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ABSTRACT

An annotated listing is presented of projects offering maternal and child health care services. These projects, referred to as special projects of regional and national significance (SPRANS), are supported by the Office of Maternal and Child Health of the Department of Health and Human Services. The first section provides information on services for prenatal care, risk reduction in pregnancy, and systems development for perinatal services. Infant health is covered in the second section; information is presented on reducing mortality and morbidity, screening for genetic disorders, breastfeeding, and parenting. Programs providing services on child health are listed in the third section. These include primary care and prevention, emergency medical services, accident prevention, and grief and hospice care. Children with special health needs are covered in section four. Entries include listings of projects dealing with early childhood intervention, family-community comprehensive services, chronic and disabling illness, the technology dependent and medically fragile, Cooley's anemia, thalassemia, and hemophilia/AIDS. The section on adolescent health focuses on preventive health services, violence/injury prevention, and youth in transition. General program concerns are covered in the final chapter. (JD)



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Office of Maternal and Child Health Active Projects FY 1989

An Annotated Listing



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

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Under auth ority of Title V of the Social Security Act, up to 15 percent of the Maternal and Child Health Services Block Grant may be set aside for the Federal Government to support certain categorical programs referred to as special projects of regional and national significance (SPRANS).

These funds are used to support applied research to expand our knowledge of and broaden our approach to health problems. They are used to support the training of specialized health professionals, upgrade the skills of leadership personnel, develop standards of care, and otherwise improve the quality of maternal and child health services. They support programs to test, counsel, and refer individuals at risk of having or transmitting genetic disorders. They support a regionalized system of comprehensive care for individuals with hemophilia, which can be a model of care for others with chronic disabling diseases. These set-aside dollars support projects that design and test innovative ways to deliver services to mothers, infants, children, and adolescents to prevent illness or injury and maximize their health. They also support the development of systems of services to provide early and effective treatment for handicapped or chronically ill children and enhance a family's ability to care for a child with special health needs.

In fiscal year 1989, the Office of Maternal and Child Health (OMCH) is supporting almost 500 SPRANS grants. This annotated listing, an annual publication of the National Center for Education in Maternal and Child Health (NCEMCH), provides brief descriptions of each such project. It is based on the project reports in the OMCH annual publication, Abstracts of Active Projects, and additional intormation provided by the SPRANS. It has been produced in order to disseminate information to individuals interested in the field of maternal and child health. NCEMCH wishes to thank OMCH and the SPRANS for providing information on current projects.

The full project report for a given SPRANS may be obtained from NCEMCH. Further information may be requested from individual projects. The name, address, and telephone number of a contact person for each project are also provided.



The Office of Maternal and Child Health was created October 1, 1987, but its roots go back more than 75 years to the Children's Bureau, established by Federal statute in 1912 to "investigate and report...upon all matters pertaining to the welfare of children and child life among all classes of our people." Among the issues the Bureau was instructed to look into were "the questions of infant mortality, the birth rate, orphanage, desertion...accidents and diseases of children...and legislation affecting children in the several States and territories." From these early inquiries flowed a wealth of information and new knowledge which influenced States to modernize their laws and encouraged the child health community to develop and improve services for mothers and children.

The first Federal grants in aid to the States for infant and maternal health came a decade later, authorized by the Sheppard-Tower Act of 1921, and administered by the Children's Bureau. The plans under which the States used these funds originated in the States and varied greatly, but as a result of widespread discussion of the whole question of maternity and child care, and the measures initiated in the States, additional progress was made.

Title V of the Social Security Act, enacted in 1935, created the first Federal-State partnership in maternal and child health. Federal funds were provided for three types of work in the States: Maternal and Child Health Services, Crippled Children's Services, and Child Welfare Services. For the most part, the States provided the services which were paid for by a combination of Federal dollars and matching State dollars, and the Federal Government provided leadership to the program. Legislative and administrative changes in the program over the years allowed it to respond to significant Changes in the Nation. Among these were the large numbers of women entering the workforce during World War II with the resulting need for day care programs for infants and children, development of new technologies which extended the lives of premature infants, medical advances in the treatment and prevention of handicapping conditions, the post-war trend toward urbanization, and the shortage and maldistribution of skilled health professionals.

Another significant change to Title V came in 1981 with the creation of the Maternal and Child Health Services Block Grant. In 1988, more than \$525 million was appropriated for this program, 85 percent of which went directly to the States. With it, and their own resources, the States provide a variety of services, including well-child clinics, family planning, immunizations, lead poisoning prevention, services for children with special health care needs, and others which serve low-income and minority women and children and those who might have no other access to services.

The remainder, known as the Federal set-aside, is used by the Federal Government to support special projects of regional or national significance (SPRANS), which include research; training; hemophilia diagnosis and treatment; genetic diseases screening, counseling, and referral; and maternal and child health improvement project grants which demonstrate and test a variety of approaches intended to improve the health of and services delivery to mothers, infants, children, adolescents, and children with special health care needs. The Office of Maternal and Child Health also provides support for pediatric AIDS health care demonstration projects and for emergency medical services for children

These projects offer the promise of more effective ways to deliver services, of new and different services to cope with both those conditions that have plagued mothers and children for years and the new morbidities, and of sensitive ways to reduce the barriers that keep people from receiving care. They expand the horizon of our knowledge and develop the leadership for our programs.

The prevention of unintentional injuries—which after the first year of life account for more childhood deaths than any other cause—is now properly seen as an issue for the child health community. The Office of Maternal and Child Health is supporting analysis of State-by-State data on 23 different causes of injury to help States identify their major injury problems and the high-risk groups of



children for whom preventive efforts are especially necessary. A landmark publication, *Injury Prevention: Meeting the Challenge*, also developed with OMCH support, provides program planners and managers with comprehensive strategies for implementing injury prevention programs. In addition, there are a number of demonstration projects cu rently esting various intervention strategies.

These projects are among the 476 reported in this book which were receiving funding at the beginning of fiscal year 1989. In order to be funded, each of these projects was reviewed by panels of professionals knowledgeable in their fields, rated highly, and recommended for approval.

In research, the Office of Maternal and Child Health supports projects which are intended to develop new knowledge and the application of such knowledge to the health problems of mothers, children, and children with special health care needs. Research grants may be made only to public or nonprofit private institutions of higher learning or to nonprofit agencies and organizations engaged in research or in maternal and child health or crippled children's (now known as children with special health needs) programs.

Training grants are available for long-term training or for continuing education by public or nonprofit private institutions of higher learning. These funds are focused on providing leadership training in a variety of specialized health professions, including interdisciplinary training, required to provide comprehensive maternal and child health care; providing specialized clinical or laboratory training and services not routinely available; providing professional consultation and technical assistance in connection with training activities; and upgrading skills and competencies of State and local MCH personnel.

Any public or private entity, nonprofit and for-profit, may apply for genetic disease testing and counseling grants, hemophilia diagnosis and treatment center grants, maternal and child health improvement project grants, and pediatric AIDS health care demonstration projects.

The genetics grants provide for the testing, counseling, and referral of individuals at risk for having or transmitting genetic disorders through broad-based, noncategorical, and readily accessible centers on a statewide or regional basis. Linkages of grantees with maternal care and family planning services extend testing and counseling services to additional persons in their childbearing years.

The hemophilia grants support development of regional programs with linkages to private clinicians, State Title V Programs, and other resources and serve as a demonstration model for issues relating to regionalization of other chronic and handicapping conditions. Hemophilia is a low prevalence disease which requires a disproportionate amount of health care dollars and resources; regionalization of care is desirable to achieve quality assurance and cost control.

Maternal and child health improvement project (MCHIP) grants support projects which demonstrate how State and local agencies and organizations can improve the health status of mothers and children through the creative modification of their health care systems. For example, they may explore the effectiveness of outreach techniques, apply innovative methods to identify individuals at risk, develop early and effective intervention techniques, or more effectively use primary providers and specialty services. They may develop systems to gather, analyze, disseminate, and store data and information so as to increase their use by any part of the maternal and child health community. Successful methods developed by MCHIP grantees should be replicable elsewhere in the Nation.

The pediatric AIDS health care projects demonstrate effective ways to prevent infection, especially by reducing perinatal transmission and by reducing the spread to vulnerable groups of young people. They also develop innovative programs for managing pediatric patients with AIDS which can serve as models for other communities.

The emergency medical services for children demonstration program is intended to improve the pediatric capacity of existing EMS systems in individual communities. State agencies or medical schools within a State are eligible for the grants. The program is designed to develop and use a body of knowledge about the characteristics of pediatric emergencies, the training of EMS personnel, and other necessary adaptations of the EMS system to handle pediatric emergencies. The program is also assisting all States and jurisdictions to incorporate this information into their EMS systems.



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The Office of Maternal and Child Health invites potential applicants to inquire about application requirements for the particular categories in which they are interested and then to make application for funding. Inquiries about possible grant support, technical assistance, or programmatic information should be addressed to the Director, Office of Maternal and Child Health, BMCHRD, HRSA, Room 9-11, Parklawn Building, 5600 Fishers Lane, Rockville, Maryland 20857.

Each year the Office of Maternal and Child Health publishes in the Federal Register requests for grant applications, giving specific dates and procedures for applying. At that time, and in guidance material distributed to prospective grantees, it indicates the priorities for funding and the issues which are of paramount concern to the program.

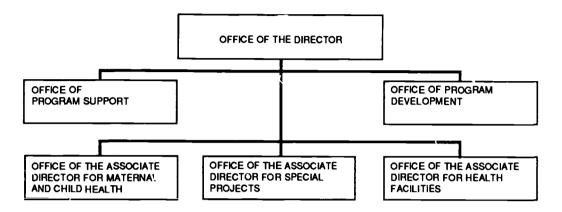
The issues affecting the health of mothers and children continue to challenge our intellect and our imagination. Infant mortality was the first such issue studied by the Children's Bureau in 1913. Throughout this century we have achieved significant reductions in infant mortality, but we know that our Nation can do still better. For that reason, the Office of Maternal and Child Health has continued to seek ways of improving maternal and infant care by supporting projects, such as those that reach out to at-risk populations to bring them into early prenatal care, that will improve the perinatal care delivery system, and that provide newborn screening for preventable disabling conditions. Other SPRANS grants to States with high infant mortality which have made significant commitments to improve the availability of maternal and infant care were coordinated with a program of similar grants from a private foundation, in order to maximize the benefits from resources expended.

In addition to providing grant support, the Office of Maternal and Child Health is exploring numerous efforts to improve maternal and infant health. For example, it is working closely with the Health Care Financing Administration in a shared goal of expanding eligibility for and availability of Medicaid funding for the care of women who are at risk of having low birthweight infants or other pregnancy complications. It is working with professional organizations to encourage provider participation in publicly supported perinatal programs. The Office of Maternal and Child Health provides leadership in maternal and child health through its partnership with the State MCH Block Grant agencies; through the Federal grant programs; through its collaboration with other Federal agencies; and through its alliances with professional, voluntary, and private organizations.

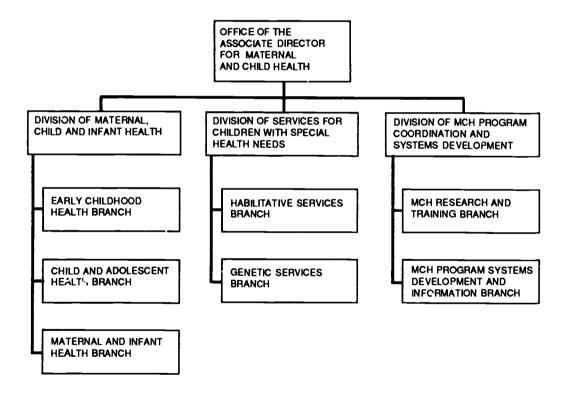
The wisdom gained from the projects and activities supported by the Office of Maternal and Child Health should be useful for the entire child health community and, when translated into prevention programs and comprehensive health services, should enhance and protect the health of mothers and children throughout the Nation.



BUREAU OF MATERNAL AND CHILD HEALTH AND RESOURCES DEVELOPMENT



OFFICE OF MATERNAL AND CHILD HEALTH





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Glossary of Commonly Used Acronyms

AACPDM—American Academy for Cerebral Palsy and Developmental Medicine

AAFP—American Academy of Family Physicians

AAP-American Academy of Pediatrics

AAUAP-American Association of University Affiliated Programs

ACCH-Association for the Care or Children's Health

ACNM—American College of Nurse-Midwives

ACOG-American College of Obstetricians and Gynecologists

ACCRN-Association of Community Organizations for Reform Now

AFDC-Aid to Families with Dependent Children

AHP—Alised Health Professionals

AIDS—Acquired Immune Deficiency Syndrome

AMA—American Medical Association

ANA—American Nurses' Association

APHA—American Public Health Association

ASTHO—Association of State and Territorial Health Officials

AZT-Azidothymidime

BHCDA—Bureau of Health Care Delivery and Assistance

BIA-Bureau of Indian Affairs

BMCHRD—Bureau of Maternal and Child Health and Resources Development

EPD-Bronchopulmonary Dysplasia

CCS—Crippled Children's Services

CDC—Centers for Disease Control

CDF—Children's Defense Fund

CF-Cystic Fibrosis

CHAMPUS—Civilian Health and Medical Program of the Uniformed Services

CHC—Community Health Center

COBRA—Consolidated Onnibus Budget Reconciliation Act (1983)

COPC—Community Oriented Primary Care

CORN-Council of Regional Networks for Genetics Services

CSHN-Children with Special Health Needs

CTD—Connective Tissue Diseases

DDAVP—Desmopressin (1-deamino-8-d-arginine vasopressin)

DHHS—Department of Health and Human Services

DMCH-Division of Maternal and Child Health

DRG—Diagnosis Related G oups

EFNEP—Expanded Food and Nutrition Education Program

EMR—Educable Mentally Retarded

EMSC—Emergency Medical Services for Children

EMS—Emergency Medical Services

EMT—Emergency Medical Technician

EPSDT—Early and Periodic Screening, Diagnosis, and Treatment

FDA—Food and Drug Administration

FEMA—Federal Emergency Management Administration

HCEEP—Handicapped Children's Early Education Program

HCFA—Health Care Financing Administration

HMHB—Healthy Mothers, Healthy Pabies Coalition

HMO—Health Maintenance Organization

HRSA—Health Resources and Services Administration

ICHP—Improved Child Health Projects

ICU-Intensive Care Unit

IEP-Individualized Education Plan

IFSP-Individualized Family Service Plan

IHS-Indian Health Service



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IMR-Infant Mortality Rate

JRA-Juvenile Rheumatoid Arthritis

MARHGN—Mid-Atlantic Regional Human Genetics Network

MCHIP-Maternal and Child Health Improvement Project

MCH-Maternal and Child Health

MHC-Migrant Health Center

MR-Mental Retardation

MSAFP---Maternal Serum Alpha-Fetoprotein

NACHRI-National Association of Children's Hospitals and Related Institutions

NASW-National Association of Social Workers

NERGG-New England Regional Genetics Group

NHANES—National Health and Nutrition Examination Survey

NHSC-National Health Service Corps

NICHD-National Institute of Child Health and Human Development

NICU-Neonatal Intensive Care Unit

NIH-National Institutes of Health

NIMH—National Institute of Mental Health

OB/GYN—Obstetrics and Gynecology

OMCH-Office of Maternal and Child Health

OSERS-Office of Special Education and Rehabilitative Services

OTA—Office of Technology Assessment

P.L.—Public Law

PHN-Public Health Nurse

PHS--Public Health Service

PKU-Phenylketonuria

PPC—Pediatric Pulmonary Center

PSA—Public Service Announcement

RD-Rheumatic Disease

RFP—Request for Proposals

RP—Reunitis Pigmentosa

SADD-Students Against Drunk Driving

SAM—Society for Adolescent Medicine

SCAN—Shared Communication and Assistance Network

SERGG—Southeastern Regional Genetics Group

SIDS—Sudden Infant Death Syndrome

SKIP—Sick Kids (Need) Involved People

SLE—Systemic Lupus Erythematosus

SOBRA—Sixth Omnibus Budget Reconciliation Act (1986)

SPRANS—Special Projects of Regional and National Significance

SSA—Social Security Administration

SSI—Supplemental Security Income

TEFRA—Tax Equity and Fiscal Responsibility Act (1982)

UAF—University Affiliated Facility

UAP—University Affinated Program

USDA—United States Department of Agriculture

USMBHA—United States-Mexico Border Health Association

VNA-Visiting Nurse Association

WAMI-Washington, Alaska, Montana, and Idaho

WIC-Special Supplemental Food Program for Women, Infants, and Children

ZDV---Zidovudine



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Maternal Health

Prenatal Care: Content and Utilization Risk Reduction in Pregnancy Systems Development for Perinatal Services



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Comprehensive Prenatal Care Networks Project

East Bay Perinatal Council 2794 Garden Street P.O. Box 7322 Oakland, CA 94601 (415) 261-4050 MCHIP MCJ-063891 10/01/86—09/30/89 Project Director(s): Lance Lindsey

The goal of this project is to reduce the incidence of low birthweight by ensuring the provision of comprehensive perinatal services to low-income, Medicaid-eligible pregnant women. The project seeks to encourage cooperation between public and private sector health care providers and to ensure early and continuous participation in prenatal care by pregnant women. Activities include developing protocols, management systems, and logistical arrangements that facilitate public and private sector participation in the Comprehensive Perinatal Services Program.

Hispanic Males Outreach Project (HMOP)

Hill Health Center 400 Columbus Avenue New Haven, CT 06519 (203) 776-9594 MCHIP MCJ-096002 10/01/87—09/30/90 Project Director(s): Carlos Salguero, M.D.

In this project two community health centers work together to demonstrate that greater Hispanic male involvement during the prenatal and infancy periods results in improved perinatal and infant outcomes. Project objectives are to: (1) Reduce the low birthweight and perinatal mortality rates throughout the project area; (2) increase the number of prenatal visits for Hispanic women; and (3) increase Hispanic male incolvement through prenatal and postpartum classes and group activities, job counseling and training, employment referrals, recreation, and health education.

Maternal and Child Health Improvement Project: Effective Pregnancy & Infant Care

Delaware Department of Health and Social Services Bureau of Personal Health Services Maternai and Child Health Robbins Building P.O. Box 637 Dover, DE 19903 (302) 736-4785 MCHIP MCJ-103737 10/01/85—09/30/89 Project Director(s): Kay D. Makar, R.D., M.P.H.

This project seeks to reduce infant mortality rates by identifying and tracking high-risk pregnant women. Project objectives are to: (1) Screen women for risk of having a poor pregnancy outcome at the time a pregnancy test is performed; (2) provide access to prenatal care and obtain WIC certification and a Medicaid application within the first trimester of pregnancy for at-risk women; (3) provide comprehensive risk assessations upon entry into prenatal care for at-risk women in public health clinics; and (4) facilitate coordination of data from key sources.



Prenatal Care: Content and Utilization

Nutritional Status, Pregnancy, and Lactation

National Academy of Sciences Commission of Life Sciences 2101 Constitution Avenue, N.W. Washington, DC 20418 (202) 334-1917 MCHIP MCJ-116011 10/01/87—09/30/90 Project Director(s): Chessa Letter, Ph.D.

This project establishes an expert committee which evaluates and documents current scientific evidence on pregnancy and lactation and proposes nutritional recommendations for pregnant and lactating women. Activities include workshops, meetings, and studies and reports on such subjects as weight gain during pregnancy; vitamin, mineral, and protein supplements; nutrient-nutrient and nutrient-drug interactions; and nutrition during lactation.

Improved Prenatal Care Utilization and Birth Outcome Project

Massachusetts Department of Public Health 150 Tremont Street 2nd Floor Boston, MA 02111 (617) 727-5125 MCHIP MCJ-253682 08/01/85—07/31/89 Project Director(s): Serena E H. Mailloux, M.D.

This project surveys 3000 postpartum women in order to identify behavioral, cultural, linguistic, structural, and institutional factors that influence prenatal care utilization and to assess systematic gaps in prenatal care service delivery. Innovative, community-based strategies will then be developed and implemented in order to reduce barriers to prenatal care, particularly for women at high risk for inadequate prenatal care utilization and poor birth outcomes.

Increasing Access to Prenatal Care Through Problem Identification and Program Evaluation

Wayne State University C.S. Mott Center 275 East Hancock Detroit, MI 48201 (313) 577-1147 MCHIP MCJ-263811 10/01/86—09/30/89 Project Director(s): Marilyn L. Poland, Ph.D., R.N.

The goal of this project is to reduce the infant mortality rate in Detroit and Wayne County by increasing prenatal care utilization and decreasing low birthweight rates. Barriers to prenatal care have been identified through a literature review, focus group discussions with patients and health professionals, and surveys of new mothers. The project also provides technical assistance to a county infant health promotion coalition which provides various outreach efforts, including a 24-hour telephone information and referral hotline for women and infants.



Migrant Lay Health Advisors: A Strategy for

Health Promotion

University of North Carolina at Chapel Hill School of Public Health Department of Maternal and Child Health CB 7400 Rosenau Hall Chapel Hill, NC 27599 (919) 966-5974 MCHIP MCJ-376003 10/01/87—09/30/90 Project Director(s): Elizabeth Watkins, D.Sc.

This project seeks to improve the perinatal and infant outcomes among migrant women and infants in North Carolina by recruiting and training lay health advisors. These health advisors are trained to disseminate accurate information on pregnancy and infant care in a culturally appropriate manner, to link members of this transitory and isolated community with health services, and to help women develop an increased awareness of themselves as leaders and advocates. A longitudinal, quasi-experimental study design will be used to determine the effectiveness of the program in improving perinatal outcomes and infant health status.

Cuyahoga County Perinatel Connection

Cleveland Metropolitan General Hospital Maternity and Infant Health Care 3395 Scranton Road Cleveland, OH 44109 (216) 459-3132 MCHIP MCJ-393819 10/01/86—09/30/89 Project Director(s): Carolyn Zaremba

This project addresses the problems of low birthweight and infant mortality by encouraging the early enrollment of pregnant women into prenatal care and by working to retain these women in the health care system. The project uses trained outreach workers to conduct a door-to-door campaign in an effort to enroll women in prenatal care and to educate the community. The project is designed to serve as a training model for those targeted cities in Region V that have high rates of perinatal and infant mortality

Enhancing Access to Maternity Care Services for

Low-Income Women
Philadelphia Department of Public Health

Division of Maternal and Child Health 500 South Broad Street Philadelphia, FA 19146 (215) 875-5927 MCHIP MCJ-423881 10/01/86---09/30/89 Project Director(s): Barbara Wesley, M.D., M.P.H.

This project aims to reduce infant mortality rates by reducing behavioral risk factors. Taking into consideration the literacy level and cultural diversity of the target population, the project's education and outreach initiatives emphasize how to become eligible for and how to use the available service programs. A guidebook on nutrition for pregnant teenagers, a videotape on how to obtain prenatal care, and a prenatal care information booklet have been produced.



Prenatal Care: Content and Utilization

Changing the Configuration of Early Prenatal

Care (EPIC)
Rhode Island Department of Health
Division of Family Health
75 Davis Street
Providence, RI 02908
(401) 277-2312

MCHIP MCJ-443841 10/01/86—09/30/89 Project Director(s): Jane de Christopher, M.P.H.

This project seeks to improve pregnancy outcomes for high-risk, inner-city women through early prenatal care home intervention. Pregnant women in the study area receive weekly visits from nurses who follow a curriculum designed to motivate pregnant women to alter those lifestyle behaviors that place their babies at risk for low birthweight. A randomized controlled trial design will be used to test the effectiveness of the program.

