PROCEEDINGS

"Social Factors in the Health of Families: A Public Health Social Work Responsibility"

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Child Health, Bureau of Health Care Delivery
sistance, Health Resources and Services
n, Department of Health and Human Services
he University of Pittsburgh, Graduate
ublic Health, Department of Health Services
ation, Public Health Social Work Program

112196

PROCEEDINGS

"SOCIAL FACTORS IN THE HEALTH OF FAMILIES: A PUBLIC HEALTH SOCIAL WORK RESPONSIBILITY"

March 23 - 26, 1986
University Inn
Pittsburgh, PA

SPONSORED BY:

University of Pittsburgh
Graduate School of Public Health
Department of Health Services Administration
Public Health Social Work Program
Pittsburgh, PA 15261

AND

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

Editor:

Gerald C. St. Denis, Ph.D., M.P.H.

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SOCIAL FACTORS IN THE HEALTH OF FAMILIES: A PUBLIC HEALTH SOCIAL WORK RESPONSIBILITY

MARCH 23 - MARCH 26, 1986

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N.B. Addresses and job titles are those recorded as of March 1986.

INTRODUCTION

The theme of our 1986 Institute was ably addressed by the keynote speaker whose presentation was entitled "Social Factors in the Health of Families: A Public Health Social Work Responsibility."

In his paper, Dr. Stanley Battle used an epidemiological approach to determine those social factors which impinge on families in our society thus rendering them at high risk for health and social problems. He cites the continued high rate of adolescent and out-of-wedlock pregnancy, the high rate of divorce, and the subsequent increase in female-headed, single-parent families, predicting that by the next century, there will be a permanent underclass of women and children who are completely dependent upon the public sector for support.

Dr. Roger White continued addressing the theme with specific emphasis on the social factors affecting infancy and childhood, and how the presence of combinations of two or more of these factors compounds the probability of an infant or child's having increased unmet health needs. He delineates roles for the public health social worker in the areas of program planning, implementing and evaluation, all with a view to enhancing family life and to minimizing where possible, the social and health risks to infants and children.

Dr. Sharon Milligan ended the first morning's session by bringing out those social factors which affect a "crucially important and often neglected period of the life cycle"---adolescence. She saw adolescents as vulnerable to peer group pressure, multi media advertsing, television, the movie and record industries, clothing and cosmetic advertisers, with different results and reactions depending upon whether the adolescent is a male or female. Although, as a group, those who are in the second decade of life have lower morbidity and mortality, the major problems they face, i.e., income and minority status, unemployment and single parenthood, necessitate preventive and treatment measures.

Our luncheon speaker, Dr. Barbara Shore, a leading social work educator, reemphasized the role public health social can play in helping ameliorate those social factors which adversely affect the health of families, seeing it as a challenge which we are equipped, by professional training and philosophy, to face and to change.

Although the first three papers were concerned with individuals and families who lived primarily in urban areas, there is a large segment of our population who are considered as rural residents. Dr. Edward Saunders offered clear examples of the need for interdisciplinary practice in rural areas, where the inhabitants face a gamut of social and health problems not unlike those in the city, but with far fewer services to call upon. Public health social workers need to be generalists when practicing in a rural environment, and must call upon their skills in working with an interdisciplinary team.

Margaret Weinberg presented a graphic picture of the consultant's role in integrating public health social work at program and bureau levels. Her examples of linking state and local delivery systems for the benefit of the client, on a state-wide basis, indicated the many roles which must be undertaken by the public health social work consultant who practices in such a situation, ever mindful of time, distance and budgetary restrictions.

An innovative approach to training mental health professionals in the provision of support services to adoptive families of special needs children was presented by Dr. Virginia Lapham, who shared with the group the complex process of mounting such a training project. Her reporting on the change in philosophy in adoption practice, both from the aspect of who are the adopters, and what kind of children are adopted, brought the group "up to date" on this important subject, and its implications for public health social workers, especially those who work with handicapped or developmentally disabled children who may be adopted.

In the panel presentation by two physicians, an educator and a social worker, the participants were given an update on the serious public health problem of AIDS, and its effect upon the populations we, as public health social workers, serve---mothers and children. Dr. Faison, the educator, discussed the model plan developed by the Pittsburgh Board of Education to be used in the event that AIDS might be found in either the pupil or faculty population of the school system. Dr. Richards, as director of a large county health department, presented the latest incidence and prevalence figures on the condition, as well as the high mortality rate over time. Dr. Harger presented clinical observations of the disease and its effect on women and children. From a social worker's perspective, Pamela Nimorwicz presented the psycho-social impact of this condition on the hemophilia population, and in her paper, outlines the changing role and responsibilities that social workers must face if they are to provide the services needed by this special group.

Three workshops were held, continuing the opportunity for further development of public health social work skills, a prime purpose of these institutes. Becky Williams conducted a workshop on "Needs Assessment and Program Planning," Drs. Kenneth Jaros and Edward Saitz on "Program Evaluation-Quality Assessment," and Dr. Lann Thompson and Phil Ludeman on "Psychosocial Factors Affecting Shared Decision Making With the Family." These sessions were well received by those attending and highlights of the workshops are in these proceedings.

Our thanks go to the Planning Committee and to our colleagues who served as faculty and to our participants, new and "old", who make an institute what it is.

Appreciation also goes to those who assisted in all the logistics of such an endeavor--announcing, registering, and preparing papers for publication--namely, Barbara Montgomery, Tina Herbst, and Cheryl Young.

Finally, our deepest gratitude for the continued sponsorship and interest of the Division of Maternal and Child Health, for us, in the person of Juanita Evans.

Gerald C. St. Denis

PROGRAM

1986 PUBLIC HEALTH SOCIAL WORK INSTITUTE

SOCIAL FACTORS IN THE HEALTH OF FAMILIES: A PUBLIC HEALTH SOCIAL WORK RESPONSIBILITY

March 23 - March 26, 1986
University Inn
Pittsburgh, Pennsylvania

SUNDAY, March 23

4:00 - 6:00 p.m.	REGISTRATION	Lobby
6:00 p.m.	INFORMAL SOCIAL HOUR	University Room (4th Floor)

MONDAY, March 24

8:00 - 9:00 a.m.	REGISTRATION	Lobby
9:00 - 9:15 a.m.	GREETINGS FROM THE DEAN Edgar N. Duncan, M.Sc. (Hyg.) USPHS ASG (Ret.) Associate Dean Graduate School of Public Health University of Pittsburgh	Oakland West
	INSTITUTE OVERVIEW Gerald C. St. Denis, Ph.D., M.P.H. Associate Professor and Director Public Health Social Work Program University of Pittsburgh	
9:15 - 9:30 a.m.	WELCOME Carl G. Leukefeld, D.S.W. Chief Health Services Officer U.S. Public Health Service Rockville, MD	

9:30 - 10:15 a.m.	KEYNOTE ADDRESS - "SOCIAL FACTORS IN THE HEALTH OF FAMILIES: A PUBLIC HEALTH SOCIAL WORK RESPONSIBILITY" Stanley F. Battle, Ph.D., M.P.H. Associate Professor of Social Welfare School of Social Work Boston University	
10:15 - 10:30 a.m.	BREAK	
10:30 - 11:15 a.m.	"SOCIAL FACTORS IN INFANCY AND CHILDHOOD" Roger B. White, Dr.P.H. Associate Professor School of Hygiene and Public Health The Johns Hopkins University	

<u>MONDAY, March 24</u> (Cont.)

11:15 - 12:00 noon	"SOCIAL FACTORS IN ADOLESCENT HEALTH" Sharon Milligan, Ph.D., M.P.H. Assistant Professor School of Applied Social Sciences Case Western Reserve University	
12:15 - 1:45 p.m.	LUNCH	Oakland East
	WELCOME Barbara K. Shore, Ph.D., M.Sc.(Hyg.) Professor and Director Doctoral Program School of Social Work University of Pittsburgh	
1:45 - 2:30 p.m.	"INTERDISCIPLINARY HEALTH CARE IN RURAL AREAS: THE ROLE OF PUBLIC HEALTH SOCIAL WORK" Edward J. Saunders, Ph.D., M.P.H. Assistant Professor of Social Work University of Iowa	

2:30 - 3:15 p.m.	"INTEGRATING PUBLIC HEALTH SOCIAL WORK AT PROGRAM AND BUREAU LEVELS: CONTENT, PROCESS AND ACTIVITIES" Margaret Weinberg, M.S.W., A.C.S.W. Social Work Consultant Bureau of Maternal and Child Health State of New Hampshire Department of Health and Human Services Division of Public Health Services
3:15 - 3:30 p.m.	BREAK
3:30 - 4:30 p.m.	PANEL: "THE IMPACT OF AIDS ON WOMEN, CHILDREN AND SPECIAL POPULATIONS: AN UPDATE FOR PUBLIC HEALTH SOCIAL WORKERS" N. Mark Richards, M.D., Director Allegheny County Health Department Moderator Helen S. Faison, Ph.D. Deputy Superintendent, School Management Pittsburgh Public Schools James H. Harger, M.D. Department of Obstetrics and Gynecology Magee-Women's Hospital Pamela Nimorwicz, M.S.W., Executive Director National Hemophilia Foundation Western Pennsylvania Chapter

<u>TUESDAY, March 25</u>

9:00 - 9:45 a.m.	"CHILDREN WITH SPECIAL NEEDS AND ADOPTIVE FAMILIES: A CHALLENGE FOR PUBLIC HEALTH SOCIAL WORK" E. Virginia Lapham, Ph.D., A.C.S.W. Director of Social Work Associate Professor Department of Pediatrics Georgetown University Medical Center Washington, DC	Oakland West

10:00 - 12:00 a.m.	*WORKSHOPS (Concurrent)	
	I. NEEDS ASSESSMENT AND PROGRAM PLANNING Becky Williams, M.S.W. Director Division of Social Services Arkansas Department of Health	Conference Room 6 (6th Floor)
	II. PROGRAM EVALUATION - QUALITY ASSESSMENT Kenneth J. Jaros, M.S.W., Ph.D. Research Associate Department of Health Services Administration Edward W. Saitz, M.D. Clinical Assistant Professor Department of Health Services Administration Clinical Assistant Professor of Pediatrics School of Medicine	Conference Room 3 (3rd Floor)
	III. PSYCHOSOCIAL FACTORS AFFECTING SHARED DECISION MAKING WITH THE FAMILY: A MODEL OF CHOICE IN MORAL, ETHICAL AND LEGAL HEALTH CARE DILEMMAS Lann E. Thompson, Ed.D., A.C.S.W. Assistant Professor and Director Social Work Section Child Development Program Riley Hospital for Children Indiana University Medical Center Indianapolis, IN	Conference Room 5 (5th Floor)
12:00 - 1:30 p.m.	LUNCH - On your own	
1:30 - 4:30 p.m.	WORKSHOPS (Continued)	

*Refreshments morning and afternoon available in each Conference Room.

WEDNESDAY, March 26

9:00 - 10:00	WORKSHOP REPORTS NEWS FROM THE FIELD	Oakland East
10:00 - 11:30	BRUNCH "WHAT IS PAST MAY NOT BE PROLOGUE" CLOSING REMARKS Juanita C. Evans, M.S.W., L.C.S.W. Chief, Public Health Social Work Bureau of Health Care Delivery and Assistance Health Resources and Services Administration Department of Health and Human Services Rockville, MD	

SOCIAL FACTORS IN THE HEALTH OF FAMILIES: A PUBLIC HEALTH SOCIAL WORK RESPONSIBILITY

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It is a great privilege and honor to have been asked to address this group of social work leaders in public health and maternal and child health care. The focus of this institute is Social Factors in the Health of Families: A Public Health Social Work Responsibility. Without a doubt there are many factors which impact the family from an intrinsic and extrinsic point of view. From a sociological perspective, many changes have occured in this country which influence personalities, values and institutions and bring about a marked change in the functioning of society as a whole. These changes have been most dramatic within the institution of the family where they have had a most telling effect on our personal lives. To some degree, we are all influenced by increasing sexual permissiveness, changes in sex role expectations, a declining fertility rate, altered attitudes toward childbearing and rearing, a continuing increase in the divorce rate and its consequences.

The mission of this Institute is to examine social factors in the context of Health and Families. The task is complex because of the many variables that must be explored. However, I will examine these factors by utilizing the social epidemiological model.

Epidemiology depends on the accurate assessment of a problem and the aggregation of case information for various populations. The goal is to identify factors and conditions which make up the causal chain leading to a manifestation of the problem. This chain is often represented as an interaction between the agent, host and environment. The agent is viewed as the cause of the pathology. For example, lead paint is the agent in lead poisoning among children who live in old, deteriorating housing.

The host is defined as the recipient of the damaging effects produced by the agent. The children who eat the lead paint risk brain damage. Both the agent and host have intrinsic qualities which increase susceptibility.

In addition to intrinsic factors in the host and agent, it is possible to identify extrinsic factors in the environment that influence exposure and susceptibility. Poorly maintained buildings with flaking paint are an extrinsic risk factor in the physical environment.

As one moves from biological and physical factors to social ones, a pattern of multiple causation emerges, and choosing the correct intervention becomes more complex. The early success in epidemiology came from 1) separating the agent and host; 2) destroying the agent; or 3) increasing the host's resistance. In addressing the complex social problems that concern public health social workers, these simple solutions do not usually exist.

The term reservoir is used to describe the part of the biological, physical and social environment that facilitates or nurtures the development of the agent. It is the environmental context in which the agent gains the strength to be harmful or changes from benign to pathological. For example, abusive parents often come from a reservoir of abuse as a child and grow up expecting children to fulfill parental needs (role reversal).

In the context of the family, the most logical place to start is the reservoir.

Society has dictated certain role responsibilities for the female and male in the context of a "family". But recent years have brought about significant changes in the marital and family patterns of many Americans. We have witnessed an era of greater sexual permissiveness, alternative family life styles, increased divorce rates, and reductions in the fertility rate.

The basis of a stable family rests on the willingness and ability of men and women to marry, bear and rear children and fulfill socially prescribed familial roles. In 1984, nearly 80 percent of women below the government's poverty level lived alone with their children. Nearly 45 percent of black families are headed by women, as opposed to 13 percent of white families. It is estimated that 70 percent of black children raised in one-family homes are raised in poverty.

Within the black community there is increased awareness of the societal pressures that influence the family. Based on data from the U.S. Bureau of Census (1983) there are 1.5 million more black women than men over the age of 14. There were approximately 1 million black males that could not be accounted for. This generally means that the male is transient or unemployed.

Since there is an excess number of black males at birth, the subsequent shortage of black males over the age of 14 must be attributed to their higher infant mortality rate and the considerably greater mortality rate with young black males through such means as homicide, accidents, suicide and drug overdoses.

The stability of the black family from a quantitative, qualitative point of view may be best explained from a study by Joe and Yu (1984). After an analysis of the economic and census data, they concluded that 46 percent of the 8.8 million black men of working age were in the labor force. Based on 1982 statistics, they found 1.2 million black men were unemployed, 1.8 million had dropped out of the labor force, 186,000 were in prisons, and 1 million were classified as "missing".

Overall, married couples still represent a majority of all households or 59%; however, married couples with young children are on the decline. The number of married couples choosing to remain childless nearly tripled from 1970 to 1982. In addition, families with three or more children are a vanishing phenomenon (a drop of 42.5 percent in one decade). The average number of children in a married couple household is smaller now than it has ever been in our history.

Another factor which influences the family is unemployment. We seem to be in a period, as Charles Dickens wrote 126 years ago, where "it is the best of times, it is the worst of times, it is the season of light, it is the season of darkness, it is the spring of hope, it is the winter of despair, we have everything before us, we have nothing before us." Many of our urban areas exemplify "A Tale of Two Cities". In Boston for instance, the city's unemployment rate is one of the lowest in the nation, while its poverty rate is one of the highest. The percentage of Bostonians living below the federal poverty line, which the U.S. Census Bureau determines as an income which is less than $10,609 for a family of four, increased from 16 percent in 1970 to 20 percent in 1980, five percent higher than the national average. The Boston Redevelopment Association estimates that in five years 23 percent of the population or nearly one in every four Boston residents will be impoverished.

In real dollars, the buying power of checks from Aid to Families with Dependent Children (AFDC) decreased by 33 percent from 1978 to 1983. Again, in real dollars compared to the average U.S. wage, the minimum wage is at its lowest level in half a century. If a person making minimum wage ($3.35 an hour) were to work full time, 40 hours a week, 52 weeks a year, he or she would earn before taxes (pre-tax income) $6,968, more than $3,000 under the poverty level for a family of four. Many have argued that these factors have led to the deterioration of the family.

When we consider the agent or cause of these developments it is difficult to pinpoint one specific variable. The agent may be a generational breakdown--for instance, the denial of appropriate opportunities. There may be some evidence of intrinsic characteristics that influence the agent, e.g., feelings of low self esteem or lack of trust. The agent could be the parent(s) who influence their offspring or the host.

Possibly two of the most important social problems challenging the family today are the rate of adolescent pregnancy and the status of infant health.

The phenomenon of unprecedented rates of adolescent pregnancy and childbearing in the 1970's, often referred to in crisis terms as an "epidemic", appears to be receding in the 1980's. By 1982, fertility rates for teenagers had declined. Yet these birth rates, especially for adolescents, are still disturbingly high. They are not only among the highest levels ever observed for the United States, but they are among the highest in the Western industrialized world.

While number of births to teenagers (656,000 in 1970, 562,000 in 1980, and 537,024 in 1981) gives us the dimensions of the problem, these aggregate numbers mask the distinct differences among age groups within the adolescent population.

Childbearing rates of teenage women have declined from the peak of their levels in 1973 until 1981. While younger mothers (ages 14, 15) have declined least from the peak of their levels in 1973 until 1981, older mothers (18, 19) have sharply decreased their birth rates over the past few decades. The decline for very young adolescent mothers has been an average of 28.5 percent from peak year to the present, whereas birth rates for older mothers have declined by 47 percent.

A combination of factors may contribute to the sharper decline rates for older teen mothers: increased used of contraception, changing patterns of sexual activity, attitudes of control, self-esteem and autonomy--these appear to manifest themselves with growing maturity.

While the uneven rates of decline in birth rates within the adolescent cohort is noteworthy, the dramatic story of the last two decades is the sharp rise of teen births that are out of wedlock. In 1970 nearly 70 percent of all teen births were legitimated by marriage. In 1980 this figure dropped to 52 percent. The number of out-of-wedlock births to women under 20 years of age tripled between 1960 and 1981. Almost 50 percent of all births to women under age 19 are out of wedlock.

The phenomenon of out-of-wedlock births is reinforced with the recognition that the number of birth to married women has declined, so that a higher proportion of children are now "illegitimate". Indeed, while the number of children living with a divorced mother more than doubled between 1970 and 1982, the overall number of children living with an unmarried mother increased by a factor of more than five.

Concern over the disproportionate share of out-of-wedlock births to young black women can be related to the information in the following table:

TABLE 1

PERCENTAGE OF ALL BIRTHS TO UNMARRIED WOMEN UNDER TWENTY YEARS OLD BY AGE AND RACE, UNITED STATES, 1980*

Age	All Races	Hispanics	White	Black
Total under 20	48.3	42.5	33.4	85.6
Under 15	88.7	73.6	75.4	98.5
15-17	61.5	50.7	45.2	92.8
18-19	39.8	36.5	27.0	79.2

*Based on Table 11, Adolescent Pregnancy and Childbearing-Rates, Trends and Research Findings, from the CPR, NICHD, April 1984.

While the disproportionate ratio of births to unwed young black women is cause for intense concern, the aggregate figures mask a significant trend: a decrease of 10 percent in one decade (1971 - 1981) in the out-of-wedlock rate for black women

(15-19) has occured, while the rate for white women in that age group increased by almost 57 percent. Indeed, as the following table indicates, a decline in out-of-wedlock birth rates is occurring in every age group for black women, while the rates for white women increased substantially for every age group from 15 to 24.

TABLE 2

OUT-OF-WEDLOCK BIRTH RATES BY AGE AND RACE, UNITED STATES, 1971-1981*

Births per 1,000 women in specified age group

	All Women			White			Black		
Age	1971	1981	% Change	1971	1981	% Change	1971	1981	% Change
15-19	22.3	28.2	26.5	10.9	17.1	56.9	96.9	86.8	-10.4
15-17	17.5	20.2	19.4	7.4	12.4	67.6	80.7	66.9	-17.1
18-19	31.7	39.9	25.9	15.8	24.6	55.7	132.2	117.6	-13.0
20-24	35.5	40.9	15.2	22.5	24.9	10.7	131.5	112.5	-14.4
25-29	34.5	34.7	--	21.1	21.6	2.3	100.9	86.4	-14.4
30-34	25.2	20.8	-17.5	14.2	13.6	2.4	71.8	47.2	-34.3
35-39	13.3	9.8	-26.3	7.6	6.9	-4.2	32.9	20.4	-38.0
40-44	3.5	2.6	-25.7	2.0	1.8	-9.2	10.4	5.8	-44.2
15.44	25.5	29.6	16.1	13.8	18.2	31.9	96.1	81.4	-15.3

*Based on data from the National Center for Health Statistics, Fertility Tables for Birth by Color: United States, 1971-73, DHEW Publication No. (HRA) 76-1152, U.S. Government Printing Office, 1976, and National Center for Health Statistics, Monthly Vital Statistics Report, "Advanced Reports of Final Natality Statistics, 1981", Vol 32, No. 9, Supplement, December 29, 1983.

Yet the problems associated with teen sexual activity and pregnancy are felt even more profoundly in the black population since it is essentially a "young population". In 1980 the median age for blacks was 25 years compared to 31 years for whites. Nationally, 22 percent of the black population was in the 15-24 age group compared to 18 percent for whites.

While we are unable to account with specificity for the rise and fall in out-of-wedlock rates by age and race, it is perhaps reasonable to assume that for young black teenage women, the concerted efforts through various social programs have produced a downward trend. The upward trend for white females is accounted for, perhaps, by an increase in sexual activity.

While the rate of out-of-wedlock births is extremely high in this country, significant variations by age and race should be noted. Younger age groups within the cohort show the least decline. Moreover, looking at the racial factor, one notes that the rate is increasing for young white women and decreasing slightly for young black women. However, this should not obscure the fact that very high rates of out-of-wedlock births exist, especially for large urban centers. In this regard, one notes that a recent study disclosed that in Chicago, Illinois, 45 out of 100 children were born out of wedlock.

Whether or not the high proportion of out-of-wedlock births signals the beginning of a family formation that will be accepted without societal stigma remains to be seen. Certainly, societal attitudes toward "illegitimacy" have changed substantially over two decades; especially interesting are the studies which coroborate a marked change among adolescents: more teenagers feel that they will never get married or do not intend to get married. They also believe that having a child out-of-wedlock will not hurt their chance for marriage.

While social attitudes of acceptance may be more the rule, the poverty status of "illegitimate" children persists. Indeed, one of the most powerful predictors of a child's destiny is the family structure into which it is born. To be born to an unmarried mother places the child at the highest risk for poverty. Among all single parent families (separated, divorced, widowed and unmarried), it is the children of unmarried mothers who suffer the greatest economic deprivation.

Taken together, perhaps all these trends suggest why adolescent pregnancy and parenting have emerged as critical issues. Assuring all infants a healthy start in life and enhancing the health of their mothers are among the highest priorities in preventing disease and promoting health. Our success in this area appears to be uneven.

Infant death rates reached their lowest point in U.S. history in 1984, yet the incidence of low-weight births has not slowed significantly. The general decline in infant mortality over the past 20 years is attributed to advances in neonatology. Low birthweight babies who weigh less than 2,500 grams, or 5 1/2 pounds, account for more than half of all infant deaths in the United States, including 75 percent of deaths occuring in the first month.

Maternal factors associated with high risk of low birth weight babies include: age (17 and under, and 35 and over), minority status, high parity, previous unfavorable pregnancy outcome, low education level, low socioeconomic status, inter-pregnancy interval less than 6 months, inadequate weight gain during pregnancy, poor nutrition, smoking, misuse of alcohol and drugs and lack of prenatal care.

With increased risk to the mother and infant, this area has been identified as a priority in the last two years. There are obvious measures for prevention which include education, community services (medical and social service), legislative and regulatory measures and economic measures. The Surgeon General has established a goal by the year 1990, that the mortality rate should not exceed 5 per 100,000 live births for any country or for any ethnic group. In 1978, the overall rate was 9.6, the rate for blacks was 25.0, the rate for whites was 6.4, the rate for American Indians was 12.1, the rate for Hispanics was not available. The cost to provide this care through neonatal intensive care units is quite high. There are also legal, moral and ethical considerations which society is not quite prepared to address.

Society or the environment preserves (and nurtures) the family. But many of our urbanized and rural areas are quickly becoming "bimodal". Our population is clustered into two groups, either rich or poor. The impoverished group is generally faced with substandard housing, limited transportation, inadequate education, social isolation, marital conflict, family conflict and drug or alcohol addiction.

Alcohol and its effects on the family and particularly the child are well documented. Fetal alcohol syndrome, a pattern of multiple congenital abnormalities that occurs in varying degrees in children of mothers who chronically ingest alcohol during pregnancy, is now the third most commonly recognized cause of birth defects. It is characterized by prenatal growth retardation; central nervous system dysfunction, including mental retardation; a characteristic facial appearance including flat nasal bridge, epicanthic folds and malformed eyes; and increased frequency of major abnormalities. Children born to alcoholic women have a 30 to 50 percent risk of Fetal Alcohol Syndrome and recent studies indicate that ten percent of women who drink as little as 1 - 2 drinks of absolute alcohol per day in the first trimester produce infants with recognizable abnormalities. It is estimated that as many as one in every fifty newborns will have sustained some alcohol related damage.

When we consider behavior and conduct disorders, i.e. delinquency, alcohol abuse among adolescents receives high ratings. Alcohol abuse as related to conduct disorders is the third largest killer of black youth in the U.S., and this includes drugs, as well as crime and vandalism.

