and Martin).[9] Alvy and colleagues reported a study of the childbearing practices of black parents of children enrolled in Headstart programs. He found that more than two-thirds of the black parents interviewed reported active church participation.[10] A majority of urban black youth, participating in a study conducted by this writer in 1982, revealed a strong religious belief in spite of the fact that many did not attend formal church services on a regular basis.[11] The influence of religion may also be observed in patients' attitudes toward preventive health behavior, preventive medicine, medical assistance, and the use of home remedies. A response commonly heard regarding potential risk or danger is, "If it is the Lord's will." This attitude presents problems for many health care professionals who interpret this response to reflect a lack of motivation or sense of not caring. For the patient, however, it may represent a coping mechanism, not simply for this particular issue but for all issues and events in the life of her and her family. For all too many women, pregnancy is simply another life event.

Stressors

It has been suggested that a woman's response to and interaction with her environment may seriously affect pregnancy outcome.[12] The black woman lives in a stress-ridden society, one in which survival itself means excessive exposure to forces that threaten an individual's emotional and physical well-being. When we consider the high rate of unemployment, constant threat of unemployment, inadequate wages, inadequate living conditions, threat of police brutality, and commercial exploitation, elevated stress levels are understandable. This often results in an increased prevalence of disease, chronic hypertension, diabetes, alcoholism, premature delivery, and other pregnancy-related complications.

American black culture teaches the black woman to deal with reality, a reality that is flexible and adaptable. Reality, as defined by her, may be and often is in contradiction to the external systems with which she must interact. A pregnant mother may use her food supplement from the WIC Program (Supplemental Food Program for Women, Infants and Children) to feed her school-age children rather than herself. Another mother may add water to a failure-to-thrive infant's formula in an attempt to stretch the milk as far as possible. For both mothers, the reality is the children she can see and touch, thus leaving the unborn infant to the care of "Divine Providence."

Currently, two factors related to pregnancy outcome are receiving research attention: physical stress and fatigue and psychological distress resulting from maternal attitudes toward pregnancy or from other external factors. For the purpose of this paper, we will briefly explore five factors which we identify as potentially stress-producing to the black mother: racism, economics (reality), relationship (partner), pregnancy desirability, and health care systems.

Racism: Racism has been responsible for denying or limiting access to various health, welfare, and social benefits associated with health care. Individual, organizational, and institutional racism continually play a vital role in erecting barriers to utilization of services by black families. Presently, in urban and rural communities black families, despite denial from administrators and policy makers, are victims of discriminatory practices. For many women, attitudes toward seeking prenatal care early in pregnancy are related to previous negative experiences with health care professionals.

Economics: Economics is another major stressor for black families. Regardless of social status, racism impacts heavily on all systems and relationships in which the pregnant woman and her family must function. It has been documented that a positive correlation exists between poverty and low birthweight infants. For black families, unemployment or the threat of unemployment presents a serious crisis. If the woman is employed by a company with rigid policies regarding absenteeism, pregnancy for her may represent potential unemployment. To illustrate:

> Mrs. A is being followed by sonography in prenatal diagnosis clinic with visits scheduled at three-week intervals in addition to her regular prenatal visits every two weeks. Mr. and Mrs. A are employed by the same company. This company does not provide health care benefits for its employees. The A's have a car, but Mrs. A does not know how to drive. Mr. A takes

> off work and brings her to the clinic, waiting several hours per visit. The A's are not considered "charity cases" because of their combined income. They are not eligible for the WIC Program and must pay the full fee for prenatal care. Each clinic visit results in loss of family income needed to maintain their current standard of living and prepare for the new baby. This couple is forced to choose between risking a poor pregnancy outcome by not coming to clinic or attending clinic and entering a state of poverty.

Unpaid medical bills are another economic stressor. Rumors, from other patients, about events such as, hospitals refusing to provide care until the bill is paid, babies being held as hostages until the bills are paid, bill collectors, and hospitals requiring large deposits, intensify families' reluctance to approach health care systems until they have no other choice. This usually means they seek prenatal care late in the last trimester. A number of black families initiate prenatal care through private physicians, but because of unexpected financial crises, such as unemployment, they find it difficult to pay the required fee and may seek a public health care system late in the pregnancy.

Mating Relationship: The relationship in which pregnancy occurs may represent another major stressor, especially if the relationship is unstable, fragile, violent, rejecting, or financially and emotionally unsupportive. Functioning within this type of relationship requires the woman to utilize all of her emotional resources to cope with varied crises, leaving her little emotional and physical energy to focus on herself and her baby. Frequently, delay in seeking prenatal care, keeping appointments, and following medical recommendations are related to the partner's response to pregnancy.

Pregnancy Desirability: What does this pregnancy mean to the mother: entrapment, punishment, the erosion of a dream? Was the pregnancy planned? Was pregnancy termination considered? Did she take home remedies to try to abort the pregnancy, resulting in guilt feelings? All these issues and others will affect her perception of pregnancy and will provide clues to her ability to accept and cope with it. Denial and depression often prohibit her from acknowledging and accepting the reality of the pregnancy until sometime late into the second trimester. It is not at all unusual for a woman to miss several menstrual periods before finally admitting the possibility of pregnancy.

Attitudes Toward Health Care Systems: The black community's regard for the health care institution is significant. If it is perceived as unsafe, hostile, degrading, and primarily interested in "research," the pregnant woman may be reluctant to seek care. They may be unwilling to accept other screening services or procedures, i.e., prenatal diagnosis, nutrition, counseling, etc.

Conclusion

This presentation has attempted to increase our awareness of the role of "culture" in influencing attitudes toward health care. At the risk of overgeneralization, the black woman and her family operate within and relate to a variety of social and economic systems. Attitudes and beliefs of family, children's father, and religion play vital roles in the decision-making process used by the black woman. Stress is alive and well in the black community and the black woman is intensely and uniquely affected. Hypertension, diabetes, fatigue, depression, drug usage, and other behaviors are symptomatic of this stress. Racism, economic insecurity, unstable relationships, and, all too often, health care delivery systems collectively serve as stressors and barriers to the utilization of prenatal care.

The black woman and her family, like other families, desire to have a normal, healthy baby. Unfortunately for many, personal circumstances and social and institutional structures prevent this from becoming a reality.

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Ethnic and Cultural Factors Associated with High-Risk Maternity Outcomes: A Hispanic (Mexican-American) Perspective

Ricardo Arguijo Martinez, R.N., M.S., M.P.H.

The Office of the Surgeon General reports an improvement in the infant mortality rate and the percentage of women receiving prenatal care in the first trimester in 1977 as compared to 1950 and to 1969. The annual decline in infant mortality between 1965 and 1973 was 3.5%. "The principal threats to infant health are birth defects that can lead to lifelong handicapping conditions, and problems associated with low birthweight. . .Unfortunately, many children are born to women with an increased risk of having a low birthweight infant, i.e., women making no prenatal visit during the first trimester, and teenagers."[1]

Of particular interest and possibly vulnerable to "high-risk" pregnancies is the Mexican-American population. Mexican-Americans have a higher fertility rate and are a younger population group, in comparison to the Anglo population. Population pyramids for Mexican-Americans resemble those of developing countries where there has been a marked decline in infant and child deaths and where fertility has not yet been reduced. In such populations, the number of people is increasing rapidly, median ages are falling, and youth and total dependency ratios are high.[2]

Several reasons for this phenomenon among Mexican-Americans may be offered. First, infant mortality has declined substantially over the last decades. Second, major epidemic diseases have been brought under control during the same period. Third, socioeconomic conditions, particularly education and income, have shown improvement since 1950 among Mexican-Americans in Texas. These three factors have contributed to a lowering of the death rate. However, fertility remains high, and more infants survive the first years of life, and more young women survive the child-bearing age.[3]

Socioeconomic conditions may be seen as both a cause and a result of health conditions. Poor health conditions may affect socioeconomic conditions in three ways: (1) by causing an interruption in or termination of employment (especially for the head of a household); (2) by preventing a person from learning or participating in those activities which would increase income and education; and (3) by causing a person to spend a disproportionate amount of income on maintaining health status or reducing disease or injury.

Adverse socioeconomic conditions may affect health status in the following ways: (1) by subjecting a person to unhealthy environmental conditions (e.g., crowded housing, lack of treated drinking water or sewage); (2) by depriving a person of the education necessary to understand preventive measures in disease control and general physical well-being (e.g., lack of knowledge about nutrition, not understanding germ theory); (3) by limiting care received; (4, by barring a person from health care services (e.g. through racial discrimination, or lack of transportation); and (5) by leading a person, through ignorance and desperation, to seek types of health care which ultimately might cause him or her harm.[4]

In view of the relationships between poverty and health, the socioeconomic status of a large portion of the Mexican-American population in South Texas indicates a number of potential health problems. These problems may be summarized as follows:

- The low income of many Mexican-Americans gives them little money for medical services. Lack of funds may require the foregoing of medical services or reliance on assistance from others (i.e., family, friends, charities, or public funds).
- The lack of formal education among many Mexican-Americans suggests that they are less likely to be aware of or to practice modern preventive health care. The low income of many, if not most, Mexican-Americans makes the practice of preventive health care difficult.
- Crowded housing and lack of basic services, such as water and treated sewers, result in a greater potential for the spreading of communicable diseases among many Mexican-Americans. Lack of these facilities also makes preventive health practices difficult.[5]

Consequently, a system of health care delivery which includes preventive health services and health education and which is designed for the relatively well-educated, middle-income probably will not meet the needs of low-income Mexican-Americans. Rather, the development of an appropriate health system must be predicated upon the health risks and health needs which exist in the Mexican-American population and must take into account the age distribution, income, and education of Mexican-Americans.

The Public Health Service has made significant progress in recent years in formulating an agenda for the nation in health promotion, health protection, and disease prevention through three publications, (1) *Healthy People*,[6] (2) *Promoting Health/Preventing Disease: Objectives for the Nation*,[7] and (3) *Public Health Service Implementation Plans for Attaining the Objectives for the Nation*.[8]

To provide a measure of progress, national objectives have been established as quantifiable goals designed to improve health, reduce risk factors, increase awareness, and improve protection and surveillance. The 19 pregnancy and infant health goals listed in *Objectives for the Nation*, emphasize reduction in infant mortality and low birthweight rates, particularly among minority ethnic groups including Mexican-Americans.

The priority objectives were identified on the basis of the efficacy of available pregnancy and infant health intervention measures. It was assumed that state agencies would make many of these intervention services available to their constituents using funds from the Maternal and Child Health (MCH) Block Grant Program. Further, it was assumed that the federal efforts, especially those of the Health Resources and Services Administration, would complement those of the states' agencies.

Part of the problem in assisting state groups, particularly in Texas, in meeting the national objectives is lack of data specific to Hispanics. The 1980 Census data has provided planners a clear picture of the Hispanic population characteristics. However, as mentioned in *Health of the Disadvantaged*, published by the Department of Health and Human Services in 1980:

> Since Hispanics are not generally considered as a separate racial group, they are placed within the white or minority categories when questions concerning race are asked. In the 1970 Census, about 93% of the Hispanics identified themselves as being of the white race. Inclusion of Hispanics in the white category tends to increase mortality and morbidity rates as compared to white category without Hispanics. Therefore, there is less of a difference between the mortality and morbidity rates for whites vs. blacks when Hispanics are considered part of the white group.[9]

The proposed pregnancy and infant health objectives for Texas call for the implementation of an effective and coordinated statewide strategy for the improvement of birth outcomes.[10] Seven of the 16 proposed objectives address the physical status of women and children. Of highest priority is the objective that includes a measure of health status at the time of birth—low birthweight (defined as under five and one-half pounds). This measure is preferred to measures of subsequent outcomes, such as mortality, because it focuses attention on prevention in the prenatal period. Prevention of low birthweight, prematurity, and birth defects can effectively reduce the numbers of infant, neonatal, and perinatal deaths. Furthermore, a preventive strategy can reduce subsequent burdens of neonatal intensive care and longer term developmental impairments.

Implementation of a comprehensive preventive health strategy requires identification and targeting of high-risk groups and individuals, as well as influencing those behaviors and other factors that contribute to poor pregnancy outcomes. Among these factors are teenage pregnancy, out-of-wedlock births (more appropriately, births without sufficient support systems), poor nutrition, smoking and alcohol consumption, and lack of early access to appropriate prenatal attention. Furthermore, minority groups, groups with low socioeconomic status, and particular regions of Texas exhibit high rates for many measures of health status and health risk.

Nine of the objectives identify the types of services that constitute a comprehensive pregnancy and infant health program. Almost all of these services are preventive in nature. Delivery of effective preventive services, such as prenatal care and educational programs, can reduce the presence of health risks and can lead to early identification and treatment of health problems. Birth outcomes consequently should improve, and birth associated mortality and defects will decline. The implementation of a comprehensive preventive health strategy will require research, planning, coordination, and development of new resources where existing resources are inadequate to assure access to comprehensive services.

The monitoring of progress toward attainment of the pregnancy and infant health objectives will require careful planning. The evaluation of birthweight information, for example, is confounded by its relationships to gestational age, multiple births, socioeconomic status, ethnicity, and teenage pregnancy among other factors. Similarly, information gathered from Texas birth certificates does not adequately identify the month in which prenatal care is initiated or who was the attendant at birth. Measures of mortality, while more straightforward, are not without problems. Infant mortality, for example, is generally thought to be underestimated along the border because of inaccurate recording of residence for some women from Mexico. Measurement will be very difficult for those objectives that address the characteristics of the desired service system.

Texas infant mortality rates for both Anglos and Mexican-Americans have fallen since 1970, with Anglo rates decreasing from 18.0 infant deaths per thousand live births in 1970 to 15.1 in 1975. Mexican-American rates also fell, from 20.2 in 1970 to 14.5 in 1975.

One explanation is that the fall of infant mortality rates in non-border cities is a result of improved neonatal facilities which are high technology systems located in many public and private hospitals. They can effectively intervene to save the lives of newborns at risk.[11]

The development of a neonatal intensive care system in the Robert B. Green Hospital, a unit of the Bexar County Hospital District, appears to have been responsible for a tremendous reduction in at-risk neonatal mortality. In 1969, prior to the development of the intensive care system, the neonatal death rate at Robert B. Green was 25 deaths per 1,000 live births. This fell to 13.1 in 1971.

The Robert B. Green Hospital, now referred to as the Brady/Green Community Health Center (B/GCHC) and Medical Center Hospital comprise the Bexar County Hospital District. They are the principal public health facilities in the San Antonio area. The neonatal intensive care facility is now part of Medical Center Hospital. The Bexar County Hospital District is used extensively by the Mexican-American population. The rapid increase in food stamps and other funds for nutrition of pregnant mothers may also have helped reduce the infant death rate.

Thus, there are two plausible explanation for the relatively low infant death rate among Mexican-Americans. The first relates to under-reporting of deaths. The second relates to the newly available services which have effectively intervened in the problem of neonatal mortality.[12]

The B/GCHC nurse-run prenatal clinic provides approximately 7,000 patient visits per year to almost 1,200 individuals. The majority of the patients are referred from the obstetrical clinic (physician-run) referred to as the "New OB Clinic." Patients referred to the nurse-run prenatal clinic from this clinic constitute about 60% of the clinic population. Approximately another 37% of the patients are referred from the "Complicated OB Clinic." These patients have been evaluated by a physician and either the complaint or problem has been resolved, does not pose threat to life, or the management regime provided by the nurse-run clinic would be beneficial to the patient. The other 3% of the patients are usually referred to this clinic from the neighborhood public health department clinics.

Just as patients are referred to the nurse-run prenatal clinic, during approximately 10% of all patient clinic visits referrals are made to other clinics. The "Complicated OB Clinic" receives about 55% of those referrals with "Social Work Department" receiving about 18%, "Family Planning Clinic" receiving 10%, and varied other clinics receiving 17% of the referrals. The average percentage of physician consultation sought daily, by the nursing staff, in the Routine OB Clinic is for 15% of the patients visiting.

The age of the clinic population ranges from 12 to 43 years old, with the mean age of about 22 years old. One-third of the clients are adolescents (under 20 years old), while up to 7% are 15 years old or younger. These individuals average seven to eight clinic visits per pregnancy, with the average week of gestation at the time of the first clinic visit being 26 weeks. Many patients have nine to 12 visits during the pregnancy and some come more than 12 times. The majority of individuals are married (72% married and 28% unmarried) and most have less than a high school education.

Although several ethnic groups are represented in the clinic, the majority of the patients, as previously cited, are Mexican-American, approximately 71%. There is about a 15% Black-American and 12% Anglo population with various others contributing the additional 1%. Up to 10% of the Mexican-American population are Spanish-speaking only and require translation for communication. Occasionally, Indo-Chinese patients require translation and sometimes interpreters for the deaf are utilized.

Most of the prenatal clinic patients are from low-income families, although there are patients rated at all levels from minimum to maximum pay, based on the Bexar County Hospital District's financial scale. Very few patients have health insurance. Some patients are receiving public assistance through welfare, food stamps, or housing, but this is a minority of the clinic population.

Demographic information is important when studying the make-up or characteristics of a particular population. For this population, probably the most noteworthy characteristic is the frequency with which clinic appointments are kept or at least cancelled and rescheduled, rather than miss the appointment. Approximately 90% of all prenatal clinic appointments are kept, or cancelled or rescheduled. Thus, of the thousands of clinic appointments made per year, only 10% or less are appointments that are not kept. This is a phenomenal response to health care services by a population that is generally plagued by limited resources to get to the clinic, distances to travel, and obstacles such as arranging time from work in order to come, and/or arranging child care for other children in the family.

The needs of the patients coming to the nurse-run prenatal clinic are varied, multifaceted, and range from simple to complex. The nurse must make the appropriate assessment and determine which individual and/or service is best prepared to assist the patient. If the determination is that the nursing staff, or nursing staff in conjunction with others, is the best means for addressing the patient's need, then the nurse proceeds with those appropriate to determine the best strategy or approach for care.

Some clients are at a level in which their basic human needs of food, clothing, shelter, and safety have not been fully met. Until such needs are resolved satisfactorily, there can be no progression to solving more complex needs. In such cases, appropriate referrals are made to the Social Work Department, which in turn refers to city welfare, housing, charity agencies such as Christian Ministries, and possibly the Women's Shelter, as in the case of the battered woman.

One of the greatest needs of women in the prenatal clinic, and in the health care system as a whole, is that of understanding the functioning of the body in order to function optimally and to facilitate taking appropriate actions when they are necessary. The patients in the clinic are kept well-informed of their progress and any concerns that we may have about them. Many of the patients state that in previous pregnancies no one spent as much time talking to them as the prenatal clinic nurses. Occasionally, it seems that women had been discouraged from asking questions. Women transferring to us from private physicians are no exception, and a frequent comment heard is, "I was never told anything."

Education is considered an essential aspect of care. Clients often assist in identifying areas where they desire more information. Examples of typical content areas covered include the following:

—Body changes with pregnancy (weight distribution, breast changes, skin changes, minor discomforts, increased lordosis)
—Posture, body mechanics, physical conditioning
—Total growth and development
—Nutrition
—Emotional aspects of pregnancy (including sexuality and male and female adjustments to pregnancy and role transition)
—Prepared childbirth classes
—Preparation for labor and delivery and the hospital experience (including mechanism and signs of labor and when to go to the hospital, the birth process, hospital procedures, analgesia and anesthesia, rooming-in, the hospital stay)
— Breathing and relaxation techniques and comfort measures for labor and delivery
—Postpartum (including physical and emotional adjustments)
—Breastfeeding
—Newborn characteristics and care of the unknown
—Well-baby and postpartum follow-up
—Family planning (including child spacing and birth control methods)

Some aspects of pregnancy care have long range implications beyond the actual pregnancy and neonatal outcome. Examples of such educational outcomes include: breast care and self-examination, child care and parenting, family nutrition, body mechanics, family planning education, feminine hygiene, and management of vaginitis.

The adolescent often presents a challenge to the nurse due to the complexities of needs and problems. An assessment of the adolescent's development level, support system, financial status, and knowledge must be accomplished in addition to determining the meaning of the pregnancy to her and what her plans may be. An early adolescent may require more parental guidance and support than a middle or late adolescent. Often the pregnancy creates the opportunity for the adolescent's first sustained contact with the health care system.

The adolescent is more likely to support a plan of care if she is involved in the planning of her care and understands the rationale for the care. For example, nutritional counseling consisting of telling the adolescent which foods to eat may be ineffective. When presented with the rationale as to why good nutrition is essential to pregnancy and information as to diet requirements, the adolescent may be creative in planning her own approach to this problem. The nurse can assist in pointing out how snacks and "fast foods" can be nutritionally sound if this is an integral part of the adolescent's usual diet.

Perhaps one of the greatest needs of the adolescent is someone to listen to her. The adolescent may be experiencing stresses from several sources, her parents, husband or baby's father, or peers. She may have concerns about herself, including body changes, as well as relationships with others, impending labor and delivery, or the baby and her role as a parent. She may have unrealistic views as to how the baby will affect her lifestyle or about parenting in general. The nurse who listens attentively and with concern for the adolescent will identify potential problem areas or the need for further information or counseling.