Uterine Activity Patterns: Definition with Home

University of Texas Health Science Center at Houston Department of Obstetrics, Gynecology, and Reproductive Sciences 6431 Fannin Suite 3286 Houston, TX 77030 (713) 792-5362

Research MCJ-480561 12/01/87—11/30/89 Project Director(s): Robert K. Creasy, M.D.

This project uses a home ambulatory uterine monitoring system to attempt to define normal uterine activity across gestational age in a group of women whose pregnancies are entirely uncomplicated. The study will test the hypotheses that uterine activity appears in normal pregnant women in the late second trimester and that the quality of uterine activity increases throughout gestation; that there is a cyclic, diurnal pattern of uterine activity through gestational age; and that uterine activity in nulliparous women is comparable to that seen in multiparous women, when matched for gestational age.



Maternal Pesticide Exposure and Pregnancy

San Diego State University Graduate School of Public Health San Diego, CA 92182 (619) 265-2443 Research MCJ-060546 11/01/86—10/31/89 Project Director(s): Winnie O. Willis, Ph.D.

This project studies the impact that pesticide exposure during pregnancy may have on specific adverse reproductive outcomes such as low birthweight, spontaneous abortion, preterm labor, and toxemia of pregnancy. The study will follow a cohort of pregnant women exposed to pesticides before or during their pregnancy, and record the postnatal condition of the women and their infants.

Physiologic Risk Assessments to Predict Preterm

Mount Zion Hospital and Medical Center University of California at San Francisco P.O. Box 7291 Pavilion, 5th Floor San Francisco, CA 94143 (415) 594-2874 Research MCJ-060580 10/01/88—09/30/91 Project Director(s): Denise Main, M.D.

This study seeks to: (1) Validate a highly predictive (retrospective) screening method using uterine contraction monitoring; and (2) determine whether the ability to identify women subject to preterm labor using this method can be further improved by the addition of pelvic examination findings. The 3-year project will attempt to determine whether these physiologic measures, when determined at standard prenatal visit intervals, can be used to identify women who subsequently experience preterm birth because of preterm labor or preterm premature rupture of the membranes. The study will also examine whether interpretation of uterine contraction data can be improved and standardized by means of a computer program.

Effectiveness of an Urban Low Birthweight Intervention

The Better Babies Project, Inc. 1717 Massachusetts Avenue, N.W. Washington, DC 20036 (202) 397-3131 Research MCJ-110558 10/01/87—09/30/91 Project Director(s): Deborah L. Coates, Ph.D.

This project evaluates the effectiveness of a community-based intervention program which seeks to reduce the incidence of low birthweight in a low-income area of Washington, DC. The intervention is based on a comprehensive services and social support model. Paraprofessional case workers identify women early in their pregnancies, link them with prenatal care and needed social services, and provide intensive preventive health education. Other key program activities include a smoking cessation program, home visits, transportation and stipend assistance for prenatal care, and a drop-in center.



North Central Florida Maternal and Infant Care Project 730 Northeast Waldo Road Building A Suite B Gainesville, FL 32601 (904) 392-4491

MCHIP MCJ-126007 10/01/87—09/30/90 Project Director(s): Diane Dimperio

The goal of this project is to reduce the incidence of low birthweight by improving the preconceptional health of women who are at high risk for delivering a low birthweight infant. High-risk women are identified at delivery and are followed for 2 years. Client services are then provided by community health workers, who make home visits and develop a risk reduction plan for each client. Intervention protocols are developed for each risk factor and involve referral to the appropriate resource, followup to ensure client compliance, and reinforcement of professional counseling or supplemental teaching.

Maternal/Perinatal Nutrition

University of Florida 730 Northeast Waldo Road Building A Suite B Gainesville, FL 32601 (904) 392-4491 Training
MCJ-009119
07/01/88—06/30/93
Project Director(s):
Charles S. Mahan, M.D.

The purpose of this project is to establish an intensive short course of national scope, focusing on management of nutrition care and organization of nutrition services for normal and high-risk women throughout the reproductive years.

Minority Connection: Reduction of Minority Infant Mortality

CONTINUUM Alliance for Healthy Mothers and Children
1252 West Peachtree Street, N.W.
Suite 311
Atlanta, GA 30309
(404) 873-1993

MCHIP MCJ-136004 10/01/87—09/30/90 Project Director(s): Mary Langley, R.N., M.P.H.

This project aims to reduce postneonatal mortality rates associated with inadequate parenting skills and poor utilization of prenatal and child health care services. Activities include establishment of a Resource Mothers Program in which church women are trained to assist pregnant women in negotiating the health care and social services systems, and implementation of a teen peer counselor program. The project also establishes self-sustaining local coalitions to monitor and address problems that contribute to poor pregnancy outcomes.



Demonstration Model of a Risk-Appropriate
Prenatal Care System to Reduce the Incidence of
Low Birthweight in Maine
Medical Care Development, Inc.
11 Parkwood Drive
Augusta, ME 04330
(207) 622-7566

MCHIP MCJ-233820 10/01/86—09/30/89 Project Director(s): Laura C. Ronan, M.P.H.

This project seeks to reduce infant morbidity and mortality due to low birthweight, and to demonstrate a cost-effective prenatal care program which is integrated with the existing system and can be duplicated in other States. Project objectives include instituting a model prenatal education, courseling, referral, and followup program in 80 physicians' offices and other sites, and enhancing the education and counseling skills of prenatal care providers.

Smoking Cessation/Relapse Prevention in Low-Income Mothers

Johns Hopkins University
School of Hygiene and Public Health
Department of Health Policy and Management
624 North Broadway
Baltimore, MD 21205
(301) 955-3018

Research MCJ-240562 11/01/87—10/31/91 Project Director(s): Ruth R. Faden, Ph.D., M.P.H.

This project uses a prospective, experimental study design to test multicomponent, prenatal, and postpartum smoking cessation and relapse prevention interventions that can be implemented in clinics serving low-income women. Smoking behaviors will be assessed during and after pregnancy by collecting behavioral reports and cotinine samples.

An Instrument to Screen and Classify Pregnant Women According to Nutritional Risk Harvard School of Public Health Department of Maternal and Child Health 677 Huntington Avenue Boston, MA 92115 (617) 732-1980

Research MCJ-250553 05/01/87—04/30/89 Project Director(s): Jane Dianne Gradner, D.Sc.

The main objectives of this research project are to: (1) Develop and test a prenatal food frequency questionnaire (PFFQ) which can be used by nonprofessional personnel to screen low-income pregnant women for inadequate food and nutrient intake; (2) assess the acceptability and practicality of questionnaire administration via interactive computing; and (3) investigate patterns of food and nutrient intake by defined demographic and medical variables. The PFFQ is being tested in Spanish and English.



Risk Reduction in Pregnancy

Preconceptional Vitamin Use and Neural Tube

Boston University School of Medicine Slone Epidemiology Unit 1371 Beacon Street Brookline, MA 02146 (617) 734-6006

Research MCJ-250567 03/01/88-02/28/92 Project Director(s): Allen A. Mitcheli, M.D.

This study seeks to: (1) Establish the potential benefit of preconceptional vitamin supplementation in reducing the incidence of neural tube defects; and (2) examine some of the potential hazards of excessive preconceptional vitamin supplementation. Study subjects (cases and controls), consisting of malformed, liveborn infants under 6 months of age, stillborn infants, and therapeutic abortions, will be identified through an existing network of birth and teaching hospitals in 3 study centers.

Reducing the Risk of Low Birthweight and Its Adverse Sequelae

Minnesota State Department of Health University of Minnesota P.O. Box 9441 717 Delaware Street, S.E. Minneapolis, MN 55440 (612) 623-5166

MCHIP MCJ-276008 10/01/87---09/30/90 Project Director(s): Judith Brown, Ph.D. Carolyn McKay, M.D.

The goal of this project is to reduce the risk of low birthweight and its adverse sequelae through prenatal weight gain intervention services. The project will identify prenatal weight gain goals (based on scientific consensus), utilize intervention services designed to promote prenatal weight gain, develop a model for case-managed prenatal intervention services, and determine the cost-effectiveness of the prenatal weight gain intervention.

Neonatal Outcome and Weight Gain of Black Adolescents

University of Rochester Strong Memorial Hospital 601 Elmwood Avenue Rochester, NY 14642 (716) 275-4673

Research MCJ-360534 01/01/86-03/31/89 Project Director(s): Elizabeth R. McAnamey, M.D.

This project conducts a 3-year prospective observational study of the relationships between maternal weight gain, maternal age, and neonatal outcome (primarily birthweight and gestational age) among 180 black primiparous adult and adolescent women of lower socioeconomic status. The adolescents will be recruited from the Rochester Adolescent Maternity Project, and the adults from other prenatal clinics at Strong Memorial Hospital.



Maternal Health

2.

The Davidson Project
Davidson County Health Department
P.O. Box 439
Lexington, NC 27292
(704) 246-5952

MCHIP MCJ-373784 09/01/85—08/31/89 Project Director(s): Richard C. Baxley

This project's primary goal is to reduce the number of low birthweight babies born to women in Davidson County by reducing both preterm births and intrautenine growth retardation. Volunteers will be recruited and trained to provide intensive support services to 120 women at risk for preterm labor. The focus of the support services will be on psychosocial risk factors for preterm labor, such as low self-esteem, poor problem-solving ability, and financial difficulty.

Maternal-Infant Risk Management in a Defined Population

Indian Health Management, Inc. 101 Jailhouse Road Rosebud, SD 57570 (605) 747-2239

MCHIP MCJ-463718 02/01/86—01/31/89 Project Director(s): Lynn Armstrong, C.N.M., M.P.H.

The goals of this project are (1) to reduce morbidity and mortality and to improve access to health services for the maternal and child population of the Rosebud Sioux Tribe, and (2) to improve the understanding of the local epidemiology of maternal and infant morbidity and mortality as the basis for health services planning. Project objectives include implementing a program of comprehensive well-child care, developing a postneonatal death risk scoring tool, and computerizing the data on the Hollister and well-child record systems.

Rural Prenatal Consultation and Care Project

Utah Department of Health Bureau of Maternal and Infant Health 44 Medical Drive Salt Lake City, UT 84113 (801) 533-4084 MCHIP MCJ-493713 10/01/85—09/30/89 Project Director(s): Ida Ripley, C.N.M.

This project aims to improve the availability of appropriate prenatal care and postnatal clinical care for low-income, high-risk women and their newborns in Utah's Southeastern, Southwestern, and Uintah Basin Health Districts. Activities include incorporating improvements into the existing health services, developing new programs in rural and frontier counties, and collecting data for better evaluation of the needs and services in the target areas.



Risk Reduction in Pregnancy

Implementation of Maternal and Child Nursing Standards for Perinatal Services

Virgin Islands Department of Health St. Thomas Hospital Sugar Estate St. Thomas, VI 00802 (809) 778-6567 MCHIP MCJ-783890 10/01/88—09/30/89 Project Director(s): Cora Christian, M.D., M.P.H.

This project will establish maternal and child health nursing standards for perinatal services within an integrated health care delivery system. Anticipated project outcomes include improved identification of low- and high-risk childbearing families, earlier intervention, use of interdisciplinary care plans, improvement in interagency collaboration, and provision of nurse training in holistic family life and sex education.

Epilepsy in Pregnancy: Developmental Followup of Infants

University of Washington Child Development and Mental Retardation Center Seattle, WA 98195 (206) 545-1350 Research MCJ-530552 04/01/87—03/31/90 Project Director(s): Mark S. Yerby, M.D., M.P.H.

This project studies the effects of epilepsy on pregnancy outcomes. A group of pregnant women with epilepsy and a group of nonepileptic pregnant women will be followed throughout pregnancy; case and control infants will then be followed until 3 years of age. If group differences are found, possible correlations between outcome and maternal prenatal and perinatal history (i.e., seizure type and frequency, and anti-epileptic drug use) will be investigated.



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2. Maternal Health

Central Alabama System of Perinatal Care

Alabama Department of Public Health Bureau of Family Health Services State Office Building Montgomery, AL 36130 (205) 261-5661 MCHIP MCJ-016010 10/01/88—09/30/90 Project Director(s): Saundra Wheeler

The goal of this project is to establish an organized system of perinatal care which will improve the present unfavorable maternal and child health indices in the project area. Registered nurses, certified nurse-midwives, and obstetrical gynecologists will be involved. The project will focus on outreach, risk-based prenatal care and planned delivery, case management, post-delivery home visits, and sick-child care.

Implementation Incentive/Healthy Generations

American Samoa Department of Health L.B.L. Tropical Medical Center Pago Pago, AS 96799 (684) 633-1222, ext. 201 MCHIP MCJ-606003 10/01/88—09/30/91 Project Director(s): Charles R. McCuddin, M.P.H.

This project seeks to reduce fetal and neonatal mortality rates in the U.S. territory of American Samoa. The project will focus on increasing the utilization of prenatal health care services by converting the present inaccessible, centralized system of care to a multilocation, community-based system.

Maternity Care Case Management Demonstration Project

Arizona Department of Health Services 1740 West Adams Phoenix, AZ 85007 (602) 255-1870 MCHIP MCJ-046006 10/01/88—09/30/91 Project Director(s): Jane Pearson, R.N.

This project seeks to reduce low birthweight rates among project participants by implementing an aggressive case management system that will improve utilization of and compliance with comprehensive prenatal care. Four demonstration project sites for Medicaid-enrolled women will be established and will provide education, referral, followup, and counseling services.



A Comprehensive Model for Preventing HIV

Infection

San Francisco Department of Public Health 101 Grove Street Room 115B San Francisco, CA 94102 (415) 558-3684 MCHIP MCJ-066001 10/01/87—09/30/89 Project Director(s): Geraldine Oliva, M.D., M.P.H.

This project addresses the need for perinatal AIDS prevention and care services by strengthening both the public and private health and social service delivery systems. Specifically, the project will (1) educate care providers about perinatal AIDS and provide them with technical assistance; (2) implement protocol and policy development and provide technical assistance; and (3) develop a model of perinatal AIDS prevention, education, and care.

American Indian Comprehensive Maternal Child Health Care Program

California Urban Indian Health Council, Inc. 2422 Arden Way
Suite A-2?
Sacramento, CA 95825
916) 920-0313

MCHIP MCJ-066005 10/01/87—09/30/90 Project Director(s): Karen Tracy, R.N., M.S.

This project aims to reduce the incidence of low birthweight among Native American infants in California by working with Indian health clinics to develop and implement a comprehensive perinatal services program. This model program will include medical, nutrition, health education, and psychosocial components, and is designed to be culturally sensitive. Data collection activities will result in the development of a comprehensive data base on Native American maternal and child health.

Regional Perinatal Health Services—Diabetes and Pregnancy Program

California Department of Health Services Maternal and Child Health Branch 2151 Berkeley Way Annex 4 Room 4(%) Berkeley, CA 94704 (415) 540-2098 MCHIP MCJ-063671 10/01/85—09/30/90 Project Director(s): Joseph V. Brazie, M.D., M.P.H. Diana M. Lee, R.D., M.P.H.

In order to enhance the State's Diabetes and Pregnancy Program, this project will develop, test, and implement a model regional perinatal data system which will collect, analyze, and review information on pregnancies complicated by diabetes, and will develop an outreach program to promote community awareness. The outreach program will be aimed at recruiting perinatal care providers and pregnant and pregnant diabetic women and maintaining their participation in diabetes and pregnancy programs.



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Maternal Health

Implementing a Statewide Comprehensive MCH Services System

Truk State Department of Health Services Federated States of Micronesia P.O. Box 400 Moen, Truk, E.C.I., FSM 96942 MCHIP MCJ-753881 10/01/87—09/30/90 Project Director(s): Kiosi Aniol, M.D.

The overall goal of this project is to establish a statewide MCH services system which will meet the health needs of all the mothers and children of Truk State. This system will include components for improved vital events registration and data management as well as for training of health workers (primarily local midwives). The main focus will be on the extension of prenatal and well-child clinic services to areas that are not presently served.

Improving Pacific Basin Perinatal Care Through a Program of Self Instruction: Outreach Education

Kapiolani Medical Center for Women and Children 1319 Punahou Street Honolulu, HI 96826 (808) 947-8387 Training
MCJ-009084
10/01/85---09/30/89
Project Director(s):
Rodney Boychuk, M.D.

This project is designed to upgrade perinatal care in the hospitals of Micronesia by fostering professional education on perinatal issues. Hospital personnel are provided with professional educational materials such as manuals, slides, and videocassettes and are given training in using these materials to educate health professionals in their own hospitals. In addition, project staff travel to hospitals to conduct skills workshops.

Louisiana "Healthy Futures" Program

Louisiana Department of Health and Hospitals Office of Public Health 325 Loyola Avenue New Orleans, LA 70112 (504) 568-5048 MCHIP MCJ-226016 10/01/88—09/30/92 Project Director(s): Caroline V. Blonde, M.D., M.P.H.

The "Healthy Futures" Program will seek to address the high infant mortality rate in Orleans Parish by increasing the number of high-risk pregnant women who receive early and continuous prenatal care services. The project will develop a system of community-based outreach, provide aggressive case management for high-risk women, increase accessibility through alternative sources of public and private care, expand prenatal care to include uniform medical/psychosocial/economic risk assessment, and arrange for Medicaid reimbursement for these services.



Healthy Generations for Maryland

Maryland State Department of Health and Mental Hygiene 201 West Preston Street Baltimore, MD 21201 (301) 225-6708

MCHIP MCJ-246005 10/01/88—09/30/92 Project Director(s): Donna Becker, R.N.

This project seeks to reduce Maryland's high rates of infant mortality and low birthweight. The project's two main objectives are to: (1) Demonstrate the efficacy of generic, family-oriented, community-based nursing services in reducing the IMR in designated urban areas; and (2) reduce the number of NICU admissions and referrals made in selected rural counties by providing high-risk obstetrical consultation services to rural providers.

Lawrence Prenatal Support System

Massachusetts Department of Public Health 150 Tremont Street Boston, MA 02111 (617) 727-5121 MCHIP MCJ-256007 10/01/88—09/30/91 Project Director(s): Ellen Gibbs

The goal of this project is to improve prenatal care utilization rates and birth outcomes among high-risk, low-income women, particularly Hispanic women, living in the city of Lawrence. The Lawrence Prenatal Support System will establish a coordinated service system for high-risk pregnant women; demonstrate a model of early and continuous case management which will include advocacy and support by bilingual, bicultural case managers; and coordinate public and private prenatal care services.

Prenatal Care Coordination

Minnesota Department of Health 717 Southeast Delaware Street P.O. Box 9441 Minneapolis, MN 55440 (612) 623-5431 or 623-5166 MCHIP MCJ-276015 10/01/88—09/30/91 Project Director(s): LaVohn Josten, Ph.D., R.N. Carolyn McKay, M.D.

This project aims to reduce low birthweight rates among low income women whose prenatal care is paid for by medical assistance. The project will work to implement the Minneseta Department of Human Services Prenatal Care Initiatives and will establish a statewide, locally based prenatal care coordination system to provide comprehensive, risk-appropriate prenatal care.



Maternal Health

St. Louis Metropolitan Perinatal Plan Project

St. Louis Regional Maternal and Child Health Council, Inc. 7305 Manchester Avenue St. Louis, MO 63143 (314) 644-0655

MCHIP MCJ-293749 09/01/85--02/28/89 Project Director(s): Gracie O. Hutchinson, R.N., M.S.N.

The goal of this project is to decrease infant morbidity and mortality amonate the program population by providing comprehensive perinatal services to high-risk women. A sys in of screening, early risk identification, and followup throughout the perinatal period has been established. Home visits are made to each client admitted to the project during pregnancy and at least once after delivery. Intensive nursing care is provided by the Visiting Nurse Association when necessary, and infants and mothers needing extended care are referred to the council's High-Risk Infant Followup Program.

Healthy Beginnings for Healthy Futures

North Carolina Department of Human Resources Division of Health Services Maternal and Child Care Section P.O. Box 2091 Raleigh, NC 27602-2091 (919) 733-3816 MCHIP MCJ-376004 10/01/88—09/30/92 Project Director(s): Ann F. Wolfe, M.D., M.P.H.

This project addresses problems such as fragmented clinical services, barriers to enrollment in Medicaid, and lack of support services, all of which contribute to North Carolina's high infant mortality rate. The goal of the project is to reduce infant mortality by increasing prenatal care services and by promoting preventive preconceptional approaches, balanced access to services for infants, and other support services.

Performance System to Reduce Prematurity and Low Birthweight

University of North Carolina at Chapel Hill School of Public Health Department of Maternal and Child Health CB 7400 Rosenau Hall Chapel Hill, NC 27599 (919) 966-5981

MCHIP MCJ-376009 10/01/87—09/30/90 Project Director(s): Jonathan B. Kotch, M.D., M.P.H.

The purpose of this project is to reduce prematurity and low birthweight in North Carolina's Perinatal Region III using a performance-based management system. This system provides a mechanism for conducting periodic, ongoing observation of program effectiveness and for monitoring public health staff performance in implementing clinic guidelines. A generic low birthweight and prematurity prevention manual has been developed, and project and health department staff in each target county will work together to adapt this manual to local needs.



Systems Development for Perinatal Services

Perinatal Care Coordination Project

Columbus Health Department 181 South Washington Boulevard Columbus, OH 43215 (614) 222-6424 MCHIP MCJ-396009 10/01/88—09/30/91 Project Director(s): Carolyn B. Slack, M.S., R.N.

This project seeks to decrease the occurrence of poor perinatal outcomes by improving both the utilization and content of perinatal care services. An interdisciplinary team will work to improve client recruitment, enrollment, and retention procedures while implementing a care coordination service delivery model to better meet client needs.

Family Shelter Project

Philadelphia Department of Public Health 500 South Broad Street Philadelphia, PA 19146 (215) 592-5410

MCHIP MCJ-426014 10/01/88—09/30/91 Project Director(s): Mark Bencivengo

This project addresses the dramatic rise in homelessness and substance abuse and the growing relationship between the two. The project will establish a city shelter for homeless families which will provide leadership and coordination for a broad range of health, social, and educational services for women, mothers, and infants within a therapeutic community.

Developing A Community MCH System in the Blackstone Valley

Brown University/Memorial Hospital of Rhode Island Department of Family Medicine 89 Pond Street Pawtucket, RI 02860 (401) 722-6000, ext. 2236

MCHIP MCJ-446006 10/01/87—09/30/90 Project Director(s): Larry Culpepper, M.D.

This project will develop a network of community organizations involved in the identification of and response to perinatal and early infancy problems and the problems of young families. Specific goals include the development of a community MCH plan, the implementation of a data system for project sites, the integration of MCH programs with ongoing caregiving structures, the implementation of interagency protocols, and the modification of health behaviors and improvement of MCH utilization patterns.



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Maternal Health

Perinatal Health: Strategies for the 21st Century

National Perinatal Information Center 1 Blackstone Place 668 Eddy Street 3rd Floor Providence, RI 02903 (401) 274-0650 MCHIP MCJ-446017 10/01/88—09/30/91 Project Director(s): Rachel M. Schwartz, M.P.H.

The overall goal of this project is to serve as a focal point in strengthening and improving the organization and delivery of perinatal health services in the United States. To achieve this goal, the project has established three major objectives: (1) To stimulate interest in what measures should be taken to improve perinatal health; (2) to create an environment for discussing the future of perinatal health; and (3) to establish a national agenda for improving systems of perinatal health care. Project activities include meetings and conferences at the State and regional levels.

South Carolina Partnership for Healthy Generations

South Carolina Department of Health and Environmental Control 2600 Bull Street Columbia, SC 29201 (803) 734-4670

MCHIP MCJ-456001 10/01/88—09/30/92 Project Director(s): Marie C. Meglen, M.S., C.N.M.