Developmentally, all families need adequate housing and a reasonable environment to raise children. Consider the following scenario. Since 1970, median income in Boston has increased by 124 percent, and median rent has increased by 329 percent. The median rent in Boston is now the highest in the country, about $530 a month. The total Aid to Families with Dependent Children grant for a family of three, including food stamps, is $565 a month. In 1980, the median income of renters in Boston was half the median income of owners, 16.7 percent of Boston families were poor, by the federal definition, and 38.5 percent of them were low income earning twice the federal poverty rate. In Boston, the waiting list for Public Housing is over 12,000.

The same scenario holds true for many major urban areas. Estimates of the homeless population range from 750,000 to 1.5 million.

Increasingly, the homeless are "intact families". Services to this population are genrally uneven and inconsistent. The federal government has virtually stopped building public housing units and instead now offers a very small number of rent vouchers that supplement rents for eligible poor families, primarily women and children with low limits which make the vouchers hard to use. The health and mental health problems are endless; by definition they are poor, out of work, sick and move from shelter to shelter. Some of their children have contagious conditions and are denied entry to shelters; they are considered outcasts within their population. The feelings of hopelessness and helplessness are permanent.

The solutions to these many problems are obviously complex. With the impending influence of Gramm-Rudman and the imposing dilemma of cuts over a five year period which amount to 30 billion dollars in domestic services, to say that the family is going to be "affected" is an understatement. By the year 2000 we will have a permanent underclass of women and children who are completely dependent on the public sector for support. Is this the coming of a new core family? Intervention must take place at the macro level of society which includes the family, community and government sectors.

Over the past thirty years, we have witnessed a gradual disintegration of the nuclear family. A number of social factors account for the increase in single parent households, out-of-wedlock births and divorces. One must acknowledge the growing independence of women economically and psychologically, and some women choose to remain single or leave marriages they regard as not satisfying their needs. This has allowed men to escape the responsibilities of husband and father.

These social factors influence many Americans, but they are more evident among ethnic minorities and the poor. There are institutional factors beyond their control which dictate how they will live. They generally have poor educational outcomes and a series of health impediments which are generational by nature.

The present state of the family is in crisis from a normative responsibility level. Certain members of the family cannot fulfill their responsibilities because of intrinsic and extrinsic characteristics which influence health and environmental conditions. The family's normative state is only a symptom of a larger problem - that being the greater responsibility assumed by society. Health objectives for the year 1990 are clearly defined but how they will be implemented and who will pay is not clearly stated. We also have institutional barriers which serve as a reservoir for poverty. In the final analysis, if we do not resolve the many social and health related problems that influence the family, the future of the family as an institution may be at stake.

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SOCIAL FACTORS IN INFANCY AND CHILDHOOD

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Without question, the circumstances and events preceding the birth of an infant significantly influence the life course for that child, family, and society. Adverse conditions preceding conception and during the gestational period will harm the child and make growth and development at best awkward, and in some cases nearly impossible. Very positive preconceptional circumstances and fetus formation, however, will not suffice for maximal growth and development if the physical, social, or emotional circumstances during infancy and childhood are inadequately perceived and addressed. Timely identification of social factors impinging upon the health and well-being of infants and children is a central responsibility of all public health personnel, but especially of public health social workers involved in the decision-making processes for planning programs, implementing them, and participating in their evaluation.

There are more than two hundred and thirty million people in the U.S., three-quarters of whom reside in urban metropolitan areas. Each year, more than 3.7 million births occur (1). More than 16 million children are under age five, and approximately 48 million under age 13. Forty-two million children are in public schools in this country today (2). Of the 3.7 million born, not all will survive infancy, and quality of life is a concern for the survivors. Although many social factors require consideration, those dealing with race and economics are the ones most frequently identified as impairments to survival and progress opportunity. In the U.S., these factors are highly interrelated. Thirty-one percent of the U.S. black population is below the poverty level, compared to 9% of the white population. Among the black population, there is three times the likelihood of geographic movement, which only accentuates the poverty. Furthermore, there is a higher proportion of female-headed families among blacks and the Spanish-surnamed, and both groups have larger median family size within female-headed homes than do whites. For example, 1977 data, the most recent available on median family size of female-headed households (3), shows the median family size for whites as 2.0, but 3.7 for blacks and 3.6 for the Spanish-surnamed.

Although black non-Hispanics represent 15% of the U.S. child population, they represent 31% of the U.S. children in poverty. Hispanics represent 9% of the children, but 16% of the children in poverty. This inequality in poverty status engenders clear physical, social, and educational disadvantages--a circular process.

Data consistently show nonwhite neonatal death rates as nearly double that for whites (14.7 versus 8.7). Among infants, the same trend exists: crude data for white mortality show 12.3 per thousand population compared to 21.7 for nonwhites (5). Furthermore, many otherwise preventible conditions may not be adequately addressed because of inadequate or inconsistent health care, preconceptionally, antenatally, or during infancy and childhood. Prenatal care is designed for early detection and the provision of guidance throughout the course of pregnancy to maximize the pregnancy outcome. The absence of such prenatal care precludes the pregnant woman from receiving medical and social information from which to make choices relative to the pregnancy progress and to plan for infant and child care. Data reflect that more than twice as many black women had no prenatal care than did white women (2.8% versus 1.1%), and that significantly fewer black women initiated pre-natal care during the first trimester (59% versus 77%) (6).

One irony in the race and socioeconomic distribution relative to conditions surrounding pregnancy is the survivorship of low-birth-weight children. Nonwhite groups have a marked disadvantage in actually securing prenatal care. Fetal death rates, however, are lower for nonwhites than for whites in all weight groupings under 3000 grams (7). Nevertheless, very real differences exist that require resisting any false sense of security about the quality of survivorship.

Contemporary changes are related to an increased need for two parent wage earners. The increased proportion of single-parent families and employment enhancement has created increasing proportions of mothers with young children employed in the labor force. The recent child care publication by the Children's Defense Fund (8) pointed out that nearly 47% of the mothers of children less than one year old and nearly 53% of the mothers with children under two were in the labor force. Two-thirds of the women in the labor force in 1983 were single, widowed, divorced, or had a husband earning less than fifteen thousand dollars annually (9). Each of these circumstances contributes to infants and young children having a diminished interaction with their parent for provision of the affectional stimulation necessary for maximal emotional and social development. This high involvement of mothers in the work force should not necessarily be considered negative. Not simply the presence of the parent in the home but the quality of that presence must be considered in evaluating infant or child stimulation and nurturing. If the mother were employed outside a two-parent family home with constructive day care arrangements, the results might be as good or even better than those for a mother in the home full-time. For example, the mother who is tense from, or unfulfilled by, providing continual child care might be a less positive influence on the child than might the mother employed in the labor force who has gained increased economic sufficiency and job satisfaction, either of which may provide some added zeal to her interaction with the child when she is at home. The absence of a father through single parenthood, divorce, desertion, or widowhood increases the emotional as well as the economic stresses on the family and influences the quality of parent-child interaction. When coupled with other familial social factors such as income maintenance dependency, low household income, minority group membership, educational disadvantage, a chronic handicapping condition, or a mental or emotional disorder, the child is at serious risk for being denied the social, emotional, and economic conditions necessary for maximal growth and development.

Many social factors affect the health of infants and children. Familial stability is a central index in recognizing advantages and disadvantages for the infant and child. The economically disadvantaged and minorities continue to have impediments to maximal growth and development. In addition, migrants, whether from within the U.S. or outside, have difficulties associated with acculturation and in understanding physical and emotional health needs for themselves and their children; they may be working with health systems that are not cognizant of, nor responsive to, their unique needs.

Immigrant women surveyed in a Canadian study were found to need more personal support from family and peers at varying times after emigrating than did nonimmigrant women (10). A study of Mexican-American migrants, based on observations of 209 children under seven years of age, found significant improvements in growth during time spent in the U.S., suggesting that improvements may be associated with improved living conditions in the U.S. (11). These and similar studies suggest that migrants have heightened, but not unique, needs that involve emotional support, access to the essentials of life, and health care programs responsive to needs.

Although great strides have been made through availability of Community Health Center (Section 330 of the Public Health Service Act) projects, the development of health maintenance organizations, and expanded public and private outreach programs, a significant problem remains in accessing health care services for infants and children. It is not simply a question of health source location (a condition particularly pressing in the very rural or center city areas) but it is also the added barriers of finances and cultural acceptability that can preclude open access to quality health care services. Among the medically indigent certified under Title XIX of the Social Security Act (Medicaid), finding providers who will accept Medicaid reimbursement is a continual problem, particularly for preventive health care and prenatal services. The diminished option of where to secure services for Medical Assistance eligibles may prevent those covered by Medical Assistance from selecting providers especially expert in areas of particular medical or health needs.

Dr. Kristine Siefert (12) provided a very succinct and well-documented paper on mothers' medical and psychosocial risks. She documented social risk factors that impinge upon the adequate use of health care resources, including:

1) poverty
2) substandard housing or environment
3) lack of transportation
4) less than a high school education
5) member of an oppressed or underserved minority group
6) single mother
7) accidental or unwanted pregnancy
8) adolescent pregnancy
9) lack of experience in infant or child care
10) social isolation

11) stressful life events or conditions
12) marital conflict
13) familial conflict
14) previous history of child abuse or neglect, and
15) drug dependency

Although each of these factors alone has been documented as an impediment to utilizing health care services timely and constructively, the combination of two or more social risk factors compounds the probability of an infant or child's having increased unmet health needs. For example, chemical dependency may likely reduce the quality of interaction between parent and child. When coupled with single parenthood, being an adolescent, or poverty, the situation is compounded with the victim being both the child and the family. If chemical dependency were the only social risk factor present, it is more likely that the family would have alternative caregivers to assist the child and would have economic resources for day care, child stimulation and educational types of programs in addition to meeting the basic needs of the child and other family members.

Other social factors that affect the health of infants and children include dependency by age, circumstances surrounding the latchkey children, and conditions experienced by children with chronic handicapping conditions. The younger children are, the less able they are to fend for themselves and to assume often inappropriate roles expected by the parent. This may be more clearly illustrated by examining a question dealing with maltreatment experiences among children with chronic handicapping conditions. It is not known whether children with chronic handicaps are more frequently exposed to maltreatment because of their conditions or whether the very conditions may make such children more visible and less able to compensate for parental inadequacies. For example, a cognitively-limited child likely has a lowered opportunity to predict caretaker response to normal childhood behavior and to control that response. Secondly, children with constraints on their physical functioning likely are less able to run from imminent danger or to be sufficiently able to care for themselves through preparing meals or removing themselves from other dangers such as may exist in a chronically neglectful home. The latchkey child may or may not have a disadvantage from parental absence, but does have health and safety risks from being left unattended for certain portions of the day and is increasingly vulnerable to everything from household accidents to child-snatching to social isolation.

The challenge of public health social workers comes in the planning, implementation, and evaluation of programs that are responsive to the needs of infants and children. Public health social workers whose responsibilities include identification of social risk factors and planning of programs to meet the needs must have prevention as a primary focus. We also must have groups or populations as our focus rather than individuals, as in the case of the clinical practitioner whose responsibility is toward the acute or chronic conditions of a single child or family.

The program planning phase involves the identification of objectives that are clearly stated and expressed in measurable terms so as to ensure that evaluation and assessment can be accomplished as an ongoing and integral part of the planning process. Such objectives must be expressed for measurement over both the short- and long-term periods and must be stated with sufficient precision to enhance program responsiveness to community needs. In expressing such measurable objectives, it is insufficient simply to express an increase in numbers or percentages of the population to be included. It is necessary to increase the precision of achieving such objectives. For example, in planning child protective service programs, it is important to develop objectives that can measure the precision of meeting program goals as opposed to simply including objectives specifying numbers of clients or patients to be served. It is insufficient to set an objective of a 15% increase in the reporting of child abuse. It is appropriate to set an objective of a 15% increase in confirmed reports of abuse, or a 15% increase in reports of abuse prior to physical injury.

In the planning phase, it is important to recognize that the federal government must take the leadership for establishing national goals for improving the health and well-being of all mothers and children, and particularly of infants and children. Such national goals can be stated through program comprehensiveness such as more thoroughly delineating the input of Medicaid in screening and treating infants and children. The majority of children in foster care in the U.S. have medical care reimbursement coverage under Title XIX (Medicaid). However, there is no national mandate to ensure that these children, and those without Title XIX coverage who are in foster care, have a comprehensive mental health appraisal to ascertain what their unique needs may be as a result of a separation from their biological families and the placement in one or more substitute care settings. Developing national objectives for meeting the needs of that special-risk group is of utmost priority.

At the program planning level, it is necessary for the professional groups and state government organizations to establish standards to ensure the health and well-being of infants and children. The professional organizations, whether social work, medicine, nursing, or other, have a responsibility to collaborate with state health and welfare officials in establishing realistic standards for care that reflect at least minimum levels of acceptable practice.

At the planning level, it is also necessary to include direct and indirect input from current and potential service recipients to ensure that their specific needs and wishes are met. Direct input is through including consumers on planning or advisory committees, such as foster care review boards, community health center boards, and citizen panels involved in maternal and child health planning. Indirect consumer input is through evaluating program components that address service use, including the adequacy, effectiveness, and appropriateness of the services.

During the 1960's there was concern that the community resources in addressing the health needs of families were inadequate in their distribution by geography and in the hours of service. Great cries were made that the agencies were open "at hours of convenience to providers." Despite the resultant establishment of evening and weekend hours for many programs, penetration to the needy population was not dramatic, requiring program planners to examine other deterrents to health services use. An outgrowth from this appeared primarily during the 1970's with the Community Health Centers (Public Health Service Act 330 projects), which developed in medically-underserved communities. Although this was very appropriate conceptually, there is a severe problem for infants, children, and their families: the enabling legislation and federal administration of the 330 programs have never provided for integrating state MCH planning with Community Health Center planning. During the 1980's we have seen Title V converted to a Block Grant, and are currently experiencing the initial impact of the Gramm-Rudman Act. Certainly these changes are affecting the ability of programs to meet the needs of many groups, especially infants and children. The impact hits the most vulnerable groups hardest--those that have the least alternatives, such as the poor, the medically poor, migrants, single-parent families, and the handicapped. Public health social workers involved in program planning must be ever aware of being advocates for all infants and children to ensure that program design and implementation further the target population's needs. To do so requires exploring bioethical issues in addition to fiscal constraints. Public health social workers must be primary advocates in ensuring the proper distribution of benefits and burdens when program development and implementation are considered. (See Lann Thompson's Workshop.)

A second phase deliberately involving public health social workers is in the implementation of programs. Before addressing implementation issues, we must remember that in the planning phase there must be not only clearly-stated and measurable objectives but also standards for delivering health services to the identified populations. These standards must clearly enunciate the experience and academic preparation required for service delivery, whether on a clinical or population base. Each public health social worker must have at least proper minimum professional social work preparation in addition to the requisite public health preparation from academic and experiential viewpoints.

Implementing a program means to conduct or cause to be conducted some activity that furthers the stated objectives of the program. Again, implementation must focus primarily on prevention, with attention when necessary to curative intervention for the at-risk population. The implementation of programs must ensure that issues of timeliness, appropriateness, comprehensiveness, continuity, convenience, and personnel standards are met. In addition, the implementation phase requires careful matching of the resources to the activities necessary to undertake the program objectives...the RAG portion of the RAGPIE matrix (13).

A final phase in addressing social factors in infancy and childhood relative to maximizing the health and well-being of a population deals with the evaluation of the program. It is certainly not possible in this brief time to address the specific methods involved in assessing needs nor in evaluating programs. During this conference, specific workshops are available on needs assessment (by Becky Williams) and on program evaluation (by Ken Jaros). The evaluation of programs is the process in which you are asking whether we are doing the right things, and doing the things correctly, and whether the things that we are doing are effective and efficient (14). The evaluation phase is the opportunity to compare and to analyze the program objectives to secure answers to the preceding questions. Public health social workers are frequently involved in only one of the program planning, implementation, and evaluation phases (usually the second). At each phase, it is important to consider how the program will be evaluated. Program planning requires setting measurable objectives and developing a monitoring system. Evaluation is not a frill but an essential component if program experiences are to be communicated to others. It is important to program evaluation that the planning phase include attention to data that will be collected from the program as well as from other programs that will be used for comparative purposes. Program evaluation must include both short-term and long-term parameters to identify strengths and weaknesses so that program resources can be utilized as efficiently as possible.

Information has been provided on the planning, implementation, and evaluation phases in programs addressing social factors especially for infants and children. Very similar concepts apply to other population groups, but infants and children have been the focus because infants and children who have families with pathological social risk factors cannot be assumed to have the opportunity for maximal growth and development. Infants and children, particularly those with any of the social risk factors identified by Siefert, must have advocates who are involved in the planning, implementation, and evaluation of public health programs. Programs to address the social factors that may impair a child's growth and development must be responsive to real needs, not based upon bias or simply subjective judgements. Although this paper has focused on infants and children, it is important to recognize the reciprocal dynamics of birth-infancy-childhood-adolescence-adulthood-reproduction and a repeated cycle.

Intervention is necessary to promptly prevent subsequent social failures of reproduction, and infancy and childhood are very appropriate times to work toward preventing subsequent pathology, interrupt the cycle of pathology, and promote the maximal well-being of infants, children, and their families.

The Surgeon General has set objectives for improving the health and well-being of infants and children (15). Public health social workers are an integral part of addressing social factors that interfere with maximal health, but cannot achieve the objectives alone. As stated by Evans and Morton, "...no one action, no one group, no one discipline can make a healthier people..." (16). Public health social workers must exert themselves where our expertise is greatest, remind planners that prevention is the hallmark of a good health care system, and promote programs for special-risk populations.

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SOCIAL FACTORS IN ADOLESCENT HEALTH

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It is a great honor to have been asked to address this group of social work leaders in public health and in maternal and child health care on social factors in adolescent health.

In recent years much attention has been given to adolescence as a crucially important and often neglected period of the life cycle (Better health for our children, 1981: 116; Mercer, 1979; Kovar, G., 1979). In the United States, one fifth of the population is between the ages of 10 and 19. The adolescent population doubled from 20 million to 40 million in the years between 1950 and 1970. From 1970-84 the number of adolescents in the population declined to 20 million. While the numbers have declined, recent social changes coupled with the physical and psychological changes inherent in adolescence, will require continuing priority attention to the health needs of this population.

Many of the health problems of adolescents are compounded by the fact that youth are in transition from childhood to adulthood. Many health related problems of adolescents result from immature judgment combined with uncertain self-esteem and strong peer pressures. Much of adolescent health care centers around treatment and prevention of health problems caused by risk-taking behavior. This risk-taking behavior results from experimentation with personal habits which are prevalent in the adult world. Unfortunately, many of the risk behaviors which pose a threat to adolescent health and life are deeply embedded in the country's adult culture and are therefore perceived by teens as desirable symbols of independence, maturity and sophistication (Better health for our children, 1981; Forward plan: Maternal and child health, 1984-89).

The types of behaviors resulting in health problems are different for young women than for young men and thus the types of "accidents" suffered differ by gender. In addition, differences may stem from such enduring characteristics as age (early or late adolescence), race and ethnicity as well as marital and household status, income, education, work force participation, and commercial pressures.

It is well-recognized that improvements in health status are less likely to come from technological "breakthroughs" than from improvements in environmental and social conditions, changes in lifestyle and behavior and participation of people in maintenance of their own health. As leading causes of morbidity and mortality have shifted from infectious diseases and other acute problems to chronic illness and accidents, the need to focus on health promoting behaviors has increased.

Identifying ways of modifying unhealthy conditions and behaviors is particularly germane to the improvement of adolescent health. The NCHS Health and Nutrition Examination Survey (HANES) of 14-17-year-old youths, indicated that two thirds were in very good or excellent health (Forward plan: Maternal and child health, 1984-89:37). The problem is how do we keep teens in good health. Adolescent health problems are behaviorally and environmentally related: accidents (Heckler, 1983) and injuries (Anderson, D., Miller, J., Kalsbeek, W. 1983) suicide (Deykin, B., Perlow, R., and McNamara, J. 1985; Mailick, M., 1985) homicide, substance abuse (Koop, C., 1983) sexually transmitted diseases (Roghman, 1981), violence and teen pregnancy (Mailick, M., 1985). In 1980, adolescents 12-19 years of age represented 7% (2.8 million) of the discharges from non-federal short-stay hospitals. Obstetrical deliveries accounted for about one-third of the female discharges while injury and poisoning accounted for about one-third of the male discharges.

Numerous contemporary social factors are thought to contribute both to adolescent mortality and morbidity, a few of these social factors are considered in this overview, which is organized around four sets of issues: (1) social values and commercial pressures; (2) economic and minority status; (3) work force participation; and (4) family and household structure.

In addition, I will be commenting briefly on some aspects of prevention, particularly life style habits or health promoting behaviors.

SOCIAL VALUES AND COMMERCIAL PRESSURES

Human behavior is shaped by current cultural values and commercial pressures. Perhaps nowhere, and at no time, have social values been more diverse, more in flux and more open for discussion than in the United States today. Very little has been written about the effects of social values and attitudes on adolescent health, and instead, personality types, motivational factors, family and individual values systems are studied, the latter as if they are isolated from societal values. In our society, adolescence is socially defined according to the context within which youth live. The culture is learned both directly and indirectly by the youth as he/she works at the process of becoming an adult. There are not clear rites of passage to adulthood. Thus, social definitions of acceptable behaviors for various roles create dilemmas for youth. For example, many of the rites of passage to adult prerogatives occur at different ages in different states - or even different localities within the same state. In most states, youth can obtain a driver's license at 15 or 16 years; in all states, the privilege to vote comes at 18. The young man may be drafted in time of national emergency when he becomes 18. Yet, the adult prerogative of purchasing alcoholic beverages is not accorded until age 21. Since these adult privileges are awarded at different points in his development, the youth gets the message that he is wise enough to choose his leaders and mature enough to die for his country - yet not mature enough to know what he should drink until 3 years later. If the adolescent's family moves from a state which permits driving a car at 15 to a state which does not grant licenses until 16, he may be disappointed and frustrated. Parents are also confused by changing social definitions of acceptable behaviors. Parents have to unlearn in order to relearn what is currently appropriate to existing roles.

The communication media reflect and shape attitudes, norms and behavior. Research on the influence of media on health has been limited, but it is thought that the images of youth and beauty, smoking and other poor health habits contribute to health problems. Teenagers are particularly influenced by commercial pressures of advertising, television, the movie and record industries, clothing and cosmetic manufacturers, and by social expectations of "normal" adolescent turbulence.

Rock stars and media provide role models of behavior involving fast cars, sex, violence and drugs. Young women and men are constantly being pressured regarding the need to be sexy, thin, and appealing (Marieskind, 1980:209). Nothing in American society is more glamorized than sexual "love" and sources of adult guidance do not make clear that there are excellent reasons to go slow in this area of life experience (Better health for our children, 1981). Youth need to discuss different aspects of sexuality relevant to decision-making and self-understanding. More recently, extreme thinness has become a goal of the society and reflected in the media. Dieting has become the norm. Eating disorders are increasingly prevalent. These conditions are noted in high school groups and on college campuses, but may well be frequent among populations not so readily observed.

ECONOMIC AND MINORITY STATUS

Poverty continues to be a major social factor affecting adolescent well-being. Poverty, minority status, and ill-health are interrelated. Disadvantaged people become ill because of poor nutrition, poor living conditions, high levels of stress and reduced access to health care. As a result of these conditions, illness may occur with greater frequency. Members of racial/ethnic minorities tend to be of a lower income and have less education than the general population (National Center for Health Statistics, 1985).

As a group, women are economically disadvantaged in comparison to men, regardless of age, race, ethnicity, or employment status; this is often referred to as the "feminization of poverty" (Sarri, R., 1985). Data from the Bureau of Census, the Bureau of Labor Statistics and the Congressional Budget Office confirm that women in the United States are becoming increasingly disadvantaged (Sarri, R., 1985). Neither employment nor educational level protect women from economic disadvantage relative to men. Low income rates have long been particularly high among black, Hispanic and native Americans, expecially those who are single head-of-households.

1981, 45% of black children and youth, 36% of Hispanic origin and 10% of white children and youth less than 18 years of age were in homes below the poverty level. Households with youth and children now account for over two-thirds of all poor people.

A greater proportion of low-income youths in low-income families report that their health is fair or poor than do high-income youth; low-income youth lose more school days and have more days of restricted activities due to chronic health problems, are more often hospitalized and remain in the hospital longer than high-income youth (Forward Plan for Health, 1984-85, p. 6).

Mortality rates have long been used as reliable indicators of health conditions because, unlike perceptions of health or decisions to use services, they do not reflect judgment but rather facts. Economic and racial differences in death rates still persist, but have narrowed dramatically. While national rates of maternal and infant mortality have declined significantly, they continue to be higher for minority teen women and unmarried teen women - all groups that experience high rates of poverty.

Although the folklore of our country is replete with Horatio Alger stories, it is true that there is a reasonably strong correlation between educational attainment and advantageousness. Some of the advantages that can affect health status are composed of three elements: The income to purchase health care services, the knowledge of which services to purchase and the knowledge of how to use the services.

The relationships among gender, race/ethnicity, economic status, education, availability of health insurance, use of medical care, and health status are complex and warrant continued investigation. Increasing poverty among young women and young men is a national issue of major proportions that will have serious implications on the health of our nation.

PARTICIPATION IN THE LABOR FORCE

Perhaps, the most significant social factor affecting adolescent well-being, however, is access to employment. As of April 1979, slightly more than 800,000 males aged 16 to 19 and slightly less than 800,000 females aged 16 to 19 were in the labor force. Of these, 17% of men, 16% of females; 34.5% of blacks and "others" were unemployed in this age group.

In 1984, more teens were out of the workforce, 65% of teen workers and 29% of workers in their early 20's could not make wages sufficient to bring an intact one-income family with a child out of poverty. Among teen black males, 44% were unemployed.

Although a job will not cure disease, it may provide support for health care, access to health insurance, and in providing a sense of productivity and achievement, do much toward preventing pregnancy, alcoholism, drug abuse and boredom. Many teens just have nothing to do.