As in the case of the adolescent, many of the patients need someone who is interested in them and who will listen to them, someone with whom to share feelings, joys, anxieties, and hurts. Personal and marital problems color the emotional outlook and reduce the physical stamina of patients; yet some women have no one else other than the prenatal clinic nurse who will lend an objective ear. Other patients can identify their own strengths, coping strategies, and support persons. In either instance, the desired outcome is to help the individual grow, to enhance coping mechanisms, or take action to alter or improve the situation. Patients seem to be extremely receptive to the prenatal clinic nurses, possibly because they know the nurse's concern is genuine.

The nurse serves the patient in the role of advocate and as a facilitator through the health care system. Nurses have been instrumental in achieving quality care from physicians both in the hospital and in other clinics when it seemed patients were being overlooked or their problems understated. Some of the patients have difficulty communicating their needs or problems to others. Others have a poor self-concept and do not know how to assert their rights; still others do not even know that they have rights. The nurse can be instrumental in assisting the patient through the sometimes complex health care system and in helping her achieve feelings of dignity and self-worth.

Women served by the prenatal clinic need sound prenatal management. Although the patients are usually classified as "low-risk," their living conditions and lack of financial resources predispose them to a variety of complications. The nurse must be acutely aware of warning signs of complications and provide skilled management while stressing the "normalcy" of pregnancy.[13]

In ministering to the Mexican-American client, the nurse or health care practitioner recognizes a difference in the interaction process from a social and personal point of view. As cited earlier, this interaction process also may be dependent on variables such as economic and educational levels. The nurse needs to be conscious of the variables affecting the interaction process, especially the level of client understanding.

Bilingualism is essential in the success of the interaction-communication process. The ability to speak Spanish and be dialectically correct is an important element in comforting clients, explaining procedures, and providing patient education.

Nurses and health care practitioners (especially those who are non-Spanish-speaking and non-Mexican) may need to analyze their feelings towards clients from a lower, economic-social level—not just feelings toward Hispanics, but toward all clients having a disadvantaged lower level of living style. Frequently the client from this disadvantaged group may lack family-planning knowledge, and too often the practitioner is critical of the life style, the family size, and the client's attitude toward "modern, health-care practices." Again, the practitioner may need to access his objectivity in interacting with his client, to avoid being critical or infringing upon the client's personal values.

The Mexican client may rely on advice from the extended family, abiding by an elder's therapeutic folk measures, including the use of herbal teas and home remedies. It should be pointed out that most herbal teas are harmless; in fact, some may even be therapeutic to some degree in controlling nausea, diarrhea, headaches, and general malaise. Nurses and health care practitioners should allow clients to maintain and continue with folk-medicinal practices, if possible. They usually will not harm the patient and do help in alleviating anxiety, stress, and uncomfortable feelings. It should be stressed that follow-up and continued visits with the practitioner are important and part of the holistic scheme of therapy.

Nurses and health care practitioners may need to become familiar with certain folk practices and beliefs common among Hispanic maternity clients. The following are health-care beliefs (including home remedies) related to pregnancy, congenital handicaps, and child growth:[14]

—Taking laxatives during pregnancy may cause one to abort.
—One cannot eat pork during the postpartum period because the pork will "tear" the stomach.
—Clients are reluctant to be seen by a male doctor due to modesty.
—Hanging out clothes during pregnancy will cause the cord to wrap around the baby's neck.
—One cannot sweep the floor for 40 days after delivery or move furniture because "your insides will drop out."
—Stuff cracks around windows and doors and keep them closed, because fresh air is injurious during the postpartum period.
—Cover the abdomen with a sulphur mixture to insure recovery from delivery.
—Do not spread or separate your legs for 10 days postpartum, for this is also injurious.
—Pregnant women should not eat sour food (e.g., citrus fruit).
—Pregnant women should not care for an ill child.

—A "belly binder" worn after delivery keeps the womb from getting too high.

—If a child is mentally ill or physically abnormal, God may be punishing the parents, or it just may be the will of God that this should happen.

—It is good to pat a pregnant woman's stomach either to prevent evil or for good luck.

—Do not cut the baby's fingernails until the baby is six months old and has been baptized, or it will cause the baby to go blind or have weak eyes.

—Wear a dime or a "deer's eye" (looks like an acorn but is claimed to be a dried deer's eye) as a necklace or anklet to avoid difficulty with teething.

—The newborn baby must be given onion or herb tea until he breaks out with hives. This prevents the hives from "going in" and injuring him.

—The infant must wear a binder with oil on it around the navel.

—Egg whites rubbed into the joints give strength.

—A red object or red string placed on the forehead will stop hiccoughs.

—For earache, take a piece of paper; roll it into cone; place in the ear; light the open end with a match (this is supposed to pull the air out and make it stop hurting); then place cotton in the ear.

—Do not give young girls onions to eat because it causes sexual excitement.

—Often, pierce ears on newborn baby girls—make hole using needle and run thread through the hole in the ear lobe. The red thread prevents infection.

—To cure an infant's cold put olive oil on the "soft spot" and on the temples at bedtime.

—Use anise tea for stomachache and colic.

—A curandera is commonly consulted by families for illness or the "evil eye."

—Put a coin on the umbilicus to flatten it.

—Give an infant water boiled with "cumino" seed and it will get "phlegm" out of the lungs and throat and prevent choking.

—One cannot cut an infant's hair until he is baptized, and often the hair is let to grow long on the female because blindness results if the hair is cut before baptism.

—Diapers washed in the morning and hung out must be brought in before noon and not used until the next day or green diarrhea will result.

—The reason a baby has diaper rash is because the mother ate chili peppers during pregnancy.

—For sunken fontanel, put thumb in the baby's mouth and press up on the upper palate. This will push the fontanel back out. The curandera has a way of blowing on the head at the same time that she pushes on the palate to cure this.

—Cobwebs or animal hair are often wound along with "monkey blood" (mercurochrome) to help coagulate the blood.

Being cognizant of cultural beliefs is prerequisite for deliberate and objective care. The nurse and health care practitioner, through understanding and appreciating individuality and cultural uniqueness, will be able to meet the physical and emotional needs of the client more effectively.

Most folk medicine practices in themselves are harmless, although adherence to these practices can create problems by allowing a disease to be left untreated. Additionally, treatment by family members or a curandero or folk healer can benefit individual mental health.

Curanderos, who may be either male or female, are considered to heal by virtue of a gift (don) from God. Through dreams, unusual traits, or magical experiences, an individual acquires healing ability. The number of healers in an area, their methods and fees, vary widely. Some famous curanderos, such as Don Pedro Jaramillo and Nino Fidencio, had enormous followings in the Southwest while they were active. They have since become folk heroes. Today, many curanderos practice in their names.[15]

In poorer Mexican-American communities a significant emphasis is placed upon sharing; one person's joys and sorrows, including illness, are symbolically shared by everyone else. Modern medical care, by contrast, concentrates on a patient's physical illness, and often excludes family and friends from the healing process. The curandero often uses religious metaphor to encourage the patient to accept suffering as a necessary share of the world's burden of suffering. The curandero represents the belief that disease may have religious or social causes (God's punishment, the malevolence of others) and deals with the patient from that perspective.

The curandero can be a comforting influence, representing familiar traditions which can be useful in treating both physical and psychological problems. Modern medical personnel usually have little knowledge of or respect for such traditions, and are unable or unwilling to incorporate these concepts into health care delivery.[16]

Given the poverty of the majority of Mexican-Americans in South Texas, health services provided by family, friends, or local healers often may be the only available health care. Many persons, lacking financial resources, may seek treatment from these alternative sources, even if the patient feels physician treatment is needed.

Socio-economic cultural factors appear to be the major determinants in the different perinatal health experiences of many Mexican-Americans. The factors which exist may be contributing elements in the health outcome of high-risk maternity client. By identifying and focusing on the underlying causes related to high-risk problems, without stripping the client of the unique cultural-ethnic characteristics, the delivery of health care for the Mexican-American may be greatly enhanced and improved.

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Ethnic and Cultural Factors Associated with High-Risk Maternity Outcomes in Southeast Asian Refugees

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Introduction

There are two interrelated factors that could negatively influence maternity outcome in Southeast Asian refugees. The first is that many women from Southeast Asia have had limited or no experience with western medicine. Their traditions and beliefs, as well as lack of English language skills, may be barriers to appropriate utilization of our health care system for their maternity care. The second factor is that Southeast Asian refugee women have a high level of stress in their lives. This stress is partly a result of the frightening and often dangerous circumstances that brought them to the United States as refugees, and partly a result of cultural shock from suddenly being in a culture drastically different than what they have known.

Barriers to Appropriate Utilization of Health Care System for Maternity Care

Language As A Barrier To Understanding

The most difficult situation occurs when a Southeast Asian woman who speaks little or no English goes into a doctor's office or maternity clinic without an interpreter. In such a situation, the best the health care team can do is to try to reschedule the appointment when an interpreter is available. If interpreters or family members who speak English are not available, the use of drawings or photos and gestures may be helpful. This can be risky, however, if they are diagrams or a type of illustration the refugee is not accustomed to. One Laotian man was shown a drawing of a cross-section of a human head in an attempt to explain to him surgery that was going to be done to his daughter's throat. It was later discovered that he thought the doctors were going to cut her head in half. If an interpreter cannot be located, and if the woman is literate in her own language, it is possible that pamphlets related to maternity care could be ordered in the refugee's own language from national sources.

Children learn a new language faster than their parents do, so children are sometimes used to interpret for their parents. This is not advisable, if other alternatives are available, as it reverses the traditional parent-child relationship roles, which in Southeast Asia include a great deal of respect and a lack of questioning of the authority and knowledge of the parent. The child may also not be mature enough to understand all of the concepts necessary to discuss pregnancy. Other family members or friends who have been in the U.S. longer than the patient may be able to interpret for her if a professional interpreter is not available.

Even in the best of circumstances, with a professional interpreter who is knowledgeable about medical terminology in both languages, the language barrier can cause confusion and misunderstandings. In a local health unit at the Arkansas Department of Health, a 25-year-old Laotian woman signed up for the Special Supplemental Food Program for Women, Infants, and Children (WIC) early in her first pregnancy. The interpreter translated the advice to eat a certain number of servings per day from each food group. The woman came back the next week and had gained twelve pounds because she thought a "serving" meant a plate full. The interpreter had translated the word the best he could, but in Laos everyone has their own basket of rice, and the rest of the food is in big bowls or plates in the middle of the table. Since everyone takes food from each bowl, as they eat it, the patient had no previous experience with the concept of a serving as a certain amount of food on a plate.

Traditional Pregnancy and Childbearing Practices

Childbearing practices in Southeast Asia vary widely. At one extreme is the urban upper-class Vietnamese woman who is likely to have her baby in a hospital in much the same way as we do in the United States. At the other end is the Hmong or Mien woman, who may have had no exposure to western medicine, and delivers her baby at home much as her ancestors have for centuries. The difficulty that a Southeast Asian patient will have in understanding and participating in her maternity care in the U.S. will depend partially on what type of experience and information she had in her homeland. The following are two examples of customs quite different than those the refugee will encounter in the U.S.

The Hmong people are from the mountains of Laos and were fairly isolated from other Laotian people until quite recently. Their language was oral only until missionaries developed a written language for them in 1954.

A typical Hmong woman would traditionally be expected to bear ten children. Birth is considered to be a natural event and there are no designated midwives. A month before a couple's first child is due, the husband's parents instruct the prospective parents about childbirth and infant care.

Only the husband and his parents are required to attend the birth unless labor is very long and difficult. If complications arise, the support system is increased, depending on length of labor. Other relatives are called first. If things continue to not go well, a male family member recites a special chant. Additional relatives may join. A group of 30 or more is not unusual. If labor continues for 24 hours, the medicine woman is called to administer an herbal tea to speed up the labor. If labor continues for two to three days she is asked to manually stimulate the birth. If the baby still is not born, medicine bowls are filled with water and placed around the room. Prayers are said over them; the number of people in the room grows, and there is a great deal of tension among them. At this point, if nothing has worked, all resources are considered to have been exhausted; no other measures are taken, and the woman inevitably dies.[1]

The Hmong traditionally believe that the spirit can leave the body if it is cut and, therefore, may be opposed to Cesarean section, episiotomy, and circumcision.[2]

Other rural Southeast Asian women would usually deliver at home, assisted by a midwife and married female relatives or other experienced women from the village.[3] It is common to be fairly ambulatory during labor, and the woman would either squat or lie on her back when stationary.

In Laos a hot fire is built under the bed after the birth. The woman is expected to stay in the hot room for a month with the first pregnancy and for less time with each successive birth. The baby is nearby, but not kept as hot as the mother. An old person says some words to make the fire the right temperature, but one Laotian woman told the author that she still had burns on her back from the fires after her four children. A hot brick is kept on the stomach to make the blood come out. The woman is given hot water to drink and takes hot herbal baths.

The degree to which women from Laos, Cambodia, and Vietnam, who had little exposure to western medicine before coming to the U.S., try to keep their traditional customs varies widely. For example, Laotian women spoken to in Little Rock, Arkansas, said that they no longer tried to stay hot and drink hot liquids after childbirth. They feel that the doctors here would be critical and that it may not be appropriate for this climate. Some Laotian women in Fort Smith, Arkansas are keeping a modified form of their traditional customs. One of them, who works as an interpreter, goes once a year to the local hospitals as a consultant to talk to the staff about the women's desire to be hot and drink hot liquids after childbirth.

Use of Health Care System in U.S.

The physician is a person of high status in Asian culture and the Southeast Asian patient will probably give the physician in the U.S. a certain amount of traditional respect. However, the Southeast Asian patient may have some reservations about their medical care for several reasons. The maternity patient may not be accustomed to the idea of prenatal care because they see pregnancy as a natural event and not an illness and only think of going to a physician for an illness.

The Southeast Asian patient may wonder about the lengthy physical examinations and many questions asked by a western-trained physician. Traditional Oriental medical practitioners make a diagnosis after taking the pulse and checking a few other signs that are relatively quick and do not require elaborate equipment. Refugee patients who have not had much previous exposure to western medicine may doubt the ability of physicians and nurses who have to ask so many questions and use so much equipment.

Southeast Asian patients may feel that American doctors may not be able to understand their health or illness because they are unfamiliar with Oriental philosophy and people. Most of the refugee women in Little Rock go to a Chinese obstetrician when they are pregnant. Although he does not speak any of their languages, they feel that he is better able to understand them than a non-Oriental physician.

The Southeast Asian patient may find the relationship with health care professionals in the U.S. much more impersonal than the healer-patient relationship in Southeast Asia. They are not used to having to make appointments in advance, having to wait so long to see the doctor, or having constraints on consultation and treatment time.[4]

The Southeast Asian patient will also probably have difficulty with the high cost of medical care in the U.S.. Most refugees work at places without health insurance when they first arrive, and they cannot afford to buy it on their own.

All of these factors tend to make the Southeast Asian maternity patient likely to underutilize the health care system in the United States.

Stress Experienced by Southeast Asians

Classification as a Refugee

In order to be classified as a refugee and to be allowed to enter the United States, a person must be able to prove that he or she is subject to political, racial, or religious persecution, or that his or her life would be in danger if he or she were to remain in the homeland. There continue to be people leaving Vietnam, Cambodia, and Laos hoping for refugee status in the United States.

Escape

A few people are leaving Vietnam now under the "Orderly Departure Program," which allows them to legally leave if they have a relative in the United States sponsoring them. The majority of people from Vietnam and all of those leaving Laos and Cambodia are still escaping in small fishing boats or by crossing the border into Thailand. This is a very dangerous and frightening experience and one from which it takes a long time to recover. The people escaping over the border into Thailand are frequently arrested by Thai police until someone can bail them out of jail, or they can bribe their way out and make it to one of the Thai refugee camps.

Piracy and Rape

Refugees escaping by sea in small, unseaworthy fishing boats, known as the "boat people," are under a great deal of danger of pirate attacks. Hundreds of victims of pirate attacks have died from shooting, beating, knifing, or other violence. If victims survive the first attack, a second attack is almost certain. The average number of attacks per boat has almost consistently exceeded two since 1981, and sometimes it has been more than three.

Of 218 boats arriving in Thailand in 1982, there were 155 deaths reported from pirate attacks and 336 abductions and/or rapes. Rapes and/or abductions were reported by 53% of the boats. Of 500 persons reported as abducted from 1980-1983, almost all were female. Of the 500, fewer than half have been found. Abductions almost always include rape. Figures on rape and abduction by pirates are probably understated. The statistics are based only on those who make it through alive and report the rape and abduction. Many are reluctant to report rape to outsiders. The statistics only show how many were raped at least once. Many are raped repeatedly.[5]

The refugee women experience long-lasting psychological effects and emotional problems from rape, including depression, anxiety over possible pregnancy, loss of esteem by family and friends, and worry over whether it will affect their chances of a happy marriage.

Few services are available for the women once they arrive in the camps. There is rarely any counseling for the rape victims. Abortions are seldom available. The women are still vulnerable in the camps. Security is weak and allegedly has been violated.[6]

> Victims are characterized by depression, shame and feelings of worthlessness. This is exacerbated by a society which places great importance on virginity. Ostracism and sexual harassment of the victims has been reported in some refugee camps. Refugee workers in the camps have observed 'extreme disorientation and inability to carry out daily tasks' among the victims.[7]

Camps

If a refugee reaches his or her destination, the next step is a stay in a refugee camp and to apply for refugee status. Most Southeast Asian refugees go to camps in Thailand and Malaysia. The stay for refugees who reach Malaysia is about six months. They may then go to another camp in the Phillipines for six months to learn English. Thailand has a policy called "humane deterrence." This essentially means that they detain the people in the camps for so long that family and friends who hear about the detention will not want to go to a camp in Thailand and will try some other route. Stays in Thai camps are typically two to four years. During this period of time a person must obtain refugee status in order to be accepted to come to the United States.

Nutrition in the camps is poor. In some camps a person has to have money to buy food. In others, they are given rice and noodles and small amounts of other food. It is doubtful that a pregnant woman's diet would be adequate while she is in the camp.

There is little to do while staying in most camps except wait. People become run down physicaly and emotionally after extended indefinite stays.

Arrival in the United States

After arriving in the United States, there is usually a period of initial euphoria because the refugee has finally arrived in the place he or she has thought and dreamed about for so long. This may last from a few weeks to a year or more. Then the realities of life in the United States, in a culture very different from his or her own, begin to be understood. At this time, the refugee often experiences a period of depression lasting from several months to years.

Lack of Traditional Support

The pregnant refugee woman in the U.S. lacks the traditional support network she would have had at home. Most of the time she will be alone or with only her nuclear family. In Southeast Asia she would have had an extended family, probably all living nearby, and all playing an important role in her sense of well-being and confidence in her role as a mother. Older more experienced family members and friends were always available for advice. If a woman needed to go to the market, she could leave her children with a neighbor or her mother or mother in-law. In the U.S., even when some friends or family are living nearby, they are usually working and do not have time to help each other as they would have at home.

Work

In Southeast Asia most women stayed at home to take care of their home and children. If they did work, it was usually in a family business and they could keep their children with them. In the United States most refugee women work. Until they learn English they have little choice in jobs and usually work in factories. They are often standing or sitting in one position for many hours. Both the change in roles and the nature of the work refugee women often do can be a strain on a pregnancy.

Strain on Family Relationships

After the refugee woman is in the United States for a while she often begins to desire a change in her role within the family. She is now earning part of the family income and she feels that she has more of a right to be an independent person within the family than she was in the homeland. Her husband may expect her to still be submissive and obedient and to do all of the housework. She begins to see that American women do not behave that way, and she wants to have more rights, too.

Another source of conflict within the refugee woman's family is the increasing generation gap. In the homeland, where life had few changes from one generation to the next, the different generations did not have problems understanding each other. In the United States, the Southeast Asian woman is caught in the middle between two very different generations. If her parents are present, they are very unlikely to learn English or change their ways much to adapt to American culture. She has been taught to have a great deal of respect for her elders and yet they are expecting her to behave in a way that does not seem appropriate in her new country. Children, on the other hand, learn a new language and a new way of living very quickly and sometimes lose respect for their parents, who seem so slow to catch on to new ways. The children do not want to speak their old language anymore and are interested in such things as computers and designer blue jeans. The woman in her childbearing years may feel neither entirely American nor entirely Vietnamese, Laotian, or Cambodian. She is somewhere in-between, and the internal struggle between the two cultures can cause a lot of stress in her life.

Traditionally in Asian culture, family problems are kept within the family and are not thought of as something to discuss with outsiders. The refugee woman may be reluctant to divulge information of this kind to professionals who are trying to help her until she has close trusting relationships with them. Counseling is a foreign idea to most Southeast Asians, so they are not likely to be willing to go to a therapist. However, they may discuss their problems with medical staff, who are helping them with their physical care, since they are likely to see physical and emotional problems as interrelated. They are more likely to somatize than American and non-refugee Asian immigrant patients.[8,9]

Conclusion

Depending on her background, the Southeast Asian maternity patient may have expectations about her maternity care which are similar to an American patient's. If she is from a rural area and had little previous experience with western medicine, she may come from a very different background and have very different expectations and understanding about her care. Knowing something about an individual woman's background in her homeland can help the medical care professionals know where to begin in working with her as a maternity patient. If her English skills are poor, communication problems are presented that can be best remedied by the use of a bilinguial and bicultural interpreter.