The goal of this project is to reduce the infant mortality rate in South Carolina. To do so, the project will work to improve access to early and continuous prenatal care by addressing individual and systems problems; establish public/private task forces in six counties; ensure coordinated systems of perinatal care; and develop a "priority programs" agenda for the legislature and Maternal Infant and Child Health Council member groups.

Maternal and Infant Care Access (MICA) Project

Texas Department of Health Bureau of Maternal and Child Health 1100 West 49th Street Austin, TX 78756 (512) 458-7111 MCHIP MCJ-486002 10/01/88—09/30/92 Project Director(s): Walter Peter, M.D.

The goal of the MICA Project is to reduce infant mortality in Texas by increasing the number of women who receive prenatal care and the number of infants who receive followup care. A pilot project will be developed in which a coordinating council will be established, a case management system will be initiated, and market ng activities (to encourage early and ongoing prenatal care) will be coordinated. These strategies will then be extended statewide.



Maternal and Infant Risk Assessment and Referral Training Project
U.S.-Mexico Border Health Association
6006 North Mesa
Suite 600
El Paso, TX 79912

(915) 581-6645

MCHIP MCJ-483840 10/01/86—03/31/89 Project Director(s): Herbert H. Ortega, M.D., Ph.D.

This project seeks to improve the health status of women and infants on the Texas-Mexico border by maximizing utilization of health resources and improving coordination of services in both nations, as well as by enhancing binational staff development efforts. Activities include distribution of the *Maternal* and Child Health Resource Directory; provision of continuing education for nurses, lay midwives, and auxiliary health workers; and implementation of an exchange observation program for nurses from the United States and Mexico.



Maternal Health

Infant Health

Reducing Mortality and Morbidity Newborn Screening for Sickle Cell and Other Genetic Disorders Breastfeeding Parenting



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Reducing Mortality and Morbidity

Infant Mortality in Hartford, Connecticut: A

Community Centered Review

Hispanic Health Council 96 Cedar Street Suite 3A Hartford, CT 06106 (203) 527-0856 MCHIP .ACJ-096011 10/01/88—09/30/90 Project Director(s): Georgine S. Burke, Ph.D.

This project addresses the high rate of infant mortality in Hartford, Connecticut, by implementing a community-based infant mortality review program that uses a holistic systems approach. The purpose of the project is to identify factors contributing to infant mortality that can be prevented by changes in prenatal care and behavior and in policy and programs, to develop policy recommendations to address these problems, and to initiate efforts to implement the recommended changes.

Identification of Risk for SIDS: Subsequent

Siblings

American SIDS Institute 275 Carpenter Drive Atlanta, GA 30328 (404) 843-1030 Research MCJ-130516 04/01/85—03/31/90 Project Director(s): Alfred Steinschneider, M.D.

The primary objective of this investigation is to evaluate, in subsequent siblings, both the effectiveness of neonatal measures of respiratory instability (obtained during feeding and sleeping) and of passive muscle tone in identifying infants at risk for episodes of prolonged apnea or bradycardia. Other objectives include an indirect examination of the hypothesis that respiratory instability and muscle hypotonicity are neonatal manifestations of the same underlying abnormality and the assumption that episodes of prolonged apnea or bradycardia are surrogate for SIDS.

Resources, Education, and Care in the Home

University of Illinois at Chicago in collaboration with the Chicago Department of Health and the Visiting Nurse Association
1740 West Taylor Street
Chicago, IL 60612
(312) 996-4125

MCHIP MCJ-173851 10/01/86—09/30/89 Project Director(s): Cynthia A. Bames

This project is aimed at reducing Chicago's infant mortality rate, which is twice that of the national rate. Cause-specific postneonatal mortality rates for selected communities will be taken from State records, and an interagency health systems model will be established to make efficient use of resources and expertise. Intervention will include prenatal education and parenting skills enhancement.



Reducing Mortality and Morbidity

Perinatal Neonatal Nutrition Training Program

Indiana University School of Medicine 355 Lansing Street Indianapolis, IN 46202 (317) 274-0185 Training MCJ-000982 10/01/78—09/30/93 Project Director(s): Karyl A. Rickard, Ph.D.

This project provides intensive education in perinatal-neonatal nutrition by means of fellowships for three predoctoral dietitians and nutritionists. The objective of the program is to provide specialized learning experiences to enrich understanding of the scope and complexities of perinatal care

Intensive Course in Pediatric Nutrition

University of Iowa Hospitals Department of Pediatrics Iowa City, IA 52242 (319) 356-2832 Training
MCJ-000256
07/01/84—06/30/93
Project Director(s):
Samuel J. Fomon, M.D.

This project provides a short-term, 4-1/2-day continuing education course in pediatric nutrition to nutritionists, dietitians, physicians, and nurse practitioners.

Home Intervention with Infants with Failure to Thrive

University of Maryland School of Medicine Department of Pediatrics 660 West Redwood Street Baltimore, MD 21201 (301) 328-2185 Research MCJ-240568 04/01/88—03/31/90 Project Director(s): Maureen M. Black, Ph.D.

The primary goal of this project is to measure the impact of a home intervention program on the growth and development of infants with failure to thrive (FTT). It is hypothesized that, among families with a child with FTT, those who receive home-based, ecologically oriented interventions over 1 year will show improvements in their child's growth, health, cognitive development, and behavior, as the result of more responsive parent-infant interactions and more effective caregiving behaviors.

The Infants of Depressed Adolescent Mothers

Boston City Hospital 818 Harrison Avenue Boston, MA 02118 (617) 424-4235 Research MCJ-250559 12/01/87—02/28/90 Project Director(s): Howard C. Bauchner, M.D

The purpose of this study is to determine whether infants of depressed adolescent mothers have poorer outcomes than those of nondepressed mothers. One hundred and twenty infants born to depressed adolescent mothers will be followed prospectively from birth and assessed at 1 year. Multiple regression analysis will be used to identify whether there is an adverse effect of maternal depression on infant growth, development, and health.



Infant Health

Mississippi Postneonatal Death Impact Project

Mississippi State Department of Health P.O. Box 1700 Jackson, MS 39215-1700 (601) 960-7464

MCHIP MCJ-283809 10/01/86—09/30/89 Project Director(s):

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

This project aims to reduce infant mortality by improving the health status of at-risk families by means of increased access to health care. Home-based case management and an information and referral service hotline will be established. Infant death review conferences will provide training for professionals and estimates of the proportion of postneonatal mortality resulting from lack of access to and utilization of health care.

State Staff Grant/MCH Improvement Project

Mississippi State Department of Health Division of Perinatal Services P.O. Box 1700 Jackson, MS 39215 (601) 960-7464 MCHIP MCJ-283122 10/01/87---09/30/89 Project Director(s): Elin Ann Holgren, C.N.M., M.P.H.

This project's goal is to implement legislation which authorized the Mississippi State Department of Health to establish a regionalized system of perinatal services. Assistance will be provided to a State Perinatal Committee in developing a regionalization plan and in disseminating information on the plan to professional and consumer groups. Mechanisms for evaluating the current emergency medical system, including neonatal and maternal transport, will also be developed.

A Multidimensional Health Status Index for Infants

Rochester General Hospital Department of Pediatrics 1425 Portland Avenue Rochester, NY 14621 (716) 338-4406 Research MCJ-360571 10/01/88—09/30/90 Project Director(s): Kenneth M. McConnochie, M.D., M.S.

The purpose of this study is to develop and validate a multidimensional index of infant health status, ultimately to be based on diagnostic information routinely collected through the encounter forms used in pediatric practices. The index is based on a conceptual model that assumes multiple determinants of health and multiple risk factors in disease etiology. The multidimensional index as proposed could be used for various purposes, such as to conduct needs assessments in population groups and communities and to act as the dependent variable in evaluation and epidemiologic studies.



Reducing Mortality and Morbidity

Infant Mortality Review, Mott Haven, New York

City

New York City Department of Health BMSFP 280 Broadway Room 303 New York, NY 10007 (212) 566-5655 MCHIP MCJ-366012 10/01/88—09/30/90 Project Director(s): Karla Damus

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

Stress and Social Support in Abuse of High-Risk

Infants

University of North Carolina at Chapel Hill School of Public Health Rosenau Hall 201H Chapel Hill, NC 27514 (919) 966-2017 Research MCJ-370521 06/01/85—12/31/88 Project Director(s): Jonathan B. Kotch, M.D.

The aim of this research is to test an ecological model of child abuse and neglect in a population of infants at risk for adverse medical or developmental outcomes. The study will identify factors (in the individual, family, and social or cultural domains) which are observable at birth and which are associated with child abuse and neglect.

Prediction of Outcome of Early Intervention in

Failure to Thrive

Case Western Reserve University University Hospitals 2065 Adelbert Road Cleveland, OH 44106 (216) 459-3745 Research MCJ-390557 11/01/87—10/31/90 Project Director(s): Dennis D. Drotar, Ph.D.

This project addresses the need for controlled studies of the psychological and health outcomes of those infants with failure to thrive (FTT) who have received early intervention, in order to assess early developmental delays and family influences which mediate intervention effects. The family, the environment, and the psychological and physical health outcomes of children originally diagnosed with FTT during the first year of life will be compared to a sample of physically healthy infants who are matched by child and family characteristics.



Infant Health

Long-Term Outcomes of Very Low Birthweight Infants

Children's Hospital of Philadelphia 34th and Civic Center Boulevard Philadelphia, PA 19104 Research
Interagency Agreement with NICHD
06/15/85—09/30/89
Project Director(s):
Marie McCormock, M.D.
George Peckman, M.D.

The purpose of this study of the long-term outcomes of very low birthweight (VLBW) infants is to provide longitudinal information on outcomes of infants treated with modern intensive care in multiple settings as these children reach school age. The project will attempt to identify some of the correlates of their status at this age (especially with regard to the contribution of prenatal events) and to compare the findings among VLBW infants with those for infants born at heavier birthweights to estimate the relative risk for problems conferred by being born at low birthweight.

MCH Manpower Development Project Republic of Palau Bureau of Health Services

P.O. Box 100 Korow, PW 96940 MCHIP MCJ-753999 10/01/87—09/30/89 Project Director(s): Masao Kumangai

The goal of this project is to decrease perinatal and infant mortality in the Pepublic of Palau by improving prenatal and perinatal care services. Consultants will be recruited to analyze problems, develop technical plans, and implement training programs on the following topics: Prenatal care standards; record keeping to identify high-risk pregnancies; prenatal consultation and referral; and data collection on program activities.

Behavioral Interventior with IUGR Infants

Women and Infants Hospital of Rhode Island 101 Dudley Street Providence, RI 02905-2401 (401) 274-1100, ext. 1232 Research MCJ-440569 07/01/88—06/30/91 Project Director(s): Cynthia T. Garcia-Coll, Ph.D.

The purposes of this 3-year longitudinal intervention study are to: (1) Examine the effectiveness of a parent-infant based behavioral intervention during the neonatal period; and (2) examine the mediating effects of cultural context and risk status on the effectiveness of intervention with IUGR infants. The planned intervention is expected to affect outcomes both directly by improving caloric intake and indirectly by improving mother-infant interactions.



Fetal and Infant Reviews in South Carolina:

Understanding Our Problem

South Carolina Department of Health and Environmental Control 2600 Bull Street Columbia, SC 29201 (803) 734-4670

MCHIP MCJ-456010 10/01/88—09/30/90 Project Director(s): Cathy Melvin Efird, Ph. D.

The primary goal of this project is to bring the survival rate of South Carolina infants to the same level as their fellow U.S. infants by solving local and State health care financing systems and services problems. This will be accomplished through increased understanding of the medical, social, behavioral, health service, and environmental factors which contribute to the local, and therefore the State, infant mortality rate. Project activities include completion of the Fetal and Infant Death Review Manual and development of a technical support network for local areas to conduct death reviews.

Neonatal Nutrition Training

Medical University of South Carolina Department of Pediatrics 171 Ashley Avenue Charleston, SC 29425 (803) 792-2112 1'raining MCJ-009117 07/01/88—06/30/93 Project Director(s): William B. Pittard, III, M.D.

The purpose of this project is to train interdisciplinary neonatal nutrition specialists using a combination of short- and long-term educational programs. These programs include an annual 3-day intensive course on perinatal/neonatal nutrition, a 1-week neonatal nutrition practicum, and a 3- to 6-month neonatal nutrition clinical fellowship.

South Carolina Adolescent Reproductive Risk Reduction (3R) Project

South Carolina Department of Health and Environmental Control
Office of Health Education
2600 Bull Street
Columbia, SC 29201
(803) 734-4650

MCHIP MCJ-453702 10/01/85 --09/30/89 Project Director(s): Joanne G. Fraser, M.D.

This project intends to reduce fetal and infant mortality by delaying initiation of sexual activity, reducing the teen pregnancy rate, preventing or delaying reproductive risk behaviors among teenagers, and encouraging parent-teen communication. Students in selected rural counties will be given 30 hours of reproductive health instruction over a 2-year period. Components for training teachers and gaining school and community support are included in the project.



Infant Health

The Utah Perinatal Case Review Project

Utah Department of Health 44 Medical Drive Salt Lake City, UT 84113 (801) 533-4084 MCHIP MCJ-496013 10/01/88—09/30/90 Project Director(s): Thomas J. Wells, M.D., M.P.H.

The goal of this project is to decrease perinatal mortality statewide and in specific high perinatal mortality sites. The Utah Project will conduct perinatal case reviews in two urban and two rural/frontier sites. Factors contributing to perinatal mortality will be identified at each site and targeted for action through the State perinatal health plan, the State Title V agency, and the local health department.

Graduate Training in Parent/Child Nursing

University of Wisconsin at Madison 600 Highland Avenue Madison, WI 53792 (608) 263-5299 or 263-5292

Training
MCJ-000134
07/01/82—06/30/93
Project Director(s):
Regina Lederman, Ph.D.

This graduate training program is designed to educate nurses for leadership roles in teaching, clinical practice, administration, and consultation in maternal and newborn nursing programs. The project prepares nurses to meet the health needs of mothers and newborns at risk for perinatal complications. Emphasis in the curriculum is given to the needs of mothers and infants known to be at risk and to the study of health care systems and policies designed to meet their needs.



Alabama Newborn Hemoglobinopathy Screening

Project

Alabama Department of Public Health Bureau of Family Health Services 434 Monroe Street Montgomery, AL 36130-1701 (205) 261-5052 Genetics MCJ-011002 10/01/88—09/30/90 Project Director(s): Doris Barnette

This project seeks to expand Alabama's present Newborn Screening Program. The program objectives are to ensure that every newborn will be screened, families of children with hemoglobinopathies will receive appropriate counseling, children with clinically significant hemoglobinopathies will receive medical treatment and social support, and health care providers statewide will receive adequate training regarding the identification and management of sickle cell disease and other hemoglobinopathies.

Arkansas Newborn Sickle Cell Screening Program

Arkansas Department of Health Bureau of Public Health Programs 4815 West Markham Street Little Rock, AR 72205-3687 (501) 661-2528 Genetics MCJ-051002 10/01/88—09/30/90 Project Director(s): Deborah Bryant, M.D.

This project seeks to provide hemoglobinopathy screening to all newborns in Arkansas. Under a collaborative program involving several agencies and foundations, the primary physicians and the parents of all newborns who have a significant hemoglobinopathy or are carriers will be notified; infants will be referred for medical evaluation, treatment, and followup; and genetic counseling and DNA mapping will be provided to detect the risk of organ damage.

Hemoglobinopathy Screening in California

California Public Health Foundation P.O. Box 520 Berkeley, CA 94704-0520 (415) 540-2553 Genetics MCJ-061006 10/01/87—09/30/90 Project Director(s): George C. Cunningham. M.D.

This project proposes to add a program of hemoglobinopathy screening, education, followup, and counseling to the existing statewide newborn screening program. It will supplement available resources and will provide the following specific elements needed for comprehensive screening: Education of health care providers and the public; implementation of screening policies and procedures regarding thalassemias and other hemoglobinopathies; and development of a hemoglobinopathy registry to support long-term followup and counseling.

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A Statewide Program for Universal Newborn Screening of Sickle Cell Anemia and Related Hemoglobinopathies

Connecticut Department of Health Services
Community Health Division

150 Washington Street Hartford, CT 06106 (203) 566-5601 Genetics MCJ-091003 10/01/88—09/30/90 Project Director(s): Vijaya V. Bapat, M.D.

The goal of this project is to decrease morbidity and mortality in infants at high risk for sickle cell anemias, related hemoglobinopathies, and traits. Through a carefully arranged plan, the Maternal and Child Health Section, two university hematology and genetics clinics, the medical provider, and the State Laboratory are involved in screening newborns and establishing an individual plan for each sick infant for treatment, counseling, and followup.

Newborn Screening and Counseling Program

Howard University Center for Sickle Cell Disease 2121 Georgia Avenue, N.W. Washington, DC 20059 (202) 636-7930 Genetics MCJ-111004 10/01/88—09/30/90 Project Director(s): Roland B. Scott, M.D.

The purpose of this project is to develop and implement a comprehensive newborn screening program. The program will be designed to: (1) Expand existing services to include education, counseling, and followup testing for families of infants with abnormal hemoglobin trait; (2) assure followup and comprehensive management of infants with clinically significant hemoglobinopathies; and (3) reduce the need for repeated screening in childhood, adolescence, and adulthood.

Counseling and Education for Famili of Newborns Identified with Hemoglobinopathies

Children's Medical Services 1311 Winewood Boulevard Building 5 Room 134 Tallahassee, FL 32399-0700 (904) 488-5040 Genetics MCJ-121003 10/01/87—09/30/90 Project Director(s): Jennifer Carnes, R.N.

The goal of this project is to develop and implement a comprehensive education program for physicians, nurses, counselors, social workers, health educators, and other health care providers which will enable them to provide information to those identified as having sickle cell trait by the statewide newborn screening program. Community outreach and educational activities will also be conducted.



Illinois Project for Statewide Screening and Followup of Newborns for Hemoglobinopathies Illinois Department of Public Health 535 West Jefferson Springfield, IL 62761 (217) 782-2736

Genetics MCJ-171002 10/01/87—09/30/90 Project Director(s): Elsic S. Baukol, M.D.

The goal of this project is to enable clients with hemoglobinopathies and their families to improve their quality of life. Specifically, the project wil expand the current statewide infant screening program to include screening for hemoglobinopathies, facilitate followup services, provide parents of affected children with counseling, and increase health care provider knowledge regarding hemoglobinopathies.

Iowa Sickle Cell and Other Major Hemoglobinopathies Screening and Followup Program: Patient Tracking and Monitoring University of Iowa Hospitals and Clinics Department of Pediatrics Iowa City, IA 52242 (319) 356-4830 Genetics MCJ-191003 10/01/88—09/30/90 Project Director(s): Pedro de Alarcon, M.D. Richard P. Nelson, M.D.

This project supports the patient tracking and monitoring component of the Iowa Hemoglobinopathy Program. The four main objectives are to: (1) Develop a computer-based data management system for hemoglobinopathy screening; (2) ensure the transfer of data from the screening program to the statewide comprehensive care centers and to the regional genetic consultation service and Child Health Specialty Clinics; (3) facilitate communication between program staff and community health professionals; and (4) disseminate the data management system to other States.

Newborn Screening for Sickle Cell Disease Kentucky Department for Health Services

Cabinet for Human Resources
275 East Main Street
Frankfort, KY 40621
(502) 564-4830

Genetics MCJ-211002 10/01/88—09/30/90 Project Director(s): Patricia Nicol, M.D.

The goal of this project is to reduce infant morbidity and mortality due to sickle cell disease in Kentucky. Project activities will include developing a multilevel sickle cell education effort, establishing a system to identify and refer infants who have sickle cell disease for evaluation and treatment, and developing a coordinated system of followup and management services for patients identified with sickle () Il disease or trait.



The Louisiana Neonatal Sickle Cell Screening and Followup Project (NSCSFP)

Louisiana Department of Health and Hospitals
Genetic Diseases Program—Office of Public Health
325 Loyola Avenue
Room 611
P.O. Box 60630
New Orleans, LA 70112
(504) 568-5070

Genetics MCJ-221004 10/01/87—09/30/90 Project Director(s): Charles Myers

To reduce morbidity and mortality of infants with sickle cell disease, this project will establish a statewide system which provides both early identification of neonates with the disease and referrals to comprehensive followup services. A sickle cell task force will link agencies in order to improve care for persons with sickle cell disease. Education on sickle cell disease and trait will be provided to health care providers and to parents of affected children.

Newborn Sickle Cell Disease Screening and Followup Program

Maryland Department of Health and Mental Hygiene 201 West Preston Street Baltimore, MD 21202 (301) 225-6731

Genetics MCJ-241006 10/01/88—09/30/90 Project Director(s): Judi Greenblatt, R.N., M.P.H. Susan Panny, M.D.

The goal of this project is to ensure the provision of high quality, cost-effective, comprehensive followup health care services for newborns with sickle cell disease and their families. The project will integrate three additional components into the existing newborn screening and followup program: (1) Outreach sickle cell followup clinics; (2) an extensive educational and training campaign; and (3) a multitask centralized computer registry/data collection and retrieval system.

Screening of Newborns for Sickle Cell Disease

Trustees of Health and Hospitals of the City of Boston, Inc.
Boston Sickle Cell Center
725 Massachusetts Avenue
Boston, MA 02118
(617) 424-5727

Genetics MCJ-251006 10/01/88—09/30/90 Project Director(s): Marsha Lanes, M.S. Lillian McMahon, M.D.

The goal of this project is to establish newborn screening for sickle cell disease in Massachusetts as a mechanism to initiate intensive comprehensive care to reduce morbidity and mortality. The program will establish a system of care, treatment, and case management for infants with sickle cell disease which will include distribution of free penicillin. Additional objectives include providing education, genetic counseling, and voluntary carrier testing; and pursuing State legislation and appropriations for universal newborn screening.



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Infant Health

Mississippi Hemoglobin Screening, Diagnosis, and Treatment Project
Mississippi State Health Department
P.O. Box 1700
Jackson, MS 39215-1700
(601) 960-7619

Genetics MCJ-281003 10/01/87—09/30/90 Project Director(s): Daniel R, Bender

The purpose of this project is to reduce morbidity and mortality due to sickle cell disease and other hemoglobinopathies in Mississippi. Project objectives are to: (1) Establish a statewide program of newborn screening for hemoglobinopathies; (2) provide education and counseling to patients and families identified through the screening program; and (3) demonstrate that the system to be implemented effects significant reductions in unnecessary repeat screenings for hemoglobinopathies.

Missouri Kemoglobinopathies Newborn Screening Project

Missouri Department of Health 1730 East Elm P.O. Box 570 Jefferson City, MO 65102 (314) 751-6254 Genetics
MCJ-291003
10/01/88—09/30/90
Project Director(s):
N. Aurita Prince

The goal of this project is to reduce the morbidity and mortality associated with sickle cell disease in the early years of life. To achieve this goal, the project will identify through screening all infants born with hemoglobinopathies; develop resources to provide comprehensive services to these infants; and educate parents, health professionals, and the public about hemoglobinopathies.

New Jersey Sickle Cell Disease Project New Jersey State Department of Health Special Child Health Services CN 364 Trenton, NJ 08625-0364 (609) 292-5676 Genetics MCJ-341003 19/01/88—09/30/90 Project Director(s): Elizabeth B. Rappaport, M.D.

