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# Meeting Minority Health Needs Through Special MCH Projects

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## Synopsis .....

*The maternal and child health programs of the Public Health Service have always been directed to*

*minority populations; however, the recent surges of immigrants from Asian and Central American countries have caused the agency to appraise its efforts to meet the special health needs of these people. Through grants for special projects of regional and national significance (SPRANS), the Office of Maternal and Child Health is funding projects to break down language, culture, and access barriers to health services for pregnant women, infants, and children. Recent and current SPRANS projects have taken innovative approaches to solving the special health problems of the minority populations. They range from a breastfeeding initiative in the Commonwealth of the Northern Mariana Islands to an areawide genetic service program in the Virgin Islands. Examples of projects that have been conducted are presented.*

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**S**INCE ITS BEGINNING as the Children's Bureau in 1912, the Office of Maternal and Child Health (OMCH) has worked to improve health care for minority populations. The legislation that founded the Children's Bureau, the earliest Federal organization concerned with maternal and child health, stated that it should "try to work out the standards of care and protection which shall give to every child his fair chance in the world." This philosophy was continued in Title V of the Social Security Act, enacted in 1935. The stated purpose was "For the purpose of enabling each State to extend and improve . . . services for promoting the health of mothers and children, especially in rural areas and areas suffering from severe economic distress."

From the beginning, MCH activities have focused on medically underserved women and children—people barred from receiving health services by poverty, ignorance of how to enter the health care system, inability to communicate, lack of transportation, and lack of facilities and providers. And people from minority populations have been disproportionately affected by these barriers.

Since 1912, the barriers to health care for mothers and children have not changed significantly, but there have been significant changes in the composition and numbers of the minority populations. The principal sources of population migration have shifted from Europe to Asia and Central America, and the numbers of minority people have increased greatly, especially in recent years.

## Minority Population Trends

Between 1970 and 1980, the total U.S. population rose by 11.5 percent. The racial and ethnic minorities (American Indians and Alaskan Natives, Asians and Pacific Islanders, blacks, and Hispanics) increased by 36 percent, or more than three times the total U.S. rate. Of the 23.3 million increase in total population during that decade, minorities accounted for more than half. In 1980 these groups made up 20.4 percent of the total U.S. population, one in every five persons. By July 1987, they made up 23.3 percent of the total U.S. 243,915,000 population. The rate of increase for the minorities (22.8 percent) during this period was, again, about three times the 7.9 percent rate of the total U.S. population (1,2).

These minority groups—blacks, Hispanics, Native Americans, and some groups of Asians-Pacific Islanders—have higher rates of death, disease, and disability than white Americans (3). Their overall health has not reached the levels that advances in medicine and technology have made possible for most people in this country, and many suffer or die from preventable or curable health problems. The inadequacy of the current health care system in addressing the needs of minority and culturally distinct populations is reflected in the higher levels of mortality and morbidity of these groups as compared with that of persons in the mainstream of American society.

The OMCH, recognizing this rapid growth of minority populations and the pervasiveness of cultural barriers to health care, has been working to make the health care system responsive to the special needs of these populations. It has funded programs through both the Federal block and set-aside grant programs that address specific health concerns of minorities. Recently the Office has established a Workgroup on Culturally Distinct Populations to survey the health status of minorities, their special needs, and the kinds and numbers of ongoing minority health programs. The Workgroup is expected to advise the OMCH on how it could best use its grant monies to improve health care for various minority groups.

### MCH Grant Programs

Under the Maternal and Child Health Services Block Grant, \$465.3 million in FY 1989 funds were allocated to the States, the District of Columbia, Puerto Rico, the U.S. Virgin Islands, and the insular areas of the Pacific Basin to provide a broad range of health services to mothers and children. The services include promotion, prevention, primary care, rehabilitation, prevention of lead-based paint poisoning, genetic disease education and referral, sudden infant death syndrome activities, adolescent pregnancy care, and services for children with special health needs. About 15 percent of the block grant funds are set aside for Special Projects of Regional and National Significance (SPRANS) in research, training, and demonstration, and projects in genetic diseases and hemophilia. These projects provide a way for OMCH to respond to changing needs and trends and to focus quickly on specific issues. In FY 1988, there were a total of 532 active SPRANS projects designed generally to improve the provision of services to mothers, infants, children, youth, and children with special health needs.

A great many projects were concerned with innovative ways to reduce the infant mortality rate (IMR), a task that has long challenged health professionals. Infant mortality was the first subject studied in 1912 by the Children's Bureau. The study, conducted in selected areas throughout the country, found great variations in infant mortality rates among the States, in different areas of the same State or individual communities, and between towns and rural districts. The variations were related to differences in social and economic conditions and in the quality of prenatal and infant care (4). More than 70 years later, the IMR has been

reduced from 99.9 deaths per 1,000 live births (1915) to 9.99 (provisional rate for 1988), the lowest rate ever recorded in the United States. But the IMR still varies substantially among and within racial and ethnic groups.