The Southeast Asian woman is likely to have experienced a lot of stress in the process of coming to the United States as a refugee. Her life here is probably much more complicated and very different than the life she left behind. This can cause a lot of stress in her life that could affect the outcome of her pregnancy. The medical, nursing, social work, and nutrition staff working with her can see what resources are available to help make life a little easier during her pregnancy.

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Brief Overview of the Maternal and Child Health System, Oklahoma Area Indian Health Service

Pamela Turner Hunt, M.S.W.

The first federal health services for American Indians were initated in the early 1880's when Army physicians began undertaking steps to curb outbreaks of smallpox and other contagious diseases among the Indian tribes who lived near military posts.

The Bureau of Indian Affairs (BIA) began as part of the War Department but was transferred to the Department of the Interior in 1849. In 1884 an Indian agent by the name of Philemon B. Hunt relayed a request from the Kiowa tribe to the Commissioner of Indian Affairs for a hospital to be built in Ft. Sill, Oklahoma to serve the Kiowa, Comanche, and Apache tribes.

By the 1880's the policy of the BIA was clear in directing physicians to promote preventive services among the Indian population. The first appropriation which was earmarked specifically for general medical services to Indians was made in 1911. In 1912 Congress approved the use of $30,000 in tribal funds and four sections of unallotted Choctaw land for the construction of a tuberculosis sanitorium for members of the Choctaw and Chickasaw tribes. This facility later became a full general medical hospital funded by the Indian Health Service until it was contracted in 1984 by the Choctaw tribe of Oklahoma.

In 1926 medical officers of the Public Health Service Commissioned Corps were detailed to certain positions in the BIA program. In 1953 when the responsiblity for Indian Health was transferred by Congress from the Department of the Interior to the Department of Health, Education, and Welfare, there were more than 50 physicians and numerous other health professionals, nurses, dentists, sanitarians, and pharmacists on detail to the Indian Bureau from the Public Health Service.

There are no other groups of citizens who share such a unique relationship with the Federal Government as the American Indians. The responsibility for this is rooted in negotiated treaties which included various provisions for medical services. There are four laws which specifically concern Public Health Service under the Department of Health and Human Services. These are:

> *Public Law 83-568* effective in 1955, to transfer the maintenance and operation of hospital and health facilities for Indians to the Public Health Service

Public Law 86-181, passed in 1957 to authorize funds available for construction of community hospitals which will serve Indian and non-Indian

Public Law 86-121, passed in 1959, which authorized the Surgeon General to provide and maintain essential sanitation facilities for Indian homes, communities, and lands

Public Law 89-702, passed in 1966, which authorized transfer of responsibility for health services for inhabitants of the Pribilof Islands from the Bureau of Commercial Fisheries (Interior) to the Indian Health Services

The goals and committment of the present day Indian Health Service are to act as the Indians' advocate in seeking out other interests and resources, to offer every assistance to Indian efforts to staff and manage their own health programs, and to provide the best possible quality of comprehensive health care.

The Indian Health Service covers a 30-state area and serves a population of approximately one million people. There are 48 hospitals, three of which are managed by tribes, 72 health centers, 12 school health centers, and 500 field health clinics and health stations, 263 of which are managed by tribes.

The geographical concept of our program encompasses both reservation and non-reservation areas. The reservation was established by treaty rights dating back to 1784 and includes many of the western and northwestern states. Arizona and New Mexico contain the largest reservation areas.

Oklahoma has no reservations as all of the reserved land in Oklahoma that was traded or sold to individual Indian tribes for the establishment of their nations was dissolved under the allotment act of 1906. The tribes in Oklahoma do maintain several million acres of tribal lands but these do not constitute reservations.

In 1984 the Indian Health Service had over four million outpatient visits and approximately 105,000 hospital admissions. Diabetes was the second leading cause of outpatient visits. Injuries were the second leading cause of death and the second leading cause of medical and surgical admissions. The area of alcoholism, long a problem within the Indian community, continues to plague the Indian people. At least 95% of the Indian population is directly or indirectly affected by alcoholism which contributes to high rates of accidents, chronic liver disease, suicides, and homicides.

The social concept spans the traditional, transcultural and non-traditional aspects of the American Indian life. There are 487 tribes within the boundaries of the United States, so that working within the structure is closely akin to working within a United Nations framework.

A large majority of the total American Indian population falls into the income category of less than $10,000 per year. Approximately 15% are in the $10,000-20,000 per year levels, with only 3%-5% having incomes greater than $20,000 per year. Within the population that the Oklahoma Area Indian Health Service serves, approximately 70% are below the poverty level established by the Federal Government.

The Indian Health Service Maternal and Child Health program currently uses a "Problem-Oriented Perinatal Risk Assessment System" to establish high-risk incidence in its prenatal population. Using the system, it has been determined that as much as 70% of all prenatal patients are high-risk in the antepartum and intrapartum stages.

The prenatal risk assessment considers reproductive history, associated conditions such as renal disease, diabetes, cigarette/alcohol use, cardiac disease, and present pregnancy in developing risk scores which will assist with developing a managment plan and obstetric prognosis. The prenatal flow is completed as the pregnancy progresses to give an instant picture in case the pregnancy develops difficulty.

The most difficult areas in the antepartum stage are blood pressure difficulties, diabetes, gallbladder, hemmorhage, and size/date problems. Intrapartum difficulties are preeclampsia, eclampsia, cord problems, and abnormal labors. Genetically speaking, the cords of the American Indians tend to be extremely long, contributing to difficulties for the infant, as well as exceptionally long labors for the mothers. The atypical preeclampsia patient will present with unusually high platelet counts, liver enzymes, hyporeflexia, pulmonary edema, and gallbladder difficulties.

Much of the difficulties seen in our Indian prenatal population have been handled with a perinatal system that includes scoring a pregnancy according to level of risk in order to determine managment and outcome, dating, electronic monitoring, ultrasound, and amniocentesis. These, together with consultation and referral, have increased substantially the levels of live births for the American Indian population. The maternal health care system, which includes sufficient blood supplies, the administration of magnesium sulfate, and antibiotics, has greatly reduced the risk to the mothers although complications of pregnancy, childbirth, and puerperium still rank as the number one illness requiring hospitalization. Statistics have been gathered which show much reduced incidences of anemia, preeclampsia, low birthweights, and fetal death when prenatal visits increase past five visits. The system continues to encourage more visits and earlier visists among the prenatal population, in order to decrease the length of hospitalizations through proper prenatal care.

The generalist prenatal team is composed of members of several professional groups, i.e., the health educator, human service worker, public health nurse, environmental health professional, and nutritionist. The tribal community health representatives, who provide home health care and attention, as well as adequate transportation, working with the specialist teams, i.e., nurse practitioners, midwives, family practitioners, pediatricians, and obstetricians, have greatly reduced the rates of infant mortality and maternal deaths from levels of the past two decades.

More education and health care is being provided earlier to assist in the development of healthier mothers and babies. Staffing still remains the biggest concern, however, as the system continues to deal with a 70% high-risk population with only 50% of the required or necessary staff of doctors and nurses.

The Indian Health Service is essentially a maternal and child health system which encourages good health throughout the life of the American Indian individual. Historically started by treaty rights, the system continues to be maintained with the goal of achieving the best possible level of health care for the American Indian population.

Acknowledgement

The author wishes to thank William P. Gideon, M.D., Chief, Maternal Child Health Branch, Oklahoma City Area Indian Health Service, for the development of much of the factual material in this paper.

Part III

Handicapped Child

Care of the Handicapped Child in the Home

M. Patricia West, M.S.W.

Introduction

In order to take care of a chronically ill or handicapped child in the home, it is necessary to examine the philosophy of treatment. This paper will address care of children in any setting, as well as care of children at home. It is critical to expand the orientation beyond the symptoms of the child to encompass the family who nurtures that child. A parent/care provider partnership is essential to gain the necessary knowledge and consideration of the family context and, thereby, to establish an appropriate treatment plan for their child. This paper will discuss the elements of a successful partnership and the consequences of this partnership for the health care system. In addition, this paper will address: (1) the history of the author's interest in families; (2) the goals of the Colorado Special Projects of Regional and National Significance (SPRANS) grant; (3) application of goals to program planning needs; (4) research issues related to families and treatment plans; and (5) a family bill of rights.

History of Interest

Colorado's interest in a SPRANS grant developed from the need to restructure the service delivery of the Colorado Department of Health Social Work Program. Staff reductions following initiation of the federal Maternal and Child Health Block Grant in 1981 created this need. Fortunately, in May of 1983, a conference sponsored by the University of Pittsburgh School of Public Health on "The Family—A Critical Factor in Prevention" was held in Washington, D.C. The concepts that were discussed at that meeting helped to provide structure and direction for the Colorado Department of Health Social Work Program. Participants felt families needed to be involved more; families needed to tell professionals their priorities, so they could be incorporated into treatment planning. In Colorado, the basic premise in working with families is to empower them with the skills and the information that they need in order to be their own best advocates. It is recognized that there will never be enough professionals to "hand carry" those needy families through treatment and rehabilitation procedures, and that to do for someone is never quite as effective as to teach them to do for themselves. In order to accompish this, there must be a regular communication process between professionals and families.

Grant Goals

The underlying concept of the Colorado SPRANS Grant Family Assessment Project is that families have the primary role in this society of caring for their own members. The goal of policy should be to help strengthen families to nurture their children and to encourage their most effective development.

In order to implement that concept in the Colorado program, communication between families and the social work staff in the Handicapped Children's Program and in the Mountain States Regional Hemophilia Center had to be improved. A method was needed for families to report to social workers their problems and needs. The social work staff wanted to be able to compare the needs of families in order to establish which families were in greatest need of social work intervention.

Consequently, over the next two-and-a-half years, the Colorado Department of Health Social Work Section will conduct a research project which will develop a standardized and statistically valid questionnaire to obtain a psychosocial data base from a sample of the patient population which will permit inference of characteristics to the total patient population.

Upon completion of this project, the questionnaire will be mailed annually to all families receiving service from the Handicapped Children's Program and the Mountain States Regional Hemophilia Center. This will serve as a screening method to identify those families most in need of and ready for social work intervention. This will not be the only way to involve social workers with families in Colorado, but it will provide a broad view of families' needs so that scarce resources can be best utilized. These decisions will be made on the basis of information from the families, with the questionnaire insuring that social workers receive the same information from all families.

Last year, Colorado social workers implemented a pilot project using this concept and surveyed 352 families. There was a 40% response to a one-page, 25-item, mailed questionnaire; 35% of the questionnaires were returned with address problems. Even from that small survey, there were some interesting preliminary findings:

- —24% of the families were single parent families, a lower proportion than expected.
- —18% had changed residence in the last six months.
- —27% had a family member lose a job in the last six months, and 64% had experienced difficulty in purchasing basic necessities in the last six months
- —Although only 10% of the families receive Medicaid benefits, 47% had a gross income of $9,600 or less, approximately the poverty level for a family of four, at that time. In contrast, the 1980 rate for Colorado's families below the poverty level was only 7.4%.
- —Perceived severity of the child's problems by family members, and its psychosocial effects [illegible] em, were in part measured through survey results; the child's co[illegible]ion was the major problem for 55% of the families.

—34% of all the respondents labeled the child's medical problems as the most important problem in the family.
—19% indicated that other family problems were caused by the child's condition.
—Although 18% of the respondents felt that they had little control over their lives, 88% felt that they basically have a good life.

These results provided momemtum to continue an exciting project.

A project like this must be computerized. The special computer needs of this project will necessitate expanding current capacity. At this point, Colorado has a data system which gives encounter and consultation information to the staff. The number of hours that staff performed consultation, the number of families that received social work intervention, the type of activity, and the kinds of people contacted can be computed. In addition, the Handicapped Children's Program has a relatively effective data system giving a variety of information such as cost, the number of clinic visits, and the number of appliances, etc.

Planning Needs

In Colorado, a relatively unsophisticated method to divide the work load is employed. The number of jobs to be done is divided by the number of people to do the job, in order to determine the size of caseloads. It is, therefore, hard to evaluate performance on the basis of what did not get done when the data system shows how much was accomplished.

Outcome evaluation is equally unsophisticated. Currently, service delivery and outcome are evaluated according to the number of complaints received, but revisions are expected as a result of the project.

Planning and Management

The last management or planning issue is a more subtle one. Most clinicians gravitate toward certain kinds of situations and families, often without critically examining which patients they are reluctant to reach out to. How many times do clinicians pat themselves on the back after spending hours with the somewhat hysterical and chaotic family? Does anyone ever ask whether there are other families who had greater need of this valuable time? In Colorado, a psychosocial risking guide (Addendum I) was developed with the goal of sensitizing health care providers to a process which frequently occurs, i.e., the process of setting up patients and their families to fail. This is done by: (1) ignoring their other priorities, (2) emphasizing their problems for which we have solutions, and (3) not asking whether expectations are realistic.

When a patient or family is in chaos, it is critical to emphasize only the most important issues and to be sensitive to other problems which may have a higher priority. How many times do public health nurses or clinic providers take on very hard, draining cases and spend many hours to no avail? Perhaps the most important job that could have been done would have been to facilitate a referral to another agency to do their job. The time not expended on the chaotic family could have been saved for four or five other families more able to benefit from scarce resources. This position might sound like heresy to some care providers, but until the needs of a total population have been examined and priorities intelligently set, *reactive* case managment cannot be justified as the most effective use of scarce resources.

Research Issues

At a time when the Colorado Department of Health was reducing staff. two of the most creative and most demanding staff members proposed a potentially important project. The issue was how to decide which families are the best possible candidates for artifical sphincter surgery on their handicapped child. The SPRANS grant was developed as a way of dealing with this issue. To date, the criteria to identify families suitable for artificial sphincter surgery has not been fully developed, but we have begun to notice other places where programs are trying to codify family dynamics in order to set priorities for service. For example, the selection for heart transplant patients is only done after careful consideration of the depth and quality of the family support network available to that patient. Some biologically very appropriate candidates have been rejected on the basis of their family. This approach puts the family in a very powerful position.

Dr. Donald Bloch, editor of the new journal, *Family Systems Medicir* (Brunner Mazel, Publishers) is doing a great deal to emphasize the importance of this information. One recent journal issue focused on the research of Dr. David Reiss, George Washington University, regarding family ties and mortality in kidney dialysis patients. Dialysis patients with close family ties were the least likely to survive for several years. Surprisingly, Dr. Reiss believes that very close families have more difficulty with chronic illness.[1]

Another researcher in this field is Dr. Salvador Minuchin. In his work at the Philadelphia Child Guidance Clinic, he identified several features of families of patients with psychosomatic illness: family members are too tightly enmeshed in each others lives; parents are over-protective and rigid; and conflicts are not resolved openly. Change in family dynamics can produce change in the symptoms of the patient with the chronic illness.[2]

As stated before, Colorado's effort is going to be to standardize the information that is received on all families. On the basis of that information, the Department of Health will be in a much better position to do some ongoing research about program effectiveness and outcomes and how it may be or may not be related to the quality of family issues.

The Colorado SPRANS grant is testing the hypothesis that approximately 20% of the families are experiencing significant psychosocial problems and are ready for social work intervention. Diane Longo and Linda Bond have pointed out that families of children with chronic illness or disability have long been negatively stereotyped by researchers. Clinicians may have unwillingly perpetuated this notion. "The empirical literature contains sufficient evidence to suggest that more optimistic attitudes and frameworks can be employed when working with families of handicapped children. Marriages are not necessarily torn apart by the presence of a chronically ill child."[3]

Family Bill of Rights

The content of this section is derived from proceedings of a meeting held in Washington, D.C., during January 1985, by "The Ad Hoc Family Advisory Committee" to Habilitative Services Branch, Division of Maternal and Child Health Services, U.S. Public Health Service. Much of the Committee's findings on families may not be new, but it is important to restate these points. Working with families means working within a complex, multi-faceted, and dynamic, *but not* incomprehensible territory. Because families are complex, multi-faceted, and dynamic, particularly the latter, which means they change over time, many health care systems choose to focus on the *patient*. The stereotype of families with chronically ill or handicapped children as being chaotic and unable to cope has further perpetuated problems in perceiving families as resourceful and strong. When health care providers work with children and their families they ought to presume competence on the part of that family to make decisions and to advocate for their child. In addition to presuming competence on the part of the family, it then becomes imperative to establish ways to use their strengths.

The Family Bill of Rights is based on the concept of a family care provider partnership. Within this partnership the family can expect four points from care providers:

1. Knowledge, development, and use of family strength
2. Consideration of family needs balanced with patient needs
3. Unbiased and complete information sharing about resources, prognosis, and pros and cons of treatment choices
4. Connecting, and helping to maintain the connection, of parent-to-parent networks

These four points presume communication or dialogue between families and their care providers. However, clinicians in the Colorado Department of Health have found several barriers in the health care setting to having a dialogue with families:

1. A primary barrier is the perception of who is in control. The author proposes that it is the parent and not the caregiver who is in control.
2. Five-minute clinic visits are an absolute barrier to any dialogue with the family, much less with the patient.
3. Another barrier is lack of awareness of other problems that the family is experiencing or of other caregivers who may be assisting the family. A social worker may be concerned that her perception of the most important priorities for this particular patient may not be regarded with the same high esteem by another caregiver who views the family as having other problems.
4. Do professionals describe themselves and their role in relation to the patient/family as a caregiver or a caretaker? How do families view the caregiver's role? The caregiver is not a caretaker; that role belongs to the family. The giving of care is the family's decision to take or not.

5. When a dialogue is occurring between family members and caregivers, frequently there are questions. Some people will propose that caregivers do not have answers that they would want to hear if they were in the family's shoes, and, therefore, caregivers close off opportunities for questions from family members.
6. Rivalry among caregivers frequently stands in the way of people talking about and with other caregivers also giving care to the same family. Although this is frequently couched in the guise of confidentiality, the author believes that is a ruse.

Overcoming Barriers to Communication

The purpose of this paper is to facilitate health care providers examining their attitudes about families. Which of these barriers are in place and how firmly are they in place? There are remedies that provide a place to start.

1. Start talking with families.
2. Start listening to families.
3. Decide in each setting those issues about the families served which are critical to care delivery.
4. Develop a communication mechanism to open dialogue with families about those issues.
5. Time to do this can be found by prioritizing efforts. Waiting for a neatly wrapped, wonderfully standardized family assessment tool is a delay tactic. There are many questions, some more clinically or psychiatrically oriented than others. In reality, each agency needs to decide for itself what questions are most important to be asked of the families. Ask all families the same questions, and then use those answers as a way to prioritize which families most need intervention.
6. Presume competence in all families.

Summary

This paper has looked at partnerships with families, barriers, attitudes, remedies, and the manner in which Colorado is approaching these issues. The benefits in creating a parent/care provider partnership and using the family Bill of Rights are:

—Better compliance with the treatment plan
—Improved utilization of the health care system
—Increased family satisfaction
—Happier, healthier children

Addendum I

Social Work Section
Colorado Department of Health
Psychosocial Risking Guide

DISCUSSION:

This guide provides a checklist of risk factors to assist you in identifying patients who may be difficult to work with because of their psychosocial problems. We know that certain personal and family issues may predispose, precipitate, and/or perpetuate the development of physical and emotional problems. As a result of these factors, the patient may be unable to make a commitment to those behaviors necessary to comply with your treatment plan.

IDENTIFICATION:

If a patient or family has one risk factor, it is cause for concern, but they can probably effectively use your services. With two or four risk factors, responding to your plan may not be possible without extra help. As the number of risk factors increases, it is increasingly more difficult for the patient to use your services, without significant help, such as referral to mental health or social services.

MANAGEMENT:

By using this guide, a caregiver can easily identify a potentially difficult patient and adjust clinic managment to deal with these barriers. Frequently, this patient's highest priorities are non-medical. Therefore, it is important to develop a realistic treatment plan—keep your expectations small and negotiate or contract on only the MOST CRITICAL MEDICAL ISSUES, until the patient's situation improves. These patients undoubtedly have genuine problems which will stand in the way of your treatment expectations for them. Rather than feel frustrated, simply try to be realistic on their terms.

In conclusion, a practical treatment plan will combine the priorities of the medical staff with the patient's priorities. Such a necessary compromise will go a long way toward keeping such clients successfully involved with your health care system.