The goal of this initiative is to reduce morbidity and mortality in New Jersey infants and children with sickle cell disease (SCD). The primary objectives are to increase the availability of comprehensive medical and psychosocial care for infants and children with SCD; to develop a system for evaluating the effects of SCD screening, followup, and comprehensive care on the health status of infants and children with SCD; and to refer all infants identified as having SCD by 8 weeks of age to an SCD treatment center for evaluation and comprehensive care.



Inborn Errors of Metabolism—Multiple Test Procedures

State University of New York at Buffalo Department of Pediatrics 352 Acheson Hall Buffalo, NY 14214 (716) 831-2351

Training
MCJ-000435
07/01/82—06/30/89
Project Director(s):
Robert Guthrie, M.D., Ph.D.

This project aims to assist existing phenylketonuria (PKU) test centers in implementing procedures for the detection of other conditions in newborn infants. The project has resulted in the development of the first newborn screening test for sickle cell disease designed for use with the PKU blood spots.

Newborn Screening for Hemoglobinopathies

New York State Department of Health and Health Research, Inc. P.O. Box 2077 Corning Tower Albany, NY 12220 (518) 474-1689 Genetics
MCJ-361006
10/01/87—09/30/90
Project Director(s):
Kenneth A. Pass, Ph.D.

The goals of this project are to: (1) Establish within the New York State Newborn Screening Program an expanded followup system; (2) establish a mechanism whereby parents of children found to have trait conditions are uniformly notified of this finding; and (3) establish a mechanism whereby adolescents with sickle cell trait are made aware of their carrier state and provided with sensitive, nondirective counseling.

Pilot Screening for Biotinidase Deficiency in

New York State Department of Health Albany, NY 12237 (518) 473-7552 Research MCJ-360542 11/01 96—10/31/88 Project Director(s): Thomas P. Carter, Ph.D.

This investigation will utilize the New York State Newborn Screening Program to estimate the incidence of biotinidase deficiency and to determine whether it is appropriate to include biotinidase deficiency in the existing mass screening for phenylketonuria, hypothyroidism, and other metabolic disorders. A new colorimetric test for biotinidase deficiency will be applied to specimens from over 500,000 newborn infants.

Training in Human Genetics

Children's Hospital of Buffalo 219 Bryant Street Buffalo, NY 14222 (716) 878-7530 Training
MCJ-000417
07/01/84—06/30/89
Project Director(s):
Robert Guthrie, M.D., Ph.D.

The main purpose of this project is to maintain the core activities of a human genetics program for the western New York area. The program provides training, service, and research in a variety of areas of medical genetics. Training activities are aimed at training independent practitioners and researchers and increasing the knowledge of project staff.



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Infant Health

Biochemical Genetics Laboratory

Western Pennsylvania Hospital 4800 Friendship Avenue Pittsburgh, PA 15224 (412) 578-7348 Training
MCJ-009086
07/01/86---06/30/93
Project Director(s):
Edwin Naylor, Ph.D.

The purpose of this project is to establish a national screening and confirmation center for the diagnosis of rare cofactor variant forms of phenylketonuria (PKU). This center will provide routine screening of all newborns diagnosed as having either classical PKU or mild hyperphenylalaninemia. Training of postdoctoral fellows, continuing education for medical personnel, and education of the general public are also objectives of this project.

Screening Newborns for Sickle Cell Disease and Other Hemoglobinopathies

Rhode Island Department of Health Division of Family Health 75 Davis Street Providence, RI U2908 (401) 277-2312

Genetics MCJ-441003 10/01/88--09/30/90 Project Director(s): Peter R. Simon, M.D., M.P.H.

This project seeks to prevent premature death and childhood morbidity and maximize the ability of individuals with hemoglobinopathies to develop optimally by implementing a cost-effective, universal, statewide newborn screening program. In addition to screening, the program will provide comprehensive heath care services, develop multilingual patient education materials, assure access to genetic counseling services, and implement a public awareness campaign.

Followup of Identified Newborns with Hemoglobinopathies

South Carolina Department of Health and Environmental Control
Division of Children's Health
2600 Bull Street
Columbia, SC 29201
(803) 743-4610

Genetics MCJ-451004 09/30/87—09/30/90 Project Director(s): Rose W. Alford Virginia Herlong

This project has two main goals. The first is to decrease infant and early childhood morbidity and mortality among children with sickle cell disease by implementing a case management system, initiating prophylactic antibiotics before infants reach 4 months of age, arranging for specialty medical services, and assuring that these infants have a primary care source. The second goal is to identify, counsel, and make referrals for couples at risk for having a child with sickle cell disease.

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Sickle Cell Anemia: DNA Newborn Screening Followup

Baylor College of Medicine
Institute of Molecular Genetics
Houston, TX 77030

(713) 799-5820

Research MCJ-480566 04/01/88—03/31/90 Project Director(s): Edward R.B. McCabe, M.D., Ph.D.

The goal of this study is to demonstrate the applicability of DNA techniques to newborn screening for sickle cell disease. DNA genotyping will be compared with the conventional hemoglobin electrophoresis approach among the study population of all newborns with a presumptive positive screen for sickle cell disease born in Texas during the study period. It is hypothesized that the DNA method will allow a confirmatory specimen to be obtained more reliably and more rapidly than will the conventional approach, and that the earlier notification of families with affected neonates will result in improved compliance with the management of children with sickle cell disease and a better prognosis for these children.

The Texas Department of Health Newborn Screening for Sickle Hemoglobin

Texas Department of Health 1100 West 49th Street Austin, TX 78756-3199 (512) 458-7700 Genetics MCJ-481004 10/01/88—09/30/90 Project Director(s): Walter P. Peter, Jr., M.D.

Since 1983, the Texas Department of Health has conducted a newborn screening program for sickle hemoglobin. Program objectives include identifying newborns with significant hemoglobinopathies, ensuring followup medical treatment, providing counseling materials and guidelines to health care providers, and developing educational media.

Statewide/Areawide Genetic Services

Virgin Islands Department of Health St. Thomas Hospital St. Thomas, VI 00802 (809) 772-3665 Genetics
MCJ-521001
05/01/86—04/30/90
Project Director(s):
Deborah McGregor

The goal of this project is to identify, as early as possible, any genetic disorders within the Virgin Islands population. Specifically, the project will implement laboratory screening; training and education of nurses, laboratory personnel, and physicians; liaison relationships and linkages with community groups; and genetic testing and evaluation of newborns and pediatric age groups.



Infant Health

Development and Implementation,
Comprehensive Newborn Screening Program for
Sickle Cell Disease
Virginia Department of Health
Division of Maternal and Child Health
109 Governor Street
6th Floor - MCH
Richmond, VA 23219
(804) 786-7367

Genetics MCJ-511001 10/01/87—09/30/90 Project Director(s): Alice S. Linyear, M.D., M.P.H.

The goal of this project is to reduce morbidity and mortality from sickle cell diseases in infants and young children in Virginia. Project objectives are to: (1) Expand an existing, limited pilot newborn screening program; (2) conduct transition activities to add the screening to the current newborn metabolic screening tests; and (3) introduce the screening program to the professional community and public though extensive education.



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Breastfeeding 6

Alameda County Infant Feeding Project

Alameda County Health Care Services Agency 499 5th Street Oakland, CA 94607 (415) 268-2626 MCHIP MCJ-063857 10/01/86—09/30/89 Project Director(s): Janis Burger, M.P.H., R.D. Art Reingold, M.D.

This project works with low-income, minority women from areas with high infant mortality rates who give birth at a county public hospital. The project's goals are to maintain breastfeeding rates at 3 and 6 months postpartum, document significant factors influencing the decision to breastfeed in this population, and report on the correlation between infant feeding methods and the incidence of infant mortality. The first goal will involve staff training, community outreach, and comprehensive breastfeeding counseling. The last two goals will involve a study of approximately 2400 women.

Lactation Management

University of California at San Diego Department of Pediatrics H-664A San Diego, CA 92103 (619) 294-3920 Training
MCJ-009108
10/01/87—09/30/89
Project Director(s):
Suzanne Dixon, M.D.

The ultimate goal of this project is to develop and maintain the expertise of State MCH staff in the management and support of lactation and breastfeeding. The program prepares multidisciplinary teams of MCH professionals to serve as specialists in this area. The program also assists with designing, reviewing, and critiquing present and future breastfeeding promotion projects and proposals.

Continuing Education in Infant Feeding and Growth: U.S.-Related Pacific Islands

University of Hawaii School of Public Health Biomedical Building C105M 1960 East-West Road Honolulu, HI 96822 (808) 948-8832 Training MCJ-009106 10/01/87—09/30/90 Project Director(s): Gigliola Baruffi, M.D., M.P.H.

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The purpose of this project is to offer a continuing education program on human lactation, infant feeding, and growth monitoring to health personnel in the Pacific Islands. It is part of a broad effort to increase breastfeeding incidence and duration and to monitor infant and child growth.

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Breastfeeding

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Indiana's Breastfeeding Promotion Program

Indiana State Board of Health 1330 West Michigan Street P.O. Box 1964 Indianapolis, IN 46206-1964 (317) 633-8518 MCHIP MCJ-183822 10/01/88—09/30/89 Project Director(s): Chery Smith, M.P.H., R.D.

This project seeks to increase the percentage of infants who are breastfed. Activities include developing and implementing industry policies that support working, breastfeeding women; conducting a public media campaign and establishing a toll-free hotline; counseling and educating low-income and minority women through WIC and MCH programs; and providing professional education.

Model Approach to Development of Breastfeeding as a Subspecialty Integrated with Private Sector Maternal Health Care

Renewable Technologies, Inc. (RTI) Community Nutrition Division 630 Utah P.O. Box 4113 Butte, MT 59702 (406) 782-2386 MCHIP MCJ-303660 10/01/85—12/30/88 Project Director(s): Rita J. Bradley, R.D.

The goal of this project is to establish a model program of breastfeeding services which provides a permanent, self-supporting means of increasing the occurrence and duration of breastfeeding. This is being accomplished by integrating the services of health care professionals with human lactation/breastfeeding subspecializations into the private sector maternal and pediatric care systems and by pursuing options for payment for these services. Other activities include a comparative study based on an infant feeding survey and breastfeeding promotion coordinated with the State MCH Bureau.

Study Group on Human Lactation and Breastfeeding

University of Rochester Medical Center Department of Pediatrics 601 Elmwood Avenue Box 777 Rochester, NY 14642 (716) 275-0088 Training
MCJ-009104
10/01/87—09/30/90
Project Director(s):
Ruth Lawrence, M.D.

This project is designed to support OMCH efforts in assuring that reliable information on matters related to human lactation and breastfeeding is readily available to professionals both in State Title V Programs and in the community at large. A study group will be established to serve as the national focus for technical assistance and consultation related to the identification and quantification of emerging issues with potential impact on human lactation and breastfeeding, the identification and evaluation of unusual maternal and infant problems associated with breastfeeding, and the study and evaluation of educational strategies and resources.



Infant Health

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Breastfeeding Promotion in a Low-Income Urban Population

The Ohio State University Research Foundation 1314 Kinnear Road Columbus, OH 43210 (614) 293-8034

MCHIP MCJ-393724 10/01/85—09/30/89 Project Director(s): Lindsey K. Grossman, M.D.

The goals of this project are to increase the proportion of low-income women who decide to breastfeed and to assist them in nursing successfully and for a prolonged period. The project evaluates data on demographic and other factors associated with the decision to breastfeed within this population, develops and tests interventions to increase breastfeeding, and designs educational materials to increase the proportion of low-income women who decide to breastfeed.

A Statewide Action Plan to Promote Breastfeeding

South Carolina Department of Health and Environmental Control
Division of Children's Health
2600 Bull Street
Columbia, SC 29201
(803) 734-4610

MCH1P MCJ-453844 10/01/86—09/20/89 Project Director(s): Robert H. Buchanan, Jr.

The purpose of this project is to increase the number of low-income and black women in South Carolina who breastfeed. To reach this goal, the project will convene a statewide advisory council, develop promotional materials, encourage active support of breastfeeding from physicians providing prenatal care, evaluate practices in hospitals that influence breastfeeding, provide inservice training for nurses, and develop support groups (primarily for WIC clients) in each county.

Tennessee Breastfeeding Promotion Project

Tennessee Department of Health and Environment 100 Ninth Avenue North Nashville, TN 37219-5405 (615) 741-0265

MCHIP MCJ-473813 10/01/86—-09/30/89 Project Director(s): Minda Lazarov, M.S., R.D.

This is a comprehensive breastfeeding promotion program involving both the public and private sectors of the medical community. The activities and materials provided in the Tennessee Department of Health and Environment's *Breastfeeding Promotion: A Handbook for Public Health Professionals* will be employed to increase the incidence and duration of breastfeeding among low-income women in two rural counties and one urban county with a large black population. Individual and group counseling, networking with the private sector, peer counseling, and a community awareness campaign will be implemented.



Breastfeeding 43

Acculturation, Psychosocial lictors, and Breastfeeding

University of Texas Medical Branch at Galveston Department of Pediatrics Route C-51 Galveston, TX 77550-2774 (409) 761-1139

Research
MCJ-480555
04/01/87—03/31/90
Project Director(s):
David Keith Rassin, Ph.D.

The long-term objectives of this project are to increase the incidence and maintenance of breastfeeding in a United States-Mexico border population, to identify the reasons mothers choose to breastfeed, to determine factors important to the maintenance of breastfeeding, and to study infant health and nutritional status as a function of breastfeeding. A number of psychosocial variables will be measured to assess their importance in the initiation of breastfeeding. These data will be analyzed within ethnic groups by degree of acculturation.

Breastfeeding Promotion Project

Washington Department of Social and Health Services Bureau of Parent-Child Health Services Mail Stop LC-16 Olympia, WA 98504 (206) 753-7353 MCHIP MCJ-533754 10/01/85—03/31/89 Project Director(s): Ilene Kasten, M.P.H., R.D.

This project has three major goals: (1) To provide breastfeeding education to professionals across Washington State; (2) to develop culturally relevant educational materials about breastfeeding for use statewide; and (3) to evaluate a model of service delivery for increasing breastfeeding among low-income women. A videotape for health professionals, a triage tool, and a series of fact sheets in Southeast Asian languages have been produced. Training and consultation have been provided to community clinics.



Interaction and Support: Mothers and Deaf

Gallaudet Research Institute 800 Florida Avenue, N.E. Washington, DC 20002

(202) 651-5206

Research MCJ-110563 10/01/87—09/30/90 Project Director(s): Kathryn Meadow-Orlans, Ph.D.

This research investigates the impact of deafness on the interaction of deaf infants and their hearing mothers in the first year of the child's life. The study focuses on the relationships between the face-to-face interaction of these mothers and infants and the infants' motivation to engage the physical environment, their ability to cope with interactive stress, and their development of communicative competence.

Promotion of Healthy Behaviors

Saint Joseph's Medical Center Women's and Children's Services 811 East Madison P.O. Box 1935 South Bend, IN 46634-1935 (219) 237-6806 MCHIP MCJ-183342 10/01/87—09/30/90 Project Director(s): Joette Wells

This parent education project aims to teach to parents or caregivers of children under 3 years of age ways to reduce stress, improve problem-solving skills, and develop stronger parent-child relationships. Seminars, group sessions, a newsletter, and materials directed at low-income parents and parents of varying cultural backgrounds are provided.

The Nature, Origins, and Consequences of Concepts of Parenting

Iowa State University
Department of Sociology and Anthropology
107 East Hall
Ames, IA 50011
(515) 294-9894

Research MCJ-190572 10/01/88—09/30/90 Project Director(s): Ronald L. Simmons, Ph.D.

This study aims to: (1) Investigate the nature of conceptions of parenting, identifying various dimensions and components; (2) analyze the manner in which various dimensions of conceptions of parenting influence parental behaviors, especially parental behaviors that have been shown to affect the physical and mental health of children; and (3) identify the origins or determinants of variations in conceptions of parenting. The study sample will consist of 200 families of seventh graders who are participating in a panel study supported by the National Institute on Drug Abuse.



Parenting

Education and Support Promotion Project

Health Start, Inc. 640 Jackson Street St. Paul, MN 55101 (612) 221-3419 MCHIP MCJ-273544 10/01/87—09/30/90 Project Director(s): Lucy Kapp

This project seeks to reduce infant morbidity and the incidence of child abuse, neglect, and failure to thrive by enhancing the parenting skills of high-risk mothers through intensive education, support, and related intervention services. This will involve the services of physicians and an interdisciplinary team including a social worker, health educator, nutritionist, pediatric nurse practitioner, public health nurse, and parent educator.

Determinants of Adverse Outcome Among Toddiers of Adolescent Mothers

Research Foundation for Mental Hygiene, Inc. New York State Psychiatric Institute 722 West 168th Street Box 10 New York, NY 10032 (212) 960-2298 Research MCJ-360540 11/01/86—10/31/89 Project Director(s): Gail Wasserman, Ph.D.

This longitudinal study compares child outcome among 100 black and Hispanic adolescent mothers and their toddlers with child outcome among a group of matched older women and toddlers. The project investigates environmental factors that influence child outcome, including caretaking situations, stressful events, coping skills, social support, mother-infant interaction, and grandmothers' involvement.

Study of Home Visitation for Mothers and Children

University of Rochester Medical Center Department of Pediatrics 601 Elmwood Avenue Rochester, NY 14642 (716) 275-3738 Research MCJ-360579 09/30/88—08/31/93 Project Director(s): David L. Olds, Ph.D.

The goal of this study is to determine the effectiveness of prenatal and postpartum nurse home visitation services in enhancing the life course development, social resources, and caregiving skills of parents living in a high-risk urban environment, and to ascertain whether these services can prevent a wide range of health and developmental problems in their children. The study group will consist of 1468 unwed, pregnant women bearing their first child.



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Infant Health

MOMS (Mothers Offering Mothers Support)

Surry County Health Department 118 Hamby Road P.O. Box 1062 Dobson, NC 27017 (919) 374-2131 MCHIP MCJ-373713 10/01/88—09/30/91 Project Director(s): J. Dale Simmons, M.D.

The purpose of the MOMS Project is to provide guidance and a role model for teen parents in order to ensure a better future for their children. Project goals include improving the perinatal outcome of participating women, improving parenting skills, promoting positive family relationships, and improving the mother's self-esteem.

South Carolina Resource Mothers Project

South Carolina Department of Health and Environmental Control
Division of Maternal and Child Health
2600 Bull Street
Celumbia, SC 29201
(803) 734-4640

MCHIP MCJ-453665 08/01/85--07/31/89 Project Director(s): Sara E. Woolbert, M.S.N., C.N.M.

The goal of this project is to redue the morbidity and mortality rates among ments born to primigravida adolescents and to improve the parenting skills of these adolescents. The Resource Mothers Project utilizes paraprofessional women to provide social support to supplement and reinforce prenatal and infant clinical services and to assist adolescents with problems related to pregnancy, childbirth, infant care, and parenting.

Listening Partners: Psychosocial Competence and Prevention

University of Vermont Burlington, VT 05405 (802) 656-2680 Research MCJ-500541 10/01/86—09/30/89 Project Director(s): Lynn A. Bond, Ph.D.

The main goal of this study is to evaluate the effectiveness of an intervention program in promoting the intellectual and ethical development of rural, isolated, impoverished mothers with children under 6 years of age. The expectation is that the mother's intellectual and ethical development can be promoted by d'ogue with peers and that this will in turn promote changes in the mother's conceptualizations regarding parenting and parent-child relationships, and in the mother's actual childrening practices.



Parenting

Mothering in Adolescence: Factors Related to

Infant Security
University of Washington
Child Development and Mental Retardation Center
Seattle, WA 98195
(206) 543-9200

Research MCJ-530535 04/01/86 03/31/89 Project Director(s): Susan J. Sieker, Ph.D.

This project studies adolescent mothers from a semirural area in order to understand the determinants of individual differences in the attachment security of infants within this high-risk population. It will examine a set of psychosocial and environmental factors presumed to incluence the quality of mother-infant interaction and the developing attachment relationship.



Infant Health

Child Health

Primary Care/Preventive Health Services
Child Care
Emergency Medical Services
Lead Poisoning Prevention
Violence/Injury Prevention
Grief and Hospice Care



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Primary Care/Preventive Health Services

Nursing Leadership in Pediatric Primary Care

University of California at San Francisco School of Nursing N 411 Y San Francisco, CA 94143 (415) 476-4697 Training MCJ-000935 07/01/82—06/30/93 Project Director(s): Barbara Durand, Ed.D.

In the development of a specialty track, entitled Clinical Nurse Specialist in Pediatric Primary Care, this project will implement a curriculum focused on health maintenance, health promotion, and disease prevention. The project includes a component on chronic illness and disability; teaches students case management skills; incorporates theory, clinical, and leadership components from Title V and other MCH programs; and prepares students for participation in interdisciplinary planning and delivery of services.

Training in the Behavioral/Developmental Aspects of Pediatric Health

University of California at San Francisco 400 Parnassus Avenue Room A-203 San Francisco, CA 94143 (415) 476-4575 Training MCJ-002001 09/01/65—06/30/91 Project Director(s): W. Thomas Boyce

This project improves children's health by including in their ongoing care the prevention and treatment of behavioral and developmental complications which arise in the course of normal growth, illness, and disability. Through fellowship training, pediatricians will be equipped to provide leadership in the promotion, dissemination, study, and integration of behavioral and developmental pediatrics. The project also trains pediatric residents, nurses, and medical students, and proposes to provide fellowship training for postdoctoral nurses and psychologists at a future date.

Behavioral Pediatrics Training

Yale University School of Medicine Department of Pediatrics 333 Cedar Street New Haven, CT 06510-8064 (203) 785-2475 Training MCJ-009087 09/01/86—06/30/91 Project Director(s): John Leventhal, M.D.

This project trains pediatricians to become leaders in the practice of the "new pediatrics," in which pediatricians incorporate into their existing base of diagnostic and treatment skills in organic pediatric disease the ability to work with issues involving child development and behavior community child care agencies, and child care policy.



Improvement of Children's Health Care in Pediatric Practice

American Academy of Pediatrics 141 Northwest Point Boulevard P.O. Box 927 Elk Grove Village, IL 60009-0927 (312) 981-7633 MCHIP MCJ-173400 10/01/87—09/30/90 Project Director(s): Gretchen V. Fleming, Ph.D.

The ultimate goal of this project is to improve children's health care in primary practice through information feedback from project activities, which will enable physicians to alter their practices when indicated. A national network of primary care pediatricians who cooperate in studies of their own choice to enhance the knowledge base on important child health issues will be developed and maintained. Study results will be disseminated to network members so that the may use this information to improve their delivery of care.

Behavioral Pediatrics Training

Indiana University Foundation 702 Barnhill Room A568 Indianapolis, IN 46202 (317) 274-7819 Training MCJ-009090 09/01/86—06/30/91 Project Director(s): Morris Green, M.D.

This project seeks to enhance the capacities of both general and subspecialty pediatricians. Specifically, the program will equip pediatricians to engage successfully in opportunities for prevention and health promotion that are available during pediatric visits by both healthy and ill children; to provide counseling regarding child development and behavior; to promote optimal parent-child interactions; and to help children and porents adapt to and cope with anticipated and unanticipated life events.

Healthy Families and Young Children

Kansas Department of Health and Environment Landon State Office Building 10th Floor 900 Southwest Jackson Topeka, KS 66612-1290 (913) 296-1202 MCHIP MCJ-203817 10/01/88—09/30/91 Project Director(s): Janice C. Dunwell, R.N., Ed.D.

This project will use the home visitor concept as a method of improving the health of young children. Trained lay visitors, supervised by registered nurses, will provide in-home family support services and link families with available community resources. Baseline data on immunization compliance levels, accidental deaths, and child abuse and neglect will be compared with quarterly statistics over the 3-year grant cycle to determine whether health status improvement objectives are met.