FAMILY AND HOUSEHOLD STRUCTURE

Health status is related to various demographic factors in addition to income and work force participation. Marital status, household structure and the timing and number of children all have implications for adolescent health. The family or household is important not only because it is the place where health behaviors are learned, practiced and reinforced, but also because it is where most short-term acute and long-term chronic care occurs.

For most people, the family or household is important as a major source of social support. Similarly, the family influences environmental conditions that affect health.

Currently, there are many family forms, household structures and life styles. Alternate living arrangements are related to later marriage, increased divorce rates, increases in the number of single parent households and of single-person households. Couples are marrying almost two or more years later than their parents did. Almost a fourth of all households were single-person households in 1982; included in this group are the never-married, the divorced, and the widowed. While marriage is occurring later, the vast majority of men and women do marry. But 50% of those people married in 1983 can expect ultimately to be divorced. Fewer black women than white have marriage as an alternative because of the ratio of men to women in each racial group. Divorce has both economic and health consequences. Assuming both partners are employed, it results in a 38 to 50 percent reduction in income for women. Rates of illness are higher among the divorced than among the married.

Recent childbearing patterns also have shown many changes. Fewer unmarried young women are remaining childless than in the past. Birthrates for the unmarried have risen steadily and are higher for women in their twenties than for adolescents and for black women than for white women.

Despite the decline in births to adolescents, more than 500,000 infants are born each year to women under age 20. Birth rates for young women aged 15 to 19 declined more or less consistently from a high in 1957 to close to an all time low in 1980. Relatively high birth rates are found among adolescent mothers over 17 (about 7.5% of 18- and 19-year-olds). Birth rates for 14- and 15-year-olds were less than 2% in that year. Overall, about 5% of teenage women bore children in 1980. Pregnancy in very young teens can be risky to the physical health of both mother and infant. The decreased birth rate can be partially explained by the fact that half of the adolescent pregnancies are terminated through abortion. There has also been a marked increase in non-marital pregnancies and births, with about 20% of births to white teens and 80% to black teenagers occurring outside of marriage. Between 1970 and 1983, the out-of-marriage birth rate declined by about 10% among black teens and increased by 70% among white teenagers. As a consequence, in 1981, there were for the first time more births to single white than to single black teen women. Both teenage women and black women have shared in changes in family patterns that have affected all women in the United States (National Center for Health Statistics, 1985).

Teen fathers are two years older than teen mothers. Most of the unmarried births are to older teen women 18 and 19, and older teen men 20 to 21 years old. Young men 18 to 21 years old are increasingly unable to fulfill the traditional breadwinner role and support the family. Of the males 20-21 years old employed at minimum wage, one-fifth are poor. Unfortunately, in the U.S., it has always been black men who have been most likely to experience these conditions.

Contrary to popular impression, teen premarital parenthood is not the largest contributor to the formation of single-parent families, but rather, separation and divorce. The implication that these are peculiar black phenomena is contradictory to studies showing that causes of family disruption are economic, not racial. Low income minority status, lack of work force participation, teen parenthood, family and household structure are intimately intertwined and affect adolescent health status.

Single parenthood is a fact, not a bad word. We should consider social policies to maximize rather than limit a woman's opportunities for choosing the living and working arrangements they judge most conducive to the purposes for which social welfare policies were orginally designed. The teen mom is in a real dilemma:

> If she works, then who's taking care of the child;
> if she doesn't work, she's a welfare bum.
> To work she needs a job and child care;
> to prosper she needs a decent wage.

To summarize, it is certainly true that morbidity and mortality are lower in the second decade of life than in the first. But it is a serious error to consider teenagers as entirely immune from health problems. The increasing problem of these contemporary social factors (i.e., income and minority status, unemployment and single parenthood) will necessitate preventive and treatment measures.

Given these (above stated) social factors, what are the responsibilities of public health social workers? The overriding goal of the social work profession is to help develop, restore or maintain the individual's (and family's) sense of control and hope in the environment.

The public health social workers surely cannot take on the entire responsibility for changing the social environment; however, in our interactions with young men and women, we may be able to give them some strengths they need in order to enlarge their life options/chances. We must encourage teens to communicate with health professionals and parents.

In order to communicate, teens need privacy and confidential care. Clearly, not all problems of teens require strict confidentiality, indeed most of the time teens want their parents' sympathy, support and advice when facing the frightening prospects. All teens do, however, require privacy for at least part of an interview or encounter.

It is important that the social worker respect their confidence in order to maintain trust and open communication. However, dependent upon the level of maturity of the adolescent and the seriousness of the health risk involved, the social worker must, at times, insure that the parents are aware of the problems with their son or daughter and are motivated to seek appropriate help. It is best if this communication of sensitive health problems to the parents can be done with the adolescent's permission and in his/her presence or, even better, by the teen himself or herself.

In the case of adolescent pregnancy as well as many other health problems, the social worker must maintain the trust and respect of the teen by giving private and confidential service.

Communications should be encouraged between parents and teens. Many parents find their children's entry into adolescence extremely stressful. This period of the life cycle can be viewed as a time of family stress in that teens are in the midst of a complex process that impacts the family system. Cohen and Irwin (1983) observed that a significant number of parents feel frightened, abandoned, or rejected as a result of their children's behavior. Parents frequently express anxieties about loss of control or inability to deal with the new developments, as well as apprehension concerning the possible dangers to their children that exist in the broader community.

Parents need information about normal adolescent behavior and roles. Remember, parents have to often unlearn in order to relearn what is currently appropriate to existing roles. Cohen and Irwin suggest helping parents through self-help groups (1983).

The benefits of self help groups apply both to teens and parents. Their success can be attributed to several characteristics of these groups. First, the members share a common experience. Recognition that others share what is believed to be a unique experience can be very encouraging and strengthening. Second, members of self-help groups provide mutual help and support to one another. A third characteristic of self-help groups which accounts for their success is the Helper Principle (Reissman, 1965). The experience of reciprocating help received from others provides reassurance of one's own competence and usefulness. The likelihood of gaining information is a fourth characteristic of self-help groups. In the course of interacting with individuals with similar circumstances or problems, each member is likely to gain factual information or workable solutions.

Teens need information through health education programs on the effects of their life style on their present and future health, but this information must be presented in a way that influences attitudes and behaviors. The older health education programs or preventive programs that relied on scare tactics and long lists of potential diseases caused by smoking, alcohol, or drugs were not very successful. Teens seem to have knowledge of the evils of smoking, drinking, etc. Teens find it difficult to do something different from their peers. New education programs have attempted to teach practical skills for resisting pressure to engage in risk-taking behavior as well as accurate, up-to-date health information. These programs emphasize a positive constructive approach to health as well as skills for fending off temptations to smoke, use drugs or drink alcohol. The media have been playing an effective role in carrying educational campaigns addressing such health related issues. A number of projects have developed in the public and private sectors instructing teenagers on "how to say no." Social workers obviously have an important role to play in both offering anticipatory guidance to adolescents and their parents and in helping to create and sustain community education efforts for teenagers.

The combination of information and skills appears to work well for middle class, upwardly mobile teens. Many teens who are at greatest risk of experiencing the harsh outcomes of unhealthy habits have poor life options, hear these messages of skills, but are turned off by their perceived irrelevance. A disadvantaged youngster with no hopes or aspirations cannot understand how having a baby or using drugs will adversely affect his or her life. Teens from low-income families need to have hope.

Self-help alone is not enough for low-income parents and their children. Preventing the negative outcomes of risk-taking behaviors requires attention to the social forces that impact adolescent health. Marian Wright Edelman of the Children's Defense Fund suggests that we must give teens hope, opportunity, employment information and skills.

- We must help teens build their academic skills. Youth who are behind a grade or who have poor basic skills or poor school attendance or are outside of schools are at high risk of becoming parents too early, and for indiscriminate drug and alcohol consumption.
- To give low-income teens hope of earning decent incomes, we must help them develop good work attitudes, occupational knowledge and specific job-related skills.
- A teen's self-sufficiency and vision of a viable future depend on the self-esteem built through both academic and non-academic experiences. Opportunities for both are too often lacking in many low-income communities.
- The relatively poor health status of high-risk teens and their poor access to the health-care system mean we must take steps to give them the full range of primary health care.

Numerous programs of education, employment, recreation and support for teens already exist. It is reasonable to assume that improved skills, broadened horizons and elevated self-esteem resulting from these efforts also bolster the resolve to have a healthier life style. There needs to be more of an effort to combine teen program activities to assault the social forces affecting adolescent health.

Coalitions have been organized in many communities to monitor adolescent health policy, legislation and funding; to share resources and coordinate local activities. Local church groups, particularly in minority communities, are developing coalitions.

What type of organized actions should a coalition pursue?

- Mounting a campaign. Someone must take responsibility for launching a movement to help disadvantaged youth gain access to education and employment. Who?

- Monitoring the public sector. Once it is formed, the coalition must direct efforts to the national scene. Existing federal, state and local programs need to be monitored to ensure equal access to education, employment and health care. A family policy needs to be encouraged as well as a federal, state and local partnership in health needs.

- Assembling research findings. The relationships between social and environmental factors and behaviors need to be documented more fully. For instance, regarding teen pregnancy in the absence of intervention, half of teen mothers do not finish high school. What has not been clarified is whether school dropout occurs before or after pregnancy. Several studies point to the former, a recent study indicates that dropout may not depend on the pregnancy, but whether the teen marries early. This study suggests black teens assuming multiple roles (mother, wife and student) tend not to complete their education but those who assume the mother role and do not marry stay in school (McLaughlin et al., 1986). More research is needed on the sequencing of the life events, educational outcome and health.

- Intervention on the local level. It is necessary to bring intervention into the schools. The responsibility should be shared. Schools are not the only place for intervention, particularly since many young people are not in school after the early years. Volunteer support programs need to be encouraged.

CONCLUSION

In conclusion, the strategy proposed envisions public health social workers advocating for child and adolescent health working in concert with advocates of educational and employment services for youth. This coming together of various advocates is a necessity. The rewards for engaging in this process are many: expanding interventions, influencing social change, and last but not least, helping to insure that the next generation is able to develop into happy, healthy and productive adults.

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GREETINGS

Barbara K. Shore, Ph.D., ACSW, M.S. (Hyg.)

It is an honor and a pleasure to bring greetings today to this important conference. I, of course, feel a special affinity for the work of this conference and for the people who have come together to make this conference possible. The emphasis of the conference on social factors in the health of families has never been more crucial. As we identify the major health problems of today, we can see that each of these has more complex causations and social solutions than has ever been true before. Some of these social dimensions are more apparent because we have eliminated, as major threats, so many of the problems that had a more purely physical or single causation. Thus we all know that the conditions that remain to challenge us are conditions with more complex and multiple roots. These conditions call out for increasing study, sharing of experience and creatively seeking solutions. That is what brings us together today and makes us especially proud to have our joint program, Public Health and Social Work, so well established. This program is one in which the public health concepts and social work concepts are integrated into joint studies and thus social workers are able to have public health concepts integrated into their practice, and also help to integrate social work concepts into public health practice.

The major issues facing all of us in public health social work are very complex and at the heart of this conference. So many of the social factors that impact on the health of individuals and families have a strong relationship to problems of poverty and discrimination. The statistics are clear indicators that illness, disease and chronic conditions fall disproportionately in the poverty group in this country. The current and major concern about the increasing numbers of teen pregnancies, especially those in which there is a single female-headed household in which the babies of these young mothers are being raised, is a case in point. The tangled maze of problems that arises with babies born to young, poorly nourished and immature parents is especially pronounced amongst poor and undereducated mothers. Although the rate of female-headed households has increased amongst all segments of society, the rate is much higher amongst poor and discriminated against populations and the consequences are more devastating since there is less of a cushion to insulate these families against illness and the pressures of child rearing. The feminization of poverty is a health issue in every sense of the broad concepts of health.

Part of the remedy is in altering the social conditions that produce such gaps and discrepancies. These gaps exacerbate feelings of helplessness and hopelessness that in turn, increase a number of other problems related to a meager use of health services, including a sense of defeatism and fatalism. This prevailing hopelessness supports the view that nothing can be done to improve one's lot in life and so the cycle continues.

Part of the remedy is in the recognition of the under-socialization of many young women, who have not learned parenting skills. Teaching parenting skills, utilizing family life education, is an important part of our responsibility to tackle the problems of under-socialization in the development of parenting skills.

Another range of social factors that is crucial to our concerns are the stresses and strains that lead to alienation of young people who turn to drugs and chemicals to cope with our addiction-prone society. This needs to be better understood in order to be changed. Our knowledge and skills are centrally relevant to a meaningful approach to these problems.

Our work since the 60's has pointed to the importance of providing services in such a way that the utilization can be increased. The visibility, accessibility, financial and stylistic suitability are all important to utilization and must occupy our attention. However, these alone are not the answer to increased utilization. A significant part of that answer lies in the stimulus and encouragement for young people and their parents to see the relevance of the health care practice and theory to them and their lives. Reaching them through all possible means via the use of health care personnel who are less threatening to the users, such as paraprofessionals, is part of what we have learned from the 60's. We have accumulated a background of experience in public health and social work that needs to be preserved and expanded.

Seeing the family as a whole system and the interactions between them as a central focus aids us in understanding complex relationships that shape behavior. Seeing the community as a system also in relation to norms and values is not only vital, but helps us to find remedies. For example, seeing the strengths of extended families and social supports helps us to aid those systems, rather than weaken them, by ill-conceived, although often well-meaning interventions.

The social consequences of the problems we have noted are clear and unremitting; but while working to offset the consequences of many socially induced problems through intervention and treatment programs, think preventively, in the best tradition and application of the public health model.

We must attempt to unmesh the tangled web of multiple causation to see the social forces at play in the causation of the problems and to attack those problems as vigorously as we can.

As public health social workers, our skills enable us to do this. We are members of a profession that has a strong value system stressing that blocks in the opportunities to achieve self-realization are our obligation to remove and that furthermore, a society must help us all to achieve our maximum potential. The social factors that are operative in the major problems plaguing us today are difficult to remove but essential to face and confront with all the talents that we have. This is the greatest challenge that has ever faced us. Let us accept that challenge.

INTERDISCIPLINARY HEALTH CARE IN RURAL AREAS: THE ROLE OF PUBLIC HEALTH SOCIAL WORK

Edward J. Saunders, Ph.D., M.P.H.

This paper is not an introduction to a new practice concept, but rather the reaffirmation of one that has long been practiced. In particular, this paper suggests that interdisciplinary practice is especially important in rural areas of the nation in which many public health social workers practice.

As few as ten years ago, there was general agreement among many social work leaders that social work service in rural areas was a neglected practice specialty. Ginsberg suggests this neglect was "understandable" given our national preoccupation, beginning in the twentieth century, with the transition of society from a rural, agrarian one to a metropolitan one, preoccupied with commerce and manufacturing.[1] Fortunately, the neglect of rural practice issues has abated in the last decade with increased recognition of the unique practice demands which rural social work professionals face. As a consequence of this recognition, schools of social work and public health have increasingly provided students with a practice model based on the "generalist" concept.

The generalist concept makes explicit the need of social workers in rural practice to be equally knowledgeable and skillful in working with individuals and families, with small groups, and with communities-at-large. In addition, the generalist social worker is expected to be skillful in research, social policy planning, and administration. Clinical, administrative and community organizing skills are all requirements for effective rural social workers.[2]

Among the unique features which distinguish rural areas from urban areas in our country, the most significant for rural public health social workers is that important life-sustaining health and mental health services are frequently unavailable to residents in isolated areas. Especially if one is seriously ill, the consequence can be fatal. Assuming that the individual even reaches the distant hospital alive, he or she must then cope with problems of transportation, isolation from family and friends, and added expense. Even routine health care or mental health care can be problematic, since we know that many rural areas are underserved by professionals. Rural areas are characterized by the most elementary of public services. There is not the abundance of private, specialized programs available in rural areas that are found in every metropolitan area of the country. However, the need of rural residents for specialized services is no less acute than that of urban residents. The assumption that "life is simple" in rural America is a false one; "a small scale of life does not imply simplicity."[3]

The public health social worker in rural America is first of all faced by a scarcity of formal services on which to draw to assist his or her clients. As suggested above, only the most basic of public service programs are available in rural communities. Typically, a county social welfare agency, a county public health nursing service, and a county mental health program will serve as many as a dozen small towns scattered among a hundred square miles. Sometimes the catchment area is, in fact, comprised of several counties, which not only compromises the access of residents to services but also compounds the problems of workers attempting to deliver services to clients in their catchment areas.

An important resource for public health social workers and other health care professionals in rural areas attempting to meet client needs in a vacuum of services is interdisciplinary practice. Ducanis and Golin define the interdisciplinary team as "a functioning unit composed of individuals with varied and specialized training who coordinate their activities to provide services to a client or group of clients."[4] Brill offers this definition of team: "A team is a group of people each of whom possesses a particular expertise; each of whom is responsible for making individual decisions; who together hold a common purpose; who meet together to communicate, collaborate, and consolidate knowledge, from which plans are made, actions determined, and future decisions influenced."[5]

The development of interdisciplinary teams can be especially beneficial to clients in rural communities because "teaming" facilitates looking at client problems "in total", rather than "compartmentalizing" problems. In rural areas in which fragmentation of services is acutely a problem, interdiscipinary practice avoids the prospect of missing a part of the problem that affects the individual and/or family system.

In addition to better meeting client needs, team members find support for their work in collaboration. This support was documented in an empirical study conducted ten years ago by a social work doctoral student. In his dissertation, Rosenberg writes that social workers and public health nurses who expressed the highest levels of satisfaction in their work had the most frequent professional and informal contacts with members of the counter profession. He suggests that the patterns of interprofessional communication and dependence which occur between professionals can meet their mutual needs for support.[6] In another study, Bloom and Parad found that within the mental health disciplines, social workers and nurses were most in favor of interdisciplinary practice. They also report that directors of training programs in social work and nursing expressed the greatest interest in interdisciplinary training.

The theme of the present article focuses on the importance of interdisciplinary practice in rural communities, and specifically on the role of the public health social worker. The introductory information should suggest to the reader that the rural social worker is faced with problems which distinguish his or her practice from that of colleagues in urban areas. The shortage of health and mental health services, in general, in rural areas demands that rural workers act creatively to meet the needs of their clients. One of the most creative of practice dimensions is interdisciplinary practice. This article suggests ways in which public health social workers are specifically networking with allied health and mental health workers to meet family needs in rural America. The interdisciplinary practice of social workers engaged in maternal and child health programs, especially programs for handicapped children, and in programs serving abused and neglected children are highlighted in this article. Following a review of selected Maternal and Child Health (MCH) programs which use an interdisciplinary model of service delivery, the role of the public health social worker in rural communities is presented.

CRIPPLED CHILDREN'S SERVICES

Public health social work practice with handicapped children and their families represents a significant area in which social workers are "teaming" with other health care providers to assure maximum service delivery for their disabled clients. Again, in areas with a scarcity of services for this population, interdisciplinary practice is critically important so that a comprehensive plan of care and rehabilitation can be developed. Crippled Children's Services in Iowa, for example, uses a service delivery model called "Integrated Evaluation and Planning Clinics." These clinics are designed to be the primary entry point of handicapped children into an "integrated, coordinated, multiagency, multiprofessional" system of care for

Iowa's children with special needs.[8] Social workers play both a diagnositc role and a consultant role with other professionals on the interdisciplinary clinic teams. Following the interdisciplinary team review of individual professionals' assessments, a plan of care is designed which takes into account the child's unique medical, educational and social needs.

The same professionals who create the plan also assume the responsibility to continue to work together as a team to carry out the integrated personalized services. A total of 24 "Integrated Evaluation and Planning Clinics" are spread across the State of Iowa, meeting the needs of 2,900 children in 1985. Using a "Care Management Team" including a nurse, a pediatric nurse clinician and social worker, families with chronically ill or handicapped children receive on-going face-to-face and telephone contacts, helping them to mobilize the community services needed for their child. In rural communities, families can be particularly confused about how to meet their child's specialized needs, since specialized programs may not be readily visible or available. Case Managers often assist the families in securing alternative resources. "No referral is abandoned without redirection" say program sponsors.[9]

Another program which deserves merit in its attempt to reach rural families with handicapped children is the "Baby Buggy" program operated by a birth-to-three project in west-central Illinois.[10] This project, utilizing a specially equiped mobile van--not unlike a bookmobile van--was developed in response to the problem of transportation in rural Illinois. Project staff decided to develop the "room on wheels"--called the "baby buggy"--to bring services to scattered rural families with handicapped children. Many social workers use the same principle practiced in this project: when the client cannot come to you, you must go to the client. This is especially true in rural areas in which few, if any, public transportation services are available. Without active outreach by rural health and human services providers, many rural families will remain without services.

CHILD ABUSE AND NEGLECT PROGRAMS

That children are abused, neglected and sexually exploited in rural as well as urban areas has long been established in the research literature on the subject. Troubling, however, has been the difficulty in organizing prevention and treatment programs for abused and neglected children in rural areas. Sefcik and Ormsby have written that a lack of awareness and education about the incidence and impact of child abuse and neglect, and its "spin off" problems of truancy, juvenile delinquency, etc. have, historically, contributed to the lack of concern, involvement and support of programs for abused children in rural communities.[11] In addition, they write, small-town conservatism, the perceived threat to parental rights and family privacy, fear of becoming involved through reporting, small-town politics and power structures, the geographic scattering of the population, and scarce or inaccessible resources all impede the development of rural child protection programs.[12] Despite these problems, however, rural communities are developing child protection programs, and almost all of them now have some interdisciplinary focus, through some programs are clearly organized around an interdisciplinary practice model, while others are not so well organized. The following examples demonstrate a commitment to an interdisciplinary practice model.

In their article in Maternal and Child Nursing two year ago, Christiansen, Schommer and Velasquez describe a human services-public health nursing agency partnership in Ramsey County, Minnesota called the "Special Families Care Project."[13] These social work and nurse clinicians describe a program designed to identify families at high risk of abusing or neglecting their infants and, equally important, providing outreach, teaching and counseling to prevent abuse and neglect. The "interdisciplinary aspect of the project was a key concept in its development," the authors write. "Interdisciplinary team practice provides a forum for examination and evaluation of ideas in light of the different frames of reference of the various team members." In their interdisciplinary project meetings, staff members from both agencies found themselves more aware and more appreciative of the other discipline's roles and responsibilities. This led, they wrote, "to the development of close, meaningful, mutually respectful work relationships among the health care professionals involved."[14]

The activities of case conferencing, consultation and co-visiting among social workers and nurses described in the St. Paul program is not unique to urban areas. Rural areas are developing similar strategies for intervention with families in which child abuse and neglect is probable, or has, in fact, occured. Eight years ago, writing in Children and Today, Joseph Leistyna, a rural Virginia pediatrician described his efforts to organize an interdisciplinary team of nurses, social workers, physicians, a teacher, a mental health worker and an attorney to review cases involving child maltreatment.[15] In their first year this team evaluated 47 cases: 29 cases involving physical abuse, including two deaths; 12 cases of neglect, and six cases of sexual abuse. Forty-two of those children, Leistyna writes, came from families that were stressed by a number of environmental and social factors (many identified in this institute): poverty, deprivation, ignorance, apathy, social isolation, and inaccessibility to supportive health care systems. Equally inaccessible were supportive social service programs, including parent aides, day care centers, crisis nurseries, hotlines or parent support groups like Parents Anonymous--services typically available in urban areas.

More recently, in an issue of Public Health Reports, Saunders and Goodall1 describe a social work-public health nursing partnership that exists in rural Minnesota.[16] Again, the authors--one a social worker, the other a public health nurse--describe the benefits of interdisciplinary practice. They write that "dysfunctional families in which child abuse and neglect typically occur have many unmet social, psychological and physical health needs. Only 'teaming' can satisfactorily address and resolve these needs."[17] They also describe the value which the partnership has in providing support among the workers in the two agencies, and the utility of the community child protection team in responding to cases of child abuse and neglect. A case study is presented in the article which identifies the specific roles which health, social service, child development and law enforcement professionals play in child abuse cases.

ROLE OF THE PUBLIC HEALTH SOCIAL WORKER

Typically, the public health social worker in rural communities plays more than one role. Gilbert writes that "the MCH social worker brings to the 'team delivered care' concept... certain skills unique to the social work profession...Some of the specific activities are:

1) assessing the individual, family and social problem situation;

2) planning and carrying out appropriate intervention;

3) interpreting the range of health and social services and how they operate;

4) coordinating health, welfare, and educational services;

5) identifying the gaps in these services;

6) community planning;

7) administering social work programs;

8) standard setting and formulating social policy; and

9) raising a social action to bring about changes in the way services are provided."[18]

Rural social workers will often find themselves assuming not one or two of these activities, but seven, eight, or all of them. Their training as a generalist, which provides them with clinical, administrative and community organizing skills, facilitates the performance of these activities equally well.

In rural practice, an important role of the public health social worker is that of case manager. He or she provides liaison between other professionals and typically organizes the interdisciplinary staffings that need to occur if all client needs are to be addressed. In rural areas, this is not small task since service programs may be spread out over a multi-county area. Additionally, some services like nutrition counseling, family planning counseling, child health clinics--to name a few--may only be offered sporadically on a weekly, bi-weekly, or monthly basis. Thus, social workers intent on the input of allied professionals in the case planning process will likely find themselves coping with scheduling problems around both service delivery for their client as well as consultation with the service providers.