RISK FACTORS

PERSONAL QUALITIES

1. Age of Mom, particularly <17 or >38
2. Low level of self-esteem
3. No sense of personal responsibility for consequences of own behavior
4. Feels no control over personal situation including health
5. Emotional status:
   a. angry, fearful, wide mood swings, depressed
   b. level of personal anxiety exceeding the presenting medical problem
6. Inability to conceptualize the future, planning and choosing accordingly
7. Substance abuse
8. High stress level
   a. number of recent moves
   b. losses (e.g. job, divorce, death, miscarriage)
   c. change in financial resources
9. Not completed high school

FAMILY SITUATION

10. Family issues
    a. child abuse, family violence, runaway
    b. neglect, failure to thrive, or abandonment
    c. step-family
    d. size of family, >3 children
    e. single parent
    f. child placed out of home
11. Absence of viable social support system
    a. extended family
    b. friends, church, etc.
12. Presence of other illnesses
    a. in patient or family
    b. genetic illness history in family
13. Financial problems
    a. minimum needs not covered
    b. absence of health insurance
    c. transportation problems
    d. no phone
14. Cultural, community or religious attitudes restricting use of health care system

Editor's Note: The author has compiled an extensive bibliography on family assessment and relationships of parents and handicapped children. This can be obtained by writing the author (see Participant List for author's address).

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Building Early Intervention Initiatives

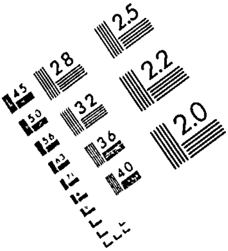
Anita Farel, Dr.P.H.

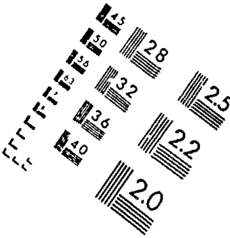
The idea of building early intervention initiatives conjures up notions of prevention—that is, not just accepting things as they exist, but taking initiative. This paper addresses ways to build early intervention initiatives through understanding federal legislation and regulations. A community-service continuum for early intervention will be examined and four major pieces of federal legislation that address early intervention will be discussed.

Although there are several federal programs that provide assistance to states who serve very young handicapped children, no single federal policy assures comprehensive developmental services to all handicapped young children and their families. Programs such as the Handicapped Children's Early Education Program, for example, provide money to start a project with the assumption that local or state agencies will maintain the program after the federal grant ends. Some states may invest Federal developmental disabilities funds in tracking programs for high-risk infants or in efforts to expand understanding of fetal alcohol syndrome. Other states may not allocate any federal disabilities dollars to services for children. Thus, services for infants and toddlers with special needs frequently appear to be simultaneously fragmented and overlapping, cutting across several federal agencies without cooperation or agreement.

Before looking at a continuum of community-based services and the legislation that addresses the needs of infants and young children with handicaps, a working definition of early intervention is needed. For the purpose of this paper, early intervention means identifying children who are at risk of having a handicap or another special need that may impede their development and providing services to reduce the negative effects of the condition. Identifying youngsters as being at risk for chronic illness or developmental disabilities implies some uncertainty about the course of their development. This is as true for infants who clearly are not expected to develop normally as it is for children whose status is less certain. Early intervention can begin anytime between birth and school age. It is increasingly clear, however, that there are compelling reasons to begin as early as possible. Barbara Smith has identified several reasons for intervening early when a youngster is identified as being at risk.[1] She argues that early intervention serves to accomplish the following:

1. Improve the child's development. Recent research on child development emphasizes the rapidity of human learning and development in the preschool years. If stages when young children are learning certain skills that serve as a crucial foundation for subsequent tasks and solving prob-





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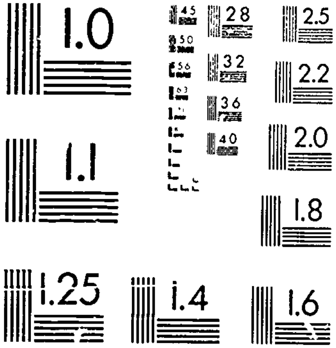

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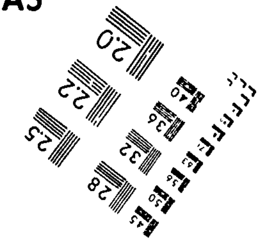

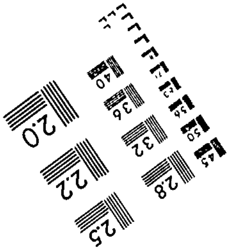

lems cannot be enhanced, a child may have difficulty learning basic skills at a later time.

2. Provide information, support, and assistance to the child's family. Most families with at-risk or developmentally disabled infants feel frustrated, frightened, financially burdened, helpless, and isolated. Thus, early intervention services are as important for the family (parents and siblings) of a youngster with special needs as for the youngster alone in mitigating stress and its sequelae that may interfere with the family's ability to provide an environment for the infant that is appropriately supportive and responsive. Families with children with chronic illness or developmental disabilities are vulnerable. They experience more divorce and suicide than families with non-handicapped youngsters.[2] There is some evidence that handicapped youngsters are abused more frequently than non-handicapped children.[3] Furthermore, the involvement of parents in their child's treatment is considered to be a critical factor affecting the success of early intervention services.

3. Insure that these children and their families make a contribution to society. All the strides toward independence that these children can make, through active participation in society's educational and economic institutions, reduce the likelihood that their dependence on social institutions will be prolonged.

Early intervention can be remedial or preventive. That is, the intervention may remediate existing developmental problems, such as hearing deficits, or may prevent their occurrence, as in early detection of phenylketonuria. Further, early intervention initiatives thus can actually refer to many different service orientations that run from information and referral, case assessment and evaluation, delivery of direct services, planning and service coordination to evaluation and accountability. It is important to emphasize that early intervention does not mean just direct services but a wide range of program activities. Furthermore, one agency may provide all these services.

Early intervention initiatives are made primarily under one of two auspices, i.e., public and voluntary or private not-for-profit agencies. This paper will concentrate on the former because most private not-for-profit organizations operate with a combination of private and public funds. Private agencies do not typically focus on services. When they do offer services, they are usually under contract and, thus, there is public reimbursement even though they are in the private sector.

Most initiatives that build on public funding are guided by four main laws. (See Figure 1.)

An important point, surprising to many people, is that the legislation that mandates the services does not describe the specific programs that must be provided or who is supposed to operate them. One reason that the laws do not go into detail is because their implementation is left up to an administrative agency. Each program has a federal agency that says how the law is to be administered. In addition, many details are left up to state and sometimes local discretion. Regulations clarify legislative language so that program administrators can interpret and implement the law. The regulations offer planners and service providers criteria that will guide requests for proposals and will be used to judge proposals, definitions of who can be served, and penalties for non-compliance with the law. A recent publication from the National Center for Clinical Infant Programs observed that "in the absence of legislation focusing specifically on the 0-3 population, executives in some states may be able, under existing education or health legislation, to use discretionary funds to request and fund proposals for needs assessment, studies or personnel preparation, and similar activities. Regulations in this instance would govern how funds were spent, even though they could not authorize funding."[4] Thus, one has to find out what the administering agency says about what has to be implemented. In most cases service providers assume someone else is doing this. Although this assumption is usually correct, providers frequently fail to take into account that the regulations are being interpreted from a particular point of view. Therefore, if one wants to build early intervention initiatives, one needs to know what can and what cannot be done under these program guidelines. Although the regulations clarify the legislation and the intent of the federal government in passing the law, there is more latitude and flexibility than many program planners and service providers realize.

In summary, it is the responsibility of administrative agencies to implement the laws by setting forth conditions under which states can provide services. These are regulations and, thus, are the key to understanding what kind of initiatives can be built. One cannot do more than the regulations allow, but they do provide flexibility. Figure 1 depicts the source of the program (the law) and the agency that administers it. Fundamental features of each law will be described in terms of some of the concepts they all have in common.

Education for All Handicapped Children

Since its enactment in 1966, the Education of the Handicapped Act (EHA) has served as the foundation for the federal role in the education of children with handicaps. Since the mid-1960's, Congress has continued to increase the federal role in special education by amending the EHA to expand existing programs and authorize new programs. An example of program expansion under P.L. 98-199, EHA's most recent amendment, was the establishment of state grants to develop and implement comprehensive plans for providing early childhood education to all handicapped children from birth through five years of age.

Developmental Disabilities and Bill of Rights Act

The Developmental Disabilities Assistance and Bill of Rights Act helps suppport planning and service activities and funds programs designed to protect the rights of persons with developmental disabilities. Although the term, developmental disabilities, originally specified disabling conditions such as mental retardation and cerebral palsy, the current definition refers to severe and chronic functional limitations. There are three major components of the federal developmental disabilities program and law.

1. Basic State Grants are awarded for planning and improving the state service systems. The Developmental Disabilities Councils, administrative activities, and projects that show new ways to provide services in states are funded through this part of the program.
2. University Affiliated Facilities conduct interdisciplinary research and training programs as part of regular university programs.
3. Protection and Advocacy Systems ensure the legal rights of all citizens with developmental disabilities.

There are also funds available for Special Projects concerned with developmental disabilities. Unlike the other three elements, which are administered locally, Special Projects funds are administered directly by the federal agency responsible for the entire program.

Maternal and Child Health Block Grant

The Federal government has funded services to mothers and children under Title V of the Social Security Act since 1935. In 1981, the Omnibus Budget Reconciliation Act consolidated numerous federal categorical programs into several block grants and shifted primary administrative responsibility to states. The Maternal and Child Health (MCH) Block Grant provides funds to states for a wide range of preventive and special health services to mothers and children. The MCH Block Grant legislation consolidated eight categorical programs: Crippled Children's, Maternal and Child Health, Lead-based Paint Poisoning, Sudden Infant Death Syndrome, Adolescent Pregnancy Prevention, Genetic Disease Testing and Counseling, Hemophilia Diagnostic and Treatment Centers, and Disabled Children receiving Supplemental Security Income benefits.

Early Periodic Screening, Diagnosis, and Treatment Program

The Medicaid law (Title 19 of the Social Security Act) was amended in 1967 to include preventive health care and services for children under age 21. The Early Periodic Screening, Diagnosis, and Treatment Program (EPSDT) is America's single largest federal program providing health care for poor children. This amendment requires every state operating a Medicaid program to provide EPSDT services to all children eligible for Medicaid. Unlike Medicaid EPSDT requires states to insure the provision of periodic screening, diagnosis, and treatment to eligible children, in addition to reimbursement for services.

Federal Documents

Two federal publications are essential in identifying the authority for early intervention initiatives. The *Federal Register*, published daily, announces major meetings, executive orders, presidential proclamations, requests for proposals, grant awards, and current program regulations developed by administrative agencies. Most program providers probably do not need to read the *Federal Register* on a daily basis, but individuals working in policy-making positions should read it regularly.

The *Code of Federal Regulations* (CFR), a compilation of all regulations by subject and agency, is published once a year. The annual publication date varies by chapter. The three chapters (of almost fifty) that will be examined here are Public Welfare, Health, and Education. Everything published in the CFR has the power of law. The CFR is the basic document for program implementation and regulation where information can be found to authorize building a particular early intervention initiative.

Figure 1 includes the purposes and target populations for the laws just described and also gives the specific CFR where the most recent regulations pertaining to the law can be found. There are only two different administrative agencies for the four laws that have been discussed.

Summary

A strong body of research documents the short-term and longer-range benefits of early intervention. It has become evident that the effects of handicaps can be reduced and subsequent handicaps frequently prevented when at-risk youngsters are identified early and receive appropriate services Thus, it is imperative that all infants identified as being at risk for handicaps or developmental disabilities be provided with appropriate care and services.

There are several tools for doing this. Figure 1 summarizes the differences among four federal programs. Once social workers have a working definition of early intervention and perspective on the broad range of early intervention services, they can think about the kinds of early intervention services they would like to see implemented. Using Figure 1, they can identify a program authority for that initiative and examine the regulations, from the CFR, for guidance about the possibilities and restrictions. When these skills are developed, social workers will not be limited to planning programs or offering services that are defined by someone else.

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Figure 1

PROGRAM/LAW FEDERAL REGULATIONS	ADMINISTRATIVE AGENCY	STATE PLAN	PURPOSES	WHO IS ELIGIBLE
Handicapped Childrens Early Education Program Education of the Handicapped Act P.L. 98-199 CFR 34:309	Department of Education Office of Special Education & Rehabilitation Services *State:* Department of Education	NO	Demonstration and outreach projects; developing and implementing early childhood state plans for a comprehensive service delivery system	Handicapped children 0-8 years of age Not income tested
Developmental Disabilities Program Developmental Disabilities Assistance & Bill of Rights Act P.L. 98-527 CFR 45:1385	Department of Health and Human Services (DHHS) Office of Human Development Services *State:* Human Resources Agency	YES	Depends on priority areas selected 1) Case Management 2) Child Development 3) Alternative living 4) Employment *Trains personnel to work with individuals with Developmental Disabilities	According to priority areas Not income tested *Facility associated with university
Early and Periodic Screening, Diagnosis, and Treatment (EPSDT) Title XIX of the Social Security Act (Medicaid) CFR 42:441	DHHS, Health Care Financing Administration *State:* Medicaid Agency	YES	Provide early, periodic screening, & diagnosis; ascertain physical/mental defects; provide treatment for chronic conditions	Medicaid recipients under 21 Income tested
Maternal and Child Health Block Grant P.L. 97-35 (1981) CFR 45:96	DHHS, Health Resources & Services Administration Division of Maternal and Child Health *State:* Human Resources Agency —Division of Health	NO	1) CC 2) MCH 3) Lead paint poison 4) SIDS 5) Adol. preg. prevention 6) Genetic counseling 7) Hemophilia 8) SSI<16	All children and mothers Income tested at state option

Part IV

Bioethical Issues

The "Baby Doe" Rule and the Care of Severely Handicapped Newborns: A Critique

John C. Moskop, Ph.D.

On April 15, 1985, the third anniversary of the death of Bloomington, Indiana's "Baby Doe," the Department of Health and Human Services published a final rule entitled "Child Abuse and Neglect Prevention and Treatment Program."[1] This recent rule is the Department's fifth and latest attempt in the last two years to formulate regulations regarding medical treatment of severely handicapped newborns. Like its predecessors, all of which were either struck down in the courts or revised in response to public comments, the author believes that this most recent "Baby Doe" rule has serious weaknesses which he will try to illustrate. First, however, this paper will briefly review the history of federal activity in this area.

The widely acknowledged stimulus for federal interest in the care of handicapped newborns was the 1982 Bloomington case in which an infant born with Down syndrome and esophageal atresia (a surgically correctable anomaly in which food is prevented from entering the stomach) died when his parents refused permission for surgery and several courts upheld their refusal.[2] At President Reagan's suggestion, the Department of Health and Human Services (DHHS) issued a "Notice to Health Care Providers" in May 1982 and an "interim final rule" in March 1983 requiring hospitals to provide life-sustaining treatment for handicapped infants or risk losing their federal funding.[3] The March 1983 rule required posting of a notice to this effect which included a toll-free hotline for anonymous reporting of potential violations. Such reports were to be investigated by federal teams nicknamed "Baby Doe squads." This first rule was struck down on procedural grounds shortly after it went into effect,[4] but the Department promptly corrected the procedural problems and reissued a slightly revised version of the regulations in July 1983.[5] Based on public comments by professional groups strongly critical of the regulations' notification and investigative procedures,[6] the Department significantly revised those procedures in the next set of proposed regulations published in January 1984.[7] The new set of regulations endorsed the idea of individual hospital committees, called infant care review committees, as the first forum for review of nontreatment decisions in those hospitals which chose to establish such committees. In June of 1984, however, these regulations were struck down by a federal court on the grounds that the regulations lacked statutory authority.[8] Congress remedied this problem in October of 1984 by passing a law, the Child Abuse Amendments of 1984, which brought nontreatment of severely disabled infants under the domain of child abuse and neglect.[9] On December 10, 1984 DHHS published proposed regulations designed to implement this law by (1) restating basic federal policy regarding necessary medical treatment, (2) requiring state child protection services to implement policies for acting on instances of potential medical neglect of disabled infants,[10] and (3) outlining the role of hospital infant care review committees.[11] The April 15 final rule, now in effect, is a revision of the December 10 proposed regulations.

Though the issues of state enforcement of these regulations and the role of infant care review committees both present serious procedural problems, critical comments will be focused on the substantive federal policy regarding treatment of disabled infants. (This policy is stated in section 1340.15 of the final rule and interpreted in a non-binding appendix to that section.) The policy includes, under "medical neglect," "the withholding of medically indicated treatment from a disabled infant with a life-threatening condition" and directs each state to develop programs and procedures to identify and correct instances of medical neglect. The key term "withholding of medically indicated treatment" is further defined as ". . .the failure to respond to the infant's life-threatening conditions by providing treatment. . .which, in the treating physician's. . .reasonable medical judgement, will be most likely to be effective in ameliorating or correcting all such conditions." According to this policy, then, if there is a treatment which can ameliorate or correct an infant's life-threatening condition, that treatment must be provided.

The regulations go on to recognize three specific exceptions to this policy, that is, three circumstances in which treatment is not required. These exceptions are: (1) when "the infant is chronically and irreversibly comatose," (2) when "treatment would merely prolong dying, not be effective in ameliorating or correcting all of the infant's life-threatening conditions, or otherwise be futile in terms of the survival of the infant," and (3) when "treatment would be virtually futile in terms of the survival of the infant and the treatment itself under such circumstances would be inhumane."

In its earlier (December 10, 1984) proposed regulations,[10] the Department had included what it called "clarifying definitions" for some of the key terms in this passage. For example, treatment which merely prolongs dying was characterized as follows: "death is imminent. . .and treatment would do no more than postpone the act of dying." These clarifying definitions, however, and, in particular, the requirement in the above passage and in several other places that death be imminent before treatment could be withheld were strongly criticized as distorting the language and intent of the Child Abuse Amendments upon which the regulations were based. These criticisms were voiced by a number of commenters, including the six senators who sponsored the Child Abuse Amendments in Congress. Thus, in its final rule the Department has abandoned its "clarifying definitions" in favor of an appendix providing non-binding "interpretive guidelines" regarding the use of key terms.

Murray argues in a recent article that this final rule "will have little or no effect on current (medical) practices" because its language is ambiguous and because its threatened sanctions are weak.[12] For two reasons, however, the author is not as confident as Murray about the innocuousness of this latest rule. First, the rule's "interpretive guidelines" remain very similar in content to the earlier "clarifying definitions." The one major difference is that the term "imminent" has been replaced by locutions using the undefined terms "near future" and "more distant future." For example, treatment which merely prolongs dying is now characterized as treatment which, "will do no more than temporarily postpone a death that will occur in the near future." 'Virtually futile" treatment is similarly characterized as treatment "highly unlikely to prevent death in the near future." Second, even though they are said to be non-binding, the interpretive guidelines are certain to have a chilling effect (the practice of physicians in today's malpractice-wary climate. Defensive medicine would surely seem to dictate cautious adherence to written federal policy mandating aggressive treatment. Thus, the language of the latest regulations provides only slight, if any, real improvement in flexibility over the old language.

In summary, current federal policy requires that all disabled infants be treated except (a) infants who are irreversibly comatose and (b) infants who will die in the near future and for whom treatment would either merely prolong the act of dying or offer a slight chance of survival with a high risk of complications and suffering. Whenever a treatment offers more than a slight chance of survival for an infant not determined to be irreversibly comatose, that treatment must be provided. It should be noted that, although it is more fully explicated, this basic substantive criterion is in essence unchanged from the first "Baby Doe" regulations proposed in March 1983. The procedures for review of treatment decisions and for protection of endangered infants have been significantly modified, but the substantive principle establishing when treatment is required has not.

The goal of this policy, namely, to protect handicapped infants from medical neglect, is surely an important one, and the policy may result in long term benefits for some infants who would otherwise have died for lack of treatment. Despite the highly publicized Bloomington "Baby Doe" case, however, it is not clear that very many infants in recent years have been harmed by the withholding or withdrawal of medical care. In fact, largely *because* of widespread scholarly criticism of an earlier decision to withhold treatment from an infant with Down syndrome and duodenal atresia, the 1973 Johns Hopkins case,[13] such neglect was probably an infrequent occurrence. In contrast to its 1983 warnings of widespread physician neglect of handicapped infants, DHHS now argues that its most recent regulations will affect the care of such a small number of infants that no regulatory impact analysis is required.[14] Thus, there may not have been a compelling need for new federal regulation in this area; especially since, as the rest of this paper will attempt to show, the current policy has at least three significant drawbacks. The three drawbacks which will be discussed are as follows: (1) though it may prevent harm to some infants, the current policy threatens the significant harm of unjustified prolongation of life to other seriously handicapped infants; (2) because of the harm it would cause, the policy would force physicians to violate their traditional and fundamental obligation to do no harm without compensating benefit; and (3) the policy may exacerbate existing problems or create new problems in the distribution of health care. These three problems will be examined in turn.