52 Child Health

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Behavioral Pediatrics Training Program

University of Maryland at Baltimore 10 Pine Street Room 3-34 Baltimore, MD 21201 (301) 328-7404 Training
MCJ-009093
10/01/86—06/30/91
Project Director(s):
Murray Kappelman, M.D.

This behavioral pediatrics fellowship program has as its goal the provision of cognitive knowledge, interpersonal insights, clinical skills, and administrative and teaching skills. It also focuses on skills in research planning, initiation, methodology, and evaluation in order to enable each graduate to assume an academic position in the field.

Behavioral Pediatrics Training

Trustees of Health and Hospitals of the City of Boston, Inc.
Boston City Hospital
818 Harrison Avenue
Boston, MA 02118
(617) 424-4235

Training MCJ-009094 10/01/86—06/30/91 Project Director(s): Barry Zuckerman, M.D.

This project expands an academic program designed to train fellows and faculty to be expert clinicians, teachers, and researchers in behavioral pediatrics. The resources provided by this grant have facilitated the improvement and expansion of all aspects of the behavioral pediatric program.

Behavioral Pediatrics Training

University of Massachusetts Medical School 55 Lake Avenue North Worcester, MA 01605 (617) 856-3028

Training
MCJ-009092
10/01/86—06/30/91
Project Director(s):
Jack Shonkoff, M.D.

This project is intended to further develop, refine, and implement a comprehensive, multidimensional training program in behavioral and developmental pediatrics at the fellowship, residency, and medical school levels at the University of Massachusetts Medical Center.



Anthropomorphic Standards for Evaluation of Growth and Nutritional Status

University of Michigan
Center for Human Growth and Development
300 North Ingalls
Ann Arbor, MI 48109
(313) 764-8577

Research MCJ-260560 10/01/87—09/30/89 Project Director(s): Roberto A. Frisancho, Ph.D.

This project establishes a set of new anthrop morphic standards that will be effective in distinguishing components of over- and under-weightness, thus enabling health professionals to accurately determine the nutritional status of children. These standards will give information on height, weight, skinfold thickness, body circumference, and estimates of body muscle, and will permit evaluations of growth and of calorie and protein reserves. The study will be based on a sample from the National Health and Nutrition Examination Surveys (NHANES) I and II.

Behavioral Pediatrics Training

Montefiore Medical Center 111 East 210th Street Bronx, NY 10467 (212) 920-6606 Training
MCJ-009096
10/01/86—06/30/91
Project Director(s):
Esther Wender, M.D.

This project expards and refines an existing behavioral pediatrics program whose primary goal is to produce future leaders capable of developing and sustaining behavioral pediatrics programs within academic pediatrics. A secondary goal is to develop and implement a quality curriculum in behavioral pediatrics that is thoroughly integrated into the general pediatric training program for pediatric interns, residents, and medical students.

Outcome Evaluation of a Pediatric Health Care Model

Medical and Health Research Association of New York City, Inc. New York, NY 10013 (212) 393-1310 Research MCJ-360539 01/01/87—12/31/90 Project Director(s): Jack Elinson, Ph.D.

This investigation tests a model of comprehensive pediatric health care provision in a team setting for low-income, high-risk patients. The research focuses on low birthweight and on adolescent pregnancy and parenthood, which are identifiable sociomedical factors for low-income populations. This model will be tested in five pediatric resource centers in order to establish its effectiveness relative to other delivery systems in the communities.



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Improving the Health of Migrant Mothers and Children

University of North Carolina at Chapel Hill School of Public Health Department of Maternal and Child Health CB 7400 Rosenau Hall Chapel Hill, NC 27599 (919) 966-5974

MCHIP MCJ-373415 10/01/84 —02/28/89 Project Director(s): Elizabeth Watkins, D.Sc

This project aims to improve the health and nutrition status of migrant farmworker women and their children under 5 years of age. Project objectives include: Assessing the health and nutritional status of pregnant women and children and implementing interventions to address identified health problems; studying the influence of the physical environment, lack of resources, and barriers to obtaining care on health status; implementing a comprehensive system of care, linking resources in North Carolina and Florida; demonstrating the effectiveness of lay health advisors; and developing educational materials.

Behavioral Pediatrics Fellowship Training

Case Western Reserve University 2074 Abington Road Cleveland, OH 44106 (216) 344-3753 Training MCJ-009088 09/01/86—06/30/91 Project Director(s): Betsy Lozoff, M.D.

The long-range goal of this project is to improve the behavioral aspects of general and subspecialty pediatric care by training academic leaders in behavioral pediatrics. The immediate goal of the program is to prepare fellows for careers of academic leadership in clinical care, teaching, and research in behavioral pediatrics.

Preventing Baby Bottle Tooth Decay in WIC and MCH Project Populations

Ohio Department of Health Division of Dental Health 246 High Street P.O. Pox 118 Columbus, OH 43266-0118 (614) 466-3263 MCHIP MCJ-393208 10/01/87—09/30/90 Project Director(s): James F. Quilty, Jr., M.D.

In order to reduce baby bottle tooth decay (BBTD) among children served by WIC and MCH programs in Ohio, this project plans activities which will estat: ish the baseline prevalence of BBTD, identify children at risk, and increase the percentage of caregivers who are aware of BBTD prevention methods. Activities will include the development of education modules and onsite training of WIC and MCH staff.



Improved Compliance with Well-Child Care:

El Nino Sano Project

La Clinica del Carino Family Health Care Center 2690 May Street P.O. Box 800 Hood River, OR 97031 (503) 386-6380 MCHIP MCJ-413816 10/01/88—09/30/91 . roject Director(s): Colin S. Wood

This project seeks to address the disproportionately high incidence of preventable and treatable diseases and conditions among the migrant and seasonal farmworker (MSFW) child population by proving to MSFW parents that well-child care and related preventive services are necessary. The main component of the program involves conducting 100 well-child care field clinics in area farm labor camps over a 3-vear period.

Healthy Children Project

Western Pennsylvania Caring Foundation, Inc. 1 Smithfield Street
Pittsburgh, PA 15222
(412) 255-8033

MCHIP MCJ-423535 10/01/87—9/30/90 Project Director(s): Dolores S. Wilden

This project seeks to demonstrate the effectiveness of an innovative financing mechanism and a tested nealth education program in improving the health status of the target population. Children from 220 families have been provided with Blue Cross/Blue Shield primary health care benefits. In addition, parents of one-half of the study population will be offered health education classes. Baseline data on health status and health care utilization patterns obtained from parent interviews will be compared with similar data collected 1 year after the child's enrollment.

Church, Home, School, Health Promotion in Rural Black Communities

South Carolina Department of Health and Environmental Control
Office of Health Education
2600 Bull Street
Columbia, SC 29201
(803) 734-4650

MCHIP MCJ-453712 10/01/88—09/30/91 Project Director(s): J.G. Fraser, M.D.

The goal of this project is to improve the health status of black children and youth in three rural South Carolina counties. Specifically, the project will work to: (1) Increase the percentage of children, youth, parents, and teachers practicing healthy behaviors; (2) increase parent-child communication about health concerns; and (3) increase the percentage of school-age children and youth with an identified "medical home." The project uses a combination of proven interventions, including health education and promotion projects based at the worksite, school, and church.



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Child Hcalth

Tennessee Medical Home

Tennessee Department of Health and Environment 100 Ninth Avenue North Nashville, TN 37219-5405 (615) 741-7353

MCHIP MCJ-473747 10/01/85—09/30/89 Project Director(s): Florence B. Roberts, R.N., Ph.D.

This project addresses the problem of the fragmentation of care for low-income children by developing cooperative arrangements between the public and private sectors of the health care system in Bradley County, Tennessee. Participating physicians provide medical services to the children in the study, whose ages range from birth to 24 months. Public health nurses provide parent education and support, along with preventive health checkups, immunizations, and home visits.

Amelioration of Health Problems of Children with Parents with Mental Retardation

Wisconsin Department of Health and Social Services Wisconsin Council on Developmental Disabilities P. O. Box 7851 Madison, WI 53707-7851 (608) 266-7826

MCHIP MCJ-553500 10/01/87—09/30/90 Project Director(s): Jayn Wittenmyer

This project attempts to improve the health status of children in families in which one or both parents have mental retardation by reducing the risks associated with lack of immunization, poor nutrition, undiagnosed medical or developmental problems, injuries, and inadequate early stimulation. Efforts will include both direct services (such as immunization, screening, and home care programs) and a consultation and technical assistance program aimed at improving the accessibility of the service delivery system for these children.



Child Care 9

California Child Health in Day Care San Diego State University Foundation 530C Campanile Drive San Diego, CA 92182 (619) 540-2109 MCHIP MCJ-063710 10/01/88—09/30/91 Project Director(s): Betty Z. Bassoff Carla K. Davis

This project seeks to demonstrate an improved data reporting system. Project objectives include: Collecting baseline data not currently available on the incidence and prevalence of selected infectious diseases and injuries in day care settings; implementing a system for organizing the training of child care providers in preventive health practices at the local level; developing a way to provide ongoing consultation and updated information to trainers and providers; and producing a reduction in the incidence and prevalence of infectious diseases and injuries as a result of widespread provider training.

Promoting Health Care to Infants and Toddlers in Day Care

Connecticut State Department of Health Services Maternal and Child Health Section 150 Washington Street Hartford, CT 06106 (203) 566-5601 MCHIP MCJ-093741 09/01/85—08/31/89 Project Director(s): Vijaya Bapat, M.D.

The goals of this project are to examine the total health care of children under the age of 3 years in group settings and to develop a model program that will enhance the quality of health care for infants and toddlers in day care settings. At 12 selected sites, the project will develop: (1) A model for the care of infants and toddlers; (2) a system of communication among child care providers, health care providers, and parents; and (3) a system for data collection on health risks of infants and toddlers in day care.

Development of National Health and Safety Performance Standards in Out-of-Home Child Care Programs

American Public Health Association/American Academy of Pediatrics c/o American Public Health Association 1015 15th Street, N.W. Washington, DC 20005 (202) 789-5627

MCHIP MCJ-113001 07/01/87—06/30/90 Project Director(s): Debra Hawks, M.P.H.

This project seeks to develop a comprehensive set of performance standards for health, safety, nutrition, and sanitation in out-of-home care. The project will conduct a national survey of existing State regulations related to child day care and will identify exemplary child care programs worthy of replication. The proposed performance standards will be widely distributed for critical review by child care providers, consumers, health professionals, and additional technical reviewers.



Child Care

Health Promotion in a Group Child Care Setting

Georgia State University School of Nursing Department of Parent/Child Nursing University Plaza Atlanta, GA 30303 (404) 651-3059 MCHIP MCJ-133711 10/01/88—09/30/91 Project Directors: Sherry Gaines, Ph.D., R.N.

The focus of this project is the provision of comprehensive health care services to a culturally diverse group of children enrolled in a child development center housed on an urban university campus. A nursing clinic will be established in the child development center. Project objectives include increasing the number of women who breastfeed; promoting dental health; decreasing the transmission of infectious diseases; decreasing the number of injuries; increasing the child care providers' awareness of cultural issues; and detecting developmental, nutritional, hearing, and vision deficiencies as well as inappropriate parenting.

Family Day Care Health Project

Massachusetts Department of Public Health Division of Family Health Services 150 Tremont Street 3rd Floor Boston, MA 02111 (617) 727-0944 MCHIP MCJ-253726 10/01/85—09/30/89 Project Director(s): Abby Shapiro Kendrick Katherine P. Messenger

This project's goal is to create healthy and safe child care environments for children under 6 years of age who are served in family day care (FDC) homes in central Massachusetts. Specific objectives include the monitoring of health status among children served in FDC homes, an investigation of the impact of health and safety interventions in reducing risks in FDC homes, the provision of training and technical assistance to FDC providers and related personnel, and the development of a statewide system to address health needs and risks in FDC homes.

Reduction in Transmission of Infectious Disease in Child Care Settings

University of North Carolina at Chapel Hill School of Public Health
Department of Maternal and Child Health
CB 7400
Rosenau Hall
Chapel Hill, NC 27599
(919) 966-5981

MCHIP MCJ-373111 10/01/87—09/30/90 Project Director(s): Jonathan B. Kotch, M.D., M.P.H.

The goal of this project is to reduce the amount of respiratory illness and diarrheal disease transmission in day care homes and centers. The project will: (1) Implement both classroom and onsite training methodologies to improve hygienic practices, health and safety policies, and behaviors in both day care centers (DCC's) and family day care homes (FDCHs); and (2) collect data to demonstrate improved environmental sanitation and child health status in DCCs and FDCHs participating in the training project.



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Child Health

Otitis Media in Day Care: Effects on Language/Attention

Pennsylvania State University
Department of Individual and Family Studies
S-110 Henderson Human Development Building
University Park, PA 16802
(814) 865-1447

Research MCJ-420565 03/01/88—C2/28/90 Project Director(s): Lynne Feagans, Ph.D.

This study is designed to determine whether there is a causal relationship between citits media, observed in a dry care setting, and developmental delays in language and attention. The study subjects will be drawn from two Pennsylvania day care centers, and a prospective, longitudinal study design without a control group will be used.

Milwaukee Infant/Toddler Day Care Health Service Centers

Wisconsin Department of Health and Social Services Bureau of Community Health and Prevention 1 West Wilson P.O. Box 309 Madison, WI 53701 (608) 267-9069 MCHIP MCJ-553420 10/01/87—09/30/90 Project Director(s): Susan Bulgrin, R.N., M.S., C.P.N.P.

The goal of this project is to improve the health and safety of the children of adolescent parents in alternative care settings. Direct health care services will be provided and will include health screenings and assessment, illness management and followup, identification and evaluation of special needs children, health education, day care provider staff development, and parent education.



Child Care

Demonstration Projects for Pediatric EMS Systems Components

University of South Alabama College of Medicine Division of Pediatric Surgery 2451 Fillingim Street Mobile, AL 36617 (205) 471-7298 or 471-7393 EMSC MCH-014001 02/01/86—01/31/89 Project Director(s): Lynn Davidson, M.D.

This project consists of seven subprojects which address issues in emergency medical services for children. Activities include educating the primary caretakers of infants and children about EMSC services; distributing a paramedic education pediatric emergencies newsletter; providing continuing education to physicians and nurses; comparing the efficacy of ground versus air transport; defining the degree of psychological impairment caused by head injury; identifying the rehabilitation facilities available locally, regionally, and nationally; and increasing compliance with seat belt/child restraint legislation.

Demonstration Grants for Projects of Emergency Medical Services for Children

University of Arkansas for Medical Sciences Arkansas Children's Hospital 800 Marshall Street Little Rock, AR 72202 (501) 370-4389 EMSC MCH-054001 10/01/87—09/30/89 Project Director(s): Debra Fisher, M.D.

This project seeks to improve the standards of and increase the levels of knowledge about emergency medical services for children. Activities include: A travelling 3-day seminar for EMSC and other hospital and critical care personnel; a statewide public education project on cardiopulmonary resuscitation (conducted in conjunction with the American Red Cross) and EMSC services; the development of EMSC standards; and research on the effectiveness of other EMSC projects in promoting adoption of effective methods for improving EMSC.



A Comprehensive Approach to Emergency Medical Services for Children in Rural and Urban Settings

Harbor-UCLA Medical Center
Department of Emergency Medicine and Pediatrics
1000 West Carson Street
Suite S
Torrance, CA 90509
(213) 328-0720

EMSC MCH-064001 02/01/86—05/31/89 Project Director(s): James S. Seidel, M.D., Ph.D.

This project works with a variety of local organizations in order to collect and analyze data on pediatric emergency medical services systems. An injury severity index which can be used to predict outcomes and to determine how specialized care would affect outcomes will be developed, and the cost of EMSC care will be calculated. These data will be used as the basis for proposing a rural EMSC system for communities with a variety of EMSC resources.

Emergency Medical Services for Children - Focus on the Neurologically Impaired Child

George Washington Univer: ity
Children's Hospital National Medical Center
Trauma Center
111 Michigan Avenue, N.W.
Washington, DC 20010
(202) 745-5188

EMSC MCH-114001 10/01/87—09/30/89 Project Director(s): Martin R. Eichelberger, M.D.

This project focuses on children who have neurological impairments which resulted from traumatic injuries or critical illnesses. The project developed a needs assessment of the tri-State area (the District of Columbia, Maryland, and Virginia) and conducted longitudinal assessments of 584 minority, neurologically impaired children ages birth to 14 years. Other activities include preventive education for lay people and EMSC education for nurses and physicians and other health professionals

Emergency Medical Services Grant for Children

University of Florida College of Medicine University Hospital of Jacksonville 655 West Lighth Street Jacksonville, FL 32209 (904) 392-6874 EMSC MCH-124001 10/01/87—09/30/89 roject Director(s): Joseph J. Tepas, M.D.

This project evaluates emergency medical services for children by coordinating the clinical, research, and educational efforts of three major components of pediatric emergency care: Pediatric critical care medicine, pediatric emergency medicine, and pediatric trauma care. A comprehensive combined data base with information on all aspects of pediatric emergency care will be developed, and an assessment of physiologic and anatomic indices of measurement during prehospital, hospital, and post-discharge phases of care will be produced.



Child Health

Emergency Medical Services for Children

Hawaii State Department of Health Emergency Medical Services 3627 Kilauea Avenue Room 102 Honolulu, HI 96816 (808) 735-5267 EMSC MCH-154001 10/01/87—09/30/89 Project Director(s): Do. na Maiava Calvin Sia, M.D.

The goal of this project is to reduce the consequences of critical illness and injury in the pediatric population. The project will develop the following: A quality assurance system for a vertically integrated EMSC program; a competency-based curriculum for training nurses in pediatric emergency care; skills, drugs, and equipment standards; epidemiological studies of critical illness and injury in Hawaii; a system for identification of special needs of handicapping conditions; a rehabilitation plan for the State; an education and training program for all levels of pediatric emergency care; a preschool injury prevention program; and a curriculum for an emergency medical system for Micronesia.

Emergency Medical Services for Children

Maine Emergency Medical Services Medical Care Development 11 Parkwood Drive Augusta, ME 04330 (207) 622-7566 EMSC MCH-234001 10/1/87—09/30/89 Project Director(s): Charles Danielson, M.D.

This project develops and evaluates a rural EMSC demonstration program an provides assistance to other rural States in adopting the successful aspects of the program. The focus of the project is the development of a modular training program on the care of pediatric emergencies which can be presented in appropriate segments to all levels of prehospital and emergency room personnel.

Organization for Comprehensive Emergency Medical Services for Children in Maryland

University of Maryland at Baltimore Maryland Institute for EMS Systems 22 South Greene Street Baltimore, MD 21201 (301) 328-3931 EMSC MCH-244001 10/01/87—09/30/89 Project Director(s): R. Adams Cowley, M.D.

This project expands a system of emergency medical services for children with life threatening illnesses and injuries in Maryland. Activities include conducting studies of the epidemiology and demographics of trauma and critical illness; developing standards for patient triage; and refining an advanced pediatric life support course.

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Improvement of Emergency Medical Services for

Children Demonstration Program
New York State Department of Health
Emergency Medical Services
74 State Street
Albany, NY 12237
(518) 474-2219

ENASC MCH-364001 02/01/86—01/31/89 Project Director(s): Robert J. Huszar, M.D.

This project establishes a comprehensive program of emergency medical services for children. Activities include developing standards for urban and rural hospitals, providing training programs for emergency medical technicians and parents, conducting an ambulance equipment needs assessment, developing triage and treatment protocols, providing a hotline for use by health professionals, and developing transport systems.

Emergency Medical Services for Children in Oregon

Oregon State Health Division EMS Division P.O. Box 231 Portland, OR 97207 (503) 229-5804 EMSC MCH-414001 02/01/86—05/31/89 Project Director(s): Toni Bachulis, R.N., M.S.

This project develops a regionalized, comprehensive EMS system for children. Activities include development of head injury treatment algorithms, a paramedic pediatric and lay child care provider curriculum, videotapes for physicians on the management of head injury, a reh, bilitation evaluation protocol, and educational materials which can be used by EMS field providers for community education.

Emergency Medical Services for Children

Washington State Department of Social and Health Services 1914 North 34th Street Suite 3405 Seattle, WA 98103 (206) 632-0066 MCH-534001 10/01/87—09/30/89 Project Director(s): Dena Brownstein, M.D.

This project seeks to decrease morbidity and mortality in pediatric emergencies by increasing the knowledge of EMS personnel and by reducing cultural and economic barriers to emergency care. Activities include developing algorithms and guidelines, creating a course for emergency room physicians, compiling a data base which focuses on outcomes and interventions, and conducting a survey on utilization of emergency medical services by Native Americans, migrant workers, and Southeast Asian refugees.



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Child Health

Improving Emergency Services for Children in Wisconsin

Wisconsin Department of Health and Social Services
Division of Health

Emergency Medical Services Section

1 West Wilson Street P.O. Box 309

Madison, WI 53701

(608) 267-6756

EMSC MCH-554001 10/01/87—09/30/89 Project Director(s): Michael F. French

This project seeks to improve the EMS system for children, particularly rural and Native American children. Activities include collection and analysis of data on the incidence, types, causes, treatments, and outcomes of pediatric emergencies; education and training for parents and over 600 EMS personnel; development and publication of assessment, transfer, triage, and treatment protocols; evaluation and comparison of modes of transport; and a needs assessment of medical control communications.



Emergency Medical Services

Lead Poisoning Training Project

Kentucky Department for Health Services Division of Maternal and Child Health 275 East Main Street Frankfort, KY 49621 (502) 564-4830 Genetics
MCJ-213001
10/01/82—09/30/90
Project Director(s):
Patricia K. Nicol, M.D., M.P.H.

This project operates and maintains a resource and training center which provides a knowledge base for State MCH professionals who develop and manage lead poisoning prevention programs. Activities include providing information services and technical assistance; providing site experience in door-to-door screening and environmental and nursing initial home visits; conducting workshops and conferences; publishing the *Lead Lines* newsletter; and cataloging available lead poisoning prevention resource materials.

Nationwide Blood Lead and Erythrocyte
Protoporphyrin Proficiency Testing Program

Wisconsin State Laboratory of Hygiene 465 Henry Mall Madison, WI 53706 (608) 262-0663

Genetics
MCJ-551003
10/01/88—09/30/93
Project Director(s):
Patricia H. Field, Ph.D.
Ronald H. Laessig, Ph.D.

The goal of this project is to improve the detection and treatment of children with lead poisoning by providing a free monthly proficiency testing program for blood lead and erythrocyte protoporphyrin (EP) to any interested laboratory. Objectives include providing lead and EP specimens, distributing survey results, serving as an information source, improving laboratory performance, and investigating possible hematofluorometer calibrators.



Child Injury Prevention Project

Alaska Department of Health and Social Services Division of Public Health P.O. Box H-06 Juneau, AK 99811 (907) 274-7626 MCHIP MCJ-023844 10/01/87—09/30/90 Project Director(s). Rita A. Schmidt, M.P.H.

The goal of this project is to improve the capacity of State public health programs to address the problem of childhood injuries through parent education. This will be accomplished through the establishment of child injury prevention programs as part of routine well-child clinics. Program components include a parent survey, parent interviews conducted by public health nurses, and safety information and education provided in clinic waiting rooms.

Child/Adolescent Injury Prevention Initiative

Arizona Department of Health Services Maternal and Child Health Division of Family Health Services 1740 West Adams Phoenix, AZ 85007 (602) 255-1880 MCHIP MCJ-043888 10/01/87—09/30/90 Project Director(s): Joyce De Vaney, R.N., M.P.H.