The case manager role encompasses the tasks of collaboration, coordination and advocacy. In addition to assessment skills and clinical skills imperative for service delivery to clients, the public health social worker in rural practice often plays a community education role, which sometimes includes in-service training for interdisciplinary groups. Gilbert writes: "The MCH social worker's becoming fully active in working with planning and training activities for any of many disciplines cannot help but complement their coordination of service activities."[19]

Preparing social workers for these roles, especially crucial in rural communities, is an obligation of schools of social work. Twenty-five years ag at a seminar entitled "Public Health Concepts in Social Work Education", sponsored by the Council of Social Work Education, interdisciplinary content in social work programs was advocated. The conference proceedings include this summary statement: "Broader knowledge and appreciation of related disciplines will be gained by students through such content as: 1) interdisciplinary relationships and collaboration; 2) information about operation of the public health system...; 3) the roles of different public health workers and the common goals they share with social work; and 4) awareness of the vital public issues in health as well as those in social welfare."[20]

In practice, the University of Iowa School of Social Work, for example, offers a course entitled "Interdisciplinary Programs for the Disabled" in which social work students join with students in other disciplines--notably nursing, special education, occupational and physical therapy--to learn the key roles, responsibilities, and complementary contributions which many disciplines play in meeting the needs of handicapped adults and children. Presenters from 16 different University colleges and departemtns represent the spectrum of disciplines invested in service delivery to handicapped persons. In their article, "Interdisciplinary Education for Health Care Professionals", Bassoff and Ludwig outline a course entitled "A Multidisciplinary Approach to Child Abuse."[21] Offered at the University of Pennsylvania, the course, not unlike that offered in Iowa, is designed to convey the advantages of an interdisciplinary approach to students of many disciplines who, in practice, will find themselves invested in the same problem or population.

Courses like these are among strategies which Lister suggests are necessary "to prevent confusion about roles [which can lead to] interdisciplinary conflict, gaps in services, or unnecessary duplication of services."[22] In addition, "training often has an energizing effect on the professionals in a health system."[23]

CONCLUSION

In general, movements from simply "case referrals" between agencies to "inter-agency partnerships", involving shared case decision-making and shared case intervention, is a process that demands both knowledge and initiative. While some program planners legislated inter-agency cooperation with formal working agreements, the bulk of interdisciplinary activity is, in the absence of structure, a "person-to-person" experience. Recognition that "I can't do it alone" is often a beginning for rural pracitioners. This recognition demands, then, a willingness to sacrifice 'turf'--defined as "holding onto the problem"--and a willingness to trust: both necessary ingredients for interdisciplinary practice. Picking up the telephone and inviting collaboration about a problem with an allied professional is a first step in interdisciplinary/interagency practice.

Facilitating this process--this initiative--is a knowledge base that includes: 1) an awareness of allied professionals' roles; 2) an awareness of the contributions which interdisciplinary practice can make in resolving client problems; and 3) an awareness of the personal and professional support that can be acquired in interdisciplinary collaboration. With respect to this last point, feelings of isolation are as prevalent among social work and health providers in rural areas as they are among rural clients. Collaboration among professionals is an invaluable strategy in remedying this isolation.

Without the kinds of interagency partnerships which have been suggested in this article, families in rural communities across the expanse of the country will remain underserved, and the health and mental health needs of many adults and children will remain unmet. We cannot afford the human costs which these unmet needs represent. With allied professionals working together, buoyed by the professional competence and inventiveness of a public health social worker, the needs of rural families can be met most effectively.

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"INTEGRATING PUBLIC HEALTH SOCIAL WORK AT PROGRAM AND BUREAU LEVELS: CONTENT, PROCESS AND ACTIVITIES"

Margaret Weinberg, M.S.W., A.C.S.W.

This conference - "Social Factors in the Health of Families: A Public Health Social Work Responsibility," - brings us back to basics and our reason for being. It is our focus whether we meet our responsibility working directly with families or supporting this work through education, research, program planning, administration and consultation activities. Those of us not working directly with families are at times necessarily preoccupied with planning, resources and implementation strategies. By seeking experiences and data to remain in tune with needs of families we will meet this public health social work responsibility.

My perspective is that of a state Maternal and Child Health Social Work Consultant in a unique state - New Hampshire- with a diverse system of delivering services to families. What activities occur between the state MCH State Plan and direct response to social factors in the health of families? How integration of Public Health Social Work at Program and Bureau levels translates into services to families will be my focus.

Dorothy Bon, in a conference paper - "The State Consultant's Role in Implementing A State - Based System of Health Care" - offered basic premises about the state consultant's role in overall program planning:

1. We are an integral part of the health care team whatever the level of our functioning.

2. We, as social workers, have a unique contribution to make in the development and implementation of health care services.

3. We already have informal networks established through our contacts with other agencies and providers. These networks can be cultivated and can be used by the administration in the development of more formal networks[1].

The applicability of the above to the Maternal and Child Health role in New Hampshire will become evident as we link state and local service delivery.

In viewing New Hampshire's uniqueness we can begin to see its influence on state and local diverseness. It is characterized in the state slogan - "Live Free or Die." First in the nation primary elections turn the state into a media event every four years. No sales or personal income tax is a source of pride to many. The third largest legislative body in the English speaking world-400 representatives and 24 senators - equaled 1 legislator for every 2,300 citizens in 1982.[2] Local government and responsibility are strong in New Hampshire and so is the desire to keep government costs low.[3] An apt description is included in the Department of Health and Human Services Consolidated Plan:

> "...New Hampshire is considered a great place to live; people talk about the lakes, mountains, the seashore, the rolling hills, and the picturesque small towns. However, New Hampshire is much more complex than usually portrayed. The state is as beautiful as described, but the beauty is counterbalanced by poverty, the pressures of growth, the aging of the population, the needs of the disabled, and underemployed.[4]

Working poor are hardpressed by high land, housing and rental costs, food and health care costs.[5]

Population is still less than a million - an estimated 977,000 residents in July, 1984, of whom only 2 percent are minorities. The growth rate has been high with peak in-migration accounting for almost 68 percent of the increase in the 70's. It has begun to level off with 57 percent of the increase in the 80's.[6]

Lest our look at New Hampshire's uniqueness divert us too far from the subject I will end it with two descriptive comments. The first is by the Director of a professional association about writing a great proposal - "Cut it to the bone and then cut the bone"--typical New Hampshire. "The second was included in Governor John Sununu's address to the Opening Session of the Legislature in January, 1986. After enumerating accomplishments of the past year he stated:

> We met all our needs and more while reducing taxes. These achievements were built on the understanding and a recognition that the New Hampshire Way is a unique,

> effective and constructive relationship among our citizens, our public institutions and our communities.[7]

That the New Hampshire Way is unique and that the services and support families receive depend on this relationship is true.

SOCIAL WORK COMPONENT IN BUREAU OF MATERNAL AND CHILD HEALTH

The Bureau of Maternal and Child Health and the social work component are the key parts of the bridge from state to local services. Based on Bureau mission and its programs is the top of the structure - the State Plan.

The Office of Family and Community Health and the Division of Public Health Services complete the structure within the New Hampshire Department of Health and Human Services. The social work consultant is a member of a consultant team including a nutritionist, health educator and nurses. Medical consultation is available although there is no physician on staff. Individually the consultants relate to certain programs and may also be responsible for a Bureau project area. The social work consultant is a member of the Child Health (Clinics) and Prenatal Program teams and coordinates the Sudden Infant Death Syndrome Program. Developing the new Adolescent Services Program was a special assignment with the Adolescent Health Program nurse and data analyst under the direction of the Bureau Chief. The Family Planning, Child Health and Prenatal Programs are the largest in terms of allocated funds and number of clients served. (Chart 1)*

Social work consultant functions relate to major pieces of the "big picture" as described by Dorothy Bon in her presentation of a state perspective at the 1985 conference - "Families at Risk: A Public Health Social Work Perspective." These functions are: (1) planning for social work service at the local level; (2) assuring the accountability of social work both to the client and to the agency; and (3) providing input into program planning and evaluation at the state level.[8] In New Hampshire these functions include program planning and evaluation, input into policy formulation, consultation and technical assistance. Bureau consultants perform an integral part of the request for proposal process. Each is responsible for guidelines and standards, training and other activities to ensure provision of quality services in the component area. There is a productive mix of individual and shared activities

*Charts located in appendix.

making the most of limited staff resources.

STATE PLAN

With the key parts of the bridge structure in place we will continue the building process from the State Plan to local services. Focus for Bureau planning evolves from recommendation of the "Governor's Blue Ribbon Commission Report of Public Health in the 80's." The Governor's threefold charge to the commission was to:

1. identify the public health challenges New Hampshire faces in the next decade;

2. identify strategies which will meet these public health problems;

3. recommend changes in the organization and function of state government which will enable the implementation of key strategies.[9]

Strong support for continuation of Bureau programs for prenatal care, child health and family planning was included in the Executive Summary. Precise targeting of the services to the more needy population at risk was called for.[10]

Social factors in the health of families are addressed within the framework of broad Bureau goals. Based on the Governor's Blue Ribbon Commission Report they are part of the New Hampshire State Health Plan.

Bureau Goal - To promote the health of all women and children, and to strengthen the family unit by encouraging specific preventive health activities and by encouraging an informed public and professional community to take an active role in the health and safety of its members.

Child Health Goal #2 - To assure that children (especially low-income children and those at special risk for health problems) have access to high quality comprehensive health services.

Maternal Health Goal #1 - Improve the health of New Hampshire women and their families by ensuring the provision of comprehensive Family Planning and Maternal Health Services.[11]

Viewed as components of bureau programs, social work, nutrition and health education are not usually identified in separate goal and objective areas. Specific consultant projects and activities may be included. Social work services are included in program descriptions in the State Plan. Child Health Programs services included physical examinations, screenings for specific health problems, immunizations, family counseling, nutrition and health education. Social work services are mentioned specifically in the Prenatal Program description.

Based on the goals, strategies and activities are identified to meet specific program objectives. The planning process begins at the program staff level. A day retreat away from the office encourages brainstorming and sharing of individual ideas for activities and projects. The next step - conferring with separate program directors may result in changes or additional projects. Each staff member prepares work plans based on Bureau goals and those of each program to which she is assigned. As social work consultant, I respond to separate Bureau, Child Health and Maternal Health Program goals.

DIVERSE SERVICE DELIVERY SYSTEM

In moving from state to local public health social work services the next step is the diverse local delivery system. Child Health and Prenatal Program services are provided through contractual agreements with a variety of local agencies. Every sizable town, and some not so sizable, has a Visiting Nurse Association or similar agency which may serve a number of smaller towns. Local Health departments are located in only three towns. Child health services are delivered largely by VNA's and similar private agencies. There are two rural health centers in the state. Some Family Planning Programs exist as separate agencies. Prenatal care services are often combined with family planning services. To encourage service coordination, maximize staff utilization and minimize administrative costs, the Bureau has given priority to funding programs in agencies with which there are already contractual agreements. This has resulted in development of a few model agencies providing a variety of reproductive and child health services. This diverse mix translates into 35 agencies with 44 service programs - a number of child health programs may operate within a family planning or prenatal program service area. (Charts 2, 3, 4)

Some advantages for service delivery can be found in

New Hampshire's uniqueness and diverse system. Small can be a positive in working on a statewide level; one can travel to the most isolated Child Health Program Agency in Northern New Hampshire and return in one day, albeit a long one. Although meetings and training activities for local staff are regionalized when possible, they can and most often do take place in one central location. Staff from related health care and human service agencies can be included. Personal contact and networking are broadened as many of the same people are involved in planning, coordinating and advocacy activities. Being located in the same building with the Divisions for Children and Youth Services, Mental Health and Developmental Services and Welfare facilitates communication and joint endeavors.

Two key mindsets emerge in delivering maternal and child health services in this diverse system with limited resources. Pragmatism requires maximizing resources and continuous prioritizing of individual activities. We consider the statewide impact and what will bring the most return for the investment. Paramount strategies become joint planning with others in shared responsibility areas, emphasis on coordinating services and building on existing services and initiatives.

INTEGRATING SOCIAL WORK SERVICES AT THE STATE LEVEL

Planning at the state level has been described - from broad Bureau goals to individual program-specific work plan strategies. One aspect of this process which defines services to be provided at the local level is structuring program requirements. They are different in the major programs - Child Health (Clinics) and Prenatal - where social work services are a component.

A social work consultant has been supported as an integral part of the Bureau of Maternal and Child Health multidisciplinary staff. Historically the services have not been seen as a separate component requiring social work staff at the local level in child health programs. An issue identified at the National Workshop on Nutrition and Social Work in Primary Care Servies in 1981 is pertinent:

> Social work and nutrition services are not universally available in primary health care programs. These services are often viewed as "Ancillary or supplemental" and are not viewed as essential servies that substantively contribute to the overall well-being of the populations

served. Social workers and nutritionists need to be viewed as providers of primary care services.[12]

Recognition of social work services as a component of child health service delivery is incorporated in a unit cost model by which agencies are reimbursed. The service schedule delineates well-child services. To conform to the unit cost reimbursement concept social work services include an initial screening or assessment at the newborn visit with interval assessments at 1 year and 3 years. A certain number of home visits are included in the schedule - some of which are assumed to relate to social factors in the health of families. The unit cost model does not reflect need for social work services but more so recognition of the need. Resources have not been identified to address this need. (Chart 5)

Another issue identified at the National Workshop on Nutrition and Social Work services is that few professionally trained social workers and nutritionists work in primary care programs. Only 8 of the 25 Child Health Programs have a staff member functioning as a social worker. Five are MSW level and one is BSW trained. Thus, one of the issue related barriers is operational. "Frequently other providers, i.e., medical and nursing staff, are designated to carry out nutrition and social work functions rather than hiring specially trained personnel, i.e., nutritionists and social workers, for this purpose."[13]

SOCIAL WORK SERVICES IN CHILD HEALTH PROGRAMS

Guidelines for Social Work Services in Child Programs relate to professional social work staff. The goal, staff qualifications, knowledge base, functions, and prevention and intervention activities are described. A separate schedule distinguishes services of a professionally trained social worker and those of other staff members responding to social factors in the health of families. The social worker performs assessments, provides therapeutic intervention and consultation to staff. Screening for needs and referrals for services may be performed by other staff. (Chart 6)

I believe many agencies recognize the need for trained social workers in Child Health Programs. The small number is more a reflection of lack of sources for reimbursement. Examples of this are found in comments from agencies in "End of the Year" reports. Agencies are asked to describe major problems (health, social, etc.) of their clients. What kinds of problems are described? As we would expect many relate to social factors in the health of families. Responses from visiting Nurse Association operated programs include:

> -One major problem we have in the area is many high risk social situations and no social worker services available.
>
> -Lack of a Child Health Program Social Worker to deal with the number and variety of problems by clientele - eviction, alcohol abuse, spouse/partner abuse, inappropriate discipline.
>
> Lack of knowledge/understanding of age-appropriate growth and development and lack of motivation for pursuing life changes remain major psychosocial problems of families.
>
> It is a dream of ours to have a social worker on staff to help with Parent Child Health and other programs. Finding the right person for the position is not easy and funding is another problem.

One activity to describe social factors in the health of families was focused on social work services provided. Monthly statistical reporting was implemented with the agency with the strongest social work component during the 1982 and 1983 calendar years. This data would also be available to the local agency for planning purposes. The largest of former Children and Youth Project sites, serving over 500 children, had incorporated as a non-profit agency. At that time Bureau funding allowed services to be maintained near the former level including those for children to age 11. Two experienced social workers shared 30 hours of staff time a week.

The report form format reflected family and child initial assessments and interval ones at designated age levels. The number of families requiring only health promotion or preventive services and those requiring intervention and type of intervention completed the service picture. Coordination and consultation activities, parent education and support groups further described social worker functions. This kind of data had not previously been collected.

The compiled statistics for 1983 revealed that a large number of the children and families required intervention services - 410 as compared to 131 who received preventive services only. The number of interventions also included other referrals from staff and the community. The problem most identified was family dysfunction followed by child behavior and parenting difficulties. We know many families experience multiple problems and not just the one identified initially or as most significant. Intervention is influenced by program structure and staff time available as well as need, so the majority of families received short term follow-up services. Sixty-nine mothers participated in over 50 group meetings. Social work staff were involved in 83 other planning and coordinating meetings and activities. On the state level this data was a tool in structuring the Child Health Program social work guidelines. (Chart 7)

After this excursion into the diverse child health social work service delivery system let's move to smoother waters in the Prenatal Program established in 1980. Program requirements for funding include a core multidisciplinary staff of nurse, social worker, and nutritionist. Identified in the state plan as a Bureau priority, eight program sites are in scattered locations serving 700 clients.

Ensuring quality services to prenatal clients is a current focus of state level staff. Comparable to those in Child Health Programs, Guidelines for Social Work Services in Prenatal Programs have been in place since 1982. They are incorporated into standards in a draft quality assurance document along with program and client outcome objectives.

While the social work component is an integral one in Prenatal Programs, limited local staff time is a barrier in responding to social factors. There is no required staff-client ratio so the level of services varies between programs. For example one program has 7.5 hours staff time a week for 25 active clients. This time is inadequate for clinic involvement and immediate client follow-up. No time is provided for community planning and coordination activities or continuing education. Many staff do the latter on their own time. As such a limited part-time status often makes it difficult to recruit qualified staff, agencies operating two or more programs are at an advantage. Some Prenatal Social Workers also provide Family Planning Services and others are shared with a Child Health Program. If reimbursement for social work services in home health care becomes more viable, a strategy may be for VNA's to share a position with the Child Health Program to increase staff resources.

Regularly scheduled meetings with prenatal social work staff have been an effective way to offer technical assistance, continuing education and program updates. They also meet public health responsibility by involving the private sector, developing linkages with related social work programs and channels for communication and sharing. Small and large programs, a variety of agency settings, and scattered locations typify the diverse service delivery system. Staff from other agencies providing health care and/or support services to pregnant and parenting adolescents and women are included in the meetings. They represent a rural health center, church related counseling and education program, VNA with Adolescent Family Life grant and a community mental health center. Members report on individual program activities, speakers from such areas as adoption services and Medicaid are invited, and written and audio visual resources are reviewed. Research studies and developments in the field are presented. Perhaps the most helpful aspect comes from the feeling of group identification, informal sharing and exchange of ideas.

A BROAD VIEW

Translating broad goals into action in meeting our public health social work responsibility means keeping a broad view. One way we do this is by sharing our knowledge and perspective through work with others in the public and private sector on behalf of families. With our mindset of maximizing resources this work with others has been focused in two areas: (1) collaboration for staff training and continuing education and, (2) child abuse and neglect prevention and intervention activities. Often the two merge.

TRAINING AND CONTINUING EDUCATION

A major impetus for training public health social workers in the New England Region has taken place during the past two years. With leadership by the Directors of Training at two Boston area University Affiliated Facilities, a group of MCH/CCS consultants first met in the Fall of 1983. Strong support came from the Division of Maternal and Child Health, U.S. Department of Health and Human Resources. The need for training for public health social work staff was identified as a priority. By August, 1984, a proposal for a SPRANS Grant to address prevention and intervention with families was submitted. It was approved providing for one training session in each of the six New England states during the three year grant period. For the first time to my knowledge, statewide training for maternal and child health social workers in New Hampshire became a reality. It was an important step toward a more effective MCH social work leadership role in the state. State level Division for Children and Youth Services staff, hospital social workers and those from other primary care settings also attended.

One focus for joint planning and coordination with other human service agencies has been statewide child sexual abuse training and advocacy for services for children and families. A planning committee was appointed by the Commissioner of the Department of Health and Welfare. With leadership and funding from the Divisions of Welfare and Mental Health, representatives from the Division of Public Health Services and community based agencies composed the Child Sexual Abuse Training Committee. Objectives of two day regional training sessions were to 1) offer a broad spectrum of community service agencies and institutions a chance to increase their awareness and knowledge of child sexual abuse and, 2) provide these agencies/ institutions with an opportunity to begin or to further develop local or regional structures to deal with the issues of child sexual abuse. State level and community maternal and child health staff participated in the training.

With recommendations from participants that the Department take a definitive leadership role in establishing initiatives for prevention and treatment services the committee continued in an advocacy role. Specific initiatives were developed for each Division of the Department and presented to the Commissioner and Division Directors. For maternal and child health staff these were 1) integration of prevention information into routine education and anticipatory guidance activities and, 2) appropriately identifying "at risk" families and potential child abuse situations. It identified the role of staff as assisting the child and family to become involved in intervention.

In response to needs expressed by local staff another training opportunity brought together state and local staff and other resources of the Bureau and the Division for Children and Youth Services. Over 100 staff from Child Health, Prenatal, WIC, Headstart and Early Intervention programs took part in a workshop on legal issues in child abuse and neglect. Roles of staff in assisting families through identification, reporting, testifying in court and coordinating services were emphasized.

Strategies for sharing social work knowledge and expertise with other disciplines and strengthening primary prevention with families were implemented through again another meeting. Entitled "Primary Prevention: Supporting Parents in the Health Care Setting,: the session was jointly sponsored by the Bureaus of Maternal and Child Health and Handicapped Children's Services (now Special Medical Services). It was also an opportunity for collaboration with the other Division of Public Health Services Social Work Consultant. Our ongoing relationship is one of sharing, support and peer consultation. With the goal of enabling staff in maximize opportunities to support positive parenting content focused on:

1. relating to parents at their stage in the family development;

2. developing an awareness of the impact of supportive interventions on parent's ability to nurture;

3. learning ways to relate to the parent as the most important person in a young child's life.

We see the merging of child abuse and neglect issues and staff training as one focus of the MCH Social Work Consultant activities. It becomes an even broader one when we view coordination and collaboration as ends in themselves. Outcomes of information sharing, developing closer working relationships and identifying resources for ongoing response to families are substantial. The consultant's membership on the Board of Directors of the New Hampshire Task Force on Child Abuse and Neglect has similar broad implications. Networking with a variety of systems impacting families is enhanced through contact with Board members and Board activities. State and local law enforcement, mental health, public and private children and youth services, education, day care, hospital based social work services, mass media (TV), and the state legislature are accessed in this way.

I now invite you to cross the bridge from state to local services. We will visit some areas where MCH program staff are meeting our responsibility for social factors in the health of families in its most meaningful way.

In the lovely tourist area of North Conway the Children and Youth Project social worker skillfully supports a mother and daughter who are revealing sexual abuse by the father. Experience with the staff has conveyed caring and a sense of trust-that this is a place to seek help. This mother may already be participating in an ongoing parent support group focusing on concerns of the parents. Other parents can attend a 6 week mother-infant workshop. Teen mothers learn about parenting, child development, nutrition and health in their own support group. Arts and crafts provide enjoyment and a sense of accomplishment.

As we continue our trip further north we see adolescent and low-income women receiving pregnancy tests at a Family Health Services Agency. The adolescent is pregnant so is referred to the Prenatal Program and applies for WIC services. She attends parent education classes. When the infant is born she receives Child Health Clinic services from the same agency and the mother continues her relationship with the social worker she knew in the Prenatal Program. She receives family planning services again and we have come full circle. This experience can happen in two towns with these unique for New Hampshire Family Health Service Agencies. All parents in the two towns can attend as annual day of family centered education - from parenting adolescents to the single parent and blended families. This community wide approach to assist families involves joint sponsorship by health and human service agencies and utilizes mainly local professionals as presenters and discussion leaders. This is "The New Hampshire Way" at its best.

Continuing to the western part of the state we observe a Well-Child Clinic. WIC services are available at the same time. A mother with a two-month old baby relates that her husband has left her. Without family or friends in the area she has no one to whom to turn. Financial worries add to her stress. She shares that she can't stand to hear her baby cry and fears she will harm him. She accepts parent-aide services from the agency. The social work plan is that this support will enable her to become involved in a Parents Anonymous group for which the social work supervisor is a co-sponsor. The agency also offers a parent group for ongoing support.

The last stop on our trip is an innovative 5 year old child health services agency located in a city in the southern part of the state. Its stated purpose is "to increase the number of children in the service area who are functioning at their capacity for well being with enjoyment." I like that. The staff see their role as "providing comprehensive health services that can adapt to needs of the defined population - families who do not use the traditional health care system." Both preventive and illness care are provided by a multidisciplinary staff. Financial support combines state and local resources, private grants, and fund raisers and makes possible services to over 500 children and their families. Six full and part time family support workers are supervised by a social work supervisor. One example of the special attention to needs of families is identification of a population of cognitively limited parents who required greater and different support, direction and staff time. A full time family support worker position was added to work exclusively with some of these families. Another example is re-assessing the needs of children enrolled in the program at 5 and 6 years of age and who are now entering adolescence. Many of these children have over-responsibility for care of younger siblings so a baby-sitting course was offered.[14]

We have experienced a diverse state and local system for delivering Public Health Social Work services to families. The bridge connecting these systems still has some ruts and frost heaves familiar to us in New England. Repairs must be made and new sections built so families can travel a smoother road to "functioning at their capacity for well-being with enjoyment."

In New Hampshire the work will continue through integration of Public Health Social Work at Program and Bureau levels. A strong foundation for the bridge is built on local staff and community independence and initiative. Planning and coordination with other building contractors will maximize resources and widen the bridge from state to local service delivery.