First, the policy threatens significant harm of unjustified prolongation of life to some seriously handicapped infants. In requiring that any infant whose life can be more than temporarily prolonged must be treated (provided that the infant is not irreversibly comatose), the policy comes close to presupposing a principle which Father John Paris calls "vitalism"; namely, that "life is the ultimate value, and something that is to be preserved regardless of prognosis, regardless of cost, and regardless of social considerations."[14] The policy's only significant departures from this principle are its statements that permanently comatose life and life which cannot be sustained beyond the near future need not be preserved. The policy assumes, in other words, that noncomatose, non-terminal life is always preferable to nonexistence; it expressly prohibits consideration of the future quality of life of the infant. This, however, is not a plausible assumption; there are conditions other than irreversible coma or death in the near future in which people would overwhelmingly choose a shorter span of life over a longer life of very poor quality. Treatment policies for adult patients recognize this possibility by requiring that physicians ordinarily obtain the informed consent of the patient even for life-saving or life-prolonging treatment.[15]

An obvious difficulty in determining the value of life-prolonging care for infants is that infants cannot express preferences regarding the continuation of their lives; indeed, they do not have any such preferences. It is not obvious, however, that this incapacity requires that some infants be consigned to prolongation of a life of significant suffering. In requiring that seriously handicapped infants be treated in almost all circumstances, the policy restricts the scope of a number of state statutes, common law precedents, and hospital policies which have allowed legal guardians or next of kin in many circumstances to authorize the withholding or withdrawal of life-prolonging treatment when it is not in the best interests of patients who cannot express their own preferences.

Infants whose conditions are severe enough to raise questions about the wisdom of aggressive treatment are not infrequently encountered in neonatal intensive care units (NICUs). Included among such conditions are extreme prematurity, severe intracranial hemorrhage, severe asphyxia, trisomy 13 and 18, and multiple severe congenital anomalies, (e.g. meningomyelocele with hydrocephalus, quadriplegia, scoliosis, and blindness). Sophisticated life support systems developed in the last two decades make it possible to sustain the lives of infants with these conditions, at least for a time, but frequently cannot ameliorate the severe underlying handicaps or prevent life-threatening complications, such as bronchopulmonary dysplasia, necrotizing enterocolitis, and intracranial hemorrhage.

In view of the suffering and often uncertain prognosis of such infants, decisions to withhold or withdraw aggressive treatment have been extremely difficult for parents and health care professionals. The author recognizes this difficulty and does not believe that a set of moral or technical criteria can be developed to provide simple and clear solutions in all cases. However, current federal policy takes these judgments out of everyone's hands and substitutes what amounts to a technological fix—whenever current technology can prolong life, it must be employed. Treatment decisions are, admittedly, greatly simplified by this policy; parents and professionals need not, indeed may not, consider the "salvageable" infant's life prospects, no matter how harmful they may appear. A graphic illustration of the potential for harm in the treatment of a handicapped infant is provided by Robert and Peggy Stinson's account of the condition of their son Andrew:

> Andrew was born at Community Hospital in our town on December 17, 1976, at a gestational age of 24½ weeks and a weight of 800 grams (1 lb., 12 oz.), at the extreme margin of human viability. He was admitted to the Pediatric Hospital Center (PHC) weighing 600 grams (1 lb. 5 oz.) on December 24, was placed on a respirator against our wishes and without our consent on January 13, and remained dependent on the respirator until he was finally permitted to die on the evening of June 14. The sad list of Andrew's afflictions, almost all of which were iatrogenic, reveals how disastrous this hospitalization was. Andrew had a months-long, unresolved case of bronchopulmonary dysplasia, sometimes referred to as "respirator lung syndrome." He was "saved" by the respirator to endure countless episodes of bradycardia and cyanosis, countless suctionings and tube insertions and blood samplings and blood transfusions, "saved" to develop retrolental fibroplasia, numerous infections, demineralized and fractured bones, an iatrogenic cleft palate, and finally, as his lungs became irreparably diseased, pulmonary artery hypertension and seizures of the brain. He was, in effect "saved" by the respirator to die five long, painful and expensive months later of the respirator's side effects.[16]

As the author understands the current policy, aggressive treatment of Andrew would be required until a judgement could be made that continued treatment was highly unlikely to prevent his death in the near future or that he was irreversibly comatose, that is, probably not before the last few weeks of his life.

If Mr. and Mrs. Stinson are correct in their judgement that aggressive treatment significantly harmed their son without the prospect of greater compensating benefits, then the physicians who treated him violated an ancient and honored Hippocratic principle of professional ethics, *Primum non nocere,* "First, do no harm." Of course, in an era in which powerful treatments often produce significant harms as well as benefits, this principle requires interpretation. One obvious interpretation is that in the absence of special circumstances such as a patient's specific request, treatments which promise greater overall harm than benefit to the patient ought not be provided. As already noted, determining when prolonging treatment constitutes a harm to the patient is not a simple matter, but neither is it impossible or purely arbitrary. At some point, the harms of painful and disabling treatment must surely outweigh the benefit of some chance at survival with a much diminished quality of life. At that point, providing further treatment violates the physician's commitment to do no harm.

The final set of problems that will be considered have to do with the impact of this federal policy regarding treatment of handicapped infants on the distribution of health care. As a high-technology, labor-intensive area of medical care, neonatal intensive care is very expensive. One 1980 study put the total annual cost of neonatal intensive care at 1.5 billion dollars for 150,000 patients, for an average of $10,000 per patient.[17] Another study cited by DHHS reports an average cost per patient of over $20,000.[1] Charges vary widely depending on the severity of the case; Andrew Stinson's bill for six months of hospitalization in 1977 amounted to $104,403.[18] Infants of poor families are disproportionately represented in NICUs, due to their mothers' poorer overall health status, younger age, and limited access to good prenatal care. Because many poor families lack health insurance and are unable to pay for their infants' care, hospitals are naturally reluctant to expand NICUs and assume a greater risk of financial losses. Dr. Arthur Kopelman, Director of the NICU at Pitt County Memorial Hospital, described the situation before the publication of the current federal policy in these terms:

> To be blunt, there are inadequate resources available to provide optimal care for every sick infant. The resources available reflect federal and state funding decisions. Intensive care nurseries often run out of space to admit more infants, but somehow we have always found a place for each infant at some center within our State. Our situation is neither unique nor the worst; sick neonates have on occasion been transferred to us who were born in hospitals several states distant because bed space was unavailable any closer. This is the best we can do under the circumstances, but it is not optimal. Because time is critical for these sick neonates, it would be better and much safer if they could be admitted to an intensive care unit close to where they are born.[18]

Current federal policy requiring treatment under almost all circumstances can only exacerbate this problem. NICUs will likely have to devote a larger and larger proportion of their beds to the most severely and chronically disabled infants, infants like Andrew Stinson who will have very lengthy stays in intensive care, some with limited prospects of ever leaving the unit. As this occurs it will become more and more difficult to provide intensive care promptly for all those infants with acute but completely reversible life-threatening conditions. Such infants may need to be transported long distances to secure care; their condition may deteriorate or they may die while physicians search for an available bed. This shortage of neonatal intensive care beds could be ameliorated by special programs to support NICUs or by increased reimbursement through programs like Medicaid and Crippled Children's Services, for which a significant number of such infants may qualify. Instead, however, current budget proposals seek to make further cuts in health care programs like Medicaid, along with most other domestic programs.

Fear of potential legal liability and financial losses may also prompt smaller hospitals to engage in a practice informally called "dumping." That is, hospitals, which may formerly have decided either to treat or not to treat some handicapped infants in house, may now invariably transfer such infants to tertiary care centers, further worsening the NICU bed shortage and creating severe and unnecessary financial and emotional stresses on families. Paradoxically, then, a policy which is designed to protect infants from medical neglect may, by prolonging the lives of a small but increasing number of the most compromised infants, result in higher overall morbidity and mortality for all those infants needing intensive care.

Recent and proposed cuts in federal health care and social welfare programs also jeopardize continuing care for those infants who do finally leave intensive care units despite their severe disabilities. Does current policy "save" infants from medical neglect in the neonatal period only to condemn them to continuing neglect of their substantial needs after they leave the hospital? Earlier it was argued that aggressive treatment and prolongation of life are not always in the best interests of severely handicapped infants Whether life will be of value for a handicapped infant obviously depends to some extent on what resources are available to help the infant develop his potentialities and meet future crises. A strong network of services providing custodial, medical, habilitative, and educational support clearly bolsters claims that such infants will benefit from neonatal intensive care. Current federal policies, however, mandate such care while seemingly seeking to dismantle many of the services upon which such handicapped individuals will later depend.

For all of the reasons discussed above, that is, the threat of unjustified prolongation of life, the violation of the physician's duty to do no harm, and undesirable effects on the distribution of health care, the continuing attempt to enforce treatment by federal regulation is an ill-advised response to the problem of caring sensitively for severely compromised infants. Our society should be proud of the ability of its health care system to care for very sick newborns, but the limits of its powers must be recognized. In medicine, as elsewhere, advanced technology cannot cure all ills. As the power of any technology increases, so also does its potential for harm.

A briefer consideration of decision-making regarding prenatal life follows. Arguments about treatment of severely disabled newborns may have a limited application to the issue of therapeutic abortion in the following way. If prenatal diagnosis uncovers a disease or disability severe enough to justify the conclusion that life would, on the whole, constitute a harm for the affected infant, then preventing that harm by means of therapeutic abortion would appear to be morally permissible and perhaps even desirable. The application of the argument about handicapped newborns to the issue of therapeutic abortion may be too facile, however, in view of several complicating factors.

First, it may be objected that the abortion procedure itself causes harm and suffering to the fetus which must be taken into account. This is the major message of the pro-life film, "The Silent Scream." A defense of abortion based on this argument must take account of suffering caused by the abortion procedure, but, despite "The Silent Scream," it is still very difficult to say how much the fetus suffers during the abortion procedure or whether significant pain or suffering is always present. Even if the fetus does always suffer during abortion and that suffering is taken into account, abortion may be justified in some cases in order to prevent greater future suffering.

Second, it may be argued that abortion is wrong because it entails the active killing of the fetus, not just the withholding or withdrawing of treatment. To this objection one might respond that abortion can be understood as the withdrawal of the infant from the biological life support system of the mother, hence not so different from the withdrawal of medical life support. Because most abortion techniques physically damage or destroy the fetus in the course of removing it, it seems more appropriate to acknowledge that abortion does kill the fetus and maintain that abortions done to prevent great future suffering are instances of justifiable killing.

The third and most telling objection to the previous argument for therapeutic abortion is that it can only be applied to very few situations with any degree of confidence. If the life prospects of severely handicapped infants are often very uncertain, the life prospects of fetuses are even more uncertain. One could, then, predict that life would not be a net benefit for a fetus only in the severest of cases, i.e., perhaps anencephaly and trisomy 18, but certainly not spina bifida, Down syndrome, or many other conditions commonly viewed as indications for therapeutic abortion.

The preceding argument for therapeutic abortion was applied earlier i this paper to handicapped infants. Applying it now to fetuses assumes tha fetuses have the same moral status as infants after birth. Thus, if it is successful in justifying therapeutic abortion in any circumstance, then the claim that fetuses are morally no different from infants does not imply the absolute prohibition of abortion. If one wishes to find a justification for therapeutic abortion in a broader range of circumstances, however, one must confront the complex and controversial question of the moral status of the fetus. One cannot do justice to this question in limited space, but perhaps the complexity of the question can be illustrated by showing why some of the simple answers one often hears are inadequate.

To begin, the pro-choice position is sometimes defended on the grounds that women have a right to control their own bodies. This right, however, is clearly not absolute; one does not have the right to act so as to kill another person, except in self-defense or other special circumstances. If, therefore, the fetus is a person with the same fundamental rights as all other persons, and especially if it is a person for whose existence and dependent status the woman is partially responsible, it is far from clear that that person may nevertheless be killed in order to restore the woman's bodily integrity.

Another pro-choice argument challenges the claim that the fetus is a person in the moral sense on the grounds that it lacks certain attributes necessary for personhood, such as the ability to reason or to act intentionally. Why, it may be asked, are just these attributes necessary for personhood, and if they are, does this imply that newborn infants are also not persons and, thus, justify infanticide as well as abortion?

In contrast to pro-choice advocates, defenders of the pro-life position often suggest that the presence of certain physical or biological characteristics justifies the conclusion that the fetus is a person. Thus, we are often shown pictures of fetal hands and feet and reminded that the fetus has a complete and unique human genetic endowment. If, however, one accepts the validity of brain-oriented criteria for the determination of death, these biological criteria cannot be sufficient for personhood, since the brain-dead body on life support systems is also physically alive, has a complete genetic endowment, hands and feet, etc., but is not a person in the moral sense. The pro-life activist will respond that the fetus, but not the brain-dead body, has the potential to develop all the important characteristics of persons. If the fetus has the potential to become a person, then it is not a person right now, and, hence, is not now entitled to all the rights of persons. Thus, we may value its potential to become a person, but need not respect it as a person.

In conclusion, although only a few of the arguments have been outlined, the author believes that empirical claims about the fetus cannot by themselves resolve the question of the moral status of the fetus. Rather, one must also focus directly on the competing values and interests at stake in deciding when and how to protect fetal life. This difficult task must be left for another time and place.

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Bioethics Related to Maternal and Child Health: The Social Work Role in Technological Times

Mary O. Holden, M.S.W.

Social workers have identified and performed in a variety of roles in the health care setting. These roles have developed and shifted during the years with a recognition of changing client, professional, organizational, and societal needs and sanctions.

Among these roles are those with such titles as coordinator, communicator, educator, facilitator, counselor, catalyst, and advocate. Various practice theories have been used which are based on a body of knowledge focusing intensely on a growing level of understanding of human behavior in the social environment. Along with the body of knowledge, a body of values including individual dignity and worth and self-determination (autonomy) has come into play.[1]

The model of the direct service worker as a generalist has been important in allowing for shifting roles. Although needs of clients, organizations, and society have made demands on the profession to perform in different roles, the basic value system on which social work was founded has changed little.

With the new challenges, as well as opportunities, that are currently presented in these technological times, the value placed by the profession on individual dignity and worth comes into sharper relief as it involves consideration of the value to be placed on sustaining the integrity of the individual or family value system of the client.

This commitment of social work in the health care field demands a further refinement of professional role as well as a more thoroughly developed body of knowledge in the field of ethics.

The roles of social workers as facilitators and coordinators of decision-making around controversial ethical issues has come to demand a firm base in "those concepts and analytical skills that will enable them to grapple with broad ethical theory in attempting to resolve both personal and professional dilemmas, as well as to reflect on the moral issues facing the larger society."[2]

To be more specific, the traditional roles of social workers in relation to controversial ethical issues require the social worker to identify the ethical principles involved as well as have an understanding of the dynamics of the client's behavior in the technological environment, a recognition of his and/or his family's system of values and the values of the attending professionals. All of this must be seen as it relates to the larger system of societal goals and restrictions. This series of activities comprises an emerging role for social work in clinical ethics which adapts to meet a need brought about by what Langdon Winner describes as "autonomous technology."[3]

No one is better qualified on a health care team (consisting of physicians, nurses, social workers, and, perhaps, physical therapist and dietician) than the skilled social worker in offering assistance in identification, analysis, and decision-making around ethical content. This statement could be construed as "damning by faint praise." It is not. It is rather an observation of the relative educational philosophies and curriculum contents of the team members' professional schools. The process of social work education, as well as the content, gives the social worker an orientation toward the process of practical clinical ethics. The value base of social work is supportive to the role. The profession's adherence to values which support human dignity and promote an ethical and responsive social order is described at length by Mary McCormick.[4] It is with the combination and the sometimes delicate balance of these values that the social worker concerns himself. This balance is not the primary orientation of the other professions on the health care team. Yet the process, the orientation, and the content are not enough. Educators in social work have begun to address the need. Reamer presents some welcome guidelines for analyzing ethical dilemmas.[5]

Over the last five years articles by social workers in publications devoted to ethical inquiry have been published. This fact is illustrated by Abramson's article, "Social Work and the Safety Net" in the *Hastings Center Report*, a journal which seldom publishes articles by social workers.[6]

Social work journals are now regularly presenting articles on ethical issues, an indication of the increasing sensitivity of the profession to the urgency to address them. This sensitivity (perhaps discomfort) is greatest among social workers in the health care field where treatment methods have begun to be "ordinary by virtue of their availability rather than their intrinsic ordinariness."[7]

Reamer and Abramson state, "It is important to help students learn to recognize ethical issues and dilemmas in social work and to think sytematically about them."[8] In doing so, it is necessary to further sharpen cognitive skills as well as to become "acquainted with the traditional schools of thought on ethical matters, and with arguments in support of and opposed to these various points of view."[9] They further note the importance of understanding one's personal attitudes, as well as being aware of the disagreement and ambiguity that frequently characterize reflection on and discussion of ethical issues.[10]

Callahan approaches the subject with wisdom in that he recognizes that both knowledge of the field of ethics and another field of particular interest is not only practical but essential. He uses the term "competent amateur" which, he explains, characterizes "the degree of training and sophistication that should be achieved by someone working in a field other than the one in which he or she was originally trained."[11] In further describing the qualities of the "competent amateur", he pictures him as having a broad familiarity with the language, concepts, and characteristic modes of thinking of another discipline.[12]

Clearly there are practical problems to becoming such an animal, but they are not insurmountable. This is a way of continuing to be unique and being able to continue to meet unique needs. According to Meyer, social work is "the only profession to draw a boundary around our work as being at the interface between the person and the environment."[13] This is being on the front line with patients and families as they find themselves in the unexpected territory of ethical dilemmas.

Currently, issues regarding abortions, Baby Doe, Baby Jane Doe, and Baby Fae continue to make the headlines. Unexpected territory related to all of these situations involved previously unencountered decisions for many individuals and families. The abortion question may seem less crucial since it is not illegal, but for many it still poses a major decision which may take some sorting out of ethics as well as feelings. This is true whether it is a teenage girl, a married woman who has determined a problem through an amniocentesis, or a prosperous professional for whom a pregnancy is ill-timed. The question in all cases is what is best for each mother and fetus in view of age, stage of pregnancy, environment, and value system.

In the case of an abortion, the role of the social worker is multi-faceted, but it may enable the client to analyze the situation at all points. It may assist the client in processing and either coping with the abortion, or developing and adjusting to alternatives, if the individual or couple chooses not to undergo the abortion. This process is consistent with respect for individuals and their autonomous choices while at the same time facilitating well-reasoned and, hopefully, growth-promoting choices.

An example of a unique place for the social worker is when problems of both ethics and family dynamics interplay. This is well illustrated by the comments of a judge who had been requested by parents of young girls seeking abortions to prevent the abortions on grounds that "it is against God's will," or "people should pay for their mistakes," or "I could not have an abortion when I got pregnant out of wedlock, so why should my daughter be able to have one?"[14] Few stated their objections in terms of the child's welfare. No one was dealing with the family system. Clearly this interface would be an ideal place for social work intervention. Another is the case of the pregnant 15-year-old Central American girl and her mother who came to the obstetric clinic with opposite views as yet uncommunicated to each other. The mother was very eager for her 15-year-old to have an abortion. Her daughter's future welfare as well as realistic view of life for the baby was in the forefront of her mind, but she was tortured by her religion's position on abortion. The daughter, by contrast, did not want an abortion. Her concerns were around her immediate desire to maintain her relationship with her boyfriend. As social workers know, the practice of beginning where each client is and helping each to identify and communicate the issues for herself and another goes a long way toward helping individuals find their own version of an acceptable decision as well as a more stable relationship.

The illustrations related to abortion may be the easier side of the coin. No one is restricted from having an abortion on demand during the first two trimesters. No one is forced to have one either. The social worker can work with individuals and their families in an effort to maximize autonomous decision-making in the light of psychosocial considerations as well as their own value systems.

Currently, this is not the case with decision-making around severely ill newborns. The decisions are not so free. One may or may not disagree with the evolution of regulations arising from the Baby Doe situation, but clearly they are here for a while, if not forever. Social workers have traditionally worked with parents who are in crisis resulting from the threatened death of a normal, but high-risk, infant or a severely handicapped baby who may require significant immediate treatment for survival.

Sometimes the risks may be anticipated through amniocentesis or sonogram, and a crisis may by minimized through initial antenatal social work intervention. Normally this is not the case. Crisis intervention with parents as they go through the impact of the situation on them and their baby is useful, but it may be more useful if the social worker is knowledgeable and confident about the issues at hand. This is a time when support and acceptance of strong emotions—anger, rejection, loss, and grief—can facilitate the course toward actions which may, at the least, minimize destruction of all concerned and, at best, result in effective coping with what may be a truly dismal situation.

A family that is being told that the law requires one thing, the physician has another view, and the nursing staff yet another is hardly in a position to begin to analyze its own view of the situation, much less cope with the presented situation. The social worker can help.

This is where the family interacts with the medical team. The social worker, being the only member of the team not directly responsible for the care of the baby, has more freedom to remain available, while emotionally removed, to help team members more clearly understand their own positions and motivations as well as the effects of these on parents and their situation. One wonders if any social worker had access to Dr. Owens, the obstetrician for Baby Doe, whose recommendations to the parents were as much based on the influence of personal experience as they were on his medical analysis. This is not to say that he would have come to a different recommendation if a social worker had helped him to express his feelings and recognize his own view, but it might have been helpful in his recognition of his influence on the family and the possibility of increasing the family's burdens and causing harm to all.[15]

Beyond this, the battle—and it was a battle—of the various physicians was not in the best interests of any concerned. The adversarial relationship between team members transforms itself easily into an adversarial relationship with families. This is indeed the front line of the environment where the social worker can use her clinical skills. Relying on her previously developed positive and professional relationships, she can intervene to create an atmosphere for the positive resolution of an ethical, medical, legal, and social problem for all concerned.