The goal of this project is to reduce accidental injuries and injury-related deaths among children and adolescents in Arizona. Project objectives are to provide professional training, develop an injury prevention clearinghouse, facilitate injury prevention programs in local communities, establish a mechanism for injury prevention program coordination, develop a State injury data base plan, and facilitate peer-based adolescent injury prevention programs and all-terrain vehicle training programs.

Regionalization of Care for Abused Children

Indiana University Foundation Research and Sponsored Programs 355 Lansing Street Indianapolis, IN 46202 (317) 274-8271 MCHIP MCJ-183901 10/01/88—09/30/91 Project Director(s): Robert A. Hibbard, M.D.

The goal of this project is to regionalize care for child abuse victims. The program will increase the number of children referred for evaluations by expanding the network of professionals who communicate and coordinate services for child abuse victims. Children will receive thorough medical evaluation and treatment by knowledgeable health care providers working together with social, legal, and mental health professionals.



Prevention of Athletic Injuries to School-Age Children and Youth

Kansas Department of Health and Environment Bureau of Local Health Services Landon State Office Building 900 Southwest Jackson Street 10th Floor Topeka, KS 66620-0001 (913) 296-1205 MCHIP MCJ-203889 10/01/87—09/30/90 Project Director(s): Virginia Tucker, M.D.

The goal of this project is to reduce the incidence of athletic injuries among children and youth grades 7 to 12, who participate in competitive sports. Objectives are to collect sports-related injury morbidity data and document sports-related morbidity rates, and to promote preparticipation physical examinations through the education of nurses, coaches, and primary care physicians.

HHS Region III Childhood Injury Prevention Program

Johns Hopkins University School of Hygiene and Public Health Department of Maternal and Child Health 624 North Broadway Baltimore, MD 21205 (301) 955-3754 MCHIP MCJ-243306 10/01/88—09/30/91 Project Director(s): Louise Wulff

This project will assist the Title V directors in the Region III States and the District of Columbia to: Assemble available injury-related data in order to estimate the geodemographic incidence of childhood injuries and the prevalence of injury-related disability for planning purposes; foster the design and targeting of State- and community-based prevention initiatives; and initiate and support coalition-building activities leading to ongoing State and local participation in childhood injury prevention activities.

Training Program in Maternal and Child Health

Johns Hopkins University School of Hygiene and Public Health 624 North Broadway Baltimore, MD 21205 (301) 955-3384 Training MCJ-000106 07/01/84—06/30/89 Project Director(s): Donald Cornely, M.D.

In addition to its function of providing master's level, doctoral level, and continuing education in maternal and child health, this program has instituted a trainceship in injury control and trauma management. The purpose of the trainceship is to identify components of a training program in injury control and management for children and to offer this experience to a pediatric trauma fellow. The project develops guidelines for other training programs for pediatric specialists in emergency medical services for children.



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Injury Prevention Implementation Incentive Grant: New England Network

Education Development Center, Inc. 55 Chapel Street
Newton, MA 02160
(617) 969-7100

MCHIP MCJ-253841 10/01/87—09/30/90 Project Director(s). Patty Molloy

This project is an adjunct to the New England Netwo to Prevent Childhood Injuries. The goal of the project is to implement the activities of the network's task force. Specifically, this project seeks to: (1) Educate relevant health department personnel about injuries so they can support injury prevention as a priority for the State health department; (2) raise awareness about injuries among members of the media and key decision-makers; (3) develop mechanisms for in-State sharing of injury data and the regular dissemination of these and regional data; and (4) foster capacity building within each State, especially the formation of coalitions and identification of complementary funding sources.

New England Network to Prevent Childhood Injuries

Education Development Center, Inc. 55 Chapel Street Newton, MA 02160 (617) 969-7100 MCHIP MCJ-253722 8/01/85—7/31/89 Project Director(s): Patty Molloy

The New England Network works with six States (Vermont, Maine, New Hampshire, Massachusetts, Connecticut, and Rhode Island) to enhance each State's resources for injury prevention. A major function is to broker information and technical assistance among the States. The network assists the States in examining mortality data, forming multiagency advisory groups, and funding special projects. The project is developing a resource directory, which will provide a list of injury prevention materials and professionals.

Minnesota Childhood Injury Prevention Project (MCIPP)

Minnesota Department of Health 171 Delaware Street, S.E. P.O. Box 9441 Minneapolis, MN 55440 (612) 623-5166 MCHIP MCJ-273111 10/01/87---09/30/90 Project Director(s): Carolyn McKay, M.D.

This project plans to expand childhood injury surveillance efforts and childhood injury prevention activities within local community health services. Project activities include compiling data on childhood-specific injury morbidity and mortality, creating a coalition of agencies with an interest in childhood injuries, providing assistance in developing local prevention programs, developing a comprehensive approach to reduce scald injuries in children ages birth to 5 years, and making long-range plans to address other types of injuries and other age groups.



Parent Outreach Project (POP)
Wilder Foundation
919 Lafond Avenue
St. Paul, MN 55104
(612) 642-2015

MCHIP MCJ-273020 10/01/87—09/30/90 Project Director: Eugene S. Urbain, Pn.D.

This project seeks to develop and demonstrate a replicable, collaborative, interagency prevention intervention model utilizing existing professional casework services, community education, and community based social support for a population at risk for potential child maltreatment. Important components of the project include home visits by nurses and volunteers. Public health nurses will conduct assessments in the home and monitor the developmental progress of the child, while a volunteer "parent befriender" will offer support to he!p build the parent's self-esteem and strengthen parent-child relationships.

Burn Injury Prevention Program for Low-Income Families

New York State Department of Health Injury Control Program Coming Tower Room 621 Albany, NY 12237 (518) 473-3391 MCHIP MCJ-363002 10/01/87—09/30/90 Project Director(s): Jeff Simon

Through the installation of home safety devices and the enforcement of building and fire codes, this project aims to reduce the incidence of morbidity and mortality from burn and scald injuries in selected rural and low-income areas of New York State. A secondary goal is to develop a comprehensive community health education burn prevention and safety demonstration program for low-income populations.

MCHIP Training

New York State Department of Health and Health Research, Inc. 1315 Empire State Plaza Albany, NY 12237 (518) 473-3393 MCHIP MCJ-363126 10/01/87—09/30/90 Project Director(s): Leslic Fisher, M.P.H.

This project's goal is the reduction of morbidity and mortality from childhood home injuries caused by fires, scalds, falls, and poisonings. Project objectives are to develop a training module in the primary prevention of childhood injuries for emergency medical technicians (EMTs) to use in their communities, and to conduct a demonstration project in a target area by mobilizing the community resources of EMTs.



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North Carolina Childhood Injury Prevention Project

North Carolina Department of Human Resources Division of Health Services P.O. Box 2091 Raleigh, NC 27602-2091 (919) 733-3816 MCHIP MCJ-373688 10/01/85—09/30/89 Project Director(s): Jimmie L. Rhyne, M.D., M.P.H.

This project aims to achieve reductions in the risk of poisoning, burn, and scald injuries for children ages birth to 4 years statewide and in the risk of these injuries and motor vehicle injuries among children ages birth to 4 years served in clinics funded by the Maternal and Child Care Section. Project objectives are to make passive injury prevention measures available and accessible; develop incentives for the use of passive injury prevention measures; provide public education on injury prevention; and develop a plan for injury surveillance.

Child Maltreatment Prevention Project: Coordination Between Public Health and Child Welfare

Ohio Department of Health and Ohio Department of Human Services 246 North High Street Columbus, OH 43244-0588 (614) 466-8932

MCHIP MCJ-393710 10/01/85—9/30/89 Project Director(s): Virgene Schafer Deborah J. Stokes

The objectives of this project are to identify families at risk for child abuse and neglect and refer them for followup services; to enhance the capabilities of the child welfare investigative team; and to expand the knowledge base of health professionals regarding child abuse and neglect. Activities include conducting and developing newborn assessments with the target population and developing a coordinated plan with children's protective services. The project also assists caseworkers and makes referrals to the health department for followup. An interdisciplinary committee assists the project in preparing curriculums on child maltreatment for students in professional schools.

Oklahoma Pediatric Injury Control Project

Oklahoma State Department of Health Maternal and Child Health Service P.O. Box 53551 Oklahoma City, OK 73152 (405) 271-4471 MCHIP MCJ-403235 10/01/87—09/30/90 Project Director(s): Diane Krous, R.N.

This project's efforts to reduce morbidity and mortality resulting from childhood injuries focus on motor vehicle accidents, fires, and drownings. Child safety restraints are promoted through the expansion of infant and toddler car seat loan programs and through parent, professional, and public education. The project provides public education on drownings, burns, and other childhood injuries, and will pursue the need for regulation and increased enforcement. In coordination with a Centers for Disease Control grant, statewide surveillance systems will be established.



South Carolina Childhood Injury Prevention

Project

South Carolina Department of Yealth and Environmental Control
Bureau of Maternal and Child Health
2600 Bull Street
Columbia, SC 29201
(803) 737-4120

MCHIP MCJ-453307 10/01/88—09/30/91 Project Director(s): Mimi Jackson, R.N., M.S.

The goal of this project is to reduce fatal and nonfatal injuries sustained by children in South Carolina by assuming leadership in bringing together the necessary data and agencies to focus on the childhood injury problem. The lack of a coordinated, centralized system to quantify childhood morbidity and the lack of public and professional awareness of the injury problem will be addressed by the development of an automated surveillance system, and by the establishment of a coalition which will provide input into the development of the surveillance system, disseminate information about childhood injury, and make recommendations on how to reduce the childhood injury problem.

Reduction of Childhood Accidental Injuries

Utah Department of Health Family Health Services Division 288 North 1460 West P.O. Box 16650 Salt Lake City, UT 84116-0650 (801) 538-6161 MCHIP MCJ-493244 10/01/87—09/30/90 Project Director(s): Peter van Dyck, M.D., M.P.H.

The goal of this project is to demonstrate a reduction in the frequency as well as the severity of school-related playground injuries among children in 20 target elementary schools. This will be achieved by making environmental modifications to the playgrounds and educating faculty and students in these schools. The PTA and other community groups will be involved, and school playgrounds will be inspected on a semiannual basis.

Child Pedestrian Injury Prevention Project

University of Washington Harborview Injury Prevention and Research Center Mailstop ZX-10 325 Ninth Avenue Seattle, WA 98104 (206) 223-8388 MCHIP MCJ-533500 11/01/87—10/31/90 Project Director(s): Frederick P. Rivara, M.D., M.P.H.

In order to reduce morbidity and mortality from childhood pedestrian injuries, this project will use four interventions: School-based education programs; a mass media educational campaign; enhanced police enforcement of speed and pedestrian right-of-way laws; and modification of environmental risk factors in targeted areas. The latter will include improved sidewalks, altered crosswalk markings, and the fencing of high-risk areas.



Wisconsin Comprehensive Child Injury Prevention Project (WCCIPP)

Wisconsin Department of Health and Social Services
Division of Health
1 West Wilson Street
P.O. Box 309
Madison, WI 53701-0309
(608) 267-7174

MCHIP MCJ-553743 10/01/85—09/30/89 Project Director(s): Hank Weiss, M.S., M.P.H.

The goal of this project is to institutionalize child injury control as an ongoing function of State and local public health services. The project is organizing an injury prevention unit which will be responsible for training health providers, educating decision-makers and the public, undertaking active surveillance and data collection, and analyzing targeted injuries and collection, and analyzing targeted injuries and collection.



Violence/Injury Prevention

Description and Evaluation of the Pediatric Hospice Demonstration Model Children's Hospital of Los Angeles 4650 Sunset Boulevard Los Angeles, CA 90027 (213) 669-4524

MCHIP MCJ-063703 10/01/85 —9/30/88 Project Director(s): Belinda Martin, R.N., M.S.

This project focuses on a home care program for families of terminally ill children developed by Children's Hospital of Los Angeles (CHLA). Project objectives include producing a detailed documentation of the program; conducting an impact assessment, with special emphasis on the patient and family unit; and producing a cost analysis. The CHLA program uses community resources from a wide variety of geographic settings and serves a multilingual, multicultural population which includes many families with a single head of household.

A Model Intervention Program for Survivors of the Sudden Death of 2 Child: A Program to Prevent the Complications of Abnormal Grief University of New Mexico School of Medicine Office of the Medical Investigator Albuquerque, NM 87131 (505) 277-3053 MCHIP MCJ-353674 10/01/85 —06/30/89 Project Director(s): Beverly C. White, R.N., M.S.

The goals of this project are to provide education about death and bereavement for professional and lay persons, crisis intervention for affected families, an autopsy on all children who have died suddenly, and autopsy information to families within 24 hours. The project has compiled an extensive library which focuses on deaths of children and adolescents from a variety of causes and the diverse ensuing grief and bereavement issues which may occur.



Grief and Hospice Care

Children with Special Health Needs

Early Childhood Intervention
Family-Centered, Community-Based, Comprehensive Services
Chronic Illness, Disabling Conditions
Technology Dependent, Medically Fragile
Cooley's Anemia, Thalassemia
Hemophilia/AIDS



Infant Health and Development Program

Stanford University Building 460 Room 112 Stanford, CA 94305 (415) 497-9685 Research MCJ-060515 02/01/85—01/31/89 Project Director(s): Ruth T. Gross, M.D.

This is a collaborative study which tests the efficacy of combining early child development services with pediatric care in reducing the incidence of health and developmental problems among low birthweight (LBW) infants. The project seeks to determine the effectiveness of medical followup plus psychoeducational and family support intervention on the health and development of LBW infants and their families to identify the LBW infants who benefit most from the program; and to determine which areas of development are most vulnerable in LBW infants.

Southeast Asian Developmental Disabilities

Prevention Program (SEADD)
San Diego-Imperial Counties Developmental Services,

Inc.
4355 Ruffin Road
Suite 205
San Diego, CA 92123
(619) 576-2965

MCJ-063792 10/01/85---10/31/89 Project Director(s): James O. Cleveland, Ed.D.

This project seeks to develop a model service delivery program which provides early identification and intervention services for Southeast Asian families with infants who are, or are at risk for becoming, developmentally disabled, to expand the network of coordinated community services for this underserved population; and to increase education and awareness in Southeast Asian communities regarding the need for prevention of developmental disabilities.

Project Zero to Three

National Center for Clinical Infant Programs 733 15th Street, N.W. Suite 912 Washington, DC 20005 (202) 347-0308 MCHIP MCJ-113271 07/01/83—06/30/89 Project Director(s): Eleanor S. Szanton, Ph.D.

The main goal of this project is to improve serv ces for disabled and at-risk infants, toddlers, and their families by developing an interstate network for early identification and intervention propulation. Activities include a national network meeting, two regional conferences, an intensive course, small topical meetings, consultations, publications, and a newsletter.



Statewide Linkage and Tracking Network of Early Identification and Early Intervention for 0-3 At-Risk and Disabled Infants
District of Columbia Commission of Public Health

1875 Connecticut Avenue, N.W.
Washington, DC 20009
(202) 727-3866

MCHIP MCJ-113908 10/01/86—09/30/89 Project Director(s): E. Elaine Vowels

The goal of this project is to develop an information management system for early identification and intervention in order to improve the health outcome of infants and children birth to 3 years of age who have disabilities or are at risk for developing disabilities. Activities include establishing a centralized data bank and an integrated network service delivery system as well as implementing a tracking system of the service delivery process.

Establishment of Native Hawaiian Child Development Centers

The Kamehameha Schools/Bishop Estate Center for Development of Early Education Kapalama Heights Honolulu, HI 96817 (808) 832-3015

MCHIP MCJ-157001 07/01/87---06/30/89 Project Director(s): Roderick P. Calkins, Ph.D.

The goal of this project is to establish an integrated system of education, health, and social service programs for families of Hawaiian children in the prenatal to 5 year age range. Four family-based education centers will be established, each of which will have three educational programs at its core: Children in the prenatal to 2 year age range will be served by a home visitation program, children ages 2 and 3 will be eligible for the traveling preschool programs, and children 4 and 5 years old will be eligible for the center-based preschool. Health promotion, social service, and case management programs will be designed to compliment the educational program.

Facilitation of Primary Care Physician Participation in Preventive Health Care

Hawaii Family Stress Center 2919 Kapiolani Boulevard Suite 30 Honolulu, HI 96826 (808) 732-0000 MCHIP MCJ-153887 10/01/86—09/30/89 Project Director(s): Gail Breakey, R.N., M.P.H.

This project aims to reduce the incidence of poor health characteristics among low-income, culturally diverse populations by promoting the involvement of primary care physicians (pediatricians) in early screening and intervention. Project goals include increasing the level of preventive health care for underserved children, reducing the severity of psychosocial problems, increasing physicians' sense of involvement as part of a team in providing services to project children and their families, and demonstrating a practical process for accomplishing these goals which can be replicated across the Nation.



Planning and Establish nt of a Parent-Child Development Center

The Kamehameha Schouls/Bishop Estate Center for Development of Early Education Kapalama Heights
Honolulu, HI 96817

(808) 832-3015

MCHIP MCJ-153565 02/01/84—06/30/89 Project Director(s): Roderick P. Calkins, Ph.D.

This project seeks to reduce the risk of health, social, and academic handicaps among children of Hawaiien ancestry. Community centers will be established to provide a home visitation program, a traveling preschool/morning playgroup, and a full-day preschool. Other activities include conducting an extensive assessment of community needs and developing ongoing ties with institutions of higher learning in the State.

PROJECT AIMS

Human Services Development Institute University of Southern Maine 96 Falmouth Street Portland, ME 04102 (207) 780-4430 MCHIP MCJ-233926 10/01/86—09/30/91 Project Director(s): Susan Partridge, M.S.W., Ph.D.

This project works to strengthen the capacity of Maine's service system to meet the emotional needs of children ages birth to 5 years and their families. Project objectives include developing and field-testing an emotional heath assessment tool; establishing a network of project associates from medicine, mental health, nutrition, and other fields; and recommending to the network methods of conducting comprehensive psychosocial assessments of children and families with emotional difficulties.

Maternal and Child Health Cooperative Agreement

Regional Center for Infants and Young Children 11710 Hunters Lai e Rockville, MD 20852 (301) 984-4444

MCHIP MCJ-243927 10/01/86—09/30/91 Project Director(s): Serena Wieder, Ph.D.

The goal of this project is to develop and implement early identification, assessment, and treatment of infants and young children who suffer from emotional difficulties and regulatory disorders and to develop family-centered intervention approaches. To facilitate this program, the Regional Center for Infants and Young Children has developed several instruments, including a parent questionnaire, a symptoms list, a health professional checklist, and guidelines for developmental assessments. In addition, infant and family mental health services, a therapeutic nursery and preschool, and a parenting psychotherapy program have been developed.



Early Intervention: A Collaborative Study of Its Impacts

University of Massachusetts Medical School Department of Pediatrics 55 Lake Avenue North Worcester, MA 01605 (617) 856-3028

Research MCJ-250533 01/01/86—12/31/89 coject Director(s): Jack P. Shonkoff, M.D.

This study analyzes how child, family, and program characteristics relate to child and family outcome for three target groups currently served by publicly supported early intervention programs in Massachusetts and New Hampshire. The study will include 180 children under 24 months of age with Down syndrome, motor impairment/cerebral palsy, or developmental delay of unknown etiology.

Nutrition Surveillance Intervention and Training (NSIT) in the Early Intervention Population

Massachusetts Department of Public Health and the Shriver Center
Services to Handicapped Children
i 50 Tremont Street
Boston, MA 02111
(617) 727-5812

MCHIP MCJ-255035 10/01/88—09/30/91 Project Director(s): Cynthia Taft Bayerl, R.D., M.S. Jacque Ries, R.D., M.P.H.

The goals of this project are to: (1) Collaborate with early intervention (El) programs in the New England region to establish an ongoing nutrition service system that provides nutrition screening and assessment; (2) establish a central reporting system to determine the nutritional status of the nutritionally at-risk population; and (3) establish a system of screening, referral, and assessment to identify children in the El program who are at nutritional risk. In addition, the project plans to develop a permanent training program and resource manual to be incorporated into the orientation program for all El providers and professionals and to develop a system for educating parents which empowers them to advocate for nutrition services and payment for those services.

Improving Memory of Educable Mentally Retarded Children Wayne State University

Detroit, MI 18202 (313) 577-5244 Research MCJ-260554 07/01/87—10/31/89 Project Director(s): Hilary Horn Ratner, Ph.D.

The aim of this project is to develop instructional strategies for educable mentally retarded children which are embedded in a social context and which enhance the children's memory performance across time and situation. All training tasks will be modeled after the mother's memory demands, which have been found to be highly correlated with children's memory performance.



Improved Auditory Testing of Multihandicapped

Children

Kent State University School of Speech Pathology and Audiology Kent, OH 44242 (216) 672-2672

Research MCJ-390548 10/01/86--03/31/89 Project Director(s): Donald P. Gans, Ph.D.

This project aims to study the routine hearing tests of severely and profoundly multihandicapped individuals (2 months to 17 years of age) to determine the need for a battery of tests versus the use of specific tests.

MATCH II: A Merged Data Base for Health and Developmental Disabilities

Ohio Department of Health 246 North High Street 6th Floor Columbus, OH 43266-0118 (614) 466-8967

MCHIP MCJ-393828 10/01/86---09/30/89 Project Director(s): M. Sue Benford, R.N., M.A.

This project seeks to improve coordination and continuity of early intervention and health-related services to infants and young children who have or are at risk for developmental disabilities or delays. The project will develop computer linkages between the existing statewide client information system of the Ohio Department of Mental Retardation and Developmental Disabilities and the client information files of the Child and Family Health Services programs in 11 counties. In addition, a microbased computerized identification, referral, and tracking system has been developed for use at the local level.

Usher's Syndrome: An Interdisciplinary Approach

Columbus Children's Hospital 700 Children's Drive Columbus, OH 43205 (614) 461-2094

Genetics MCJ-391003 10/01/85--09/30/89 Project Director(s): L.E. Leguire, Ph.D.

This project seeks to develop an Usher syndrome screening program that can be applied at the State or national level; to increase the opportunities for counseling, vocational guidance, and training for children with Usher syndrome; to detect and treat vision problems other than Usher syndrome; and to reduce the cost of health care to the deaf, blind population. The study population involves children 6 to 22 years of age in a school for the hearing impaired, who were given ophthalmologic examinations and followup services as needed.



Early Childhood Intervention

Alabama's Care Management Project

Alabama State Department of Education Division of Rehabilitation and Crippled Children's Services 2129 East South Boulevard Montgomery, AL 36111 (205) 281-8780 MCHIP MCJ-015030 10/1/88—09/30/9 (Project Director(s): Charles E. Ryals

This project addresses the need for coordination of services in the community as a means of empowering families to be knowledgeable primary caregivers for their special needs children. Using a family-centered, community-based system, the project will seek to: (1) Develop and implement a program that effectively provides case management services to families of special needs children; and (2) develop and implement a pilot project that uses parents of handicapped children as family managers who provide case management services, function as an advocate of the family, and help the family in its natural and pivotal role as primary caretaker of the special child. In addition, the project plans to facilitate the implementation of this model in other areas of Alabama and in other States, as needed.

Nutrition Care for the Child with Special Health Care Needs
Sparks Center for Development and Learning Disorders
P.O. Box 313
UAB Station
Birmingham, AL 35294

(205) 934-0803

Training
MCJ-009116
09/01/88—06/30/93
Project Director(s):
Harriet H. Cloud, M.S.