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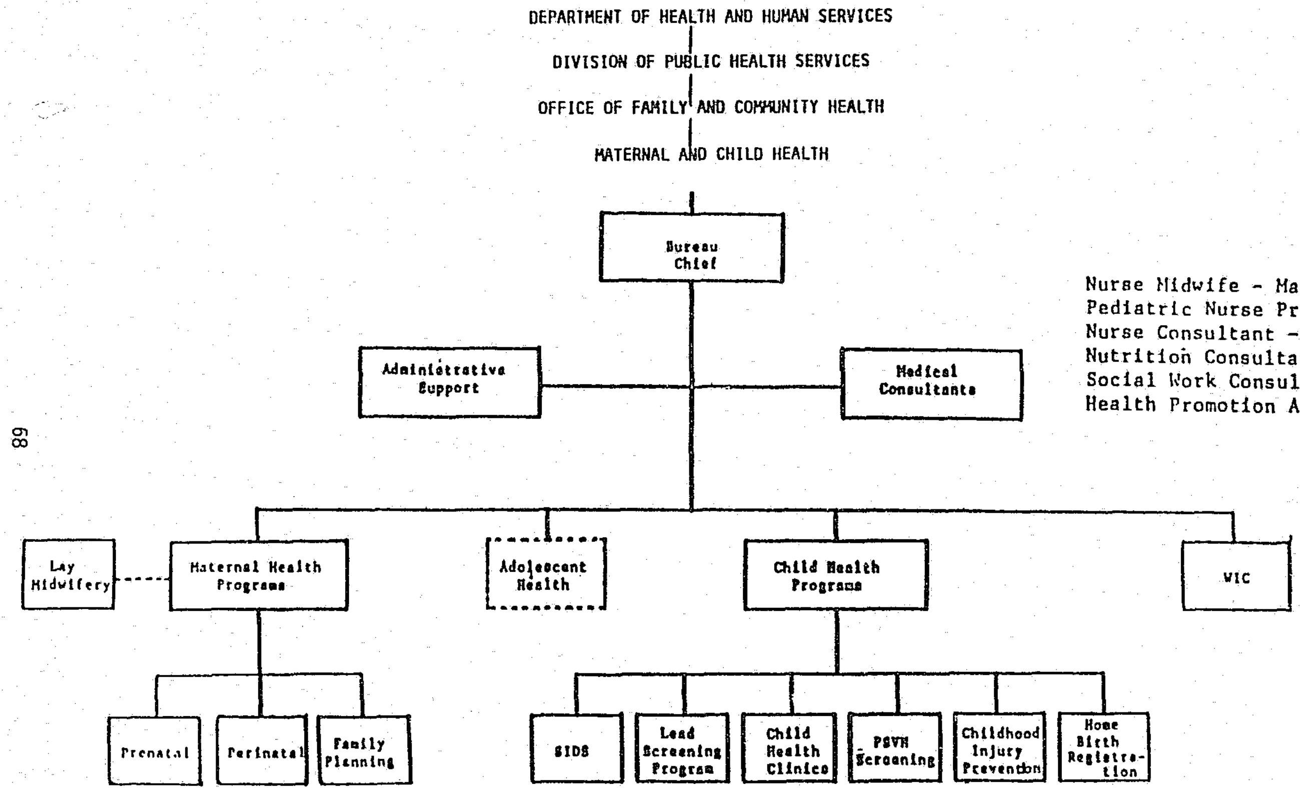
CHART 1



Nurse Midwife - Mat. H. -
Pediatric Nurse Pract. - CH
Nurse Consultant - Adol. H.
Nutrition Consultant
Social Work Consultant
Health Promotion Advisor

July 1985

CHART 2

ype of Service Program

Child Health	25	+ 6 Sites
Family Planning	11	+ 6 Sites
Prenatal	8	
Total Programs	44	

Number of Agencies by Kind of Services Provided

Child Health	21
Family Planning	5
Family Planning/Prenatal	3
Prenatal	2
Child Health/Family Planning/Prenatal	2
Child Health/Prenatal	1
Child Health/Family Planning	1
Total Agencies	35

CHART 3

N. H. DIVISION OF PUBLIC HEALTH SERVICES
BUREAU OF MATERNAL AND CHILD HEALTH

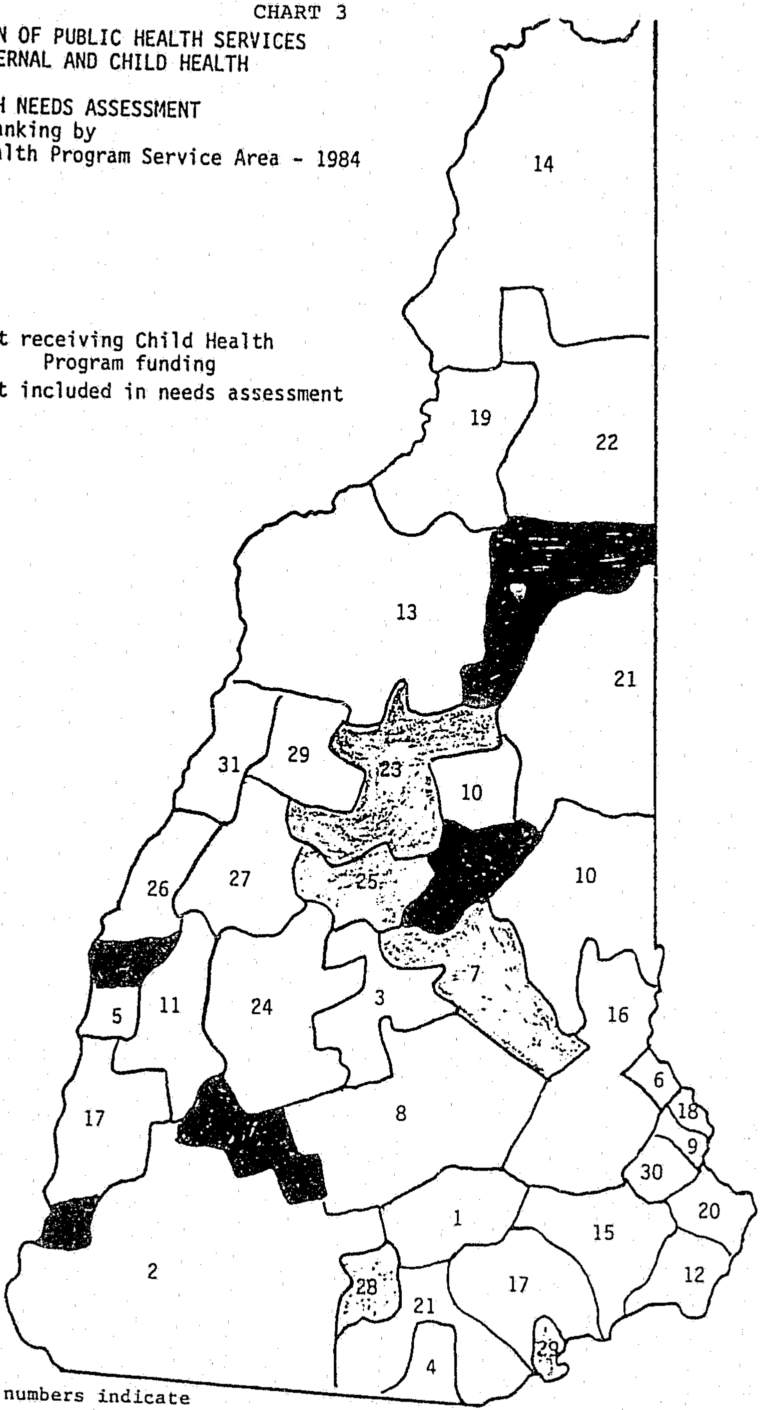
CHILD HEALTH NEEDS ASSESSMENT
Statewide Ranking by
Child Health Program Service Area - 1984

Legend

High need = 1
Low need = 10

▨ Areas not receiving Child Health Program funding

■ Areas not included in needs assessment



NOTE: Duplicate numbers indicate a tie score on needs assessment

. PRENATAL
GRAMS FY '86

CHART 4

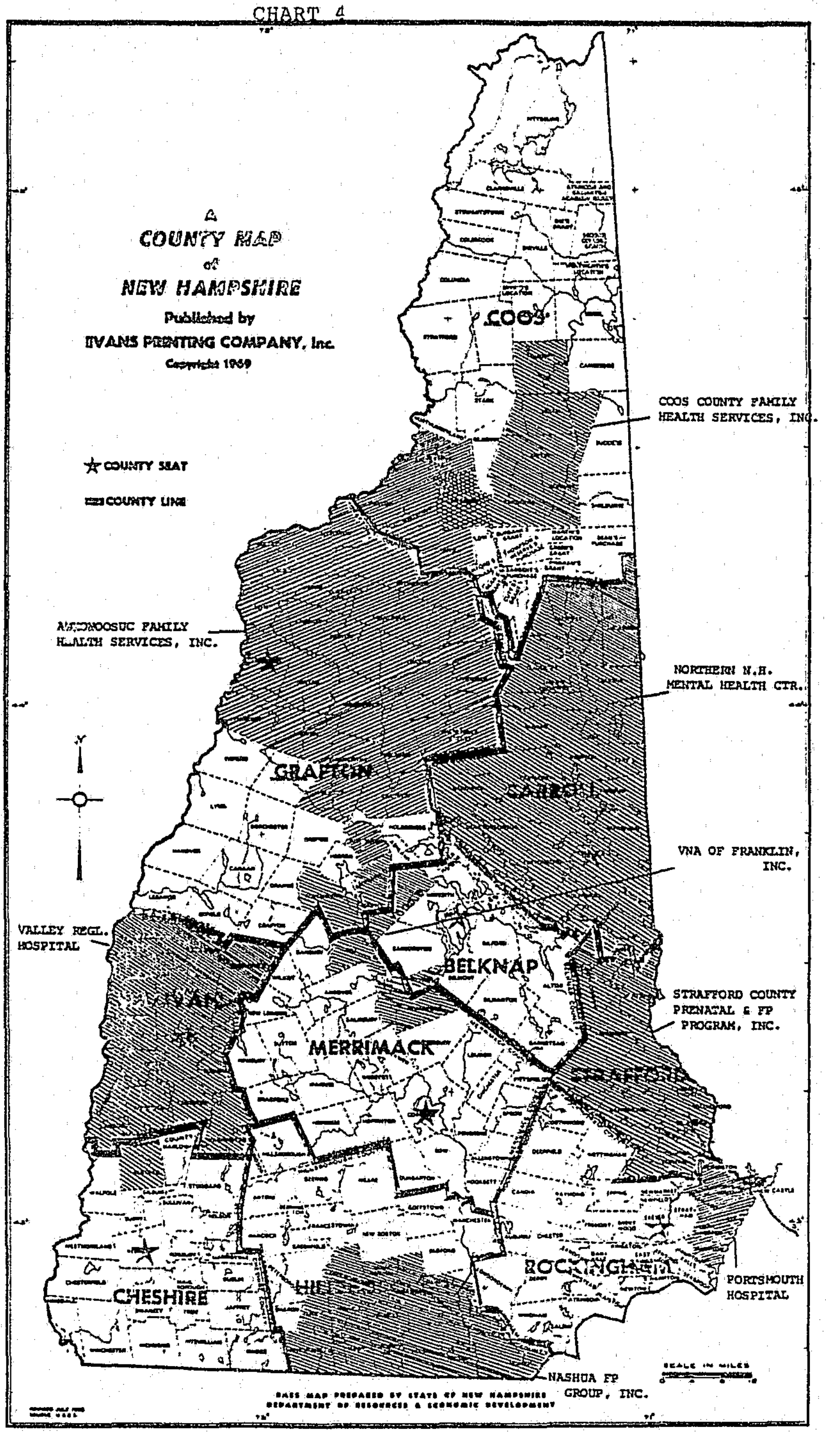


CHART 5

Unit-Cost Model - SERVICE SCHEDULE

FY'87

	0-28 Days	*29 days to 2 mos.*	*4 mos.*	*6 mos.*	*9 mos.*	*1 yr.*	*15 mos.*	*18 mos.*	*2 yrs.*	*3 yrs.*	*4 yrs.*	*5 yrs.*	*6 yrs*
Anticipatory/Guidance/Injury Prevent	X	X	X	X	X	X	X	X	X	X	X	X	X
History & Physical Exam	(Y)	X	X	X	X	*	X	X	X	X	X	X	X
Development Assessment/Guidance	#	#	#	#	X	#	#	X	#	#	#	#	#
Height & Weight		X	X	X	X	X	X	X	X	X	X	X	X
Head Circumference	(Y)	X	X	X	X	X	X	X	X				
DPT Immunization		X	X	X									
Polio "		X	X										
DPT Booster Imm'n.								X				X	
Polio Booster Imm'n								X				X	
Measles/Rubella/Mumps							X						
Hib Vaccine									X				
Lead Testing						X			X	**			
Blood Pressure										X	X	X	X
Hgb./Hct.				(X)	X	(X)	X			X		X	
Dental Education										X	X	X	X
Dental Administration										X	X	X	X
Vision Screening											X	X	X
Nutrition Services	(Y)	X	X	X	X	X	X	X	X	X	X	X	X
Hearing Screening											X	X	X
Social Work Services	(Y)	X				X				X			
Home Visit	X	X				X	X	X	X	X			
Referrals	(Y)			X			X		X				
Record Keeping	X	X	X	X	X	X	X	X	X	X	X	X	X

(X) - Timing optional for Hct/Hgb

(Y) - Components of Newborn Home Visit

1/86

* *Nursing Visit - Physical Exam Optional. Please emphasize Nutrition Counseling, Family Assessment, Child Development, and Injury Prevention*

** *Lead Test Not Required - funding included to offset costs of postage, handling for lead testing.*

An interval developmental assessment should be part of the history and physical examination at each visit. A DDST should still be done at 9 & 18 month

CHART 6

SOCIAL WORK SERVICE COMPONENTS

Functions/Activities	*Description*	*Level I would be performed by RN or other staff with Bachelor level education.*	*Level II would be appropriate for a MSW or Master's in Counseling.*
Screening	*Basic family psychosocial -economic data is obtained and reviewed.*	*Emphasis is on identifying "High Risk" factors or areas where intervention is indicated*	
Assessment	*In addition to the above involves data about attitudes, behaviors, relationships, events influencing past and present well-being of the child and family.*		*Determination of need for intervention based on evaluation of psychosocial and economic data, including related strengths, needs, and barriers to change.*
Care Planning	*The process of setting goals and identifying the activities by which to achieve them.*	*Based on screening.*	*Based on screening and psychosocial assessment.*
Intervention and Follow-up.	*Carrying out planned activities to promote physical, social and emotional development and well being of child.* *Assisting parents in coping with stresses and problems which interfere with this.*	*Examples of activities* *Referral to other agencies, programs, coordination of plan and services, health promotion counseling and guidance, educational or social support group.*	*Specific casework, group and counseling techniques are utilized to maintain, improve or change functioning.*
Consultation	*Sharing of knowledge and expertise with staff, volunteers, to expand knowledge of psychosocial factors and their application in working with children and families.*		*Examples-* *Inservice training* *Team conferences* *Case consultation*

CHART 7

Children and Youth Project
Social Work Report

Period January - December 1983

1. Assessments

	Family	Child	Total
Initial	59	38	97
Interval	221	129	350
Total	280	167	447

2. Results of Assessment

Health Maintenance/Promotion Only	131
Plan for Social Work Intervention	410

3. Problems requiring intervention

Child behavior/parenting difficulties	215
Lack of/problems managing financial resources	154
Inappropriate utilization of health care system	46
Problems/needs related to developmentally disabled, chronically ill, handicapped child.	14
Family dysfunction related to Marital, parent/partner, other.	270
Other - Drug, alcohol, mental illness, physical problem	65

4. Intervention

Short Term Follow-up	282
Casework treatment	118
Crisis Intervention	14
Referral to other agencies	97

5. Groups

Number of group meetings during period	52
Unduplicated count of number attending	69

Type group(s) Teen Mother's, Mothers Support

6. Other program activities

Planning, coordination with other programs, agencies	38
C&Y Staff, Planning meetings	39
Consultation to staff or other persons	6
Total	83

THE PSYCHOSOCIAL IMPACT OF HTLV-III INFECTION ON THE HEMOPHILIA POPULATION

Pamela Nimorwicz, M.S.W.

Hemophilia is an inherited, sex-linked abnormality of the blood-clotting mechanism, which is genetically carried by females and physically manifested in males in a wide range of clinical severities. A mild hemophiliac may have rare bleeding episodes but a severe hemophiliac usually has multiple hemorrhagic episodes each year, many of which occur spontaneously and without apparent injury. All significant hemorrhages are treated with a blood product which contains the clotting protein which the hemophiliac lacks.

With the advent of modern blood component therapy, blood products have been developed which may be given intravenously at home by severely affected patients. Home therapy programs have helped hemophiliacs attain more freedom and mobility. Adults are often able to treat themselves while at work at the first sign of a hemorrhage and then continue normal activities. Parents, who have been trained for home therapy, can treat their children and decrease the time spent in clinic and hospital waiting rooms and increase the time their children spend at school and at play. However, since 1981, when some of these blood products were contaminated with the AIDS or HTLV-III virus, the medicine which had been life-saving and life-normalizing, also became a potential threat to their lives.

As of January 1, 1986, 145 hemophiliacs nationwide, including 32 children, have been diagnosed as having AIDS. Eighty-two of those diagnosed hemophiliacs have died from this disease which is thought to be uniformly fatal.

The only known route of transmission of HTLV-III is by exchange of blood or body fluids. Important steps have been taken to guarantee the safety of the blood supply. All blood donors are now routinely screened for the presence of HTLV-III antibodies. Manufacturers of the concentrated blood products used by most hemophiliacs no longer collect plasma in high risk areas. In addition, all of the manufacturers of these concentrates now use a heating process to inactivate any virus that might be present. Therefore, hemophiliacs can be reasonably certain that they are no longer being exposed to the AIDS virus.

This does not mean that the crisis is over for individuals with hemophilia, their families or their children. It also does not mean that the need for services has decreased. On the contrary, because of its long incubation period, uncertainty about the range and duration of clinical manifestations, and the need to decrease the risk of transmission, HTLV-III infection continues to cause stress for the person with hemophilia, his spouse or sexual partner(s), his family, and his caregivers. Routine testing for the presence of HTLV-III antibody for all hemophiliacs, which was implemented in Pittsburgh as well as other Hemophilia Centers around the country last year, has heightened the anxiety level for all concerned and increased the need for education and counseling regardless of whether the antibody result is positive or negative.

Since there is no test for the HTLV-III antigen, it is impossible to determine how many of the individuals who have already been exposed are infectious. Focused counseling efforts are being developed in many comprehensive treatment centers whose goal is to decrease the current 1-5% per year rate of sexual transmission of this virus by hemophiliacs to their sexual partners as well as decrease the risk of fetal transmission.

Sex education was never a routine part of comprehensive hemophilia-related care. Patients are uncomfortable with this sudden probing of the intimate details of their sexual lives, and Hemophilia Center staff are even more uncomfortable now that the role of sex counselor has been added to their job descriptions. All sexually active individuals with hemophilia should be educated about HTLV-III infection and transmission and strongly encouraged to routinely use condoms to protect their sexual partners. The need to provide this education in the interest of public health raises many ethical issues about confidentiality. We encourage patients to bring their partners to the clinic for anti-HTLV-III testing and education. We also use regular clinic check-ups to discuss with them the recommendations for condoms, demonstrate proper condom use, and provide samples of condoms to encourage this change in their life styles.

Couples are advised to defer pregnancy until more is known. Spouses who are now pregnant or who have recently borne children to seropositive mates are advised not to breast feed. We have recently begun to do antibody testing on children born to hemophiliacs within the past 4-5 years. Couples are also asked to avoid sharing personal hygienic items, such as razors and toothbrushes, which may have been contaminated with antibody positive blood.

Children with hemophilia are now also routinely tested for HTLV-III antibodies and closely followed. Many of them have been switched from single donor blood products to heat treated concentrates, which are thought to be more protective against AIDS, but, because they mean exposure to thousands of donors with each treatment, may render these children more vulnerable to hepatitis and liver disease. The testing and treatment changes continue to require a large amount of staff time for education and counseling.

Since the advent of anti-HTLV-III testing, patients and families have been unable to deny their sense of personal vulnerability. The new information, changes in treatment, and behavioral recommendations are intrusive and have an impact on household interactions and usual sexual behaviors. In addition, anxiety regarding contagion among health care providers, school personnel and community agencies has been noted in Western Pennsylvania and around the country. This further reinforces the hemophiliac's perception of himself as infectious, defective and socially isolated.

The importance of continued medical surveillance through comprehensive hemophilia evaluations, education, support and counseling for individuals living with hemophilia is vital. Health care workers must guard against being so overwhelmed by AIDS that they overlook other medical and psychosocial problems. The importance of comprehensive care when dealing with something like the AIDS epidemic cannot be overstated. The Commonwealth of Pennsylvania Hemophilia Program provides an excellent illustration of the effectiveness of the comprehensive care model. However, numerous states have sparse facilities and resources for the provision of such care. In the face of shrinking budgets experienced by many over the past few years, psychosocial support staff were frequently the first to be cut. Social workers need to be involved in the development of AIDS-related programs. They need to be available on-site to staff for consultation as well as being involved in the provision of education and community services. Finally, it is essential that we provide outreach to educate and allay the fears of others in order to safeguard the well-being of the hemophilia population and the community at large.

CHILDREN WITH SPECIAL NEEDS AND ADOPTIVE FAMILIES: A CHALLENGE FOR PUBLIC HEALTH SOCIAL WORK

E. Virginia Lapham, Ph.D., M.S.W.

Children with special needs, in particular children with developmental disabilities and/or chronic illnesses, and adoptive parents are two populations that have only recently come together. Traditionally, these two groups have been separate units of society with little contact. Until the 1960's, children with special needs were often separated from their families and reared in institutions while adoptive parents (who were often childless, middle-class, married couples) sought healthy, non-disabled infants to rear in their families. Except for the secrecy often surrounding both institutionalization and adoption, the two groups had little in common.

In this decade of the 1980's, however, most chronically ill and disabled children are being reared by their own parents and when this is not possible, these special needs children are increasingly being adopted by a wide variety of families including single parents, older parents, and parents with several other children. How and why societal changes occurred that enabled these two populations to come together, current mandates and issues in the child welfare system related to special needs adoption, and the need for post-placement services are considered in this presentation. Specific emphasis will be given to a special needs adoption training program now underway at Georgetown University Child Development Center.

BACKGROUND

A review of the care of chronically ill and disabled children and a discussion of the relatively brief period of adoption in the United States provide a framework for understanding current issues in special needs adoption.

Children with Special Needs

Institutional care of disabled children was started in the 1830's as a humane reform to the incarceration, abandonment and homicide of earlier periods in our history. Following World War I, the institutional movement was expanded as new and larger facilities were built in rural areas around the country to house disabled persons of all ages. Taber (1980:3) refers to this period as one in which there was a policy of "exclusion" and "custody". Professionals routinely advised parents to institutionalize their disabled children as quickly as possible after birth or diagnosis. This was considered to be in the best interest of the family as well as the children. Disabled persons did not have high value in our society, little was expected of them, and few resources were allocated for their rehabilitation and education.

This situation began to change following World War II, when a large number of wounded veterans survived the war because of the significant advances in medicine and technology, but were left with residual disabilities. These veterans who were heroes in a popular war ushered in a new era of understanding and treatment of disabled persons. An example of this change occurred in 1943, while the War was still going on, when the original Rehabilitation Act of 1920 was replaced by a law which substantially broadened the concept of rehabilitation to include "any services necessary to render a disabled individual fit to engage in remunerative occupations" (Straus in Sussman, 1965: 12). These services included diagnostic, medical and psychological examinations, corrective surgery including hospitalization, and the costs of books, travel, tools or other equipment, as well as maintenance to enable the disabled adult to participate in work and become or remain self supporting.

Gradually these medical and technical advances were expanded to treating and rehabilitating disabled children and as the children responded and became more independent, separation from their families became less likely. While parents still wanted to have a "perfect child", most were able to adapt to the child they had and to rear the child at home. This was sometimes done in opposition to the traditional professional advice to institutionalize disabled children.

The media exposure of some of the worst conditions of institutional care and the subsequent legal actions requiring institutions to phase out their programs and return residents to the community began a momentum toward deinstitutionalization during the 1960's that continues today. In many situations, the provision of services in the community did not occur as quickly as did the deinstitutionalization movement and some families experienced significant isolation and stress in trying to meet the special needs of their disabled children at home. In a few cases, the stress of rearing a special needs child became overwhelming for families and with insitutions non longer an alternative, the primary solution to caring for the child outside the family was to voluntarily place the child in foster care.

In some instances, family situations became so acute, the entry of the child into the child welfare system was because of abuse and neglect. The child welfare agencies who received the children were also unable to refer them to mental retardation and mental health agencies so began placing them in foster families. It was the cost of maintaining large numbers of children in foster care, however, that led to the big push toward adoption of children with special needs.

Adoptive Families

While the popular image of adoptive parents has been that of white, middle-class, infertile couples adopting infants of unwed parents who look as much as possible like the adoptive parents, this phenomenon occurred for a relatively short period of time. According to Simon and Altstein (1979:9), the history of adoption is the history of "hard-to-place" children and as recently as the 1920's, this included almost every child needing a home including white, healthy, infants. Agencies initially had to recruit adoptive parents for all children without homes and to "sell" the country on adoption. Societal attitudes toward unwed mothers, "illegitimacy", and bringing children of "different" blood into the family set up strong barriers to adoption (Reid in Feigelman and Silverman, 1986:219). Prospective adoptive parents had to be convinced that they would not be contaminated by adoption.

Among the measures taken to alleviate the anxieties of prospective adoptive parents was to match physical characteristics of the child with that of the adoptive parents, to seal the original birth records of the child, and to create new documents identifying the adoptive couple as the child's parents (Feigelman and Silverman, 1986:219). So successful were the child welfare agencies of this era that the United States became the only country in the world in which adoptive children have all of the same legal and inheritance rights as biological children.

In the late 1940's, less than 30 years after adoptions were started, the concept of matching physical characteristics of children and adoptive parents began to change as a few white couples began adopting black children. Transracial adoptions gained momentum until the mid 1950's and then became very controversial as black professionals and political leaders opposed this trend. Transracial adoptions were dismantled in the early 1960's, rose again in the mid 1960's, waned in the early 1970's and almost ceased to exist by 1975. In 1973, 4,665 black children were adopted by families unrelated to them, 1,091 of these in white families (Simon and Altstein, 1979:10).

Transcountry adoptions also began following World War II, initially with infants and young children from Germany, Estonia and Latvia. Later, children from Asia, Africa and Latin America were also adopted by families in the United States (Simon and Altstein). The next barrier that was broken was the secrecy surrounding adoption as older children began to be adopted who could remember their parents and sometimes several foster homes as well.

Adopting children 5 years of age or older was considered "a courageous experiment conducted by a group of adoptive parents" (Kadushin, 1970:3) as recently as sixteen years ago. The recognition that there were advantages to keeping together two or more children from the same family, added "sibling groups" to the "hard-to-place" category. While some prospective parents chose to adopt minority children, older children, and sibling groups because of ideological beliefs, the number of healthy infants declined considerably during this same period as contraceptive technology improved, abortion became legalized, and single parenting became more socially acceptable.