The proposed infant care review committees, as well as the more generally established hospital bioethics committees, have a place for a social worker, whether they know it or not. It is up to social workers to make this known.

The obligations, as well as the skills, of the experienced social worker need not stop at the hospital door in these situations. Social workers are beginning to develop a body of knowledge related to the policy reformulations needed if a policy of maintenance of "life" rather than maintenance of living continues to exist.

Our society may have to make up for the expected deficiencies families may demonstrate in the face of caring for such infants. Young, in a study of the care provided for disabled infants in Britain and Sweden, points out two important factors which may be of great importance for social workers to recognize:

1. Prevention
2. Resources consistent with the need[16]

No one is in a better position to focus on the need for prevention of the abnormalities caused by general poverty and, more specifically, poor nutrition, alcohol, and drug abuse than the public health social workers. Many problems can be prevented if social policies can be influenced.

Regarding resources, the needs of Britain and Sweden are smaller because of both prevention and clear policies related to less aggressive treatment of babies under 750 grams in weight. When the baby is aggressively treated and survives there is a financial commitment and program support for these children and their families which is consistent with the need.

Social workers in this country are in a position to influence the resource policy in terms of consistency with the results of the "autonomous technology" or to change the "technology for all" policy to keep it consistent with the resources. They may be in a better position than any group to assist in identifying needs and influencing policy decisions. Organized social workers, the subgroups, i.e., maternal and child health, perinatal, and developmental disability social workers, may be in the best position to build a case for policy reformulation. It may be part of what Pellegrino describes as the "act of profession" which implies a promise to help to the maximum degree possible.[17] This may be the maximum degree.

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Parent's Rights vs. the Child's Rights for Care

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The concept that children have rights that may be in opposition to parent's rights is relatively new. As far back as 2150 B.C., under Babylonian common law, a child was considered to be the property of the parent. In fact, in order for the child to have any status as an individual, he had to be accepted by his father. "As an indication of acceptance, the father would blow into the child's face, imparting a soul, and giving the child his own name or the name of a family ancestor."[1] If the father did not accept the child as his, the child could be killed.[2]

The basic concept of the child as property of the parents changed little through the centuries. The Elizabethan Poor Laws (1601) tried to address the issue of starving children by removing them from their parents and putting them to work.[3] In effect, this established the state as a substitute parent who had total control over the child.

American law was patterned after the English law and continued the concept of the parent's absolute rights over the child. It was not until the late nineteenth century that children had the legal right to not be beaten nor treated cruelly or inhumanely.[4] In 1899, with the creation of the juvenile court system, the state of Illinois established the *parens patriae* concept where the state would take the role of the parent.[5] Again, the child did not have rights independent of the state, i.e., the juvenile court judge. The basic assumption seemed to be that the parent or parent susbstitute knew what was right for the child and had absolute control of the child.[6]

Even today there is not a clear-cut, legally binding statement of children's rights. The child's rights are basically negative rights: the right not to be denied an education, the right to not be so neglected that his life or health are endangered, and the right to not be physically abused.[7]

It was not until 1967 that the Supreme Court established the right of due process for juveniles in court proceedings. This decision represented a major step toward the recognition that the child's rights might not always be represented by the parent or the state acting as the parent.[8]

The one area of children's rights that seems to best be protected by the law is child abuse. All states have laws relating to child abuse and neglect. However, even this seemingly universally accepted protection leaves many gaps where the child's rights may not always be protected. What are the types and severity of conditions which constitute neglect? When does the parent's right to correct his or her child as he or she sees fit become child abuse? Should a parent's refusal of medical care for his or her seriously ill child be considered abuse?

This paper will look at some of the unresolved issues of parents' rights vs. children's rights related to the area of health care. The focus will be on two major areas: current issues in children's rights vs. parents' rights and some possible future issues in the rights of parents vs. the rights of children.

Current Issues

One of the major areas of interest for the public health social worker is the issue of the child's right to appropriate medical care. Is there a difference between a parent who fails to provide medical care for his or her child due to lack of resources, lack of knowledge, etc., and a parent who does not provide medical care due to religious beliefs? In some states, the law would view these two types of cases differently. Both types of cases could be prosecuted if the child suffered serious injury or death, but in many states (e.g., Oklahoma) the state child abuse law specifically excludes families who are acting on religious beliefs. The law states:

> No provision of this section shall be construed to mean that a child has been abused or neglected because said child's parent, guardian, or custodian in good faith selects and depends upon spiritual means or prayer for the treatment or cure of disease or remedial care of such child. (Oklahoma State Law 21-S846)

According to information obtained from the Office of the Chief Medical Examiner in Oklahoma, there have been at least eight deaths in the state since 1982 related to lack of medical care due to religious reasons. All of these deaths are related to one religion, Church of the First Born. Some of the causes of death were ruptured appendix, sepsis, and uremia. Ages of the children involved ranged from birth to 15 years.[9]

Although some of these religious neglect cases have been prosecuted and the jury has found the parent guilty of neglect, so far all convictions have been overturned through the appeals process.[10] In many of these cases it is probable that had these children come to the attention of the health care system early enough, court orders could have been obtained to force treatment and save the child's life. In this type of case, however, these children usually have died before the authorities become aware of the situation.

Should the law protect these parents because they acted "in good faith"? Do parents have the right to let their child die in the name of religion? Is this a form of human sacrifice? These are difficult issues with which to deal not only as an individual, but as a social worker who is committed to the concept of client self-determination. Should the parent's right to freedom of religion take precedence over the child's right to life? Whose self-determination should we protect—the parent who is able to verbalize his beliefs or the child who may be too young and/or too immature to express his own beliefs?

What about the adolescent? Should he/she have the right to consent to their own care? If so, what are the factors that give them that right? Age? Maturity? Marital status? These issues are addressed in many ways through legal statute. Most states do have laws related to the consent of minors for specific health services. The most common areas of consent are for treatment of venereal disease, drug and/or alcohol abuse, pregnancy testing, and birth control information or devices.

How these consent laws are stated varies greatly from state to state. In Oklahoma, for instance, an unemancipated minor can consent for services under certain conditions:

> Any minor who is or has been pregnant, afflicted with any reportable communicable diseases, drug and substance abuse or abusive use of alcohol; provided however, that such self-consent only applies to the prevention, diagnosis and treatment of those conditions specified in the section...[11]

What this law means, in practical terms, is that Oklahoma has a "squeal rule" similar to the one President Reagan wanted to pass nationally. An unemancipated minor cannot self-consent for family planning services unless she is or has been pregnant. Prevention of the first pregnancy requires parental consent! It is not surprising that Oklahoma has one of the highest teenage pregnancy rates in the country.

On the other hand, under the same self-consent law an adolescent, if she is pregnant, can self-consent for an abortion. The condition of pregnancy emancipates her from parental control. (In reality, many physicians will not perform an abortion without parental consent, but it is legal and available.)

What values are being expressed through these laws? This paper does not attempt to address the issue of abortion from a moralistic standpoint but will examine abortion from both the parent's and the child's point of view. Health professionals generally encourage the adolescent to involve their parents in the decision-making process, but there are limits as to how far professionals can go if the adolescent does not want her parents to know she is pregnant.

Another issue health professionals will be facing more and more is the very young teen or pre-teen who is pregnant. Should the law apply differently to the 12- or 13-year-old pregnant teen and the 17-year-old? The Oklahoma law does not distinguish between the two.

In terms of parents' rights, do the parents not have the right to know about what health services are provided to their child? If the child is taking prescription medication (i.e., birth control pills) does not the parent need to be aware of this due to the dangers of side effects and the possible long-term effects of the medication?

From the teenager's point of view, why is it possible to self-consent for treatment for drug and alcohol abuse but not be able to self-consent for treatment of depression. In Oklahoma, suicide is second only to accidents as the major cause of mortality among teenagers.[12] Parents are often the last person with whom a teen wants to share their problems. If mental health services were available upon request for teens would this have a positive impact on suicide statistics?

When professionals talk about the rights of teenagers to self-consent for medical care, another issue is brought up, i.e., who will pay for these services? It is clear that parents are financially responsible for services for which they consent, but can they be held financially responsible for the service their adolescent seeks without their consent? If the adolescent has no income of her own, does society bear the financial responsibility? Social workers are often asked to deal with these issues in trying to find resources for their adolescent clients.

Future Issues

In trying to look at the future there seems to be some new issues of parents' rights vs. children's rights for health care that must be faced. Several of these deal with the prenatal area. With more and more research showing the deleterious effects of tobacco, alcohol, and drug use during pregnancy, can a woman's right to chose to use these products be condoned? Does the unborn child have the right to a better start in life?

In the recent study by the Institue of Medicine, *Preventing Low Birthweight,* smoking and alcohol were cited as two factors contributing to low birthweight. Smoking can increase the relative risk of pre-term birth 1½ times.[13] The relationship between mothers' smoking and lower birthweight infants has been documented by more than 50 studies. The correlation holds across all classes, age groups, ethnic groups, and geographic locations.[14] In the face of all this evidence regarding the potential harm to the unborn child, can society still defend the woman's personal right to use substances that are harmful to the health of her baby?

The full range of the effects of alcohol on the unborn child are not yet fully documented. It is known that heavy alcohol use can lead to fetal alcohol syndrome thus producing low birthweight babies with multiple congenital anomalies.[15] If professionals are aware that a woman is a heavy alcohol user, do they have the right to protect the unborn child by committing her to an alcohol rehabilitation center throughout her pregnancy?

Should a woman be charged with child abuse if she continues to engage in practices that pose a threat to the health and well-being of her unborn child? This issue has not yet been addressed in the legal system but may become an issue in the future as society becomes more and more concerned about the price being paid for unhealthy lifestyles.

Summary

All of the issues addressed in this paper create a legal and ethical dilemma for society as a whole. They are issues which have only been addressed in piecemeal fashion, if at all. There seems to be reluctance to take a strong stand for children's rights. Several organizations have proposed bills of rights for children, but no such bill has been sanctioned by laws.

In the absence of a clear-cut legal stand, health professionals are left to wrestle with the issue on a case-by-case basis. Being humans, their own biases often come into play in relation to these issues. The fundamental belief in the client's right to self-determination provides guidance in most circumstances. However, in situations where the parent's right of self-determination infringes on the health and well-being of the child, this concept begins to weaken. The child is often incapable of determining what is best for him.

Should professional responsibility then flow to the protection of the child against his parent's wishes? What if the negative effects of the parent's actions are not clear-cut? Where should the line be drawn, between protecting the child and imposing personal values on the family? These are not easy issues with which to deal.

The purpose of this paper has been to ask some questions which are difficult to answer and bring up some issues for discussion. Currently, there are no definitive answers to these questions.

As a group, public health social workers need to take a closer look at some of the issues presented. The major issues are: the refusal of medical treatment on religious grounds, the rights of the adolescent to self-consent for services, the right of parents to know the services their child is receiving, and the right of the unborn child to not be endangered by unhealthy lifestyle practices of the mother. Public health social workers are not expected to formulate definitive answers, but, hopefully, they can clarify some of their own feelings toward these issues.

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Critical Issues in Working with Terminally Ill Adolescents, Young Adults, and Their Families

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Professionals working in health care settings are involved in a spectrum of care—from prevention of disease to treatment, to comfort care of the terminally ill, to support of surviving family members. Each of these areas of focus has its own peculiar demands. The challenge of working with patients, for whom there is no hope of cure, and of assisting their family members in their grief is one of the greatest faced by caregivers in our field. This is particularly true when the patient is young and the impending death, therefore, "untimely."

While the traditional pattern of providing medical care was that of the physician as "supreme leader," surrounded by a retinue of "assistants" who did her/his bidding, a more effective method has emerged which involves an interdisciplinary team, each member with her own area of expertise, working in concert to benefit the patient. This team may include physicians, social workers, nurses, nutritionists, various medical/technical workers, child life workers, psychiatrists, chaplains, and even lawyers. Regardless of their discipline, these caregivers should be characterized by compassion, warmth, sense of humor, integrity, and have good communication skills.

When cure is no longer a viable option for a patient, the team's goal becomes assisting the patient to achieve an "appropriate death." Someone who dies an appropriate death is helped to remain relatively pain free and to operate on as high and effective a level as possible, with emotional and social impoverishments kept to a minimum. He is treated with dignity, kept informed, and given the right to participate in decisions affecting life/death. The death process should be experienced in the presence of caring individuals, and the opportunity to talk with them about it should be offered.

A key issue in working with this group of patients is an ethical one centered on the patient's right to knowledge about her/his condition. Once the terminal diagnosis has been established, all too often, a fantasy of protection occurs in which family members —and sometimes health care professionals—attempt to "spare" the patient by witholding information regarding the lethal nature of the illness. This is especially true when the patient is young. In reality, attempts to offer this protection are both ineffectual and a disservice.

Studies have shown that direct statements about their disease from professionals responsible for their care is but one of the ways patients learn the truth about their illness. They also learn by overhearing comments among staff, by direct statements from friends, from changes in the behavior of others toward them, from changes in medical routines, from changes in physical location, by signals from their body, and from self-diagnosis, including reading medical books, records, and charts.[1] Therefore, it is unlikely that the "secret" can really be kept.

This attempted conspiracy of silence is a disservice to the patient in that it frequently results in feelings of powerlessness, isolation, and abandonment, which in turn lead to mistrust, resentment, lack of cooperation, and failure to attend to important matters. The survivors too are losers in the conspiracy because of the potential for guilt, unfinished business, and a more difficult grieving process, having denied themselves the opportunity of resolving significant issues.

The question, therefore, becomes not whether to tell the patient, but when, how, and with whom. As soon as the terminal diagnosis is confirmed, the physician and team member(s) most likely to be involved in the psychological aspects of the process (generally the social worker) meet with the family. Which members of the family constellation should be present is decided on a case-by-case basis; certainly both parents, if possible, and the spouse, when the patient is married. They then talk with the patient, in the presence of the family, about the nature of the illness.

In breaking the news the message should be kept simple, not overly detailed, and be given in language the family and patient can understand. Time should be allowed for questions and questions elicited. While nothing should be said which is not true, hope should not be destroyed but rather refocused on shorter range goals.

The physician has the primary medical responsibility for the patient care and should present the information regarding the diagnosis. Social workers, because of their training in counseling techniques, are extremely important members of the terminal care team. They can perform a great service by using communication skills to facilitate what Kubler-Ross has called "the most meaningful help that can be given any relative, child, or adult: the opportunity to share his feelings before the event of death and to allow him to work through those feelings, whether they are rational or irrational."

Knowledge of developmental stages is important in helping young people do death work. Characteristically, the adolescent does not have a well-developed sense of longevity and hence is more concerned about the quality of life than the length. The young adult who is on the threshold of long-awaited experiences is more likely to feel keen frustration and disappointment at realizing that these expectations will not be fulfilled.

An awareness that the dying person may fear suffering and pain, the unknown, loneliness, sorrow, loss of body, loss of control, loss of identity, or regression will make the social worker more effective in assisting the patient to talk about these feelings. It is also important for caregivers to understand that Dr. Kubler-Ross's "Stages of Dying" (Denial and Isolation, Anger, Bargaining, Depression, and Acceptance of Death)[2] do not always take place in a neat and tidy manner, and that the reality for a patient may be anger one day, depression the next, and back to anger, with acceptance never forthcoming. Furthermore, they need to know that it is no reflection on their professional competence when this is so.

Social workers' knowledge of community resources can also be of great benefit to the dying person and her/his family. One assistance which can be offered is helping provide access to other professional services. This can range from religious personnel for the person who wishes to prepare spiritually for death to lawyers who may be required so that financial and legal issues can be resolved.

Another key issue in working with dying patients and their families is their right to make decisions about death. Ideally, once treatment for disease is ineffective, the patient or her/his representative should have the opportunity to choose that the focus be changed from aggressive treatment to comfort-care and to decide, within the limits of the law, to what lengths the physicians are to go in maintaining life. In most states, competent adults can expedite this by the mechanism of a "Living Will". For the patient to execute this responsibly and legally, she/he must be given a clear understanding as to what kind of interventions are appropriate under a variety of circumstances. Including family members in the discussion will facilitate their carrying out the patient's wishes in the event that mental competence is lost.

When the patient is an incompetent adult, the laws are unclear relative to the representative's right to decline extraordinary treatment which offers no promise of cure or to decide to discontinue the use of life-support devices. In cases where brain death has occurred, the declaration of death by use of an established protocol makes it possible to disconnect life-sustaining equipment in most states. In instances where irrevocable brain damage has occured, although not brain death, the laws are less clear and can lead to lengthy, expensive, and extremely difficult processes for the family, as in the case of Karen Ann Quinlan.

States' laws pertaining to minors vary, but tend to be similar to those pertaining to incompetent adults. The family must agree on the course of action; discontinuing aggressive treatment or life-support measures in spite of disagreement by either parent, a spouse, or a minor patient himself has grave moral implications, and, in some states, legal ones as well. In all of these situations the decisions are fraught with pain for the families. The social worker needs to be available to help them deal with their anxiety and frustration and to be knowledgeable of the laws of the state and of legal and financial resources available to assist them in their distress.

A third key issue for this group of patients is where to die. Although most Americans die in hospitals, there are alternatives. Hospitals are designed and organized to treat and cure; they may not be the best place for the process of appropriate death to occur. Home care, home care with hospice services, or residential hospice programs can provide terminally ill patients the opportunity of spending their last days surrounded by their loved ones at home, or in a more home-like setting than the hospital provides. It is incumbent on the social worker, as patient advocate, to make certain that these options are explored.

Even when they are "prepared" for death of their terminally ill loved one, the actual event of death is still upsetting to families. The social worker can be of great assistance to them in making certain that hospital staff have arranged to have the body ready for the viewing and that they have ample time to spend “saying goodby”. Managing the “traffic flow” at this time to provide some privacy for the immediate family is important.

While it is preferable for issues such as autopsies, organ donations, and funeral arrangements to have been decided earlier, this is not always the case, and the social worker needs to be knowledgeable about hospital policies and options in order to be helpful to families. Awareness of funeral costs, alternatives to the traditional burial, and local arrangements for the burial of indigents are all important parts of the social worker’s knowledge base.

The final key issue considered here is the survivors: parents, siblings, spouses, other patients, and the caregivers themselves. Social workers can help prevent grief pathology, family disruptions, and other adverse reactions if they teach survivors to anticipate some of the problems which may arise. Survivors need to know that people grieve differently and that comparison of grief as judged by outward display or expression is non-productive. They need to know that some of the emotions which they may feel, especially in the period immediately following the death, are, while strange to them, not uncommon among people in acute stage of grief. Most of all, they need to communicate openly with one another and with their friends. Siblings should not be “protected” by exclusion but should be involved in the expression of the family’s sorrow.

In *Macbeth,* a play by William Shakespeare, a character advises, “Give sorrow words: the grief that does not speak whispers the o’er-fraught heart, and bids it break.” After a young person’s death, bereaved families need substantial support if they are to successfully resolve their grief. In our highly mobile society there are people who do not have numerous friends and who mourn in loneliness and isolation. Self-help groups like “Compassionate Friends,” which has chapters in many communities, can offer meaningful assistance.

The effective professional person needs to be able to distinguish appropriate mourning from grief pathology in order to assist survivors. As soon as patients, families, and clinicians learn of a terminal illness, they are likely to begin the process of “letting go,” referred to as anticipatory grief. This can be helpful in cushioning the shock of eventual loss. It is problematic, however, if the withdrawal proceeds too far in advance of the actual loss.

Acute grief may be characterized by sensations of somatic distress, tightness in the throat, choking, shortness of breath, sighing, a sensation of emptiness in the abdomen, lack of muscular strength, feelings of distress, a sense of unreality, gastrointestinal complaints, emotional distance from others, and preoccupation with the image of the deceased. These are normal responses. It is problematic, however, if the grief is intense to the extent of potentially destructive acts.

Mourning is the longer-term resolution of the acute grief, the successful completion of which leads to a resumption of satisfying function in living. Problems arise if mourning is abnormally prolonged.

The caregiver should be concerned by the seeming absence of grief, by manic activity, dysfunctional hostility, or by symptoms of clinical depression (depressed mood, anxiety, insomnia, work problems, suicidal thoughts, somatic problems, or preoccupation with guilt) and should consider making a referral to an appropriate mental health provider.

When the deceased young person has had frequent hospitalization during the course of the illness, it is likely that other patients have come to know and care for her. In these cases it is important that the patients be told of the death in a straightforward manner by someone on the staff with whom they have a close relationship, and that they be given an opportunity to ask questions. A small group meeting is often a good way to do this. Patients who have the same disease as the person who has died will likely anticipate their own death at this time and will want to know about the extent of the patient's suffering and the family's reactions. Staff members must allow adequate time to be available to them during this period.

Professionals are also moved by the loss of a young person for whom they have cared. Few work environments have the potential for such high levels of chronic stress than those involving terminal care. It is important that hospitals provide emotional suppport and facilitation of communication to those who work in these stressful settings. Social workers can provide leadership in making sure that the institutions in which they work are responsive to this need.