The purpose of this training project is to offer a short-term intensive course in nutrition care and services for children with special health care needs. The intended outcomes of this training are: (1) That program directors who plan pediatric services will recognize the need for nutrition services as an integral part of family-centered, community-based care for children with special health care needs; (2) that other health care professionals (i.e., physicians, nurses, and therapists) will gain new knowledge and skills related to nutrition care so that screening for nutritional problems and reinforcing nutrition intervention strategies become a team function; and (3) that dietitians and nutritionists in all health care and educational settings serving children with special health care needs will develop the expertise necessary to provide optimal nutrition care.



Family-Centered, Community-Based Project Arkansas Children's Medical Services P.O. Box 1437 Slot 526 Little Rock, AR 72203 (501) 682-2277 MCHIP MCJ-055018 10/01/87--6^30/90 Project Dire....r(s): Sandra J. Mathes, L.C.S.W.

This project addresses the need to establish a regionalized system of community-based service centers to assist the families of children with special health care needs in coordinating and obtaining-access to needed pervices. Strategies include instituting a multidisciplinary team to ensure coordination and service delivery through support of case planning, case management, referrals, and education of the client population and general public; and developing linkages between community service providers and the centrally located, more fully developed resources in Little Rock.

ACMS (Automated Case Management System)/
Community-Based Care Coordination
Project for CCS Children and Their
Families in Los Angeles County
California Children's Services (CCS) of
Los Angeles County
2064 Marengo Street
Los Angeles, CA 90033
(213) 226-2405

MCHIP MCJ-065020 10/01/87—09/30/90 Project Director(s): Dale C. Garell, M.D.

The goals of this project are to develop and implement an automated case management system in Los Angeles County to improve and enhance the existing CCS system; to establish a CCS community-based care coordinator program within Los Angeles County to coordinate and implement an individualized service plan for children with special needs and their families; and to test the feasibility and desirability of these goals in Los Angeles County, California, and other States.



An Automated Information and Data System for Improving Case Management Services for Children with Special Health Care Needs
San Diego-Imperial Counties
Developmental Services, Inc.
4355 Ruffin Road
Suite 205
San Diego, CA 92123-1648
(619) 576-2932

MCHIP MCJ-065017 10/01/87—09/30/90 Project Director(s): Raymond M. Peterson, M.D.

This project aims to improve case management services by developing a computerized system for using the Individualized P ogram Plan/Individualized Family Service Plan for intake and periodic assessments; developing and disseminating a computerized directory of resources for children with special health needs; expanding the network of community agencies serving these children; and planning for interagency collaboration to obtain information regarding the costs and effectiveness of services for children with special health care needs. The automated system will serve to assure the integration of client evaluation with treatment planning and to coordinate services to effectively serve children with special health care needs and their families.

Chronic Iliness in Children in Rural Areas

National Jewish Center for Immunology and Respiratory Medicine 1400 Jackson Street Denver, CO 80206 (303) 398-1378 MCHIP MCJ-083867 07/01/86—06/30/89 Project Director(s): J. Roger Hollister, M.D.

This project addresses the need to find better ways to utilize resources in the delivery of services to chronically ill children in rural areas by developing an approach which considers the problems and problem-solving strategies common to different chronic diseases. The objectives of the project include reducing morbidity among children with arthritis and epilepsy in the State of Montana; assisting care providers in developing a network of coordinated services; and developing lecture materials, orochures, and videotapes for distribution in Montana and other States in Region VIII.

Graduate Training in Pediatric Occupational Therapy

Colorado State University 200 Occupational Therapy Building Fort Collins, CO 80523 (303) 491-7567 Training
MCJ-009105
10/01/87—06/30/92
Project Director(s):
Elnora Gilfoyle, D.Sc.

The purpose of this project is to develop a model curriculum which is sensitive to differing family, social, and cultural issues; is interdisciplinary in its approach; and is adaptable to the needs of a variety of home and community settings. The design of the training program includes interagency collaborative relationships as a means to provide training for both occupational therapists and families of children with handicaps. The program will combine resources from Colorado State University in Fort Collins, Colorado, with resources from The Children's Hospital in Denver.



Handicapped Children's Resource Center (HCRC)

Commonwealth of the Northern Mariana Islands
Department of Public Health and Environmental Services
Commonwealth Health Center
P.O. Box 409
Saipan, MP 96950
(670) 234-8950

MCHIP MCJ-695006 07/01/87—06/30/90 Project Director(s) Jose T. Villagomez, M.D.

The goal of this project is to reduce the barriers to obtaining health and educational services for children with special health care needs by providing a community-based, family-oriented system of comprehensive and coordinated services. Strategies include increasing community awareness of services; establishing interagency collaboration; and developing a centralized data collection system related to health status, service, and educational needs.

Family-Centered Care Project

Association for the Care of Children's Health (ACCH) 3615 Wisconsin Avenue, N.W Washington, DC 20016 (202) 244-1801

MCHIP MCJ-113793 01/01/86—12/31/88 Project Director(s): Beverley H. Johnson

This project seeks to promote parent-professional collaboration and a family-centered approach in the care of children with chronic illnesses and disabling conditions. Activities include increasing parent involvement in ACCH; providing technical assistance to health professionals in developing effective partnerships with parents; and developing and disseminating resource materials, including the *Parent Resource Directory*.

Networking and Community-Based Services for Children with Special Needs
Georgetown University Medical Center
Department of Pediatrics
3800 Reservoir Road, N.W.
Washington, DC 20007

MCHIP MCJ-113806 07/01/86—06/30/89 Project Director(s): Phyllis R. Magrab, Ph.D.

This project seeks to achieve comprehensive, coordinated, community-based services for children with special health care needs and their families by means of improved collaboration among public and private agencies and parents at all levels within the service delivery system. Activities include maintaining a national network of health-related agencies from all States; facilitating coalitions of public agencies, private agencies, and parents within the States; providing and brokering training and technical assistance; organizing conferences; developing knowledge and resources to aid States and communities in improving the provision of services; and facilitating collaborative planning at the Federal level.



(202) 687-8635

Systems Development Project for Children with Special Health Needs

Federated States of Micronesia Department of Human Resources P.O. Box 490 Kolonia, Ponape, FM 96941 (691) 320-2643 MCHIP MCJ-645029 10/01/88—09/30/91 Project Director(s): Eliuel Pretrick, M.O.

The goals of this project are to: (1) Identify and analyze the handicapping conditions present in the Federated States of Micronesia; (2) introduce concepts of coordinated care services, family- and community-based networks, and case management services to the providers who care for children with special health care needs; (3) provide training for the development of communications systems and linkage networks among the agencies involved with caring for these children; and (4) consider mechanisms for the development of systems to enable the ongoing identification, monitoring, and treatment of children with special health care needs. Extensive needs assessments will be implemented to establish a data base of children with special health needs and to determine the current knowledge and perceptions of providers, families, and the community concerning the needs of these children. Thereafter, strategies will be acveloped to meet the project goals and objectives.

Home Health Care Management System

Illinois Division of Services for Crippled Children 1919 West Taylor 8th Floor Chicago, IL 60612 (312) 996-6380 MCHIP MCJ-173617 07/01/85—06/30/89 Project Director(s): Edward F. Lis, M.D.

This project addresses the challenge in the pediatric home health care field to develop a case management system that maintains family integrity and meets the perceived needs of families while assuring cost-effective, quality care. Objectives include the development of criteria for the identification of children suitable for a home care program and the development of a comprehensive case management system for children with chronic, complex health conditions within a State program for children with special health care needs.

Analysis and Expansion of Community-Based Interagency Collaborative Efforts

University of Iowa Child Health Specialty Clinics (CHSC) Hospital School Room 246 Iowa City, IA J2242 (319) 356-1118 MCHIP MCJ-193860 i.J/01/86—09/30/89 Project Director(s): Richard P. Nelson, M.D.

This study seeks to document, evaluate, and disseminate information about two community-based projects designed as models of collaborative, interagency service provision for children and families. The overall goal of the project is the expansion of collaborative efforts among providers of specialized child health and maternal and child health services.



CHSC Parent Partnership

University of Iowa Child Health Specialty Clinics (CHSC) Department of Pediatrics Iowa City, IA 5224 (319) 356-1118 MCHIP MCJ-195025 10/01/88—-09/30/91 Project Director(s): Richard P. Nelsen, M.D.

This project seeks to strengthen family-centered care for Iowa children with special health care needs by expanding parent participation in CHSC services development, by creating a statewide parent consultant network, and by enhancing community opportunities for parents to meet with one another and with professionals in a family-oriented experience. Program plans include an annual statewide issues forum; a regional parent consultant network composed of 2 parents from each of the 13 CHSC service regions; and family enrichment weekends, designed to bring together parents and children for discussion, reflection, and recreation.

Family-Centered Management for Children with Special Health Care Needs

Maryland Department of Health and Mental Hygiene Children's Medical Services 201 West Preston Street Baltimore, MD 21201 (301) 225-5580 MCHIP MCJ-245028 10/01/88—09/30/91 Project Director(s): Judson F. Force, M.D.

This project proposes to address the current fragmentation of the service and care financing programs and systems for children with special health care needs by establishing a framework within Maryland and Virginia to provide locally based, comprehensive, family-centered care management services. The project will seek to empower families by providing opportunities for parents to increase their skills in service and financial planning and management, and by providing assistance in the development of community parent-to-parent networks for family care management. Additional plans include the development of a repository of information on care financing resources and discussion with Title XIX and private insurance providers to explore possible funding options for statewide case management services for disabled children and for direct and support service provision.

LINC: Local Individualized Networks of Care

Michigan State University
Department of Pediatrics and Human Development
Life Sciences
Room B-240
East Lansing, MI 48824
(517) 353-5333

MCHIP MCJ-265009 07/01/87—06/30/90 Project Director(s): Barbara W. Desguin, M.D.

The goals of this project are to develop a comprehensive local support service network which will provide case-managed care to families with children with special health needs and to facilitate the development of financial reimbursement plans which will assist communities in providing comprehensive, family-based support services. Four community agencies will participate in the multiprofessional network, contributing mental health, nutrition, education, health education, and social services.



Developing Community-Based Care/Case Management Services
Mississippi State Department of Health
P.O. Box 1700
Jackson, MS 39215
(601) 960-7614

MCHIP MCJ-285021 10/01/87—09/30/90 Project Director(s): Sam Valentine

This project seeks to develop a statewide system of community-based, comprehensive care/case management and family support services. Program strategies include developing a training curriculum for the skilled delivery of home-based family support services by medical professionals, paraprofessionals, and parents; piloting a respite providers network; providing statewide training on the provision of family support services; and developing and disseminating a statewide directory of trained family support service providers.

Montana Project for Children with Special Health Care Needs

Montana Department of Health and Environmental Sciences Cogswell Puilding Helena, MT 59620 (406) 444-4740 MCHIP MCJ-305015 10/01/87—9/30/90 Project Director(s): Sidney C. Pratt, M.D.

The purpose of this project is to develop a care management system that is family centered, community based, and comprehensive in its approach to providing services for children with special health care needs. The program will follow four major steps: (1) Providing case management and intervention skills training for public health nurses; (2) establishing community resource networks and coalitions; (3) empowering families as caregivers; and (4) recruiting training consultants to conduct educational and working seminars.

Health and Development of Families with Young Children Dartmouth College Hazen Drive Concord, NH 01101 (603) 271-4495 Training
MCJ-009112
10/01/87—12/31/88
Project Director(s):
Robert Chamberlin, M.D.

The purpose of this project is to conduct a 3-day workshop aimed at improving the health and developmental status of mothers and children in the United States in general and northern New England (Maine, New Hampshire, and Vermont) in particular. The workshop objective is to enhance the capabilities and practices of key State officials and community leaders who develop and carry out communitywide approaches to promoting the health and development of families with young children.



Case Management for Parents of indian Children with Special Needs
Southwest Communication Resources, Inc.

Southwest Communication Resources, Inc. P C. Box 788
Bernalillo, NM 87004
(505) 867-3396

MCHIP MCJ-355014 10/01/87—09/30/90 Project Director(s): Randi Suzanne Malach

This project provides a model program for Native American families and the professionals who serve them. The program goals are to identify cultural, systemic, institutional, and policy barriers that inhibit Native American family participation in the "western" health care/case management system; improve case management by facilitating effective communication between Native American families and the non-Native American health care professionals who serve them; and increase Native American family participation in health care policy development and planning forums in order to promote changes that improve services for Native American children and families. Activities include developing a videotape illustrating effective cross-cultural communication strategies for non-Indian health care providers and training a Native American parent advocate to help families seen at IHS special pediatric clinics.

Families and Communities in Transition (FACT)

SKIP of New York, Inc. 500 East 83rd Street Suile 1B
New York, NY 10028 (212) 734-0728

MCJ-365004 07/01/87—06/30/90 Project Director(s): Marguerite Mikol

The purpose of this project is to encourage and expand home care as an option for families of children with special health needs. Objectives include empowering families who choose home care with the necessary skills and knowledge to become their own effective case managers; creating a collaborative system between parents and professionals in planning and caring for children; and improving and expanding both current home health and other community service provisions for children and their families.

A Demonstration Project to Develop a Pediatric Service Coordination Model

Cleveland Metropolitan General Hospital Department of Pediatrics 3395 Scranton Road Cleveland, OH 44109 (216) 459-5446 MCHIP MCJ-395026 10/01/88—09/30/91 Project Director(s): Lyn Cooper Gi¹l

The goal of this project is to enable families to provide home-centered care for their special needs children, when home is the best option, by establishing a service delivery system. This system will (1) promote the availability and accessibility of comprehensive quality services that address physical, psychosocial, spiritual, and developmental needs; (2) encourage continuity and coordination of care among all components of the child and family's interdisciplinary team; (3) promote communication among caregivers; and (4) be reimbursable, accountable, and responsive to changing needs. The 3-year project is designed to implement the pediatric service coordination model in the greater Cleveland area and to document the financial, administrative, and socioeconomic costs of providing home-centered care when service coordination is available.



Family-Centered, Community-Based Services for

Children with Cancer

The Children's Hospital of Philadelphia 34th and Civic Center Boulevard Philadelphia, PA 19104 (215) 596-9604

MCHIP MCJ-425027 10/01/88—09/30/91 Project Director(s): Beverly J. Lange, M.D.

Traditionally, treatment of pediatric cancer has required high-technology, provider-intense care, which is expensive and disrupts family life and the child's socialization and education. The goal of this project is to design alternative means of treatment by (1) moving the delivery of some high-technology care for children with cancer from a Level III he spital to the community and home; (2) providing community-based intervention for those children at risk for learning disabilities caused by cancer or its treatment; and (3) developing a community-based system of followup services for long-term survivors.

Caguas Crippled Children Service Network

Caguas Regional Hospital Caguas Pediatric Center P.O. Box 5729 Caguas, PR 00626 (809) 743-4406 or 743-6796 MCHIP MCJ-433638 08/01/85—07/31/89 Project Director(s): Maritza Diaz de Oniz, M.D.

This project seeks to improve the provision of habilitation/rehabilitation services to children and youth with special health care needs in the Caguas Health Region. Strategies include implementation of a computerized central register, implementation of a common referral form between agencies; development of educational materials for providers, service agencies, citizens' committees, and others; provision of training; and organization of an interdisciplinary health team for the development and implementation of an individual habilitation and/or rehabilitation plan.

A Care Management Model for Genetic Services

University of Tennessee Medical Center Birth Defects and Human Development Center 1924 Alcoa Highway Knoxville, TN 37920 (615) 544-9031 MCHIP MCJ-475005 07/6¹/87—06/30/90 Project Director(s): Carmen B. Lozzio, M.D.

This project seeks to reduce the discontinuity and fragmentation in health care delivery for children with genetic disorders in east Tennessee, to empower the parent/guardian of a child with a genetic disorder to become an effective manager of the child's special health care needs, and to determine the applicability of the MacQueen Child Profile Reporting Form as a data collection tool for genetics programs Strategies include an active outreach program and the provision of case management services.



Expanded Care, Detection, and Counseling in Genetic Disorders
Vanderbilt University
21st Avenue at Garland
T-2404 Medical Center North

Nashville, TN 37232 (615) 322-7601

Training MCJ-002046 07/01/87—06/30/89 Project Director(s): John Phillips, M.D.

The purpose of this project is to reduce the frequency and burden of genetic disorders. Strategies include increasing the number of families with access to genetic services through local and outreach training programs; establishing training programs for clinical genetics and clinical cytogenetics; serving as a regional testing center for determining hemophilia carrier status by DNA analysis; developing applications of recombinant DNA techniques to the detection of genetic disorders; and training fellows, pediatric and public health nurses, social workers, and physicians.

Coordinated Care Program for Children with Special Health Care Needs

Kelsey-Seybold Foundation for Medical Research and Education 700 Fannin Suite 1860 Houston, TX 77030 (713) 791-8784

MCHIP MCJ-485001 07/01/87—06/30/89 Project Director(s): Earl J. Brewer, Jr., M.D.

The goal of this project is to more fully ment the specialized medical, physical, and psychosocial needs of children with chronic illnesses in order to improve their functional abilities and their families' coping skills. Program activities include the development of five Level II Care Management Health Teams (CMHTs), the development of a CMHT within a tertiary care center, training to establish other community center teams and to develop a compatible interface between personnel at the various levels of health care, the development of financing methods for team care, the promotion of family participation in care at all levels, and the development and dissemination of educational materials.

A Program of Family-Directed Case Management

Vermont Department of Health Handicapped Children's Services 1193 North Avenue P.O. Box 70 Burlington, VT 05402 (802) 863-7338 MCHIP MCJ-505016 10/01/87—09/30/90 Project Director(s): Carol R. Hassler, M.D.

The goal of this project is to increase the family-centeredness of care for children with special health needs by empowering families with the knowledge and skills they need to become case managers for their children. Program strategies include: (1) Restructuring service delivery models within Handicapped Children's Services; (2) training staff in the process of family-centered case management by parents; (3) fortifying interagency coalitions; (4) developing a philosophy statement for Vermont children with special health needs that reflects a commitment to support families and community-based care; and (5) defining and implementing the case management process.



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Native American Children in Wisconsin with Special Health Care Needs

University of Wisconsin at Madison Statewide Genetics Services Network 104 Genetics Building 445 Henry Mall Madison, WI 53706 (608) 263-6355 MCHIP MCJ-555024 10/01/88—09/30/91 Project Director(s): Raymond Kessel, Ph.D.

This project is part of an ongoing effort to identify and address issues related to developmental disabilities among Native American children in Wisconsin to assure that proper diagnostic and followup services are provided to this population. Tribes, State and local agencies, and volunteer organizations are involved in a collaborative effort to design and establish a long-term, community-based, high quality program in each tribal community in Wisconsin to serve the special health care needs of Native American children. The two main goals of the project are to (1) become an integral part of the tribal service systems, and (2) improve those systems in such a way that they address both the needs of developmentally disabled children and the issues related to the prevention of disabilities.



Center for Developmental and Learning Disorders Training

University of Alabama at Birmingham P.O. Box 313 University Station Birmingham, AL 35294 (205) 934-5471 Training MCJ-000910 07/01/85—06/30/90 Project Director(s): Gary Myers, M.D.

This project prepares professionals to provide health and health-related care from an interdisciplinary perspective to children with multiple handicaps and mental retardation. Training is directed toward long-term graduate and postgraduate students with career interests in maternal and child health, and is comprised of orientations, workshops, conferences, seminars, courses, and continuing education programs at both preservice and inservice levels. The center serves the five-State region of Alabama, Florida, Georgia Mississippi, and Tennessee.

Medical Genetics in Prevention of Mental Retardation and Birth Defects

University of Alabama at Birmingham University Station Birmingham, AL 35294 (205) 934-4973 Training
MCJ-000905
07/01/82—06/30/93
Project Director(s):
Sara Finley, M.D.

The purpose of this project is to provide a comprehensive training program in medical genetics for present and future health care practitioners. The project includes didactic and applied instruction at a tertiary university medical center for students in a variety of clinical disciplines in the maternal and child health field.

Pediatric Pulmonary Training Center

University of Alabama at Birmingham The Children's Hospital 1600 Seventh Avenue South Birmingham, AL 35233 (205) 934-3574 Training
MCJ-000987
10/01/85—06/30/90
Project Director(s):
Ralph Tiller, M.D.

This project conducts clinical training at the graduate level for nurses, social workers, and nutritionists; pediatric pulmonary fellowships at the postgraduate level; and undergraduate training courses for respiratory therapists. These are superimposed on a background of services rendered to patients from a wide geographic area who have all varieties of pediatric pulmonary disease, both acute and chronic.



A Survey of Chronically III Children's Use of Time Out of School

University of California at San Francisco Family Health Care Nursing San Francisco, CA 94143 (415) 476-4663 Research MCJ-060550 04/01/87—03/31/90 Project Director(s): Bonnie Holaday, R.N., D.N.S.

The objective of this study is to collect data on the out-of-school activities of chronically ill children and to examine the effects of different ecological contexts on their experiences apart from school. The project will survey 400 California and Alabama families with children who have organic chronic illnesses, are between the ages of 10 and 12, are attending school, and have not moved or changed schools in the past 12 months. A 59-item questionnaire will be administered to each child selected for participation. Parents will complete an 82-item questionnaire on their beliefs about parenting and the child's activities as well as a 20-item medical history questionnaire. The study results will provide information about the social and psychological impact of chronic disease on the child and family.

Biochemical Genetics Laboratory Training

University of California at San Diego School of Medicine Department of Pediatrics M-009-A La Jolla, CA 92093-0609 (619) 534-4150 Training
MCJ-004007
10/01/88—06/30/93
Project Director(s):
William Nynan, M.D., Ph.D.

This project provides up-to-date biochemical evaluations of patients with inherited disorders of metabolism and trains health professionals in the use of the laboratory for diagnosis and management of their patients. The program functions as a major regional and national center for the detection, definitive diagnosis, and treatment of patients with metabolic disease.

Biochemics/Cytogenetics Lab and Training

University of Southern California Medical Center Professional Staff Association of Los Angeles 1739 North Griffin Avenue Los Angeles, CA 90031 (213) 226-3816 Training
MCJ-000286
07/01/82—06/30/89
Project Director(s):
Atsuko Fujimoto, M.D.

The primary goal of this project is to develop genetic services by providing a specialized, high quality program to a large high-risk patient population which otherwise would be unserved. Specific objectives are to support a cytogenetics laboratory and a training program primarily directed at postgraduate pediatricians and obstetricians.



Center for Metabolic Disorders Children's Hospital of Los Angeles Box 54700 Los Angeles, CA 90027 (213) 669-2178 Training
MCJ-000911
07/01/67--06/30/89
Project Director(s):
John Barranger, M.D., Ph.D

Through its multidisciplinary approach to training, this project utilizes clinical and laboratory facilities to provide comprehensive training to postdoctoral pediatric trainees in medical genetics, postdoctoral biomedical trainees in medical genetics, pediatric interns and residents, third and fourth year medical students, allied health professionals, oncology fellows, and medical and premedical summer student fellows.

Comprehensive Training of Pediatric Dental Residents University of Southern California USC Dentistry School Room 304A University Park Los Angeles, CA 90089-0641 (213) 743-7296 Training
MCJ-009098
07/01/87---06/30/92
Project Director(s):
Ronald Johnson, D.D.S.

This program is directed toward training dental school graduates in advanced pediatric dentistry and craniofacial biology. The purpose of this program is to prepare highly qualified specialists in pediatric dentistry who can assume leadership positions in dental education, service to the community, and dental research and care for the developmentally disabled, the medically compromised, or the handicapped.

Interdisciplinary Training in
Mental Retardation
University of California at Los Angeles
405 Hilgard Avenue
Los Angeles, CA 90024
(213) 825-0395

Training
MCJ-000927
07/01/84—06/30/89
Project Director(s):
James Simmons, M.D.