These changes paved the way for special needs children in the child welfare system and adoptive parents to get together. It was still necessary, however, to add another legislative mandate, some funding, and a broader definition of prospective adoptive parents before the two groups came together.

CHILD WELFARE SYSTEM

A major re-examination of the child welfare system in the 1960's and 1970's showed the sharp increase in the number of children being placed in foster care, many of them children with special needs. For example, a study of 23 states showed that in 1965 there were a total of 5,779 children in foster care, and by 1972 these same states had 77,527 children in foster care, or a 13 fold increase in seven years (Dore and Kennedy, 1981:374). By 1979, it was estimated that there were 500,000 children in foster care with approximately 375,000 living in foster homes (Shireman, 370).

According to Horejsi (May 1985), other findings of this period included: the longer children remained in foster care the less likely they ever were to return home; once placed in foster care, agencies and workers tended to provide few services to the children's parents; few efforts were made to prevent foster placements; and too many children remained in the system drifting from one placement to another with no chance of either returning home or becoming legally free to be adopted. Concerns about children and their families as well as the spiraling costs of maintaining the system led to what is commonly referred to as permanency planning.

Permanency Planning

The major child welfare reform of this decade was enacted with the final passage into law of Public Law 96-272, The Child Welfare and Adoption Reform Act of 1980. The major thrust of this legislation is to provide permanency planning for all children, including those termed "special needs". A "special needs child" is defined in this legislation as one with physical, mental or emotional handicaps; one of a sibling group needing to be placed together; members of minorities, and older (over the age of 10 years) individuals.

Permanency for children is an ideal that expresses the kind of environment considered best for rearing children and holds the promise of opportunity for children in the child welfare system to grow into well adjusted adulthood (Madeline Will, Fall 1985:1). It reflects the notion that children grow better in families and the family of choice is first and foremost the child's birth family. When the birth family is not able to care for its own even with supports, permanency considers adoption the next best option. Permanency is also an intent and not a guarantee that all children will be provided with the best possible family situation. It acknowledges that even the best planned adoptions can result in disruption or dissolution under certain circumstances. Permanency planning, however, seeks to minimize the risks of disruption while simultaneously maintaining that every child is adoptable.

Special Needs Children

Of the estimated 273,000 children in foster care on any given day, approximately 36,000 are free for adoption with 29,000 waiting for adoptive homes (Livingston, 1986). (Those not waiting for homes include older adolescents waiting for emancipation at their 18th birthday and other adolescents living in peer group situations.) According to Jane Burnley, Associate Commissioner for the Children's Bureau of the Administration for

Children, Youth and Families, (April 1986) the children in care have an average age of 11 years, are disproportionately minority, and in 1983, 27% had handicapping conditions. Since comprehensive evaluations are not provided to all children in foster care, even these figures may be low. The population is also one that is highly vulnerable to a range of emotional, learning and medical problems being manifested after adoption (Waldinger, 1982:521).

Adoptive Parent Recruitment

In nearly every state, increased efforts are being made to recruit adoptive parents for special needs children. Media campaigns to increase the pool of prospective adoptive parents include pictures of adoptable children in newspapers and on television. Agencies are no longer considering only white, middle-class, childless couples as adoptive parents. In fact, the qualities of the ideal parent(s) to adopt a developmentally disabled child are commonly listed as: maturity, flexibility, lower-middle-class status, high school education, blue collar employment, family-centered life, religious orientation, previous parenting experience, experience with stress (such as divorce or having another handicapped child), and a desire to adopt a disabled child (Coyne and Brown, March-April 1986:192).

In contrast to the past when foster parents were not allowed under any circumstances to adopt a child in their care, foster parents are now the primary source of adoptive parents for special needs children. In many cases, bonding and psychological parenting have already occurred between foster parents and children in their care before the adoption occurs (Meezan and Shireman, 1982:529). Since foster families have traditionally been of lower income than adoptive families, the provision of adoption subsidies, another part of the permanency concept, has enabled many foster families to adopt children with disabilities and chronic illnesses.

The inclusion of adoption subsidies as part of the Adoption Assistance and Child Welfare Act of 1980 marks the first time that the federal government has regulated or provided partial funding for adoption and represents a major commitment to rearing children in families (Waldinger, 1982:516). In a recent presentation (April 1986), Dodie Livingston, Commissioner of the Administration for Children, Youth and Families reported that in 1984, a total of 10,500 children per month received adoption assistance and by 1985, 16,000 children per month were receiving adoption subsidies totaling $34.5 million dollars annually. The estimated amount for 1986 is $44 million.

Even as the successful recruitment of adoptive families continues and special needs children are being placed in adoptive homes, the issue of what happens to the families and children after placement is a vital concern. Disruption of an adoptive placement is not only a serious threat to the well being of the child who feels rejected but also to the parents who feel they have failed.

POST-PLACEMENT

Families who adopt children with developmental disabilities or chronic illnesses are vulnerable to increased stresses and adjustments related to the special needs of their children. This does not mean that the families are pathological or have anything wrong with them but is a recognition that the children often require more time, attention, energy and resources than children with normal development. They need more from their environment than do other children and these needs may produce stress in adoptive families just as they do in biological families if resources and supports are not available.

Adoption workers have traditionally provided supportive services to families during the pre-placement and placement periods but once the child was adopted, the contacts ended. This ending has been important to many adoptive parents who consider this the time when they really become parents and no longer need agency oversight. When supportive services were later needed by some adoptive families and sought in the community, however, adoptive parents have encountered other problems including negative attitudes toward them for adopting a special needs child.

Few mental health professionals have been at the forefront of providing support services to adoptive families of children with special needs. They have not only failed to understand the developmental problems for which the families sought help, but sometimes questioned the motives of the families in taking on this responsibility. Instead of being helped, the families were sometimes blamed for the problems for which they sought help. A recognition of this lack of appropriate post-adoptive services was stated by the Office of Children, Youth and Families in their request for proposals to develop model programs aimed at training mental health professionals to provide post adoption services for special needs children and families. Georgetown University Child Development Center was one of the successful applicants for this funding and the project is now midway into the 17 month period of the grant.

Special Needs Adoption Collaborative Model of Training

With the primary goal of the training project being to enable mental health professionals in a variety of settings to provide support services to adoptive families of special needs children, three objectives were identified:

1. Provide specialty training in developmental disabilities and handicapping conditions to professionals (psychiatrists, psychologists, social workers, counselors, etc.) to enable them to extend the scope and range of their supportive services to the adoptive families of special needs children.

2. Develop a collaborative model between child welfare agencies and other agencies/professionals to improve services to this target population.

3. Develop a training guide for use in training personnel worldwide.

In this presentation, two aspects of the project will be described: the training implementation and content, and the process and results of a needs assessment survey designed to identify mental health professionals with experience in working with persons with physical illness and disability.

Training It was initially decided to implement training at three sites representing populations with diverse characteristics. These sites included a major city with a largely minority population, a medium sized city that is also a state capitol, and a five county area that ranges from an upper middle-class suburban population to a more rural group that includes blue collar workers and farmers. Since these areas are not unlike those of many areas of the nation, the model is expected to have national applicability. An average of 40 mental health professionals in each location were recruited to participate in the training.

The professionals targeted for training included social workers, psychologists, psychiatrists, and other counseling professionals who provide direct services in both public and private agencies. Organizations represented included child welfare agencies, family services, community mental health programs, schools, and health agencies. Additionally, professionals in private practice settings were included. An underlying assumption in providing the training to these professionals was that an increase in the knowledge base of children with developmental disabilities and chronic illnesses and their impact on family functioning would have a positive effect on both the affective and performance behaviors of the professionals in providing support services to adoptive families.

The training was divided into three phases for a total of 36 hours. The first phase consisted of 24 hours, typically a three hour sesion once a week for 8 weeks. Each training session included didactic material, case presentations including panels of parents telling their own stories and giving advice on how best to help them, and clinical application of theory. The course content of this phase included:

- An Overview of Adoption and Developmental Disabilities
- Genetic Disorders and Fetal Alcohol Syndrome
- Mental Retardation
- Spina Bifida, Cerebral Palsy
- Learning Disabilities, Attentional Deficit Disorders, and Autism
- Family Issues, Impact
- Psychosocial Development and Future Expectations
- Accessing Resources and Agency Collaboration

The second phase of the training program consists of three additional three-hour sessions held at approximately monthly intervals. These sessions are considered as integrative periods in which the theoretical material presented earlier is utilized by the professionals in their work and new questions and concerns arise that can be discussed with other professionals in the group as well as with those providing the training. In some cases, additional topic areas have been identified for further training. These have included issues of sexuality of developmentally disabled persons, specific chronic illnesses, and family and child assessment.

The third phase of the training is anticipated to be a one day update conference for all trainees to include speakers, panels, and small group discussions. Both pre-tests and post-tests have been administered as part of the evaluation process. It is anticipated that at the completion of the training, the trainees will have achieved the following:

- Understand the major developmental disabilities and how they may affect the life cycle and quality of life of individuals with developmental disabilities.
- Understand the developmental expectations of the special needs child and be able to explain them to the foster or adoptive family.
- Understand interdisciplinary assessment findings so as to be able to interpret the process to families and to contribute to the identification and referral of individuals in need of such assessment.
- Have increased knowledge of educational and behavioral approaches to management of developmentally disabled individuals so as to include these in his/her practice or to make referrals to other professionals.
- Demonstrate an understanding of the special psychosocial issues for the family of the developmentally disabled through appropriate supportive counseling practices.
- Articulate his/her own perception of society's attitudes toward developmentally disabled persons and their families.
- Identify specialized health, educational, financial, legal, and social resources as well as specialized consumer and social action groups serving the special needs adoptive child, so as to guide the family in appropriate utilization of resources.

Needs Assessment As part of the effort to identify mental health professionals in the private practice sector who might need and be interested in participating in the training as well as to find professionals who already had experience and training in developmental disabilities and chronic illnesses, a three page questionnaire was developed and mailed to approximately 1800 social workers, psychiatrists and psychologists. A cover letter explained the purpose of the needs assessment and asked if those professionals with experience working with chronically ill and disabled persons would like to be listed in a directory that would be a resource for families of children receiving evaluations at Georgetown University Child Development Center and for other interested individuals and agencies.

The responses began coming in two days after the first mailing and a total of 280 questionnaires were returned with 240 of the respondents reporting experience in providing mental health services to one or more of the 36 categories of persons with chronic illness of developmental disabilities listed, and wanting to be listed in the directory. The largest group of respondents were psychiatrists, then psychologists, and social workers as indicated in Table I.

TABLE I

PROFESSION OF RESPONDENTS

Psychiatry	109
Psychology	80
Social Work	51
TOTAL	240

An analysis of the disabilities and illnesses in which the mental health professionals already had experience indicated that the most frequently mentioned areas of experience were learning disabilities, alcoholism and chemical dependency, mental retardation and developmental disabilities, impact on parents of rearing handicapped children, and seizure disorders. Approximately half of the respondents were experienced in these areas as noted in Table II.

TABLE II

AREAS IN WHICH MENTAL HEALTH RESPONDENTS REPORTED MOST COUNSELING EXPERIENCE

	Number	Frequency
Learning Disabilities	130	.54
Alcoholism/Chemical Dependency	129	.54
Mental Retardation/ Developmental Disorders	118	.49
Impact on Parents	118	.49
Seizure Disorders	110	.46

At the other end of the spectrum, the mental health professionals had the least amount of experience in providing counseling to persons/families with muscular dystrophy, spina bifida and other neural tube defects, cystic fibrosis, cleft lip and palate, and fetal alcohol syndrome. This may be seen in Table III.

TABLE III

AREAS IN WHICH MENTAL HEALTH RESPONDENTS REPORTED LEAST COUNSELING EXPERIENCE

	Number	Frequency
Muscular Dystrophy	19	.08
Spina Bifida/Neural Tube Defects	25	.10
Cystic Fibrosis	25	.10
Cleft Lip/Palate	31	.13
Fetal Alcohol Syndrome	33	.14

The results of these findings provide information that is relevant not only for training in the area of special needs adoption but in many other areas as well. The directory of mental health professionals is expected to be an important resource for agencies and a help to adoptive and other families with special needs children.

PUBLIC HEALTH SOCIAL WORK

In considering comprehensive post-adoption services in general, Waldinger (1982:521) argues forcefully that these services should be presented from a public health perspective of prevention, like pediatric checkups and immunizations, rather than from any implication of pathology, and that professionals should be able to anticipate when families might experience stress or disequilibrium. In the case of special needs children who are adopted this prevention perspective means putting together what is known about family stress in the field of adoption with what is known about the stress of rearing children with disabilities and providing both professionals and adoptive families with the guideposts. Additional research is needed to see if these factors are additive or interactive and if there are other stress factors not yet identified.

Prevention also means identifying resources to help families deal with stresses. Conducting needs assessments that identify existing resources and provide information about what additional training is needed by mental health professionals to more effectively provide services to adoptive families of special needs children may also be helpful. Mental health professionals have a vital role to play in addressing the needs of foster and adoptive special needs children and their families, both to facilitate adjustment and to prevent disruption. Public health social workers can facilitate this process.

A training manual being developed as part of the special needs adoption project at Georgetown University is expected to be available by December 1986 and may be ordered at that time by any group interested in special needs adoption training. The contact person is Nancy Striffler, Director of Training, GUCDC, 3800 Reservoir Road, Washington, DC 20007.

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ASSESSMENT OF NEEDS, PROGRAM PLANNING, AND RESOURCE ALLOCATION

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Purpose of Needs Assessment

It may sound overwhelming to study the needs of a community when staff and funds already seem stretched to the limit, however there are four valuable reasons for carrying out needs assessments.

The community can benefit from assessment through identification of the primary social problems and needs of the population currently served by an agency. An assessment can also pinpoint the primary social problems and needs of the population not served and help delineate the reasons why services are not accessible.

The staff of an agency can benefit from needs assessment in identifying common goals and an achievable purpose. Assessment allows combining all the available staff resources and using them to the maximum extent possible to alleviate identified problems and needs. Through focusing energy toward specific problems, staff can see progress, find success in reaching goals, see alleviation of suffering and need, and feel value in their jobs. Focusing on identified needs also prevents or relieves job stress which occurs when goals have been too broadly defined, such as "the elimination of poverty."

A third reason for carrying out a needs assessment is to obtain funding for social work positions. Assessments can identity critical needs impacting on people's lives which require social work intervention and which can be reduced or eliminated with such staff. To accomplish this, goals must be specific, obtainable, and then publicized when reached. Social workers also are trained to carry out community assessments and thus provide accurate, objective data which can be used for agency planning.

The final purpose for assessing needs is to facilitate the building of coalitions around common concerns. The potential for effectiveness can be strengthened by several agencies working together. In addition, assessing and prioritizing needs creates a specific common purpose towards which several historically uncooperative agencies can combine positive forces, possible building future long term working relationships.

Two Success Stories

Two widely different examples of needs assessments illustrate the effectiveness of assessing needs as a strong tool for social change. In 1915 the British Women's Cooperative Guild published Maternity: Letters from Working Women. In these letters, 160 British working-class women, writing in 1913 and 1914, talk about their experiences in childbirth and mothering. A questionnaire, with a short letter, was sent to about 600 members who were, or had been, officials of the Women's Cooperative Guild.

The questions asked were:

1. How many children have you had?
2. How soon after each other were they born?
3. Did any die under five years old, and if so, at what ages and from what causes?
4. Were any still-born, and if so how many?
5. Have you had any miscarriages, and if so how many?

As stated in the introduction, "The writers were not suffering innocents who happened to be caught by a survey. They were mostly experienced activists working for a political purpose: to propagandize for nationally funded maternal and infant care grants for needy women." Some of the benefits they gained included a maternity benefit under the new National Insurance law, four weeks sick pay at childbirth for the employed, and the establishment of Municipal Maternity Centers for pre and post-natal care as well as delivery (Davies, 1978).

In a second study, the state of Maine completed in 1980 an assessment of the child death rates for 1976-1980. Although vastly different in its techniques and methodology, the outcome of this study is similar to the 1915 survey. The Maine study by the Department of Human Services which compiled existing data showed primarily that there was a three-fold difference in death rates between poor and non-poor children for all causes of death. The magnitude of these differences shocked Maine legislators and prompted them to enact special legislation providing approximately $5 million for prenatal care, foster home payments, additional staff for child abuse and neglect,

Method	Example	Strengths	Limitations
1. Survey or Questionnaire	Survey of needs of newly arriving refugees	1. Systematic and objective 2. Encourage respondent to think about issue at question 3. Provide data from population at risk, not just through observers	1. Vary greatly in technical sophistication 2. Can be expensive 3. Rapid rate of obsolescenc 4. Often not taken seriously because so few result in action
2. Experience Survey - produces data on a second-hand basis through inquiry among social agencies, schools, hospitals etc.	Inquiry to churches, hospitals and social svcs. as to need for bereaved parents group	1. Top solutions recommended based on familiarity of problems 2. Respondents are accessible 3. Gives staff and other organizations sense of participation in planning effort	1. Data collection open for biases 2. Socio-cultural difference often between respondents and those in need
3. Available Data - collection, review, analysis and interpretation of already existing statistical (U.S. Census) and non-statistical (newspaper reports) data	Healthy Beginnings program in Arkansas showing need fo better prenatal care	1. Availability and accessibility of data 2. Most economical and expedient	1. Data may not have been collected in many areas 2. Technically available but very difficult to obtain due to red tape 3. Ages quickly 4. No opportunity for dialog with consumer or provider
4. Experiences of Other Communities - informal examination of remedies used by nearby locales in terms of their success	Information from other Social Service Departments in neighboring states	1. Economical 2. No need for professional researchers or consultants	1. Locales may not be simila 2. No conclusive facts about levels of need 3. Involvement of community is small
5. Resources Inventory - put together inventory of service programs already existing	Review of available literature on community resources	1. Data easily secured from directories 2. Inherently comprehensive when covering all resources 3. Final results easily understood	1. Basic listing may be unavailable 2. Problem of classificatio 3. Difficulty inherent to mechanics of a valid and reliable resource inventor
6. Consumer Utilization - monitoring of rates of inquiry, request or delivery of services as indicators of community need	Management information system	1. Integrates need research function into service delivery process 2. Gets at needs of motivated clients 3. Can make comparisons of need over time	1. Automatically excludes those apathetic, isolated, or uninformed 2. May not measure pervasiveness of need

Method	Example	Strengths	Limitations
6. Consumer Utilization, continued		4. More feasible as a routine operation	3. Interests of service delivery may conflict with needs of research
7. Community Outreach – outreach staff collect information on needs while providing outreach services	EPSDT outreach services	1. Field workers bridge link between agency and community 2. Reaches those who might not have been 3. Field workers provide information to people in community 4. Allows staff observation	1. Staff faces pressure of providing service for need 2. Difficulty in getting acros difference between outreac and professional service roles 3. Staff may begin helping rather than referring
8. Case Histories – illuminate the range of existing problems and unmet needs	Case history presentation used to teach role of Social Worker in intensive care nursery to Health Department staff	1. Dramatic in showing level of need 2. Gives overall picture of individual 3. Illicits human feelings which support desire to meet needs	1. May be biased by selection process 2. Does not yield any overall data 3. Difficult to compile and analyse
9. Study Committee – convened to consider a particular problem, is representative of entire community. Professional staff gathers data for committee	Committee to study reorganization of Department of Human Services	1. Do very comprehensive assessments of problem 2. Broad representation of community 3. Uses as many as possible in community with expertise	1. Not a continuing, comprehensive assessment by lay citizen leaders over period of years 2. Larger the committee, more difficult to work with 3. Committee may be biased 4. Time consuming
10. Public Meetings and Hearings	Block grant public hearings	1. Immediate feed back to participants' questions 2. Divergent viewpoints expressed 3. Can be educational forum about alternative solutions to problems 4. Involvement early gains support of community during implementation 5. Brainstorming can create ideas	1. Unrepresented factions unaccounted for 2. Risk involved in stating unpopular positions – may be left unsaid 3. Responses may be severly biased by manner hearing i conducted 4. Time consuming 5. Undue influence by dominant personalities

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Name ______________________________

SOCIAL WORK NEEDS/SKILLS ASSESSMENT

Please rank yourself with a plus (skill is well developed) or a minus (needs work) for each of these skills.

Skill	Ranking	Suggestions for training to help you improve your skill
Writing: case records goals & objectives position papers		
Counseling		
Planning		
Group work		
Community organization		
Delegating		
Communication with patients with staff		
Other areas of importance in your job:		

Division of Medical Social Services
Arkansas Department of Health
March, 1985

Please give an estimate of the percentage of time you spend in each of these areas at work. This is an estimate, an average. The total should equal 100%.

% of time

________ 1. Casework: counseling one to one in clinic or home visit, finding resources or doing follow up for individual clients.

________ 2. Groupwork: educational, support, therapeutic group for clients or staff.

________ 3. Community organization: working with other agencies, professionals in developing resources, developing alternatives to meet the needs of a group of clients.

________ 4. Teaching: providing inservice to group of staff or community persons on a particular topic.

________ 5. Consultation: discussing with other professionals (Health Department or otherwise) regarding case management or having case staffings to obtain referrals.

________ 6. Staff counseling: individual counseling for Health Department staff regarding personal or work related problems.

________ 7. Program development: grant writing, budget preparation

________ 8. Supervision: supervising social work staff, students, interpreters

________ 9. Other: ____

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Name
Medical Social Services Division
Arkansas Department of Health
May 1983

expanded AFDC benefits, employment assistance, and family counseling projects (Maine Department of Human Services, 1983).

Types of Community Needs Assessments

Byrne and Gimmel in their unpublished paper Methods of Need Determination for the Community do a fine job of delineating ten types of needs assessments and the strengths and limitations of each. The various types of needs assessments each fall on a continuum relating to several categories:

1. Technical, professional study----Self study
2. Subjective or soft data----------Objective or hard data
3. Subjective involvement-----------No subject involvement
4. Stress on implementation---------No stress on implementation
5. Singular technique --------------Combination of techniques

The following chart summarizes the ten methods and also includes examples of each which were carried out in Arkansas. For further discussion of the various assessments refer to the Byre and Gimmel paper (Byrne and Gimmel, 1979).

Resource Identification

"Resources may range from complete solutions to service delivery problems to partial solutions or parts of solutions. Resources include funds, manpower, materials and facilities. At the end of this phase of the planning process the planners should have a listing of the needs accompanied by a listing of relevant program elements which are currently available" (Salvatore, 1973).

To identify resources, start with the social work staff themselves. Begin by making a list of the staff, take a survey of their education, previous experience, special areas of interest, and areas of special training. It is also helpful to list the responsibilities or limitations placed on them by their funding source or by agency policy. Two assessment tools from Arkansas which can be used to evaluate staff resources are a social work needs/skills assessment and a time allocation form. After each staff member fills out the two forms a composite picture is obtained of the abilities or "resources" available through the staff.

The second step in resource identification is a review of one's budget or any other available financial resources. The general rule is that there are never sufficient funds for what one wants to do. However, it is important to begin by putting in writing what is available whether that be a regularly allocated budget, donations or contributions, or earned funds. The important factor in the use of funds is how they are used and that will be discussed further in resource allocation.

A final component of resource identification is brainstorming. The opportunity provided through brainstorming is to view the community in a creative way. Things which might not generally be considered resources may be identifed as such. In fact what generally may be thought of as a liability may turn out to be the best asset. An example from Arkansas will illustrate the use of creative thinking. A public health social worker was working with community people in building a battered women's shelter. The group had no money to purchase a facility. The town however had an old city jail which was unused and actually was an eyesore for the community. The group persuaded the city government to let them use the jail which was remodeled through donated labor and materials. The town no longer had an unsafe building and the battered women had a safe place to go in times of crisis.

The brainstorming session begins with the social work staff and community representatives, if desired, reviewing the needs of a community. Then they develop a list of every possible available resource. The emphasis at this point is on creativity and not practicality. The feasibility of specific resources comes into play in resource allocation.

Setting Needs in Priority

The function of priority setting is to rank identified needs so that the order in which they will be attached through program development can be established. The rationale for setting priorities is an inherent scarcity of resources which precludes working on all needs at one time.

Four approaches to ranking are:

1. Ranking needs as to severity
2. Ranking needs according to availability of resources
3. Ranking as an administrative prerogative-this adds clout to the ranking
4. Ranking as a process of participation-consumer involvement (Salvatore, 1973)

In ranking it is also helpful to consider these criteria:

- numbers of people affected by the problem
- geographic distribution of people
- political, social, cultural climate of the community (timing)
- organizational capability to address/resolve the problem
- monies potentially available
- parallel efforts made by other groups locally or elsewhere (visit and learn from their similar programs)
- projection of impact of reducing or eliminating the problem (Nichols, 1972)

Objectives

Generally the next step in program planning is writing objectives. As the focus of this workshop is in other areas please refer to the numerous books and articles available for information on writing concise, obtainable objectives.

Resource Allocation

At this point needs and resources have been identified and objectives written. Resources must now be allocated to meet community needs. As stated under resource identification, resources include funds, manpower, materials and facilities.