While providing terminal care is challenging, difficult, and stressful, it is also rewarding to know that professional interventions have been instrumental in assisting a patient to achieve an appropriate death and the survivors to work through their grief and resume normal living. Since death is one of life's inescapable eventualities, helping make the process go well is an extremely important function for health care professionals.

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Part V

Advocacy

Strategies and Organization for Advocacy

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Maternal and child health as a public policy issue has attracted more and more attention in recent years. Health professionals, elected officials, and policy makers frequently debate whether poor health is on the rise, what remedies exist, and who should pay the cost of services. We see this concern in the editorial pages of local newspapers, in the platform of candidates for public office, and in the journals of professional organizations. We see it in the studies produced by such organizations as the Southern Governor's Association. We also see it in the statements of former Assistant Secretary of the Department of Health and Human Services, Dr. Edward Brandt, who commented that the recent slowdown in the rate of decline for infant mortality is "disquieting" and "worrisome."[1]

For those of us who have been involved in maternal and child health for years, this new and growing interest is both welcome and a bit mystifying. Yet, there do exist circumstances today which distinguish the mid-1980's from earlier times.

First, the United States has achieved a level of technological sophistication unsurpassed by any other nation. These developments have focused on the two population groups who are most susceptible to illness and death, the very old and the very young. Some of the most remarkable achievements include prenatal testing for genetic abnormalities, fetal surgery, and neonatal intensive care. Ten years ago few people would have thought that there would now be the ability to sustain the lives of babies born weighing less than two pounds. Regardless of individual opinions on the merits of technological life-saving services, it is clear that these new developments have caused many professionals to think differently about health and medical care for mothers and infants.

This period is also distinguished from others by the thoroughness with which considerations of cost have been integrated into thoughts about health care. Ten years ago the enormity of health care costs was beginning to be recognized; today the merits of procedures and programs are judged based on "cost-effectiveness." (Those arguments may be rejected or ignored, but cost remains an important planning consideration.)

One area of health care where cost evaluations are commonly used is maternal and child health. Because expensive neonatal intensive care and medical technologies for pregnant women have contributed so greatly to spiraling health care costs and the cost arguments in favor of prevention are so strong, efforts to reduce health care expenditure frequently focus on maternal and child health.

However, the most prominent and disturbing feature which distinguishes this period from others is the apparent worsening of maternal and child health status in many communities. While it is difficult to arrive at firm conclusions until more data are available, most observers, including Reagan Administration officials, have expressed concern over recent maternal and infant health statistics. The decline in the nation's overall rate of infant mortality has dramatically slowed. While the national rate of infant mortality declined by an average of 4.6% a year from 1965 to 1982, the rate of decline in 1983 and 1984 was "well below the annual average decline." According to Dr. Brandt, "...slowing to this degree has not been observed since the plateau in infant mortality between 1955 and 1965."[2] If the 1983 provisional infant mortality rate of decline was the same as that of the past decade, 700 fewer babies would have died.

These new problems are indeed alarming. We must also be concerned about the continuation of old problems. For example, the rate of infant mortality among black infants remains twice that of white infants. In 1982, the latest year for which race-specific data are available, the national infant mortality rate was 11.5 deaths per 1000 live births. For white infants, the rate was only 10.1, while for black infants it was 19.6.

Infant mortality is particularly high in southern states. When all states and the District of Columbia are ranked in order of lowest to highest for infant mortality, southern states are disproportionately distributed at the high end of the scale; among the 17 states with the highest rates, 14 are from the southern region.

As dramatic and alarming as these figures are, it is even more disturbing to know that many infant deaths and infant health problems are preventable. Numerous studies have documented that the chances of a healthy pregnancy and healthy baby are increased substantially through early and continuous prenatal care. Among these are:

—A Colorado study found that women who have complete prenatal care have a prematurity birthrate of 5%; women who receive no care have a prematurity rate of 28%.[3]

—A Missouri study found that white mothers with inadequate prenatal care have a 50% greater prematurity rate than white mothers receiving adequate care. For non-white women the prematurity differential is 15%.[4]

—The California Obstetrical Access Program, initiated in 1979 in response to the inability of poor pregnant women to obtain care, has provided maternity-related services to over 7000 women in the last three years. Statewide results at the end of the first year of the project showed low birthweight rates 50% lower than those among comparable infants whose mothers did not participate in the project.[5]

—A study in Cleveland conducted in the late 1970's found that women who received comprehensive prenatal care at the city's Maternity and Infant Care Project experienced 60% less perinatal mortality and a 25% lower rate of preterm deliveries than comparable women not enrolled in the project.[6]

The importance of comprehensive prenatal care—including prenatal examinations, nutritional supplements, pregnancy counseling, health-related services, and appropriate inpatient delivery care—cannot be overstressed.

Once a woman has entered prenatal care, problems which may affect her pregnancy and her baby can be detected and treated, thereby greatly improving the chances of a healthy outcome. For many women, prenatal care also represents the first opportunity to use the health care system. Without this entree a woman who is a non-health care user is not likely to use the system for her child after its birth. Prenatal care is the basic gateway to good maternal and child health.

In spite of the known effectiveness of prenatal care, thousands of women do not receive the care they need. In 1982, only 79% of white women and 61% of black women began prenatal care in the first trimester of pregnancy. In that year, just over half of teenage mothers began early care.[7]

In southern states, these figures are even more alarming. On the average, only 72.1% of women in the South begin prenatal care in the first trimester.

Why don't women receive early prenatal care? Many people assume that pregnant women do not get the care they need because they do not know what is available or do not understand that care is important. Social workers may have encounters with people for whom information and outreach facilitates their receiving needed services. However, the failure of women to obtain prenatal care is a far more complex problem. For women who must commonly delay care—the poor and non-white—there exist barriers so enormous and prohibitive that information becomes only minimally useful. That is, if affordable, accessible, and appropriate services are not available, the informational component is of limited value. Yet in many communities, particularly neighborhoods populated by the poor and working-poor, affordable, accessible, and appropriate prenatal services are rarely available.

The most formidable and pervasive of these barriers is inaffordability. Evidence documenting the inability of poor women to obtain prenatal care for financial reasons abounds.

—One in every seven women of childbearing age is uninsured. Most live at less than 200% of the federal poverty level.[8]

—In the face of growing poverty, Medicaid reaches only 31% of the poor and near-poor. The number of women and children served has decreased during the past decade because of federal budget cuts and overall program stagnation.[9]

—Other programs are very inadequate. The federal Hospital Discharge Survey shows that in 1982, 500,000 women delivered babies without any source of public or private financial assistance.[10]

—State after state has now documented, through special task force reports on the medically indigent, the fact that thousands of persons, especially women and children, are unable to pay for health care and are going without essential services. The Robert Wood Johnson Foundation found that in 1982 one million families were turned away when they sought health care.[11]

In other cases, where financial barriers have been eliminated through the establishment of free care or through broad Medicaid eligibility, poor women face other obstacles to care. Remote geographic locations and lack of transportation can prohibit women from obtaining care, particularly in rural areas. Limited hours, long waiting periods, and lack of day care on-site can make it extremely difficult for women who work, or who have other children, to keep monthly appointments. When health care providers do not speak the patient's native tongue or are unaware of cultural preferences, women can be discouraged from returning to care.

All of these barriers describe a health service delivery system that is, at present, generally ill-equipped to meet the needs of traditionally underserved populations. Can our society afford to address unmet needs for prenatal care? The answer is that it cannot afford *not* to. In addition to the individual social costs that premature death and disability bring, which are of themselves reason to ensure access to care, there are enormous financial costs associated with lack of prenatal care. Without appropriate health services, states and localities will face the sobering task of having to care for thousands of sick children, many for the rest of their lives.

For every 100 babies born without adequate care, it is estimated that 16% will be low birthweight; 30% of deliveries will include expensive maternal complications. Half of the low birthweight infants could be expected to need expensive hospital care at least once in the first year of life. At least two might need a lifetime of institutionalization. Others may grow up moderately impaired and in need of special supportive education and social services. Many others will simply never realize their full potential as healthy and productive adults. Both the short-term and long-term costs of not investing *early* in children are simply too great.[12]

What can be done? The task of improving maternal and infant health may seem overwhelming. Fortunately, infant mortality reduction has been identified by several organizations, including the Southern Governors' Association, as a primary objective. The Children's Defense Fund has also identified prenatal care as a focus of its work. Because its approach differs in some respects from that of most other organizations its program will be described.

Early in 1985, in response to the above-mentioned statistics, the Children's Defense Fund (CDF) launched a five year Prenatal Campaign. The Campaign seeks to do three things: first, expand funding for and access to prenatal care for poor mothers and adolescents; second, educate communities—women, teenagers, community groups, and service providers—about the importance of ensuring that mothers receive care; and third, involve a range of community and public decision-makers in setting and implementing goals to see that the number of babies born to mothers without prenatal care decreases significantly over the next five years.

The Campaign is based on several assumptions:

—First, although a variety of reasons may account for the high proportion of women who do not receive early prenatal care, among poor women the most important reasons are lack of affordable, accessible, and appropriate maternity services.

—Second, although generalizations can be made about the problems women face when attempting to obtain prenatal care, particular problems are likely to vary from community to community and from state to state. It is, therefore, critical that local information always be collected.

—Third, in order to succeed in removing barriers to prenatal care, local organizations and individuals must be intimately involved in identifying problems, developing solutions, and implementing the strategies. With some technical assistance and support, communities can develop effective local and state prenatal campaigns.

—Fourth, in communities across the country, exciting efforts are already underway which can serve as helpful examples.

Working intensely in selected states and communities, Children's Defense Fund will provide technical assistance and support to community organizations in developing analyses of the maternal and infant health status in their community and evaluating the availability of services, creating action agendas for addressing these problems, and implementing these plans. Since CDF has just initiated the campaign, explicit examples of these agendas cannot be given. However, a discussion of some of the areas on which CDF is likely to focus its attention follows.

Medicaid

There are two major policy areas in which CDF is likely to be involved on a state level, Medicaid and Maternal and Child Health Services. The wisdom behind expanding eligibility for Medicaid is well documented, and many states have acted upon this information. Because of the cost-effectiveness of maternal and child health care and the incentives to finance health care improvements through Medicaid, *over the past 18 months, 10 states have passed initiatives to expand Medicaid eligibility for mothers and children.* Several others are seriously considering doing so; CDF will work with other states that follow suit.

Medicaid expansion generally takes one of two forms: expanding benefits, or broadening the categories of services covered under the plan. States also may use a third and extremely important means of strengthening health services for the poor under Medicaid: through more liberal Medicaid reimbursement levels for providers that serve the poor, including local health department clinics, Maternity and Infant Care (MIC) Projects, Children and Youth (C and Y) Projects, community health centers, and public hospitals. Through enhanced Medicaid reimbursement, community providers generate revenues that allow them to serve more of the near-poor who are not themselves Medicaid-eligible, as well as to provide Medicaid recipient more health-related services that are not directly reimbursable under Medicaid (such as nutrition supplements and social services).

Non-Medicaid Policy Initiatives

Since 1981, states and counties have been faced with reduced funding levels and increased responsibility for maternal and child health services. It has been estimated that the budget cuts from 1981-1982 were about 15%. For Fiscal Year 1985, appropriations for the Title V Maternal and Child Health Block Grant program were increased from $399,000,000 to $478,000,000, but this amount is still less than Fiscal Year 1982 constant service levels for the programs consolidated under the block grant. Decisions regarding the distribution of scarce Maternal and Child Health funds have thus become increasingly difficult.

As previously mentioned, a number of states have responded to tightened federal health funding with Medicaid program expansions. These initiatives have the advantage of maximizing federal financial participation, insuring large numbers of women and children, and making scarce state and institutional dollars available to programs for the near-poor. In contrast, other special initiatives tend to focus on a narrower population group and have short-term funding mechanisms. However, it is important to note that Medicaid and non-Medicaid initiatives are often highly complementary. Medicaid provides the poor with a means of purchasing health care, while many of the non-Medicaid initiatives are designed to make services actually available to the poor, regardless of whether they are eligible for Medicaid. For example, in many communities there exist shortages of obstetricians willing to treat Medicaid patients. In these situations a publicly operated maternity clinic is important to both Medicaid-eligible and ineligible women.

States' overall responses to the widening gap between maternal and child health needs and available resources have taken several paths. First, some states have put renewed energy into more targeted needs assessments in order to better allocate available funds for emergency needs. Others have expanded and strengthened their public health service delivery systems. Expanded services have been a particular focus in the case of special populations such as poor pregnant women, pregnant adolescents, and their infants. Finally, some states have responded by seeking to make permanent changes in state public health laws to assure a minimum package of maternal and child health services. A few recent examples follow:

Florida

The number of low birthweight infants born in Florida has been increasing since 1975. Florida has a well-developed maternity care system with regional perinatal care hospital centers for extremely high-risk mothers and babies, but these centers cannot meet the level of need for specialized care. In 1982 the Department of Health and Rehabilitative Services estimated that only 25,000 (38%) of the 65,000 low-income pregnant women were receiving comprehensive prenatal care. In an effort to reduce infant mortality and morbidity, the state has funded statewide maternity projects for indigent women and collaborated in a March of Dimes Preterm Labor Program.[13]

The Improved Pregnancy Outcome Indigent Maternity Program was started in 1983 and is designed to improve access to prenatal care and to identify women at risk for delivering low birthweight babies. The program began with one federally funded demonstration project. Since the loss of federal dollars for this project, the state legislature has allocated funds to maintain the existing project and to expand the number of projects. Currently, projects operate in all but six counties. The nature of each project is dependent on community need and resources. For example, in some counties direct services are provided in the health department with county government providing funds to cover the cost of delivery care. In other counties, prenatal care services are provided through counties with private providers. Health officials hope to be able to meet all of the need for prenatal care services for indigent women with a $5,000,000 budget in fiscal year 1985.

To help ensure access to adequate health care, Florida also passed legislation this year which creates a pool of funds to pay for health care for the medically indigent. These funds are to come from hospitals, counties, and the state. Some of these funds will be used in 1985 to extend Medicaid coverage to pregnant women and children in two-parent families and to children in unemployed families. Florida also plans to further expend its Medicaid program in 1986 to reach medically needy children and pregnant women.

Texas

In Texas, legislation was recently approved which is aimed at reducing the number of low birthweight infants and perinatal deaths. Approximately one-third of all births in Texas occur in families who live near or below poverty guidelines (an estimated 90,000 poor women at or below 150% of the poverty level). Access to facilities is a serious problem in Texas. Most counties have no hospital facilities for indigent residents. Several of the large public hospitals cannot respond to the level of unmet need. Many infants are being delivered at home as a result of the barriers to care.

Under this legislation, the Texas Board of Health will create a Maternal and Infant Health Improvement Services Program which would provide any or all of the following services to eligible women and infants: comprehensive prenatal and perinatal intensive care, medical and hospital delivery services, neonatal intensive care, transportation, follow-up services, and services to pregnant adolescents. As outlined, the program would provide a framework for the equitable provision of services, using existing services where possible and creating new programs when necessary.

South Carolina

In South Carolina, the infant mortality rate has been among the highest in the nation for a number of years. Using available data on the causes of infant death, the health department identified care for pregnant women and newborns as a critical area. The statewide High-Risk Perinatal Program (HRPP) seeks to identify patients likely to have a poor pregnancy outcome and to assure that they receive appropriate care. In 1983, all pregnant women enrolled in the Special Supplemental Food Program for Women, Infants, and Children (WIC) Program (40% of South Carolina's pregnant women) were screened for high-risk status. A study of the HRPP showed fetal and neonatal mortality rates to be significantly lower for the infants of women participating in the program. This state also had a Low Birthweight Prevention Program similar to the one established in Florida. However, the state has expanded the Florida program by targeting not only women at risk for preterm delivery, but also women at risk of delivering infants who are full-term births but small for gestational age.

Arkansas

The state of Arkansas has targeted special services to the indigent pregnant women and children of Eastern Arkansas through a project called Healthy Beginnings. The nine-county project area has a disproportionate number of people who are poor, black, and living in crowded conditions. The adolescent pregnancy rate, low birthweight rate, and infant mortality rate of the area are all higher than the comparable state rates. The project is designed to provide non-Medicaid-eligible, low-income women with increased access to appropriate maternity services.

Community-Based Solutions

Sometimes problems do not lend themselves to broad policy solutions. It is likely that in some communities, local strategies and local remedies will be most appropriate. For example, outreach and education programs are often best developed and administered on a local level. Providing services in underserved communities may also require local, rather than state-wide action. Similarly, it is easy to envision addressing clinic- or provider-specific problems such as cultural insensitivity, inconvenient hours of operation, or long waiting times. Therefore, in concert with efforts to develop policy alternatives and Medicaid reforms, CDF will work with community organizations toward developing local solutions to local problems.

Meanwhile, in addition to offering technical assistance designed to improve access to prenatal care and providing a vehicle for sharing information, the Campaign will continue to educate policy makers, elected officials, and community leaders about the importance of early and continuous prenatal care. Until there is widespread acknowledgement that poor women are effectively denied care by the barriers they face in obtaining services, babies will continue to die needlessly. Until there is a national commitment to ensuring access to comprehensive prenatal care, we can expect progress only in states and communities that have made that commitment.

Some recent developments in Washington, including the introduction of new legislation, are encouraging. Senator Cranston introduced a bill which recommends the expansion of Medicaid eligibility to include all poor pregnant women. Congressmen Waxman and Hyde introduced a similar bill in the House which calls for greater flexibility in the maternity benefits package. Senator Durenberger also introduced a bill which is designed to allow provision of special benefits packages to pregnant women. These bills build on the Child Health Assurance Program (CHAP) package to pregnant women which was passed last year. The bills are seen by many as a cost-savings move, particularly in light of the fact that all newborns born to poor women are eligible since passage of CHAP.

Conclusion

In this limited way, the Children's Defense Fund intends to make a difference. CDF brings to this effort a strong ability to identify problems as well as an understanding of how the health care system and programs operate. We also bring a single overriding commitment to improving the availability and quality of health care for the poor, but obviously this will not be enough. If access to prenatal care is to be improved, hard work, imagination, and persistence will also be required. The author hopes that public health social workers will be responsible for part of this effort. A social worker's role could be educating his or her colleagues, family, or clients about the importance of prenatal care or organizing a local prenatal care campaign. The prenatal care campaign kit put out by CDF could be helpful in such an effort. Public health social workers should integrate the concept of full access to prenatal care into their thinking about health care and services for pregnant women.

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Examples of Advocacy on the State Level

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Parents of handicapped children have been perceived by professionals as consumers of services; target populations for counseling, training, and groupwork; and sometimes as adversaries demanding their rights to services for their children.

The author would like to describe Louisiana's experience with the Spina Bifida Association in a "partnership" building role, which has already resulted in dramatic and sweeping improvements in the care of spina bifida children and promises to continue to grow into improvements for the spinal-cord-injured children as well. They used strategies that any well-motivated, hard-working group of parents could try.

It began in 1979 when a few Louisiana parents attended a national meeting of the Spina Bifida Association of America (SBAA) and learned of multi-medical disciplinary teams serving these children in one visit to the clinic. The orthopedist, urologist, neurosurgeon, and pediatrician were available to see the child, plan together, and share ideas with the other team members (nurse, social worker, nutritionist, physical therapist, and occupational therapist).

Louisiana's Handicapped Children's Services (HCS) clinics for spina bifida children were segmented at that time. Many families had to return to clinic three or four times a month in addition to therapy sessions, X-ray consultations, laboratory work, etc. They also learned a variety of things that other states were doing to improve their case finding, information and referral, and many other services as well. The parents came home with a dream to revamp the Louisiana system of services!

However, the state was becoming aware of the loss of oil revenues and hopes of state Crippled Children (CC) staff for expansions of programs were dim. The parents group realized that if they were to get help it would have to come from the state legislature. Parents studied the districts of the state representatives and senators and matched these with their strongest and most motivated parents statewide to choose at least one representative that would listen and be willing to make a commitment to trying to make a change. Having found that one interested representative, the first strategy used by the group was to ask him to spearhead a request for a "concurrent resolution" to have a legislative task force study the broad picture of gaps in services to children with spina bifida. Since "concurrent resolutions" are usually virtually cost-free they pass through legislative bodies with greater ease. However, the danger inherent is that if not followed up closely with a precise plan of study they can be most ineffective. It was important that the study was preplanned with the sponsoring representative(s) before the resolution was passed so that there were no surprises after its passage.

The parents urged that this study take the form of five public hearings, spaced four to six weeks apart, in different areas of the state. The committee was made up of legislators representing the areas where hearings were held. A portion of each day-long meeting was planned to educate the panel on a variety of issues from "Right to Life" through Vocational Rehabilitation. Time was devoted to getting answers to questions that were raised in previous sessions. Finally, in each session was an opportunity for parents (many with their children) to tell their legislator of problems they had experienced or were experiencing in obtaining services and paying for services. Young adults with spina bifida were very visible and spoke about their concerns.

A second strategy the parents used was to obtain a small state Developmental Disabilities grant entitled "Public Education Relating to Persons with Spina Bifida." The parents association used this money to plan and prepare for the meetings, to publicize each meeting, and to invite a wide range of specialists to speak (including out-of-state practitioners). They also printed a large number of the final reports for distribution among all state representatives, state senators, service providers, and chapters of the Louisiana State Bar Association (SBA).