### IMR by Ethnic Groups

Of the 3,756,547 babies born in 1986, 39,068 died before their first birthday. The rates for the various ethnic groups in the following table show that black babies died at twice the rate of white babies.

<i>Group</i>	<i>Rate per 1,000 live births</i>
White .....	8.9
Black.....	18.0
American Indians and Alaskan Natives.....	10.3
Hispanic.....	<sup>1</sup> 8.0

<sup>1</sup> Available for the first time, based on 18 reporting States and the District of Columbia.

SOURCE: National Center for Health Statistics, Centers for Disease Control.

But the table does not show the substantial variance within racial-ethnic groups. The relatively low American Indian rate does not reflect the diversity among Indian communities; some of them have IMRs approaching twice the national rate. The Hispanic subgroups also vary—7.7, Mexicans; 8.6, Puerto Ricans; 5.5, Cubans; and 9.1 for other Hispanics. The 1983 National Birth Cohort Study, a linked birth and infant death record file for the year 1983, raises serious questions about the validity of IMRs for races other than black or white. In that study it was possible to compare race of child on the birth certificate with race of child on the death certificate. The IMRs for blacks and whites differed little from published rates, but the rates for other races indicated a serious underestimation, and the IMR for Hispanics has not yet been computed (5).

The study points up the lack of accurate information needed for planning health care for minority mothers and children. It is necessary to have better data on the IMR, adolescent pregnancies, low birth weight infants, and maternal mortality. It is also necessary to reach the members of minority groups with health information and to help them access the health care system. The OMCH has supported and continues to support many programs developed to overcome cultural, communication, and systems barriers. Projects supported by the Office reach beyond the ordinary, as evidenced by

the following examples of programs developed to improve infant and maternal health.

### **Examples of SPRANS Projects**

**Honolulu, HI—Facilitation of primary care physician participation in preventive health care of children ages 0-5 from underserved, culturally diverse populations.** The project is concerned with the low-income, culturally diverse populations who have poorer health status than the general population and are more at risk for psychological, developmental, and behavioral problems. These problems are critical for the birth to 5-year age group who have much greater preventive health care needs than adults and for whom preventive services are most cost-effective. The project staff proposed to intervene by promoting the involvement of the primary care physicians and pediatricians in early screening and intervention. Since initial funding in 1986, this SPRANS grant has generated many activities.

One of these is Project Healthy Start, piloted in a specific area on Oahu. It was initiated to offer family support services to psychosocial at-risk infants to prevent child abuse and neglect and assist with child development. The identification of infants at birth followed by home visit services has reduced child abuse and neglect substantially. The pilot project was so successful that the program will be extended during the next 2 years to more than 60 percent of the island's at-risk infants ages 0 to 3 years.

Physician training on awareness of the needs of children with special health needs through the use of visiting professors, workshops, and conferences was another objective of the grant. A continuing medical education course on this new morbidity was extended to physicians on the neighboring islands of Maui and Hawaii.

**Bernalillo, NM—Case management for parents of Indian children with special health care needs.** This project has three principal goals: to identify barriers that inhibit Native American families' participation in the health care management system, to facilitate effective communication between Indian American families and their western health care professionals, and to increase Native American families' participation in planning health care for their children. Staff members worked hard to ensure participation by representatives of all the area's Indian tribes in developing a videotape to orient new, non-Indian health professionals to In-

dian cultural issues in New Mexico. The representatives sought the advice of the tribal elders in determining what could and should be included in the videotape. The tape, "Listen with Respect," represents one step in overcoming the cultural barriers between Indian families and non-Indian health care providers.

Indian participation in public policy has been broadened because of this project. Native Americans, both professional and nonprofessional, are serving on several major State level boards and committees including the Advisory Board of the New Mexico Children's Medical Services Program, the New Mexico Developmental Disabilities Planning Council, and the New Mexico PL 99-457 Interagency Coordinating Council. In addition, Indians served as parental representatives at the Workshop on Children with Special Health Care Needs held in New Orleans in November 1988. The workshop was a regional followup to the Surgeon General's Conference on Children with Special Health Needs held in Houston, TX, in June 1987. Both meetings brought together parents, planners, and providers of the comprehensive services for children who have special health needs.