COUNTY PROFILE

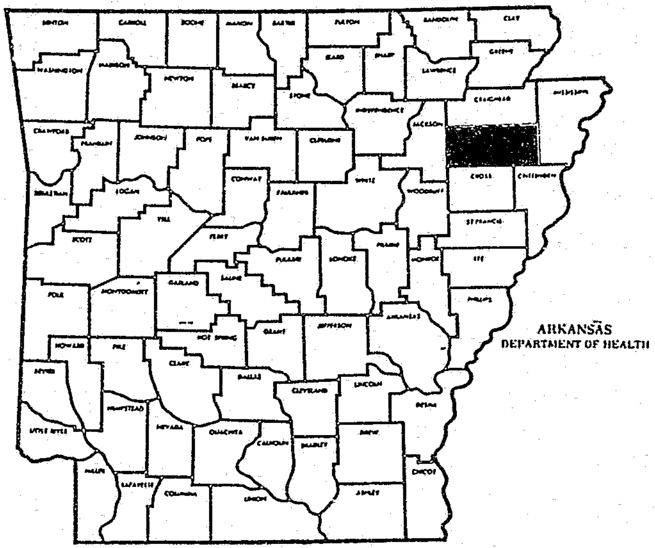
Poinsett County

HEALTH DEPT. CLINIC CASELOAD

Family Planning Patients 808
Child Health Patients 629
Home Health Patients 185
Maternity Patients 261

GENERAL POPULATION DATA

Total Population 27,032
Population by Age Group:
  under 18 8,409-31%
  18-65 15,159-56%
  over 65 3,464-13%
High School Education 42%
Income Levels:
  Median Income-Families $12,951
  Per Capita Income $ 5,138
Labor Force Females, 16 yrs. & over, with Children under 6 yrs. 52%
Below Poverty Level 22.5%
Unemployment Rate 13.8%
#Births 411
#Teenage Pregnancies 110



Data such as this can be collected from Census reports and Health Department Vital Records. Rankings can then be made of various regions, counties, cities, or even communities in prioritizing the need for social work coverage.

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Begin by reviewing financial resources. Develop a time limited plan such as for one year or even six months for expenditure of funds. Filling out an actual budget sheet with categories for expenditures may be of value. It is important to match the use of funds with the development of other resources to maximize the impact of limited finances. One invaluable way to stretch money is to invest it in staff. People are the one resource which can be broadened, stretched, and expanded more than any other type of resource. At this time review the staff needs/skills assessment carried out during resource identification. Budget funds to purchase training materials, pay for registration to local continuing education workshops, have staff meetings with community speakers or have staff procide training themselves to each other in their areas of expertise. Money for education, orientation materials and training are often considered superfluous. However, over a longer period of time these expenditures are investments. They not only upgrade staff skills and abilities, they build staff morale by showing the staff they are worth the investment of time and money.

The second component to consider in resource allocation is to develop priorities for placement of new staff as funding becomes available. A chart used in Arkansas in which priorities are established follows. In allocating staff it also is important to consider such factors as the recruitment potential for a particular geographical area, the expertise needed for a specific geographical location or population, health clinic caseload size, and available community resources. To stretch the manpower resource it is possible to use graduate and undergraduate field placement students, summer student volunteers, and well trained volunteers in conjunction with staff. Be careful that volunteers do not take away more staff time than they are able to contribute to the total work effort.

A final thought in the allocation of resources is the development of coalitions both within and outside the agency. With adequate preparation and strong leadership coalitions can resolve a broad spectrum of community problems and can provide a base for further cooperative projects.

Now the assessment and program planning are almost complete. The final step is perhaps the most important. Once these steps have been accomplished go out and tell everyone what you have done. Write a report, submit a paper for publication, give lectures, produce a slide show or videotape. The impact of having assessed and then met needs carries great potential. It allows you to not only survive in a time of tight budgets and limited resources, but to grow and thrive.

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[This summary previously appeared in the 1985 Proceedings "Families at Risk: A Public Health Social Work Perspective." However, due to illness, Ms. Williams did not conduct the workshop at that time, but did so in 1986.]

EVALUATION AND QUALITY ASSESSMENT IN HEALTH CARE SETTINGS: IMPLICATIONS FOR PUBLIC HEALTH SOCIAL WORK

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Kenneth J. Jaros, M.S.W., Ph.D.

Health and human service organizations have been under increasing pressure to evaluate their programs and to indicate to others that they are providing adequate and appropriate services. Evolving reimbursement mechanisms, competition among providers, and concerns about legal liabilities, are but some of the factors which have stimulated an interest in service delivery and quality of care. As a result, evaluation of health-care services has become more common as agencies become more familiar with the principles of research, efficient management and record keeping systems. Most evaluation in the social work area has focused on the efficiency and amount of output of the organization. An important additional goal of evaluation is to assess the quality of service being delivered to the clients. Social work has typically attempted to maximize quality of care through supervision and other monitoring procedures.

A relatively recent mechanism for studying service organizations, which has emerged from the field of medicine, is quality assessment. Quality assessment can be described as a formal analytic review that evaluates the quality of patient care, typically in medical-care settings (hospitals and clinics). The quality assessment models, although designed for evaluating care provided by physicians and other health-care professionals, also have relevance for the less exact science of social work. In the context of a coordinated approach to evaluation, these models can become another useful tool for both the clinician and manager of social work organizations.

EVALUATION STRATEGIES

Most evaluation of health and human services is designed to determine whether the program is effecting any changes. Essentially, this is an issue of the quantity and quality of service that is directed toward an established need in the community.

Evaluators believe that evaluation should be an integral component of any program implementation and management plan.

Consistent and routine evaluation should provide information on which to base program decisions about modification, expansion or even discontinuation. Although a rational evaluation strategy should be designed early, and implemented throughout the life of a project, in many cases programs are only evaluated after they have been operating for a long time. Under such circumstances, evaluation usually occurs haphazardly and decisions are frequently made on the basis of subjective opinions. In addition, resources for evaluation are often unavailable, and many managers as well as clinicians are threatened by an assessment of their own organizations.

Regardless of these factors, we should not be deterred from seeking to use evaluation methods more often. In its simplest formulation, evaluative research involves the development of objectives, and the subsequent measurement of progress toward them. There is basic structure that can be used to assist social service and health-care organizations in developing an evaluation strategy. (See Figure 1) In order to clearly define the objectives, it is first necessary to state the issues that the program is designed to address. Objectives can be defined in one of three basic categories: ultimate objectives, which are typically general agency goals or missions that are never fully attainable, program objectives, and program sub-objectives. The objectives and sub-objectives are the measurable indicators upon which the evaluation can then be based.

FIGURE 1

TYPES OF OBJECTIVES

Ultimate objectives - goals or mission
(not measurable)

Program objectives
(measurable)

Program sub-objectives
(measurable)

Numerous strategies are available to indicate how well an agency is meeting objectives. Suchman's categorizations of evaluations as listed in Figure 2 provide a useful guide.

Within the context of any evaluation strategy, an assessment of the quality of care can also be included.

FIGURE 2

CATEGORIES OF EVALUATION

EFFORT EFFECT (OUTCOME)

STRUCTURE/PROCESS

ADEQUACY EFFICIENCY

OVERVIEW OF QUALITY ASSESSMENT AS RELATED TO MEDICAL CARE

The basis of quality assessment in medical care is the need to demonstrate to others that quality exists. As early as the 1910's, Dr. E. A. Codman began a process of examining the end-results of surgical procedures with the goal of determining whether the surgery was really needed. Unfortunately, this early interest in quality assessment did not continue, and it was not until the early 1970's that quality of health care again became an important issue. Accreditation procedures of the Joint Commission on Accreditation of Hospitals (JCAH), requirements of the Professional Standards Review Organization (PSRO), and legal accountability of the hospital stimulated much of the renewed interest.

To assess quality, it is first necessary to define what is meant by quality. According to Donabedian, "quality is a property that medical care can have in varying degrees." Assessment of quality is then a judgment whether a specified instance of care has this property and if so, to what degree. Also, it is necessary to define the specific unit of care that is to be evaluated. The simplest situation involves one problem, one patient or client, and one provider. In reality, most medical-care situations prove to be much more complex.

In considering quality, two domains are recognized: the technical and the interpersonal. The technical aspects involve medical diagnostic procedures and treatment while the interpersonal aspects involve the human, interactional factors as well as environmental amenities involved in care. These domains are often thought of as the science and art of medicine respectively. In addition, while medical care usually implies a benefit to the patient, all care is accompanied by some degree of risk. Consequently, Donabedian would define quality as "that kind of care which is expected to maximize an inclusive measure of patient welfare, after one has taken account of the balance of expected gains and losses that attend the process of care in all its parts." Notice that this statement reflects a focus on the patient, which should be central in any assessment of health care.

QUALITY ASSESSMENT VERSUS QUALITY ASSURANCE

First and foremost, quality assessment must be distinguished from the now popular concept of quality assurance. For multiple reasons, we agree with Donabedian that quality assurance is "too optimistic a term." Quality assessment tools are not yet particularly sophisticated, and few causal, or attributional, relationships between the processes and outcomes of care are scientifically established. Also, it is impossible to assure quality considering the real world constraints of human error and equipment failure. Finally, the word assure implies a guarantee, which is not only impossible, but also unwise from the legal perspective. Therefore, it is more reasonable to monitor and assess the quality of care with an objective of enhancing that quality when indicated.

What are the basic approaches to quality assessment? Direct observation, document-based review, and interviews and surveys are the typical methods employed. These methods can focus on retrospective, concurrent, or prospective analyses. Also, they can be used intermittently or on an onging basis. The conventional type of quality assessment study involves a retrospective review of existing medical records. The type of data usually collected is "soft", and not consistent or objective enough to be validly used for comparative studies among different institutions.

Patient-care evaluation, medical-care evaluation and medical audit are all similar terms that physicians have used for studies that are designed to assess the quality of care. The basic approach for such a study focuses on a review of patient records and relies on a non-physician, i.e., a medical data analyst (MDA), to abstract information from the records. It is essential that the physicians provide explicit instructions for the medical data analyst. These instructions, known as screening criteria, tell the MDA what information to collect, how to display it, and which individual records should be reviewed in more detail by the physicians. No final judgment about the quality of care is made, however, until the entire study is completed and reviewed by the physicians.

The following are some suggestions for developing quality assessment studies for public health social work organizations that have been adapted from the medical area:

Guidelines for Study Design

Has the topic been defined in operational terms?

Have study objectives been written to focus attention on specific aspects of care? What is the reason for the study?

Should any records be excluded from the study? If so, will it be necessary to hand sort them or can they be excluded in other ways?

Should there be any age or sex limitations of the study population?

Will a bias be introduced by the way the records are selected? Consider index codes (if used), and sequencing of statistics.

Have a reasonable number of records been included in the study considering the topic and the facility's size?

Is the time period of record selection broad enough to minimize sampling bias?

Is the time period of record selection recent enough to realistically correct any problem that may be identified?

After the records have been obtained from the files, were the diagnoses or problems to be included in the study verified by the medical data analyst?

Guidelines for Screening Criteria

Screening criteria are guidelines for record review that rely on the medical data analyst to collect specified information. The objective is to predefine the majority, but not all, of acceptable care. The records that do not satisfy the screening criteria will be reviewed later by the professionals. Such records, however, have no predetermined value and may represent acceptable, unacceptable, or an indeterminate quality of care.

Principles of Criteria Development

The screening criteria should be simple: collect only the least amount of the most essential information.

Establish the rationale for each criterion.

Why is this information important?

Is it really relevant to the care of the person?

Determine whether the information will be valid and reliable.

Is the information present and measurable in the existing record?

Are the instructions for the medical data analyst explicit? (Could two or more medical data analysts who read the criterion come to the same interpretation of it?)

Limit the number of criteria. Few, rather than many, are preferable.

Also, it is generally advisable to adapt, rather than adopt, criteria prepared by others.

As organizations become increasingly responsible for actions of their professional staff, assessment of quality is a relevant issue not only for medical care, but also for professions such as social work. Defining the quality, and the aspects of care to be evaluated, is not an easy task, but guidelines do exist to assist organizations in developing evaluation methods and screening criteria. The quality assessment methodology described above should be considered when designing evaluation strategies for any service delivery program.

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PSYCHOSOCIAL FACTORS AFFECTING SHARED DECISION MAKING WITH FAMILIES: A MODEL OF RECIPROCAL CHOICE IN MORAL, ETHICAL, AND LEGAL HEALTH CARE DILEMMAS

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ABSTRACT:

This paper discusses the rationale for reciprocal decision making involving the patient, family and professional in health care treatment dilemmas. A shared decision making model developed by Thompson and Thompson (1981 and 1985) is presented with case examples which identify and analyze moral, ethical and legal health care dilemmas. Specific emphasis is given to the psychosocial factors that impact the shared decision-making process. The process guidelines encourage health care professionals to systematically develop case specific awareness of their own beliefs, the complex variety of beliefs in moral positions extant for patients, families and professionals, in order to better delineate the moral, ethical, legal dilemmas in today's world of high technology and cost-restraint in health care service delivery.

BACKGROUND OF THE PROBLEM:

Approximately 4 percent of the annual 3.3 million live births in the U.S. are infants who have one or more congenital anomalies. In addition, 7 percent of all live births, or 230,000 infants, weigh 2500 grams (5 1/2 pounds) or less at birth. These low birth weight infants are prone to sustain higher risk for congenital abnormalities and mortality. (President's Commission, 1983, pages 200-202).

Indeed, many severely handicapped infants have been beneficiaries of advanced technological medical treatments. However, many questions surround the appropriateness of such treatment with those who are irreversibly dying, for those with unknown or deleterious treatment outcomes and for those with chronic/severe mental and/or physical impairments. A major concern within these treatment dilemmas is that there is no clear consensus regarding which handicapped infant should receive life-saving treatment and which should not. On the other end of the continuum these same issues are present for adults who are irreversibly dying and/or who have severe, chronic physical and/or mental impairments.

Shaw, Randolph and Manard (1977), presented the results of a survey of 400 members of the Surgical Section of American Academy of Pediatrics and included an additional 308 chairpersons of Pediatrics and Chiefs of Divisions of Neonatalogy and Genetics and Departments of Pediatrics. Anonymous responses were obtained for 267 of the former (66.8 percent) and 190 of the latter (61.7 percent). Major findings were as follows:

1. 76.8 percent of the pediatric surgeons and 59.5 percent of the pediatricians said they would "acquiesce in parents' decision to refuse consent for surgery in a newborn with intestinal atresia if the infant also had Down Syndrome.

2. 23.6 percent of the pediatric surgeons and 13.2 percent of the pediatricians would encourage parents to refuse consent of treatment for a newborn with intestinal atresia and Down Syndrome. Only 3.4 percent and 1.5 percent of pediatricians would get a court order directing surgery if the parents refused.

3. 63.3 percent of the pediatric surgeons and 42.6 percent of the pediatricians said in cases of infants with duodenal atresia and Down Syndrome, where they "accept parental withholding of lifesaving surgery" they would also "stop all supportive treatment including intravenous fluids and nasal gastric suction."

4. 62 percent of all respondents who believe that children with Down Syndrome "are capable of being useful and bring love and happiness to the home" would nevertheless acquiesce in parents' decision not to allow surgery for the atresia. Only 7 percent who so believe indicated that they would go to court to require surgery.

The lack of agreement in regard to treatment dilemmas is further compounded by the very diversity of ethical beliefs which health care professionals, parents and others hold about such issues as "person" or humaneness of the handicapped individual, the sanctity of human life, the future quality of life projected for the patient, the right of individuals to receive treatment, the right of parents to refuse treatment for their infant, and the right of handicapped or chronically/ terminally ill adults to refuse treatment. Consequently, the underlying ethical beliefs influence the orientation to and/or decisions for treatment or non-treatment. Many articles in the literature have discussed the divergent points of view relevant to the moral, ethical and legal dilemmas of treatment while very little has been written about the utility of a shared decision-making process for working through these dilemmas. (Fletcher, 1972; McCormick, 1974; Tooley, 1976; Bartholome, 1977; Ramsey, 1978; Swinyard, 1978; Weber, 1977; and Shaw, 1983). Lack of agreement without a clear shared decision making framework has often led to inconsistent and, at times, inequitable treatment decisions for handicapped infants at one end of the continuum, and the chronically and/or terminally ill adults at the other end. Fletcher (1977) noted that most of our major moral, ethical and legal dilemmas are created by scientific discoveries and the subsequent technical know-how we gain, in the control of life, health, and death. The resultant ethical questions are immense and confront us from every laboratory and clinic. Should we exercise these controls at all, we wonder- and if so, then when, where, and how? Each advance in medical capabilities is an increase in our moral responsibility, which increases the range of our decision-making obligations. What are the major issues in decision making and how can we best address them?

STATEMENT OF THE PROBLEM:

Moral, ethical and legal dilemmas can be defined as problem situations or predicaments which do not appear to have a satisfactory solution. The predicament forces the decision maker to choose between two options of near or equal value. The moral, ethical and legal dilemmas which confront health care professionals generally result from treatment alternatives which create additional problems and potential harm for the patient and/or related others. For health care providers, professional dilemmas are the ethical predicaments that they face in their practice. McCarthy (1986) has developed the following typology of ethical predicaments:

1. Ambiguity and uncertainty-making professional decisions without precisely knowing what the consequences of such choices will be.

2. Conflicting obligations and expectations-making professional decisions in the face of multiple, often conflicting

obligations, demands and expectations, coming from many different role opposites including patients, colleagues, supervisors, employers, society and others.

3. Professional knowledge/patient rights-making professional decisions on the basis of one's professional knowledge and experience, even while respecting the right of patients to choose what they believe is best for them.

4. Informed consent-making professional decisions based on the patient's informed consent, even while realizing that patients rarely understood all the implications or consequences of the choices facing them.

5. Sharing limited resources-making professional decisions on the basis of sharing limited resources equally among all patients to whom one has a professional obligation, even while realizing that a specific patient needs a much greater share of these resources.

6. Priority of patient's interest/worker's interest-making professional decisions on the basis of what is best for the patient even if the worker's job or life may be at stake as a consequence of such a choice.

7. Choice of effective interventive methods-making professional decisions on the basis of one's own expertise, even while another modality (in which the worker is less expert) may be more effective for a given problem situation or a particular patient.

8. Limited nature of the professional relationship-making professional decisions which permit only the use of the limited professional relationship, even though the patient needs a total relationship.

9. Suspension of judgement-making professional decisions on the basis of suspending one's value judgement even when one's own values or societal values clearly indicate a preference or demand a judgement.

In an attempt to resolve these issues the health care provider must ethically examine his views, the patient/family views and societal views. Ethics is the field of study which identifies, organizes, analyzes and justifies human actions by applying principles of decision making. Most authors agree that the principles of ethical decision making are derived from the following two sources:

1. The duties, responsibilities or obligations which attach a person or persons to a certain situation in life.

2. The consequences or outcomes of human action which determine whether the actions are desirable or undesirable because they are harmful to one's self or to others.

Curtin (1983) cautioned that while health care providers can judge the actions of other people they can not judge the moral good or bad of another human being who performs a given act. But in any case the most crucial moral, ethical and legal dilemmas that health care professionals face are related to the choice of treatment alternatives. The range of treatment issues is broad and complex, including highly publicized cases such as Baby Doe (Bloomington, 1981-infant with Down Syndrome and intestinal atresia was allowed to die), Baby Fae (California, 1984-infant who received heart transplant from a baboon), Karen Ann Quinalan (New Jersey, 1975 parents sought court order to remove her from a ventilator) and Elizabeth Bouvia (Calfornia, 1984 patient with cerebral palsy who was seeking and recently, in court appeals, attained the right to die by starvation). Certainly, the moral, ethical, and legal issues for the patient, family and health care provider have dramatically increased in recent years because of the advances in medical treatment in genetic engineering, amniocentesis, abortion, organ transplants, artifical hearts and prolongation of life. What then are the patient's rights? What are the family's rights? What are the professional's rights?

The subsequent questions that arise generally fall into four areas: what to decide? when to decide? who decides? and how to decide?

1. What to decide:

The question here most often focuses on if we can treat, should we treat and if we treat, at what level of health care do we treat? Inherent in that question is the right to life versus the quality of life argument. Does an absolute "right to life" exist without respect to quality of life? Are there instances where a life is not worth living? On the other hand if the "quality of life" thesis is affirmed how does a pluralistic society define norms of meaningfulness? Should intelligence be the crucial factor? Clearly "quality of life" decisions can only be based on values of quality which are defined relative to the individual, family, or society. What if the individual is born in a subculture where eye color is the determining variable for "quality of life"? In other words, does the "quality of life" argument betray strains of authoritarianism? What then happens to those individuals who lack the necessary "quality" as defined by the consensus of the majority? Who gets the expensive medical treatments? Who gets the organ transplants?

2. When to decide?

It is only logical that decisions should be made proactively where possible versus reactive decision making during a crisis. However the evidence indicates that the majority of decisions are made on a reactive basis with little planning or forethought, largely because many times, such decisions have never been confronted before. A major question that emerges here is at what point do we make the "right to life" or the "quality of life" decision? Frequently, it is difficult for individuals or families to make an immediate decision in the face of strong emotional reactions such as shock and grief, but the treatment protocol may demand a quick decision. Are there times when an individual, family or professional does not have the competence to decide?

3. Who decides?

Essentially this becomes a legal issue that is theoretically based on a balance of rights or natural tension between the individual, the family, the professional and society. The issues form across private, professional and public lines where standards of harm and benefit must be carefully weighed. For example, where do the child's rights start and where do parent rights end? No one has absolute rights. Do children belong to the parents, society, the state, or God? Do parents merely exercise a stewardship? If the infant does belong to the parents, when should the health care agency, hospital or the state take responsibility for a child? If the parents are not given the ultimate power of decision and are overruled by other parties, or by an ethics committee, where should the infant be placed? If the state or an ethics committee intervenes on behalf of an individual, to what extent do they assume the responsibility for that individual? To what extent are such interventions a violation of individual, parent or family privacy rights?

4. How to decide?

The issues here are primarily ethical and political and most often pertain to whose or what interest one is advocating for. If the individual or the family is incompetent should an advocate be appointed to speak on their behalf? In essence many of the questions in this category relate to individual versus societal good. Should resources and effort be expended on behalf of the handicapped, the chronically ill, the terminally ill, when the same amount of money allocated to other individuals would show more cost-effective results? Does society have an obligation to care for all its members, i.e., is health care a right or a privilege? Do the more fortunate have more rights? Are the handicapped, the chronically and terminally ill a powerless subgroup which, like other ethnic or racial minorities, possess little leverage with the larger society? Labels and diagnostic terms are inherently value laden, e.g., developmentally disabled, mentally retarded, brain damaged, terminally ill, and may intrinsically or extrinsically preordain our attitudes toward treatment for such individuals? If individuals are no longer productive according to societal norms and society must continually support them, then what value do such individuals have to society? Do labels and diagnostic terms throw all individuals together in an objectionable category, i.e., are such terms pejorative?

Elements of Ethical Decision Making

Janis and Mann (1977) presented 3 prerequisites to true decision making that enhance understanding the nature of ethical decisions.

1. The parties involved feel that all obvious choices are risky, which keeps them from simply doing what feels good or right.

2. The parties involved feel that there could be a better choice that is not immediately obvious so that time should be taken to search for alternatives.

3. The parties involved have sufficient time to search for the best and most ethical alternative.

At the most simplistic level we accomplish decision making through observation which requires looking, listening, and asking until a consensus or judgement is reached on the most ethical alternative. Beyond observation we are often required to make judgements on what is the best treatment alternative. To make a judgement is to weigh the alternatives in terms of harms and benefits. Judgements can be made at 4 levels: the level of instinct or habit, the level of rules, the level of principles, or the level of premises. The level of instinct or habit is perhaps the most common and is prereflective in that it is based on "gut" level reaction or custom in terms of what is commonly considered harmful or beneficial. The level of rules involves a moral judgement based on laws, professional codes or moral summaries as to what is harmful or beneficial. Rankings of the various alternatives are also involved at this level in that one seeks to find the least drastic alternative and of course, the alternative where the beneficial aspects clearly outweigh the harmful ones. The level of principles involves morality that is common, general and impartial. Certain principles are stated, ranked and applied per moral dictum that identify the best alternative. The level of premises is most complex and involves the discipline of ethics which is the study of morality. Committments, loyalty and cultural perspectives are weighed and ranked in terms of duties, results, rights and any combination of the three. Decisions at this level are then made primarily on duty-based criteria, results-based criteria, or rights-based criteria. Duty-based criteria involves basing the decision on what will be the least harmful for the individual but there is a tendency to error on the side of freedom. Results-based criteria weigh the decision alternatives relative to what will give the greatest number of people freedom to act without hurting others. In other words, what actions will accomplish the greatest good. Rights-based criteria weigh the alternatives in terms of human rights with human rights always outranking legal rights. The implicit negative factor here is that assertion of legal rights may not always afford the best and most ethical alternative from a humanistic standpoint. For example, it is very hard for some to understand why the American Civil Liberties Union on the one hand supports demonstration rights for ADC mothers and at the same time supports the right for free speech and demonstration for Nazi party members. The issues are legally consistent but are the issues humanistically consistent?

Thompson and Thompson (1985, pp 121-122) noted that divergent alternatives are a reality in health care. They indicated that the earliest marker of an impending or actual ethical/moral dilemma is an awareness of something happening that is inappropriate. The awareness may be intellectual (cognitive dissonance or an emotional awareness, affective dissonance where things do not feel just right). They classify ethical issues in 5 categories, realizing that any grouping will involve extensive overlapping. Their categorization of ethical issues is as follows:

1. Issues of Principle.
    a. Autonomy, self determination of patients and professionals.
    b. Do good, do not harm (beneficence non-maleficence).
    c. Justice, fairness (allocation of resources).
    d. Truth telling (veracity).
    e. Informed consent.
    f. Quality of life/sanctity of life.
    g. The Golden Rule.

2. Issues of Ethical Rights.
    a. Right to privacy (confidentiality).
    b. Right to decide what happens to one's self/one's body (self-determination).
    c. Right to health care (currently debatable; some say equal access only, others say not a right at all).
    d. Right to information (informed consent, access to records).
    e. Right to chose whom you care for (frequently limited to physician in non-emergency situations).
    f. Right to live, right to die.
    g. Rights of children.

3. Issues of Ethical Duties/Obligations.
    a. Respect persons.
    b. Be accountable for decisions/actions.
    c. Maintain competence (professionals).
    d. Exercise informed judgement in professional practice.
    e. Implement and improve standards of profession.
    f. Participate in activities contributing to profession's knowledge base.
    g. Safeguard clients from incompetent, unethical or illegal practice of any person.
    h. Promote efforts to meet health needs of public.
    i. Participate in the formulation of public policy.