At the beginning there may have been legislators that saw these hearings only as an opportunity for excellent press coverage, as well as television coverage, of the hearings, as they appeared helping handicapped children and their families. However, ultimately every task force member became motivated to do something about "all this." The final report of the task force outlined several major issues and recommendations. These were immediately turned into two pieces of legislation. Both the House and Senate unanimously passed and gave appropriations for that legislation.

A third strategy was to build into the legislation an advisory committee made up of parents, disabled adults, physician specialists, and other service providers which was ordered to report annually, just prior to the legislative session. This strategy insured that program progress would be monitored and the budget needs reviewed before the appropriations committee met. This assured against cuts and managed to help the program to grow for three years. The proof of the quality of the strategy is that when that report came only from the state agency after three years and not the parents, it was buried in tabled actions with no priority given.

A fourth strategy involved state employees who saw the parents as adversaries and started to deny or defend the "state of the art" of their services. Other professionals decided that the parents had very legitimate rights to ask for improved services and responded cooperatively, so that by the end of the five hearings the leading parents, legislators, and HCS administrator were working together to find the means to address the problems.

When asked to suggest an appropriation level, a fifth strategy used by Louisiana professionals, who felt it was extremely important not to overestimate, was to ask for a phased-in program. This strategy led to a high trust level between legislators and program administration. It also enabled them to make what seemed like drastic changes slowly. They felt it was better to be successful slowly than unsuccessful quickly and at great expense.

Louisiana has five teams operating in four locations. Local chapters of the Louisiana SBA associate themselves with these clinics and even today (four years later) do many things to support the clinic staff in their efforts. Two more teams are planned.

Editor's Note:

The author recommends two booklets which the federal Crippled Children's Program made possible. They are entitled *Power Brokering on the State Level* and *Power Brokering in the Community,* available from Georgetown University Child Development Center, 3800 Reservoir Road, N.W., Washington, D.C. 20007.

Every Number Has a Name

Judith K. Barber, M.S.S.W.

The Children's Defense Fund (CDF) has prepared a valuable "Prenatal Care Campaign Kit" which provides national and state data showing how states rank in infant mortality, low birthweight, and early prenatal care. The book jacket carries the message "You Must Speak Out... Because the Victims of Infant Mortality and Birth Defects Can't Speak for Themselves." As CDF has pointed out, in the next six years, 22,000 American babies will die primarily because they were born too small to survive. Of these babies, 2,700—one out of every eight—might be saved if we ensure that their mothers receive early and continuous prenatal care. In 1980 the Surgeon General of the United States set the national goals that, by 1990, the national infant mortality rate should be reduced to no more than nine deaths per 1,000 live births, and that by 1990, 90% of all pregnant women should obtain prenatal care within the first three months of pregnancy.

The Mississippi State Department of Health has been active in developing a major public awareness campaign addressing these national goals.[1] They have been assisted by the Children's Defense Fund, as well as by a grant from the Division of Maternal and Child Health, Department of Health and Human Services, under their program of grants for Special Projects of Regional and National Significance (SPRANS). They have also received help from a strong coalition of maternal and child health advocates and the dedicated efforts of state health department social workers and their health team members. Public health social workers in Mississippi believe the linkage of data with stories at the local level is the key ingredient to turning goals into programmatic changes. Moreover, it is the responsibility of public health social workers to build that mandate for change into their job descriptions.

The problem addressed by the Mississippi Perinatal Awareness Project is that of access to appropriate perinatal care for women below the poverty level.[2] [3] Mississippi does provide prenatal care through county health departments in every county to any woman who requests service, but the problem is helping her find access to delivery and hospital services appropriate for her risk assessment if she does not have insurance or Medicaid.

For the past eight years, the Mississippi Coalition for Mothers and Babies has used a low-budget approach to make the public aware of the discrimination by Medicaid against married poor women who need maternity services.[4] Through the use of an audiovisual program, a newsletter, press releases, and regional meetings, all put together by volunteers, the Coalition called attention to the need for public funding for maternity and child health services for the married poor. With the receipt of a SPRANS grant, the Coalition was given the resources to print county data sheets and glossy handouts. It was able to undertake more sophisticated studies of uncompensated hospital costs for mothers and studies of reasons for physicians' reluctance to participate in the Medicaid program. The Coalition found that 25% of the cost of hospital care is shifted from indigent patients to paying patients, with a rise in insurance premiums, everytime the hospital daily rate goes up to cover indigent care. It was shown statistically that nearly 7,000 deliveries in Mississippi are in the charity or bad-debt categories, accounting for over $7,000,000 of uncompensated maternity care. Statistics were translated to county data sheets, which showed how many babies died in each county and pointed out that for every baby who dies, three will live with handicapping conditions. Newspapers in each county printed the data showing how many of the state's 2,052 institutionalized retarded citizens came from each county, at a cost of providing care for over $14,000 per person per year. CDF data demonstrates that for every dollar spent on prenatal care, up to $11.00 in costs associated with caring for permanently disabled children can be saved.

From each county stories were collected from maternity files that showed how poor married women were ineligible for Medicaid. The basic story was repeated over and over from county to county:

> A 25-year-old mother of two children is married to a man who lost his job and lost the family medical insurance. She was dismissed from her job when she became two months pregnant. She did not come in for prenatal care because she did not want to use the gasoline money that her husband needed for job hunting, and she did not know that prenatal care is free to anyone under poverty-level income. She was frightened about how she was going to get into the hospital and contemplated a home delivery. She was ineligible for Medicaid because she was married.

A story from northeast Mississippi describes the conditions more graphically:

> We were called to make a home visit on a cold windy day in January. The three-room house was under construction and very poor-looking construction at that. The rooms were partially sectioned off, no doors to close, plastic over the windows. The heating system was a 50-gallon drum made into a heater for burning wood. It was to say the least a miserable sight. Upon arrival, we found the whole family there, father, mother, two daughters, a two-year old son, and a seven-pound baby girl born the night before. We went right to work... Joan checking the mother, Yvonne checking the baby, and I asked all the questions a social worker could think of like income, insurance, food-stamp eligibility, and why no hospital. We urged the mother to get a PKU done as soon as possible. I think the best service I was able to give was to hold a quilt over the door while Joan did the exam.

While home deliveries are the exception rather than the rule in Mississippi, they are a dramatic example of the alternatives available to women who do not have insurance or Medicaid. Stories are used to look at the problems that can be addressed with existing resources and to look at those problems that will need a change in program priorities or a change in state or national legislation.

Another story of a woman who did not seek prenatal care until she was in trouble was that of a 26-year-old patient from Calhoun County:

> When she arrived at the health department she had not eaten in two days since she had been made to leave her grandmother's house. With help from the social worker, this patient received prenatal care and High-Risk state funds for her delivery. She was not eligible for Aid to Families with Dependent Children (AFDC) and Medicaid because she had no permanent residence. She could not obtain public housing because she did not have any income. She could not leave the county to go to a maternity shelter in Jackson because she had been indicted as an accomplice to a crime. Eventually she overdosed on painkillers provided by a dentist. Although she survived, the baby died.

There are many implications for policy change in this case. This is another dramatic story, but social workers experience dramatic stories daily. The question is how to translate the stories into policy change.

The policy change that was addressed in Mississippi was that of creating a Medicaid-funded program for poor married women with the same income as single, separated, divorced, or widowed women receiving AFDC.[5] In a three-year struggle Limited Medically Needy legislation was produced but not funded.[7] After a two-year delay the unfunded Limited Medically Needy Program was changed to a funded Optional Categorically Needy program which has the potential of providing inpatient, as well as outpatient, health care to 3,700 pregnant women and 18,000 poor children up to age 18. The new program, which begins July 1, will cost only $4,000,000 state dollars, in contrast to the $7,000,000 in uncompensated obstetrical care documented by our Hospital Association.[8] Federal matching rates will bring an additional $10,000,000 into the state for maternal and child health care.[9]

The social work program in the Mississippi State Department of Health has attempted to empower social workers to use the material from their case loads to address the problems portrayed by national, state, and local statistics.[10] In Mississippi, as in other states, it is clear that every number has a name, every name has a story, and every story has implications for policy change. In addressing the areas of infant mortality and the importance of early prenatal care, comparison tables of data provided by the Children's Defense Fund demonstrate that Mississipppi ranked 49th in infant mortality in 1982 and by 1983 was back in 50th place.[11] Mississippi ranked 26th in the chart for births to women who received late or no prenatal care. The data shows that in 1983, by the end of the first trimester, 74.7% of Mississippi mothers had begun prenatal care. This number rises to 91.6% by the fifth month of pregnancy. Pregnant women are being reached but not early enough. The rate for early prenatal care is 85.2% for whites, but it is only 63.2% for non-whites. CDF analysis of the characteristics of those who receive first trimester maternity care shows that to reach the national goal, Mississippi will have to progress at three times its past participation rate of increase. It is predicted that Mississippi will reach the Surgeon General's goal for early prenatal care for whites by 1990, but not for non-white mothers. How can the progress necessary to reach the goal be made? How can that progress be made in other states?

Mississippi has been improving its rate of progress toward the Surgeon General's goal for infant mortality by adding social workers to its county health departments. This is an example of a success story from one of the Mississippi State Department of Health social worker's monthly reports.

> An 18-year-old female with a five-day-old infant walked into a WIC clinic. She was without a place to sleep, food to eat, or clothing for her baby. With social work planning, arrangements were made to house her for three months in a trailer. WIC approved the client right away. Emergency Food Stamp and AFDC applications were to take several weeks. Local stores donated diapers. Baby clothing and blankets were donated by staff members and the Ministerial Alliance. Think what we could do with a social worker in every county.

However, scrounging and donations cannot address the overwhelming problems of poverty in Mississippi or other states.

In Mississippi in 1983 statistics show that of the 43,992 babies who were born, 664 of them died in the first year of life.[6] There were 3,921 babies who were low birthweight. There were 406 women who had no prenatal care at all. How can these statistics be given names and their stories told? One way is to write out their first names on a long banner of computer paper and stretch it around meeting rooms as Mississippi social workers have done. Another is to write stories for county newspapers about the statistics and the stories they tell. The best way is to empower women to tell their own stories to policy makers and the press. A 20-year-old woman who came to the county health department to give up her forthcoming baby for adoption shared her story. In the initial interview, where she and her husband and their two children were present, the parents explained their anxiety about their inability to support another child. Finally, the husband admitted that the issue of giving the baby up was not as traumatic as having to say that he could not afford to pay for his wife's maternity care. The hospital had garnisheed his salary to collect $2000 still owed for the last maternity bill. The county health department provided state high-risk hospitalization funds and the family kept the baby.

In July 1985 Mississippi began a major outreach campaign to find pregnant women in need of health care for themselves and their children. Part of the project is modelled after that of the Continuum in Georgia and after the British Citizen Advice Bureaus, which not only provide information and referral services, but also analyze the stories and the data to address the gaps in services and lacks of service. As a move is made with Children's Defense Fund and others toward the establishment of a national Medicaid minimum income standard no lower than poverty level for all pregnant women and children in this country, other issues must be addressed.[12] In many county health departments there is more than a two-week waiting period for new maternity visits. The Mississippi State Department of Health has declared that unacceptable if we are to meet the Surgeon General's goal for early prenatal care. Maternity visits and the necessary staffing for them will be given priority. The medical community and the members of the hospital association are being involved to support a legislative study committee on indigent care.

If social workers can find and provide services for the 3,700 pregnant women newly eligible for Medicaid and demonstrate that this is a cost-effective way to address indigent health care costs, perhaps the medical community will move with social workers to support both raising the state Standard of Need and the question of a federal minimum Medicaid standard no lower than poverty level.[13] Of the quarter million poor children in Mississippi, only half of them are Medicaid-eligible. If Mississippi State Department of Health social workers can find the new 18,000 potentially Medicaid-eligible children, there will still be 76,400 children under age 18 in Mississippi without Medicaid, any insurance, or any other way to pay for health care; 21,000 of those children are under age five. Names must be given to these statistics, too.

> In Leflore County two of these children are boys with epilepsy and vision problems. Their mother was turned down for Medicaid because she was said to have too much income from her job delivering newspapers. The Lions Club turned down her application for glasses and eye surgery for the children because they could not believe she had reported her income honestly. Lions Club members said they could not believe that anyone could live on so little money.

In Hinds County, a clerk who works for Blue Cross/Blue Shield Insurance Companies called to say that she had no insurance coverage because of her pre-existing condition when she took her job. She had no prenatal care. Her baby was born in January weighing one pound and nine ounces. By March the baby was still in the hospital and the bill was over $43,000. These stories are overwhelming to the patients and overwhelming to the social workers. One social worker wrote,

> Many times people ask me what I do. When I say I am a social worker, most people say, 'You have a depressing job.' My job is not depressing. What is depressing is seeing the public ignore the problems of poverty because it is depressing to them.

It is the responsibility of social workers to take on public awareness as part of their jobs. They cannot do it alone. They need the help of their co-workers, their supervisors, the physicians in their communities, and the hospital staffs. They will help, motivated by the enabling leadership that social workers can provide.

In conclusion, at the recent national Children's Defense Fund Conference, Gloria Steinem asked her audience to promise that in the next twenty-four hours they would do at least one outrageous thing in the cause of simple justice. She said:

> It doesn't matter whether the act is as small as saying 'Pick it up yourself' or as large as calling a strike. The point is that if each of us does as promised, we can be pretty sure of two results. First, the world one day later won't be quite the same. Second, we will have such a good time that we will never again get up in the morning saying, 'Will I do anything outrageous?', but only, 'What outrageous act will I do today?'

I urge you in the name of the mothers and children in your state to take one advocacy action tomorrow: call your legislator; write a letter to the editor, encourage your neighbor to run for office, and write her a check. The first black woman in the history of Mississippi has just been elected to the state legislature. She is a staff member for a community health center. She can help Mississippi turn its stories into new policies for families that will ensure children a healthy, productive future.

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Healthy Children Initiative of Tennessee

Lerlie M. Cleveland, M.S.S.W.

Many people have become increasingly aware of the importance of good health, not only for themselves, but also for future generations. If adults can recognize and accept prevention and the early identification and treatment of illness as key parameters in establishing and maintaining good health, then, subsequently, adults must accept the responsibility of guaranteeing optimal health care for their children. Health professionals in Tennessee believe many of the health problems affecting children are preventable and have embarked upon a mission that specifically addresses this goal. The Healthy Children Initiative, a four-year program launched by Governor Lamar Alexander, represents a combined effort on the part of several state departments, private physicians, and volunteers to ensure the health of Tennessee's children.

An appropriation of approximately two million dollars was made available for the current year. An increase in Healthy Children Initiative funds is anticipated for the next fiscal year. Other participating state departments received a portion of this money to help support their services to children. The majority of the funds has been designated for direct services to children and their families served through programs of the Department of Health and Environment.

Because state and community networking is essential in attaining child health goals, the Governor's Initiative involves a variety of public and private agencies, interested professionals, and concerned citizens—all advocates for children's health. The Initiative has as its guiding force the Governor's Task Force on Healthy Children, chaired by First Lady Honey Alexander.

The Initiative's slogan is a descriptive statement of what advocates are endeavoring to do: "Our children—Tennessee's Most Precious Resource—Don't Take Their Health for Granted."

Professionals in Tennessee feel there are four major factors that have a significant influence on child health. These are personal health and heredity, lifestyle, social environment, and physical environment. Some of the recommended services addressing these influences include family planning; prenatal, intrapartum, and postnatal care; medical and dental care; immunizations; counseling; provision of support services; health and wellness promotion; nutrition counseling; and home visiting. Attention has also been paid to improving the physical environment.

Strategies and specific action plans for improving the health of Tennessee's children are continuously being developed and implemented at the state and local levels with strong support from private health care providers, voluntary agencies, community groups, and interested individuals.

One of the most wonderful and rewarding outcomes of this endeavor has been the "joining of forces" or networking between the private medical sector and public government. The Initiative continues to receive enthusiastic support from the Tennessee Pediatric Society and the Tennessee Chapter of the American Academy of Pediatrics. One physician in each of Tennessee's thirteen regions has been recruited to serve as regional health officer. They, in turn, have solicited 300 physicians to help make our objective of assuring a "medical home" for every child, 0-5 years of age, in Tennessee a reality. Ideally, a "Medical home" is a personal physician to whom a child goes regularly for his or her total health care. The term "medical home" refers to the provision of preventive and acute care services 24 hours a day, seven days a week.

The concept of "networking" is manifested also via strong interdepartmental involvement between the departments of Human Services, Health and Environment, Mental Health/Mental Retardation, and the Tennessee Children's Services Commission. The primary leadership is being provided by the Department of Health and Environment.

The Initiative is a four-year plan and a major program focus has been targeted for each year. During the first year the emphasis was on prenatal care. A statewide prenatal program to assure that expectant mothers receive the care they need in order to deliver healthy babies had been in progress one year prior to the Initiative. Prenatal services are now available in Tennessee with funds provided through the Healthy Children Initiative in all 95 counties. The total number of prenatal patients seen in local health departments one year prior to the Healthy Children Initiative was 4,500. During fiscal year 1983-84, 11,500 patients were served through the statewide prenatal program.

The second year is now ending. This past year the Initiative's focus was on "Infant Follow-Up," a natural outgrowth of work in the area of prenatal care. A commitment has been made to establishing programs that identify and follow infants who have special needs so that they can grow up to be as healthy as possible. "At-risk" infants in this target group will include some infants born to mothers served in the state's prenatal program, infants discharged from regional perinatal centers, and infants referred from other health department programs and community health providers. Concentrated effort is being made to provide a "medical home" for this special population. A companion component of infant follow-up is the High-Risk Registry which is due for implementation July 1, 1985. It is designed to identify infants whose birth circumstances suggest a special risk for developmental delays or other handicapping conditions. Early intervention and treatment can be provided, together with appropriate ancillary services, to these infants and their families once identified. Children who are born with low birthweight, low Apgar score, and family history of hearing loss will be entered automatically on the registry. Using this method, approximately 2,000 children will be identified as high-risk.

A "medical passport," an abbreviated medical record, has been developed to be used by parents when their child receives care from a medical provider. The parents are requested to carry this pocket reference at all times and to present it during each visit to a medical provider. Pertinent data relevant to hospitalization; allergies; abnormal test results; screening tests for the Early and Periodic Screening, Diagnosis, and Treatment Program (EPSDT), and immunizations are to be recorded by the service provider.

Because of the broad scope of services being provided under "Infant Follow-Up," it will continue to be the program focus of year three with special emphasis on the High-Risk Registry children.

The fourth year of the Initiative will highlight school health. Plans are already underway. A first draft of a comprehensive school health plan has already been prepared. Health education and health services will be the component parts of this program area. Participants in the "Healthy Children Initiative" feel this will be an exciting culmination to their concerted efforts to provide for and protect Tennessee's most precious resource.

To be successful in conveying to the public the importance of good health care, mass media must be relied upon to enhance awareness. Campaigns corresponding to each program area have been developed with media involvement and support. A sampling of such has been provided for review.

Health problems cannot be treated in a vacuum. The psychosocial influences strongly determine the success of preventive health care. Addressing social problems demands networking between various agencies, professionals, and community volunteers who seek to prevent or change these circumstances.

The role of the medical social work consultant in Tennessee's Department of Health and Environment has been directed toward identifying and strengthening already existing medical social work services, providing medical social work input into various programs, subcommittees, and work groups, and giving consultation to social workers within the framework of the Initiative. To this end, the medical social work consultant, working collaboratively with other staff, is developing a booklet on pregnancy prevention. Teenagers in the age range of junior high school comprise the target audience for this information.

The medical social work consultant is a member of the social environment subcommittee of the Task Force whose charge is to concentrate on the social environment parameters and its relationship to health. This charge is broad in scope. However, because the prevalence of child abuse and neglect is high in Tennessee, the subcommittee has narrowed its agenda and is now focusing on this problem, its identification, prevention, and treatment. It will make appropriate recommendations to the full Task Force. A concurrent departmental assignment for the medical social work consultant has been her appointment to the Board of Directors of Parents Anonymous, Incorporated, of Tennessee, whose goal is to establish local "self-help" chapters across Tennessee. The Parents Anonymous educational and supportive approach represents an effective dimension in the treatment of child abuse. The Department of Human Services has approved funding of a parent Help-Line, staffed by volunteers with the back-up of professional social workers. This is still another excellent example of networking between state and private agencies.

The concept of voluntarism is especially important. The Department is cognizant of the myriad of services volunteers can and do provide and is quite anxious to capture these talents and appropriately use them within the scope of programmatic goals and objectives of the Initiative. The social work consultant is serving as resource person for the Department, working with local health departments and regional offices wanting to initiate or improve their volunteer programs.

Site visits, technical assistance, and development of standards all fall within the purview of social work. As our concerned efforts unfold in the realization of the Initiative's goals and objectives, so will those of social work services be promulgated to ensure that health care for Tennessee's most precious resource is not taken for granted.

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