**New Haven, CT—Hispanic males outreach project.** The staffs of two community health centers in New Haven, the Hill Health Center and the Fair Haven Community Health Clinic, developed a program to reduce adverse perinatal and infant outcomes among Hispanics, mainly Puerto Ricans, through outreach activities for the male partners. The program offers two types of activities: encouraging the men to become equal partners in the prenatal period and offering them educational, vocational, and recreational resources. Staff members are involving both partners in prenatal visits, postpartum classes, and activities for the male partners, including job counseling and training. This approach is proving to be difficult to accomplish because of economic, educational, and attitudinal barriers and the transient nature of the population, but there have been some positive results. All of the women participating in the project have enrolled in the Department of Agriculture's Women, Infant, Children Program. Men participating have overcome their original feelings about using the clinic.

**Atlanta, GA—Reduction of minority infant mortality in Georgia.** The objective of this project is to reduce racial-ethnic disparities in rates of infant mortality in the State by reducing nonwhite teenage

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pregnancy rates, improving parenting skills, and increasing usage of prenatal and child health care services. The program uses the church as the key mechanism for reaching at-risk groups. The largest black organization in the State is the General Ministry Baptist Convention of Georgia, and the black churches have always had a deep effect on their communities and members.

Local church women have also been trained by the project staff as Resource Mothers to help pregnant women negotiate the health care and social services systems. The Resource Mothers, all volunteers, teach the young women how to cope with barriers that prevent optimum maternal and child health care. They educate them about existing resources and how to use them, and they establish peer support groups.

The program is now established in six counties, and more than 20 churches are participating in the activities. Ministers of the churches are working with the projects' staff and provide transportation for women seeking care.

**Rosebud, SD—Maternal-infant risk management in a defined population.** This project seeks answers to the high infant mortality among the Rosebud Sioux. The Tribe's IMR is three times higher than that of the white population of South Dakota. The staff uses community-oriented primary care principles to identify persons in need of specific services and to help them obtain the care needed. Special efforts are made to reduce the incidence of inadequate prenatal care, inadequate weight gain, alcohol abuse, and smoking. During the first 13 months of the project, the incidence of low birth weight was reduced from 8.8 percent during the baseline period to 5.7 percent.

**Philadelphia, PA—Cohort study of the uterine contractions in black women.** This investigation used technological advances in external monitoring

of uterine contractions in women who have uncomplicated term pregnancies to establish baselines for these contractions with respect to frequency, duration, and intensity. The researchers compared profiles of women who developed preterm labor to those who did not and investigated whether uterine-contraction responses to specified physical activities differ between women who develop preterm labor and those who do not.

**Hood, OR—Improved compliance with well-child care: El Niño Sano Project.** Between 20,000 and 40,000 migrant and seasonal farmworkers live in the Hood River and Wasco Counties during the peak agricultural season. Nearly 100 percent of them are Mexican nationals or of Mexican American origin; most are monolingual in Spanish. Their children have an unacceptably high incidence of preventable and treatable conditions, largely due to inadequate utilization of well-child care and other preventive services. There are measurable deficiencies in the children's health status regarding parasitosis, positive tuberculin reactivity, dental disease, anemia, accidental injuries, toxic exposures, under-immunization, and nutritional inadequacies. Project staff members have found that the parents have inadequate knowledge of how to care for their children's health and safety and are unaware of the value of preventive care. They have also found a lack of culturally and educationally appropriate pediatric health materials.

The El Niño Sano Project strives to bring unserved children into contact with well-child care and other preventive services, to help parents develop a lasting involvement in and commitment to the health of their children, to teach parents about their children's health and safety, and to train health professions students to give health care in rural settings. In the first year, project staff have hired and trained seven "promotoras de salud," or health educators, ranging in age from 23 to 60. Three are bilingual and four are monolingual and literate in Spanish. The staff has also contacted growers and, with their support, conducted field and day care center clinics and home visit activities; met with county health department personnel bi-weekly to coordinate activities and to devise strategies for sharing information about the migrant families when they leave the project area; developed linkages with many organizations including educational institutions, health foundations, State and county offices, and service organizations; conducted a mini-campaign on accident prevention at day care centers; and produced recordings, includ-

ing some made by the promotoras, for airing on Spanish-language radio programs.

El Niño Sano staff members are discussing their activities with others working to provide medical outreach to migrant workers and their families. They advocate the adoption or adaptation of two features of El Niño Sano—using promotoras all year and conducting extensive training for them that includes helping at the clinics.

**Chapel Hill, NC—Migrant lay health advisors.** The Department of Maternal and Child Health, School of Public Health, University of North Carolina, is working cooperatively with two county health departments, two migrant health centers, and one community health center in the State to improve the perinatal and infant outcomes among migrant women and their infants through the use of lay health advisors. The advisors, recruited from the migrant population, provide health information in a culturally appropriate manner and link the women with community health services. Chosen for their leadership qualities and their ability to be articulate, caring, and empathetic, the advisors are trained in health education and community relations. Their intervention efforts will be evaluated.