4. Issues of Ethical Loyalty.
    a. Professional/patient relationship (covenant fidelity, contract, seller of services).
    b. Accountability to whom as an employee.
    c. Professional/professional relationships.
    d. Professional/patient-family relationship.
    e. Who decides.

5. Issues of Concern and Life Cycle.
    a. Contraception and sterilization.
    b. Genetic engineering and embryo transfer.
    c. Abortion (when does life begin)?
    d. Infanticide.
    e. Adolescent sexuality.
    f. Allocation of scarce resources.
    g. Lifestyle.
    h. Euthanasia

More specifically, treatment options can be classified at the following three levels by the health care provider per treatment outcome:

1. Clearly beneficial outcome.

2. Ambiguous or uncertain relative to outcome.

3. Futile relative to outcome.

Consequently, the patient or family can chose either to accept the treatment or to forego the treatment. In either case, if the treatment option is clearly beneficial treatment it is generally provided, but if they choose to forego treatment there is generally a review process which may involve the courts. If the treatment outcome is ambiguous or uncertain and the individual or family choses to accept the treatment, treatment is generally provided. If on the other hand, they chose to forego treatment, the treatment is not provided. If the treatment option has a clearly futile outcome and the individual or family chose to accept the treatment, the treatment is generally provided unless the provider declines to do so. Obviously, if the patient/family choses to forego treatment, no treatment is provided. Table 1 depicts the relationship between these treatment options and the outcome variables.

Table 1

Treatment Alternative Variables and Decision Outcomes

Health Care Providers Assessment of Treatment Alternative	Individual or Family Prefers to Accept Treatment Decision Choice	Individual or Family Prefers to Forego Treatment Decision Choice
Clearly beneficial outcomes	provide treatment	provide treatment during review process or appeal to court
ambiguous or uncertain outcome	provide treatment	forego treatment
futile outcome	provide treatment unless provider declines to do so	forego treatment

Rationale for Shared Decision Making

Curtin (1983) stated that ethical dilemmas are generally not scientific and not replete with facts. This requires the professional to fully consider the individual's values without imposing his values on others. A clear perspective is imperative because moral, ethical, and legal treatment dilemmas are so complex, threatening, and inherently perplexing. A systemic shared decision-making process is necessary to thoroughly delineate the consequences of any decision, as well as who will make the final decision (a patient/family with little power versus a very powerful health care delivery system). The process is needed to routinely identify the decision makers or agents and to carefully examine the beliefs of all the people involved, their rights and their ability to exercise their rights, along with a determination of each individual's role in the decision-making process. A shared decision-making process affords the examination of all options and the consequences of each option with opportunity to reach a solution to the problem that considers the value of duties and outcomes.

Increased reliance on advanced technology, the high degree of specialization and segmentation of health care among an imposing array of professionals who are often times strangers to the family, may make participative decision making difficult for families. Families who have the ability to make decisions about the health care of their children must be permitted to do so and should have all the relevant information regarding the condition and alternative treatments, possible benefits, risks, costs and other consequences. The family is also entitled to be aware of any significant uncertainty surrounding such information. This is an ethical imperative. It is based on the belief that parents have a universal desire for information, choice, and respectful communication about decisions. In addition, adults are entitled to accept or reject health care decisions for their children on the basis of their own personal values and furtherance of their own personal goals. Yet, parental choice is not absolute; practitioners can not be asked to furnish services which violate the bounds of acceptable practice, or their own moral beliefs or which draw on limited resources over which the family does not have a binding claim.

The capacity for individuals and/or families to make decisions must also be ascertained. Decision-making capacity must be considered in relationship to the case-specific psychosocial factors and to each particular area of concern. Decision-making incapacity is found to exist only when people lack the ability to make decisions that promote the individual's or child's well being in conformity with their own previously expressed values and preferences. Unpleasant information should only be withheld when patients request that it be withheld or when its disclosure would cause substantial detriment to the individual's or child's well being.

Although information may be provided by various health care team members, there should always be one individual charged with the responsibility of assuring that all the necessary information is communicated and that the individual and/or family's wishes are communicated to the treatment team. Individuals and/or their families should have access to the information they need to help them understand their child's condition to make informed treatment decisions.

To provide for self-determination and insure the well being of the individual or child, decisions made by families when possible should attempt to replicate the ones that the individual or child would make if they were capable of doing so. They should protect the individual or child's best interest. In order to provide for these beliefs, policies and procedures should be promulgated by institutions regarding how and by whom decisions are to be made--by individuals or by families for their child or themselves.

Patients, families, health care professionals, and institutions should work together to make equitable treatment decisions. Recourse to court intervention should occur only when the concerned parties are unable to resolve their disagreements over matters of substantial impact. Institutions should explore and evaluate alternatives such as ethics committees for review and consultation in matters requiring health care decisions for those who are incapable of deciding.

Clearly, health care providers are frequently confronted with questions without clear-cut answers. Most often it is difficult to determine who should decide what should be done. Laws regarding informed consent have become the means by which society regulates the relationship between families and health care providers. However it is not always quite that simple. There are many issues involved with decision-making capacity, psychosocial factors present many ethical and moral conflicts in the present state of our assessment, diagnostic, and predictive abilities, and resource availability. To address these difficulties Thompson and Thompson (1981) developed a framework for identifying and analyzing ethical dilemmas with the family and the interdisciplinary health care team. The framework provides for critical reflection and study of the ethical components of decision-making. It is meant to raise the consciousness of professionals to their own beliefs or moral positions and the variety of beliefs and moral positions of families and others, as well as to assist in demonstrating how psychosocial factors impact the ethical dimensions of health care delivery specifically within the family context.

Subsequently, when treatment decisions require choosing from a number of equally plausible alternatives, and often we as health care providers cannot determine which alternative has the greatest potential benefit, the decisions become ethical rather than medical. It may be said that, when we do know the answer, individuals, parents, or families should be left to decide. Ethical decisions often involve value conflicts that are specific to the psychosocial factors of each case and in particular to family values, or specific to values held by different professionals, thus documenting the need for a participative multi-dimensional framework for decision making. The shared decision-making model carefully examines the case specifics and evaluates the potential outcomes. The primary intent of this model is to promote respect for persons and promote well being which is representative of the most beneficence within familial value systems and the health care team.

SHARED DECISION-MAKING MODEL

The shared decision-making process model; Table 2 (below) utilizes critical inquiry and moral reasoning. According to Thompson and Thompson (1985) steps 1-7 involve the analysis process; step 8 employs the weighing and justifying processes, step 9 involves making the choice and step 10 is the subsequent evaluation of that choice. The model is built on the importance of asking the proper questions for analysis while systemically following a step-by-step reasoning process. The process can be used in a variety of clinical situations by gathering and analyzing relevant information prior to deciding upon a course of action. The model cannot be used in cookbook or recipe fashion with expectations that result in correct answers via mere mechanical application. In a pluralisic society there are many differences and variations in values on how intellectual and rational people make ethical and moral choices, particularly in hospitals or other health care settings.

Theoretically, the model is based in ethical systems, stages of moral development and values clarification. The model assumes that all participants in the group are encouraged to be truthful in their responses to each step. This demands an environment of trust, confidentality, and mutual respect where each member of the discussion groups/health care team listens carefully to others, tries to understand what is being said and accepts statements. Those statements representing what the other person believes are values. Respect denotes acceptance of others but not necessarily agreement with them. Where disagreement occurs respect demands stating the disagreement clearly without implication of the other persons position necessarily being right or wrong. Through application of the model it is hoped that the group/team will work toward possible consensus for decision and action to resolve the moral, ethical, and legal dilemmas in the given health care situation.

Table 2

The Shared Decision-Making Model
(Modified from Thompson and Thompson, 1981 and 1985)

1.0 REVIEW THE SITUATION AS PRESENTED AND-

  1.1 DETERMINE WHAT HEALTH PROBLEMS EXIST,

  1.2 IDENTIFY WHAT DECISION(S) NEED TO BE MADE;

  1.3 SEPARATE THE ETHICAL DECISIONS THAT CAN BE MADE SOLELY ON A SCIENTIFIC KNOWLEDGE BASIS;

  1.4 IDENTIFY ALL THE INDIVIDUALS/GROUPS WHO WILL BE AFFECTED BY THE DECISION(S).

2.0 DECIDE WHAT FURTHER INFORMATION IS NEEDED BEFORE A DECISION ON A COURSE OF ACTION CAN BE MADE, AND -

  2.1 GATHER THE ADDITIONAL INFORMATION

3.0 IDENTIFY THE ETHICAL ISSUES INVOLVED IN THE SITUATION AS PRESENTED -

  3.1 DISCUSS THE HISTORICAL, PHILOSOPHICAL, AND RELIGIOUS BASIS FOR EACH OF THESE ISSUES.

4.0 IDENTIFY YOUR OWN VALUES/BELIEFS (MORAL STAND) REGARDING EACH OF THESE ETHICAL ISSUES.

  4.1 IDENTIFY YOUR PROFESSIONAL RESPONSIBILITIES AS INDICATED BY THE ETHICAL CODE OF YOUR PROFESSION, e.g., NASW CODE OF ETHICS, CODE FOR NURSES.

  4.2 IDENTIFY PROFESSIONAL OBLIGATIONS DICTATED BY AGENCY POLICY AND PROCEDURE.

  4.3 IDENTIFY CLEARLY APPLICABLE GOVERNMENTAL REGULATIONS AND/OR LAWS IF ANY.

5.0 IDENTIFY/CLARIFY THE VALUES/BELIEFS OPERANT IN THE OTHER PEOPLE INVOLVED IN THE SITUATION.

  5.1 USE KNOWLEDGE OF HISTORICAL, PHILOSOPHICAL, AND RELIGIOUS BASIS OF ETHICAL ISSUES TO ENHANCE UNDERSTANDING OF OTHER PEOPLE'S MORAL STANDS ON THE ISSUES.

6.0 IDENTIFY THE VALUE CONFLICTS, IF ANY, IN THE SITUATION.

7.0 DISCUSS WHO IS BEST ABLE TO MAKE THE NEEDED DECISIONS(S)

  7.1 IDENTIFY THE PATIENT/FAMILY ROLE(S) IN THE DECISION-MAKING PROCESS.

  7.2 IDENTIFY THE PROFESSIONAL(S) ROLE IN THE DECISION-MAKING PROCESS (WHO OWNS THAT PROBLEM(S)?)

8.0 IDENTIFY THE RANGE OF DECISIONS/ACTIONS THAT ARE POSSIBLE -

  8.1 IDENTIFY THE ANTICIPATED OUTCOMES (CONSEQUENCES) OF EACH DECISION/ACTION FOR ALL PEOPLE INVOLVED IN THE SITUATION.

  8.2 IDENTIFY HOW CLOSELY THE SUGGESTED ACTIONS CONFORM TO:

    8.21 AGENCY POLICY AND PROCEDURE
    8.22 APPLICABLE GOVERNMENTAL REGULATION AND LAWS
    8.23 YOUR RESPECTIVE PROFESSIONAL CODE OF ETHICS

9.0 IF APPROPRIATE, DECIDE ON A COURSE OF ACTION AS THE PROFESSIONAL IN THE SITUATION AND FOLLOW THROUGH.

10.0 IN RETROSPECT, EVALUATE/REVIEW THE RESULTS OF THE ACTIONS OR DECISIONS IN THIS SITUATION.

  10.1 UTILIZE THE EVALUATION FOR SPREAD OF EFFECT i.e., APPLICABILITY TO FUTURE SITUATIONS WITH SIMILAR DILEMMAS.

Psychosocial Factors Affecting Application of Shared Decision-Making

It is important to recognize that the psychosocial context in which these decisions are made has major ramifications upon the eventual outcome. One's beliefs, values, perceptions, and actions impact upon their capacity to make "clear" decisions. It not only is important to understand that the psychosocial context for all involved individuals is different in each case, but that the context changes for each individual in the process of making the decision. One's belief system is enormously affected by conflicting motives, and to understand and master reality and to ward off threatening aspects of reality, the individual's beliefs system tends to be more closed to opinions that reinforce this underlying stress. Actions, then, tend to be based upon the perceived social/emotional consequences rather than the bio-medical issues of certain treatments or prolonging life for the child or individual. Within this framework, attitudes and beliefs toward authority greatly influence the involved individual's receptiveness to differing and painful communication received from and sent to the "experts".

The health care team is subject to the same group dynamics as any social group and yet is often expected to function as a "rational" unit (removed from the extraneous variables outside of the control of the team). In turn, parents or guardians are subject to the dynamics of the immediate and extended family and are expected to make decisions based on what is best for the child or individual given the medical information and advice from the team. All these factors interact during a time of immense crisis for the family and, at least, moderate stress for the team. Thus, we must apply a crisis model to the process of shared decision-making. We need to view these events as ambiguous and communicate to the family (and the team) that they cannot be expected to know the "right" answers. Such high expectations often only serve to further incapacitate the individual's ability to decide and create disasterous latent effects, such as psychological decompensation, marital/family stress, and polarization of the team and the family. None of these additional problems serves to benefit the child. In the final analysis, the shared decision-making model is very strenuous and requires an open system communication approach. This is often hard to achieve given the paradoxical realities of high technological medical treatment and the politics of cost-restraint health care, but well worth the effort over blind and latent uninformed, non reciprocal choice.

APPENDIX

CASE EXAMPLES WITH APPLICATION OF SHARED DECISION MAKING MODEL

Note: The following case examples were adapted from Thompson and Thompson (1981 pp. 35-36 and 1985 pp. 192-196).

CASE EXAMPLE 1

Amniocentesis

Dr. Q. came out of one of the obstetric clinic examining rooms and headed for a quick drink. He stopped suddenly and asked a social worker to go into Room 408 and "talk some sense into Ms. P!" When the social worker asked the doctor for further explanation, the doctor stated that Ms. P needed to have an amniocentesis performed to see if her fetus was free of Down syndrome and she refused to come for the appointment. Ms. P. was thirty-nine years old and pregnant for the first time. She was receiving care in a regional medical center where all first-time pregnant women over thirty-six years of age were encouraged to have amniocentesis performed for genetic screening. She had been scheduled for an amniocentesis three days ago but did not come for the procedure. The social worker decided to talk with Ms. P. and found her quietly crying alone in the examining room. After a few moments, Ms. P. looked at the social worker. The social worker stated that Ms. P. seemed very upset and asked if there was anything she could do to help. Ms. P. immediately responded that Dr. Q. wanted her to have some test that would tell him if her baby was mentally retarded and, if so, he said she could have an abortion. When the social worker asked Ms. P. how she felt about knowing if her child were healthy or affected with Down syndrome, Ms. P. said that she would never consent to an abortion so she would wait until the delivery to know the condition of her infant. She went on to say that she had always wanted a baby and this was her only chance, so she wasn't about to give up the pregnancy. The social worker was convinced that Ms. P. had made a firm decision about amniocentesis and suggested that she get dressed and ready to go home. Her next appointment for antepartal care was given for three weeks and the charge nurse cancelled the appointment for amniocentesis. The doctor was told of the patient's decision, and his only comment was, "She's crazy! I wouldn't willingly bring a Down's baby into this world! Let's go have another drink!"

Analysis- Using the Shared Decision-Making Model

Step One: Review the Situation

a. One might identify the health problems as whether Ms. P. is carrying a genetically defective fetus and/or the potential risk of the amniocentesis procedure to Ms. P. and the fetus. What you identify as a health problem here may be relative to your definition of health or even your own beliefs about quality versus quantity of life.

b. The decision to be made at this point was whether Ms. P. should submit to amniocentesis because of her age, and Ms. P. made the decision not to do so. The physician seemed to want to make the decision for her, and the social worker seemed to support the woman's right to choose or refuse the procedure.

c. The ethical component of the decision appears to be who has the right and/or responsibility to make the decision.

d. The individuals currently involved in the situation are Ms. P., the fetus, and the doctor, the social worker, and, possibly, society as a whole, depending on one's view of who should care for defective children /adults.

Step Two: Gather Additional Information

Further information might be gathered about the father of this fetus and other circumstances surrounding Ms. P's pregnancy, as well as Ms. P's understanding of Down syndrome.

Step Three: Identify the Ethical Issues

The ethical issues involved in this situation include the patient's right to decide on the issue of genetics screening, quality versus quantity of life for the fetus, rights of the health professionals, rights of society, and rights of the institution.

Step Four: Identify Personal and Professional Values

Your own thoughts belong here--your values and beliefs.

Step Five: Identify Values of Key Individuals

It would appear that Ms. P. values her pregnancy a great deal and is currently not concerned about the potential quality of the outcome of her chances of producing a defective child. She believes in control over her own body and has exercised her right to decide against amniocentesis. The physician apparently has some preference for quality rather than quantity of life, though it's difficult to know how much he is influenced by an "institutional policy or perhaps even alcohol." The social worker appears to give priority to the patient's right to make a decision and could be interpreting her role as providing a caring support for Ms. P. in her decision.

Step Six: Identify Value Conflicts, if Any

The most obvious value conflicts appear to be between the physician and Ms. P. on the issue of whether genetic screening should be performed.

Step Seven: Determine Who Should Decide

The "best" person to make the decision will depend on one's beliefs about whose rights should predominate in this situation-Ms. P's? Dr. Q's? Social Worker's? Society's? (It's unclear from the data given if anyone is speaking for society as a whole).

Step Eight: Identify Range of Actions with Anticipated Outcomes

The range of decisions possible includes "yes" or "no" to aminocentesis today or in the near future, especially if abortion were an acceptable option to a finding of Down syndrome. The physician could support Ms. P. in her decision, but he may have difficulty going against his own personal value system even after a few drinks. The social worker appears to be in conformance with the NASW Code of Ethics, client's rights of self-determination. On the other hand, the social worker could have tried harder to convice Ms. P. of the "value" of amniocentesis.

Step Nine: Decide on Course of Action and Carry Out

How would you have responded if you were the social worker? the doctor? the patient (Ms. P.)? the fetus? State rationale.

Step Ten: Evaluate Results of Decision/Action

Is amniocentesis ever warranted if the pregnant woman (family) has made a decision to do nothing if the baby is affected with a genetic disorder?

Case Example 2

Elective Sterilization

Blanche has received health care from a social worker and an RN, a Women's Health Care Specialist, over the last 3 years. Blanche is 28 years old and has recently married. Her husband, Ralph, has accompanied her on this visit. During her annual checkup, Blanche asks what needs to be done to have her tubes tied. Upon further questioning, both Blanche and Ralph are adamant that they do not ever want any children. All temporary forms of contraception are unacceptable. When pushed for reasons for the tubal ligation, Blanche admits that she could never accept the idea of an abortion-morally, physically, or emotionally. She is not willing to take the chance of having intercourse which might result in pregnancy.

A review of Blanche's past medical history and current health status reveals no contraindication to any method of contraception of pregnancy. She is very healthy and has no family history of birth defects. She has no unusual fear of pregnancy or children. The social worker is convinced that both Blanche and Ralph have put a lot of thought into their decision not to have children. They express the view that it is their responsibility to take action to avoid having children they do not ever want. They ask the social worker to help them find a physician who will be willing to perform the tubal ligation.

Analysis - Using the Shared Decision Making Model

Step One: Review the Situation

First of all, Blanche appears to be in good physical health, with no apparent medical or physical contraindication to any form of contraception. She is sexually active and wishes to continue this activity. She also is not willing to get pregnant. The health problem can be defined as the need to prevent an unwanted pregnancy. In the fullest sense, health for Blanche and Ralph can be defined as freedom from the threat or potential for bearing children. From the professional's view, the health problem may be defined as a request for sterilization from a relatively young woman or this couple's refusal to bear children. Another perspective on the health problem could be the potential discrimination implied in the woman seeking tubal ligation versus the man seeking a vasectomy.

Blanche and Ralph appear to have jointly made a firm decision not to have children. The primary decision for them now is how and who will provide the requested tubal ligation. The social worker might raise the question of whether the tubal ligation should be done at all as well as to whom the referral for surgery should be made. The physician will have to decide whether to perform the procedure on Blanche. The social worker may also have to decide whether further counseling is indicated. Have Ralph and Blanche considered all the critical factors as they decided not to have children? The social worker may decide to take the time to explore their decision process herself if time and expertise allow.

The major ethical component of the situation is whether a relatively young couple have the right to decide not to have children. If so, should they be offered some form of permanent contraception at this time? A physician must perform the surgery and, therefore, will have to decide to agree or refuse. Another ethical dimension of the situation is what responsibility does the social worker have to support Blanche's decision and refer her to the appropriate physician?

The key individuals involved in this situation include Blanche, Ralph, the social worker, the nurse, physician, and potentially other professionals. Society may be affected in the long run if every young couple decided not to have children, but its interest at this time seems minimal. Blanche and Ralph are adults and presumably competent to make their own decisions. However, other family members might hold a different view.

Step Two: Gather Additional Information

The social worker will probably want more information from Blanche and Ralph on why they do not want children. Why are they choosing permanent contraception? Why are they choosing the ligation rather than a vasectomy? The social worker has had a long-term relationship with Blanche and may choose to ask her these questions in private and the same with Ralph. The social worker also recognizes that a value judgement on these issues may be made as Blanche talks about her reasons. The social worker may also review all methods of contraception and ascertain Blanche's and Ralph's knowledge of them. Explanation of risks and benefits of each method, including male and female sterilization, are important to identify the level of knowledge and understanding that Ralph and Blanche have. Knowledge of Ralph's health status is important in this situation as well.

The social worker may need more information on what qualities the couple are seeking in physician referral and their understanding of the costs and other factors. The physician receiving the referral will probably want the same information collected by the social worker, though the physician may choose to obtain it personally.

Step Three: Identify the Ethical Issues

The ethical issues in this case include Blanche and Ralph's right to decide not to have children (quality of life, self-determination) and their right to permanent contraception (autonomy). Other issues include informed decision making (consent, the physician's right to refuse to perform the surgery, and the social worker's responsibility to insure informed decision making (advocacy) as well as referral to a competent physician (Accountability). Contraception has been considered immoral in the past, and some groups and individuals still consider it wrong. The purpose of sexual intercourse was to produce children. This does not appear to be the value system of the individuals here but may influence the choice of a physician. In times past, mutilation of the body has been considered wrong unless it was for a justified reason, such as saving one's life. This does not appear to be a problem for this couple. The choice of tubal ligation over vasectomy raises several questions about the value of male and female virility. In some cultures, the macho male has tended to identify vasectomy with castration. The ethics of submitting the female to surgery rather than the male appear to be in the background here if the decision has already been made by the couple. However, the reasons may influence the relationship both now and later. The simpler, less invasive vasectomy performed in the office might be considered preferable on the ethical grounds of the allocation of scarce resources or the lesser risk of the two procedures.

Step Four: Identify Personal and Professional Values

The social worker would need to examine how she feels about women (couples) who decide not to have children (value of parenting), about unwanted children (value of wantedness), about women having the responsibility of contraception rather than males, and about clients'rights to decide for themselves what their health care and lifestyles will be (autonomy). She may wish to list her personal values on these issues (what she would do) as well as note what the NASW of Ethics Code states is her professional responsibility.

Step Five: Identify Values of Key Individuals

Blanche and Ralph's values related to lifestyle and children seem clear and obvious. Where these values came from remains unclear, as is their choice of ligation rather than a vasectomy. They appear to accept responsibility for their decision not to bear children by seeking sterilization. They support marriage and sexual intercourse without accepting pregnancy and children. They expect the health professionals to accept their decision and provide the needed surgical procedure. They trust the social worker and respect her judgement on referral to a compentent physician. We do not know who will pay for the services (insurance, Medicaid, Blanche and Ralph themselves). Some would suggest that ability to pay should not influence health providers' willingness to provide services.

The physician or other health professionals are not yet involved in the situation. Presumably if a physician accepts the referral, he would be supportive of permanent contraception for this couple.

Step Six: Identify Value Conflicts, If Any

No value conflicts are evident yet. It is possible, however, that the social worker may not know of a physician willing to perform tubal ligation on a woman of this age for Blanche's reasons. It is also possible that the social worker will not be able to support this couple's request once further information on their reasons are explored. The social worker may find it possible to support a vasectomy but not the proposed tubal ligation.

Step Seven: Determine Who Should Decide

The most logical decision-makers in this situation appear to be Blanche and Ralph regarding permanent contraception. Their decision not to bear and raise children affects them directly. The physician, however, must agree to tubal ligation, since it is not something they can do for themselves. The social worker may support and become the advocate for Blanche's right to decide if she is satisfied with the information provided on reasons and informed decision making.

Step Eight: Identify Range of Actions with Anticipated Outcomes

The range of actions in this situation includes (1) referral to a physician who agrees to perform tubal ligation, (2) suggest counseling to help Ralph and Blanche review their decision, (3) the offer of other forms of contraception while Ralph and Blanche spend more time thinking about tubal ligation, (4) refusal to refer for tubal ligation or offer a non-permanent form of contraception, and (5) Ralph and Blanche can decide to use another form of contraception and accept a minimal risk of pregnancy. The anticipated outcomes of (2) and (3) actions may be a loss of trust in the social worker as a health care provider, anger and resentment toward health care professionals, and a review of the decision. The last could strengthen the couple's initial request for tubal ligation or result in a new decision, e.g., for a vasectomy or for non-permanent contraception. It seems unlikely that the couple would change their minds and have a child. If the social worker refuses to refer the couple to a physician, Ralph and Blanche can seek a physician on their own. If they agree to another method of contraception and retain the fear of unwanted pregnancy, their sexual activity and emotional relationships may become troublesome.

Step Nine: Decide on Course of Action and Carry Out

If Blanche and Ralph's decision for tubal sterilization is supported and a physician is willing to perform the surgery, that action can now be taken. It would appear to be most in keeping with informed decision making, self-determination and autonomy of adults, and responsible non-parenting. Contraception and choice are values supported by many people in our society. The refusal to bear children has rarely been discussed openly. Governments tend to oppose it (loss of manpower), as do some individuals and some religious groups.

Step Ten: Evaluate Results of Decision/Action

Evaluation will depend on what decision was made and whether the expected outcomes occurred. At this point, one would review each step of the model and analysis to see if anything was left out or overlooked.

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