**Stanford, CA—Study of health and nutritional status of Mexican American children.** This study used existing national data to quantify the health problems of Mexican American children. The researchers analyzed the relationship of poverty to poor nutrition, constraints on services use, and the relationship of health and nutrition problems to children's behavioral, academic difficulty, and other problems. A product of this study was a 2-day conference held in the spring of 1989 at Stanford on these topics. The presentations provided the basis for discussions on how research on Mexican American children can be used to formulate future public policies.

**San Diego, CA—The Southeast Asian Developmental Disabilities Prevention Program.** This program provides outreach, identification, intervention, and education services to infants at risk for developmental disabilities in the Southeast Asian communities. The staff has developed a model service delivery system which provides early identification and intervention services to Southeast Asian families with infants who are at risk for becoming, or who are, developmentally disabled. Goals of the model service are to expand the network of coordi-

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nated community services for this underserved population and to increase the education and awareness in Southeast Asian communities regarding the need to prevent developmental disabilities. The staff has developed health educational materials in several Asian languages to meet the needs of the patients and their families. A videotape, "Baby Care," for example, has been produced in the Cambodian, Hmong, Laotian, Vietnamese, and English languages.

### **Genetic Disorders in Minorities**

Hemoglobinopathies represent one of the major health problems in the United States and constitute the most common genetic disorders in some minority populations. Sickle cell disease alone affects about 1 in 400 American black newborns. We have known for more than 20 years that babies born with sickle cell anemia have an increased susceptibility to severe bacterial infections and that approximately 30 percent of them will become infected in the first 3 years of life.

In 1986 research and experience demonstrated that the diagnosis of sickle cell disease at birth along with early therapeutic intervention could reduce mortality among identified patients. At that time, only eight States were providing newborn screening for sickle cell disease. Today, 29 States and the District of Columbia are screening newborns: 23 of them are funded by the OMCH. Six States are screening without Federal support. More than \$4 million were spent to support newborn sickle cell screening in 1989, and the cost is expected to reach \$6 million in FY 1990.

Through SPRANS grants, the OMCH supports genetic and other programs that provide services to the Southeast Asian refugees. Hereditary anemias

are important preventable causes of morbidity and mortality in ethnic minorities in the United States. Hereditary variants in hemoglobin (Hb) structure and expression are common in persons of southern Chinese, Filipino, other Southeast Asian, African, or Mediterranean ancestry. Examples of ongoing projects or projects that were recently completed include the following:

**Honolulu, HI—Comprehensive hereditary anemia program for Hawaii.** This project aims to screen Asian American families in Hawaii for hemoglobin or glucose-6-phosphate dehydrogenase variants in order to educate the medical community and the ethnic populations about hereditary anemias and to improve diagnostic criteria for these variants so that they can be distinguished from iron deficiencies. A laboratory will be established to analyze hemoglobin genotypes at the DNA level and provide fetal diagnosis. The researchers expect to be able to calculate gene frequencies among Asian Americans for these traits so that estimates of future health needs can be made for these populations.

**Boston, MA—South Cove thalassemia screening and education program.** The South Cove Clinic is one of the principal providers of primary care medicine for the Asian community in the Boston area. This is particularly true for the pediatric population since there are no other Asian, bilingual primary care pediatricians in the city. In a previous study conducted at South Cove it was found that 9 percent of the patients tested had the alpha thalassemia-1 trait, and 4.8 percent had the beta thalassemia trait. The project staff is expanding the routine testing of the Asian patients and is developing a screening program to address their needs. They also counsel persons about genetic risks to the unborn.

### Minority Publications

The OMCH, through contracts and grants, supports the production of publications and other types of educational materials for minority populations or for those who work with them. Information about these products can be obtained from the National Center for Education in Maternal and Child Health or the National Maternal and Child Health Clearinghouse, both funded by OMCH.

The Center, located at Georgetown University, responds to information requests, maintains a reference collection of MCH program materials, de-

velops publications on maternal and child health topics, and provides technical assistance in developing educational resources, program planning, and topical research. The address is 38th and R Sts., NW, Washington, DC 20057. The phone is (202) 625-8410.

The Clearinghouse provides current information through the collection and dissemination of publications on maternal and child health topics. Each month the Clearinghouse distributes more than 50,000 publications to more than 2,000 requesters nationwide. Although most of the publications are written in English, many publications are available in Spanish, Chinese, Korean, Lao, Tagalog, and Vietnamese. A free catalogue which lists the available publications is available from the Clearinghouse. The address is National Maternal and Child Health Clearinghouse, 38th and R Sts., NW, Washington, DC 20057. The phone is (202) 625-8400.

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