This project provides interdisciplinary training regarding chronic disabilities to 12 disciplines related to health and mental health. Ancillary purposes include the development of innovative services, particularly services which may either prevent the exacerbation of problems or the condition itself; research on the efficacy of treatments, on assessment procedures, and on training; dissemination of new developments; and technical assistance to private and public agencies.



Chronic Illness, Disabling Conditions

Medical Genetics: Diagnosis and Management

University of California at San Francisco Box 0106 San Francisco, CA 94143 (415) 476-2981 Training MCJ-000445 07/01/84—06/30/93 Project Director(s): Charles Epstein, M.D.

This project provides service and training in the general area of medical genetics, with particular emphasis on comprehensive genetic counseling and the diagnosis and management of human developmental abnormalities. The program was established in response to the dual needs to make training in the many aspects of medical genetics available and to develop a system for making high quality genetic counseling services available to a broad consumer community.

University Affiliated Training Center

Children's Hospital of Los Angeles 46.50 Sunset Boulevard Los Angeles, CA 90027 (213) 669-2151 Training MCJ-000914 07/01/84—06/30/89 Project Director(s): Wylda Hammond, M.D.

Since its establishment in 1956 as a training and resource center, this project has provided interdisciplinary training for health and education professionals based on services for children who have, or are at risk for developing, handicapping conditions. Associated purposes are to develop and disseminate related teaching and other instructive materials; to provide appropriate consultation and technical assistance; and to carry out activities in close cooperation with other agencies devoted to the care of mothers and children. The training program has a strong emphasis on prevention, detection, early intervention, and provision of exemplary and culturally appropriate care.

Nutrition Services for Children with Handicaps

Colorado Department of Health Handicapped Children's Program 4210 East 11th Avenue Denver, CO 80220 (303) 331-8359 MCHIP MCJ-085034 10/01/88—09/30/91 Project Director(s): Daniel J. Gossert

In response to the current lack of nutrition services for children with handicaps in Colorado, the Colorado Department of Health intends to develop and disseminate a replicable nutrition service delivery system which can be adapted to a variety of health settings and will include a method of reimbursement from third-party payers. This system will be designed to reduce or resolve the following nutritional risks for children with handicaps: Poor growth, underweight status, obesity, behavioral feeding problems, developmental o. mechanical feeding problems, and inadequate or inappropriate diet.



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Children with Special Health Needs

Regional Biomedical Diagnostic and Treatment Program

University of Colorado 4200 East Ninth Avenue Denver, CO 80262 (303) 394-7301 Training
MCJ-000252
07/01/84—06/30/93
Project Director(s):
Stephen Goodman, M.D.

This project provides a regional biochemical diagnostic and treatment program for children with inherited metabolic diseases in Colorado and the surrounding western States. The program is now in its 17th year of providing specialized laboratory evaluation and clinical management required for children with inborn errors of metabolism in the Rocky Mountains and High Plains Region.

Interdisciplinary Graduate Training in Developmental Disabilities

Georgetown University Medical School Department of Pediatrics Child Development Center 3800 Reservoir Road, N.W. Washington, DC 20007 (202) 687-8635 Training MCJ-000925 07/01/84—06/30/89 Project Director(s): Nina Scribanu, M.D.

The mission of this project is to improve the quality of life of individuals with handicapping conditions and chronic illnesses and their families and to reduce the incidence of handicapping conditions in our society. This university affiliated facility was developed through the involvement of a consortium of local universities to ensure a broader role in the academic community and to implement interdisciplinary training. It has been instrumental in forming the oncology team, the renal dialysis team, the cystic fibrosis team, and many others within the Department of Pediatrics.

Training in Communication Disorders

Howard University 2400 Sixth Street, N.W. Washington, DC 20024 (202) 636-7690 Training
MCJ-002011
07/01/84—06/30/92
Project Director(s):
Orlando Taylor, Ph.D.

This project trains advanced level professionals, particularly minority individuals, to assume leadership positions in providing services to linguistically and culturally diverse persons, as well as to all mothers and children in the general population. In addition, the program provides inservice training to practicing professionals in communication disorders who wish to update their knowledge and skills.



Transgenerational Project for Children with Learning Disabilities, Their Parents, and Schools
Howard University Child Development Center 525 Bryant Street, N.W.
Washington, DC 20059
(202) 636-6973

MCHIP MCJ-113853 07/01/86—06/30/89 Project Director(s): Roselyn P. Epps, M.D.

This project aims to improve the academic functioning of low-income, developmentally disabled, preadolescent youth. This project provides interdisciplinary evaluations of learning disabled children, assures appropriate school recommendations for them, and trains and counsels their parents. Other activities include continuing education workshops for health professionals regarding developmental and other learning disabilities.

Biomedical Lab Services and Training

University of Miami Department of Genetics Miami, FL 33101 (305) 547-6006 Training MCJ-000288 07/01/82—06/30/89 Project Director(s): Herbert Lubs, M.D.

This project was designed to plan for the optimal utilization of genetics laboratory resources by introducing the most appropriate methods and screening programs in order to accomplish the maximum prevention and treatment of severe inherited disorders. It is also expected to contribute both to the national pool of geneticists who can deliver contemporary genetic services and to the body of health care providers who can understand and effectively utilize new advances for improved health care.

Pediatric Pulmonary Training Center

University of Florida Box J-296 Gainesville, FL 32601 (904) 392-4458 Training MCJ-002013 07/01/85—06/30/90 Project Director(s): Sarah Chesrown, M.D.

The purpose of this project is to provide exemplary health care for a segment of the large and increasing number of children with pulmonary disease and to provide the interdisciplinary training for health professionals that is required to meet the needs of the patient population. The center serves patients in Florida, Georgia, and South Carolina.



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University Affiliated Training Center

University of Miami Mailman Center for Child Development P.O. Box 016820 D820 Miami, FL 33101 (305) 547-6635 Training MCJ-000903 07/01/84—06/30/89 Project Director(s): Robert Stemfel, M.D.

The primary purpose of this project is to increase the quality and number of professionals in leadership roles in the fields of mental retardation and other developmental handicaps through advanced training programs emphasizing prevention, early detection, diagnosis, evaluation, and intervention. These programs have been developed in collaboration with the State system addressing the areas of legislative planning, program development, and implementation.

Physical Therapy in Maternal and Child Health Training

Emory University 1441 Clifton Road, N.E. Atlanta, GA 30322 (404) 727-5564 Training
MCJ-000989
10/01/79—06/30/92
Project Director(s):
Pamela Catlin, Ed.D.

The purpose of this project is to train professionally qualified physical therapists in maternal and child health care. The program emphasis is on implementation of a pediatric specialty area of a master of medical science program in physical therapy that stresses clinical management through prevention, early detection, and intervention as well as preparation of physical therapy leaders and educators with expertise in maternal and child health care.

Leadership Training for Pacific Island Nurses

University of Guarn UOG Station Division of Human Ecology Mangilao, GU 96923 (671) 734-3300, ext. 322 Training
MCJ-009100
07/01/87—06/30/91
Project Director(s):
Anne Rohweder, M.N.

The intent of this project is to extend the education of a significant number of Pacific Island nurses beyond the associate's degree or diploma. The specific purpose of the extended education is to develop and expand leadership skills in the area of maternal and child health.



Illinois and Northwest Indiana
Pediatric Rheumatology and Chronic
Disease Outreach Program
La Rabida Children's Hospital
and Research Center
East 65th Street at Lake Michigan
Chicago, IL 60649
(312) 363-6700, ext. 520

MCHIP MCJ-173917 07/01/86—07/01/89 Project Director(s): Helen M. Emery, M.D. Arthur F. Kohrman, M.D.

This project provides clinical and case management services to children with rheumatic diseases using a system of regionalized clinics, local resources, and consulting expertise from the tertiary center, La Rabida Children's Hospital. Other activities include assisting local health professionals, developing and disseminating a case management guidebook, conducting continuing education programs, and publishing parent education materials and a professional newsletter.

Training for the Care of Handicapped Children

Indiana University 702 Bamhill Drive Room A 576 Indianapolis, IN 46223 (317) 274-2051 Training
MCJ-000924
07/01/84—06/30/89
Project Director(s):
Emest Smith, M.D.

This project implements and coordinates the interdisciplinary training of professionals involved in the health and related care of children with mental retardation and other long-term handicaps. The training encompasses diagnostic, treatment, and longitudinal management of children relative to individual, family, and community needs, with special focus on prevention, early detection, and timely intervention. The project serves as a consultative referral resource for the diagnostic and management problems of children in the State.

Cytogenetic Technologist Training Program

University of Iowa Hospitals and Clinics Division of Medical Genetics Department of Pediatrics Cytogenetics Laboratory W-101GH Iowa City, IA 52242 Training
MCJ-009123
10/01/88—06/30/93
Project Director(s):
Shivanand R. Patil, Ph.D.

This program, in association with the Great Plains Genetics Service Network and the Medical Technology Program at the University of Iowa, will train cytogenetic technologists to fill the expanding demand for trained technologists, particularly in the areas of prenatal diagnosis and molecular and cancer studies.



Pedodontic Training in Care of Handicapped Children

University of Iowa
Department of Pediatric Dentistry
Iowa City, IA 52242
(319) 353-3292

Training MCJ-000347 07/01/87—06/30/92 Project Director(s): Jimmy Pinkham, D.D.S.

This program provides special training in meeting the dental care needs of chronically impaired children, handicapped children, and children with other special needs. It focuses on the comprehensive care of the disabled and on interdisciplinary training in patient management.

Kansas University Affiliated Facility

University of Kansas Medical Center 39th and Rainbow Boulevard Kansas City, KS 66103 (913) 588-5900 Training
MCJ-000944
07/01/84—06/30/89
Project Director(s):
Joseph Hollowell, M.D.

This university affiliated facility is one of the 19 origina!!y constructed clinical training programs authorized in 1963. This project provides innovative and effective interdisciplinary training programs for graduate students and professionals dedicated to maximizing the growth and development of the multiply handicapped child within the family. It also conducts research, disseminates research findings, and serves the tertiary diagnostic needs of children in Kansas and western Missouri. This is the only clinical interdisciplinary training program for health professionals in Kansas or Missouri.

Nutrition for Children with Special Health Care Needs University of Kansas Medical Center 39th and Rainbow Boulevard Kansas City, KS 66103 (913) 588-5630 Training
MCJ-009111
10/01/87—9/30/89
Project Director(s):
Sarah McCammam, M.S.

The primary purpose of this continuing education project is to improve the overall health status of children with special needs in Region VII through early, comprehensive, nutrition-related interventions. The project seeks to the cilitate the improvement and/or initiation of an interdisciplinary approach to common nutritional concerns, and will place special emphasis on developing a regional philosophy for nutrition services for children birth to 3 years of age.



Intravenous Antibiotic Therapy in Cystic Fibrosis: Home versus Hospital Tulane University School of Medicine 1430 Tulane Avenue
New Orleans, LA 70112
(504) 588-5601

Research MCJ-220556 05/01/87—10/31/90 Project Director(s): William W. Waring, M.D.

This project conducts a multicenter, prospective, randomized study of cystic fibrosis patients with acute pulmonary exacerbations, and is designed to compare the short- and long-term effects of conventional therapy in the hospital to similar therapy in a combination of hospital and home settings. The study will focus on the cost, safety, patient acceptance, and psychosocial aspects of home care.

Pediatric Pulmonary Center Training Tulane University School of Medicine 1430 Tulane Avenue New Orleans, LA 70112 (504) 588-5601 Training
MCJ-000952
07/01/85—06/30/90
Project Director(s):
Robert Beckerman

The purpose of this project is to develop and refine an interdisciplinary training program. Program activities include developing mechanisms for the orderly transfer of care of patients from neonatologists to pediatric pulmonologists and from pediatric pulmonologists to adult pulmonologists; exploring means by which the intensity of hospital care and the quality of home care can be combined in the same environment; finding ways to reduce the costs of care without sacrificing quality; and capitalizing on a longitudinal patient data base to gain insights into the natural history of pulmonary disease. In addition, the project will explore the rich potential of interdisciplinary and multicenter clinical research made possible by the pediatric pulmonary center concept.

The Chronic Illness Program Children's Hospital 200 Henry Clay Avenue New Orleans, LA 70118 (504) 899-9511 MCHIP MCJ-223631 07/01/85—06/30/89 Project Director(s): A. Joanne Gates, M.D.

The goal of this project is to develop a regionalized system of care for chronically ill children and their families. To achieve this goal, the project will identify the needs of children with chronic illnesses and their families, develop a network of existing resources for this population, and establish new resources. Activities include developing a network of parents, community providers, and health professionals; conducting education/training sessions for school and Title V personnel, parents, and health professionals; producing educational packets and training materials; and developing a computerized information and referral system for State MCH and school system staff.



Children with Special Health Needs

Project ABLE—Altering Bowel Learning Effectively
Kennedy Institute for Handicapped Children 707 North Broadway
Baltimore, MD 21205
(301) 522-5455

MCHIP MCJ-245007 07/01/87—06/30/89 Project Director(s): Michael F. Cataldo, Ph.D.

This project addresses the problem of fecal incontinence in children with myelomeningocele by developing an affordable instructional package for health care providers and a parent instruction program in order to help these children develop bowel control. The training program will include a videotape and written provider and parent manuals.

University Affiliated Training Center

Johns Hopkins University School of Medicine The John F. Kennedy Institute 707 North Broadway Baltimore, MD 21205 (301) 550-9483 Training
MCJ-000917
07/01/85—06/30/90
Project Director(s):
Gary Goldstein, M.D.

This multistate, regional resource center provides advanced degree professional training, exemplary services, internationally recognized research, and community outreach services to children and families. The program was established in 1937 as are Children's Rehabilitation Institute in Reisterstown, Maryland, and moved to its present location in 1967, when it was first designated as an MCH-funded University Affiliated Facility. It serves over 6000 children with a wide range of handicapping conditions each year.

A Regional Program to Improve the Health Status of Children with Rheumatic Diseases

New England Medical Center Department of Pediatrics Coordinating Center 750 Washington Street Box 286 Boston, MA 02111 (617) 956-5071 MCHIP MCJ-255012 07/01/87—06/30/90 Project Director(s): Jane G. Schaller, M.D.

This project seeks to improve the health status of children with rheumatic diseases in New England as measured by reductions in the number of days lost from school by these children. Activities include development of discipline-specific standards of care; education of local school systems, parents, and tertiary center teams; outreach to underserved areas; and development of community-based programs for families, including parent support groups and telephone networks.



Chronic Illness, Disabling Conditions

Collaboration Among Parents and Health Professionals (CAPP) Federation for Children with Special Needs 312 Stuart Street Boston, MA 02116 (617) 482-2915 MCHIP MCJ-253607 07/01/85—06/30/89 Project Director(s): Betsy Anderson

This project works with the Technical Assistance for Parent Programs (TAPP) Project and the U.S. Office of Special Education Programs in order to increase and enhance parent involvement in the health care of children with disabilities and special health needs. Activities include developing workshop materials, providing forums for discussion for health professionals, and disseminating models for collaboration to parent organizations nationally through the TAPP Project, the project newsletter, and other publications.

Physical Therapy/Occupational Therapy Program in Therapeutic Studies

Boston University
Sargent College of Allied Health Professionals
1 University Road
Boston, MA 02215
(617) 353-2727

Training
MCJ-000901
07/01/65—06/30/92
Project Director(s):
Anne Henderson, Ph.D.

This project is designed to expand the Boston University, Sargent College Interdisciplinary Doctoral Program in Therapeutic Studies to include a specialization in occupational therapy services for chronically ill children and their families. It is anticipated that the result will be a model curriculum for training graduate level therapists in the care of these children.

University Affiliated Training Center

Massachusetts General Hospital Eunice Shriver Center 200 Trapello Road Waltham, MA 02254 (617) 642-0230 Training MCJ-000906 07/01/84—06/30/89 Project Director(s): Philip Reilly, M.D.

Since its inception in 1970, this university affiliated facility has provided training to 750 graduate students. Through this program, approximately 5600 clients with mental retardation and other handicaps receive evaluation and program planning each year. The Shriver Center established one of the first early intervention programs in the region, offered the first demonstration project inservices to siblings of clients with mental retardation, and began the first area program for mentally retarded mothers. It is a leader nationally and internationally in the prevention, early detection, and treatment of fetal alcohol syndrome.



University Affiliated Training Center

The Children's Hospital of Boston Fegan 10 300 Longwood Avenue Boston, MA 02115 (617) 735-6509 Training MCJ-000928 07/01/85—06/30/90 Project Director(s): Allen Crocker, M.D.

This developmental evaluation clinic/child study center is devoted to the concerns of young persons with mental retardation, other developmental handicaps, chronic illnesses, and/or genetic diseases. Activities include advocacy for young persons with mental retardation or other conditions which impinge on development; strategic, interdisciplinary, preservice education for students; diagnostic assessment, therapeutic program planning, and follow-along services for children (and some adults) who are in particular need of developmental assistance; high quality, inservice and continuing education to workers in the field; parent training and public education; technical assistance for relevant programs; and research aimed at improving knowledge and insights.

Program in Dental Care of Handicapped Children

University of Michigan Dentistry School 1011 North University Avenue Ann Arbor, MI 48109-1078 (313) 764-1523 Training
MCJ-000243
07/01/87—06/30/92
Project Director(s):
Richard Corpron, D.D.S.

The purpose of this 2-year graduate program is to recruit and train dentists in the comprehensive, quality care of handicapped children, adolescents, and young adults. Upon completion of the training, participants are prepared for leadership roles in administration, teaching, research, and service-related oral health programs.

Pediatric Cardiac Care Quality Assurance Consortium

Corporation for the Advancement of Pediatric Cardiac Services Box 288 UMHC 420 Delaware Street, S.E. Minneapolis, MN 55455 (612) 626-2790 MCHIP MCJ-275013 07/01/87—06/30/90 Project Director(s): James H. Moller, M.D.

This project will develop severity-adjusted outcome standards for the major pediatric cardiac surgical procedures and a review protocol which incorporates these outcome standards. This system will then be incorporated into the ongoing quality assurance programs of pediatric cardiac centers and serve as a model for individual cardiac centers across the Nation.



Chronic Illness, Disabling Conditions

Meyer Children's Rehabilitation Institute
University Affiliated Interdisciplinary Training
University of Nebraska Medical Center
42nd and Dewey Avenue
Omaha, NE 68105
(402) 559-5700

Training
MCJ-000405
07/01/86—06/30/90
Project Director(s):
Bruce Buehler, M.D.

This program provides a coordinated, interdisciplinary, clinical graduate training program in developmental and handicapping conditions of children and youth, stressing a total approach to the child and family. The project encourages innovative use of manpower for training developmental pediatricians, family practitioners, pedodontists, MCH nurses, nutritionists, graduate social workers, speech pathologists, geneticists, special educators, psychologists, and physical and occupational therapists. The project also provides clinical and consultative services to the State Department of Health's Genetics Program and provides Title V clinics, tertiary assessments, consultations, training, and resources development under a contract with the Department of Social Services.

Development of a Model System of Nutrition Services for Children with Disabilities

New Mexico Health and Environment Department Public Health Division MCH Bureau and Nutrition Bureau P.O. Box 968 Santa Fe, NM 87504-0968 (505) 827-2517 or 827-2350 MCHIP MCJ-353815 10/01/86—09/30/89 Project Director(s): Ann Taulbee

This project seeks to improve the delivery of nutrition services to children of New Mexico's low-income, tricultural, rural population. Activities include a comprehensive needs assessment of existing services; education and training for health professionals, parents, and lay groups; development of nutrition education materials; development and implementation of nutrition screening, assessment, and referral procedures; assessment of funding sources; and publication of a handbook for other nutrition service projects.

Home-Based Support Services for Chronically III Children and Their Families

New York State Department of Health Bureau of Child Health Empire State Plaza, Tower Building Room 878 Albany, NY 12237 (518) 473-3400 MCHIP MCJ-363624 07/01/85—06/30/89 Project Director(s): Barry R. Sherman, Ph.D.

This project seeks to facilitate the provision of home-based care for chronically ill children and their families in order to reduce stress and decrease the need for more costly, less normalizing hospitulization. Program objectives include: Developing a regional network of medically skilled respite providers; establishing self-help mutual support groups for chronically ill children and their parents and siblings; training professionals, paraprofessionals, and volunteers; and disseminating project findings and recommendations.



Children with Special Health Needs

Nutrition Services for Chronically III and Handicapped Children
New York State Department of Health and Health Research, Inc.
Bureau of Nutrition
Corning Towers
Room 859
Albany, NY 12237
(518) 473-8286

MCHIP MCJ-363827 10/01/86—09/30/89 Project Director(s): Janice M. Dodds, Ed.D., R.D.

This project seeks to demonstrate the potential for improved growth and nutrition practices among chronically ill and handicapped children in New York State through the provision of comprehensive and coordinated nutrition care services. Activities include assessing the needs of parents and caretakers, monitoring service delivery, documenting the nutrition problems of the target populations, participating in a regional advisory committee, providing parent and professional education, and providing services to children enrolled at affuliated sites.

Pediatric Pulmonary Center University of Rochester

601 Elmwood Avenue Rochester, NY 14642 (716) 275-2464 Training
MCJ-009071
07/01/85—06/30/90
Project Director(s):
John Brooks, M.D.

The purpose of this project is to develop new models of interdisciplinary education and to become a national model for the interdisciplinary education and regionalized care of pediatric pulmonary patients. The project is also intended to provide a comprehensive and coordinated referral service for all types of pediatric pulmonary patients and to increase the capabilities of the various communities in order to eliminate the need for long distance travel to Rochester. Additional resources are being devoted to comprehensive case management of technology-dependent infants and children with chronic respiratory disease.

Pediatric Pulmonary Center, New York City Mount Sinai School of Medicine

1 Gustave L. Levy Place New York, NY 10029 (212) 650-7788 Training
MCJ-001069
10/01/85—05/30/90
Project Director(s):
Meyer Kattan, M.D.

This project is designed to enhance the delivery of care to infants and children with chronic pulmonary disease directly and through involvement with health care systems at the State and local levels. The major focus is on long-term graduate training at the master's level with emphasis on maternal and child health in the fields of pediatrics and pulmonary disease.



Chronic Illness, Disabling Conditions

Social Work Training in Maternal and Child Health Care

Syracuse University School of Social Work Brockway Hall Syracuse, NY 13244-6350 (315) 443-5583 Training
MCJ-002036
10/01/79—06/30/92
Project Direct((s):
Claire Rudolph, Ph.D.

This project is designed to meet the needs of graduate social work education by providing new approaches in educating future professionals who will perform social work functions in public health. A special emphasis is placed on prevention and promotion with a focus on meeting the needs of families with chronically ill children.

Training for Maternal and Child Health Leadership in Care of Chronically Ill Children

Albert Einstein College of Medicine Rose F. Kennedy Center 1410 Pelham Parkway South Bronx, NY 10461 (212) 430-2440 Training
MCJ-000241
07/01/86—06/30/90
Project Director(s):
Herbert Cohen, M.D.

The Rose F. Kennedy Center for Mental Retardation provides comprehensive interdisciplinary training for medical, dental, and nonmedical professionals in the care of children with mental retardation and developmental disabilities. Emphasis is on long-term training of health professionals, including the training of residency physicians for assumption of leadership roles in the field; the clinical training of dental specialists in the care of handicapped children; and internships, fellowships, and long-term clinical experiences for nonmedical professionals.

Training in Diagnosis and Treatment of Metabolic Disorders

New York University School of Medicine New York University Medical Center 550 First Avenue New York, NY 10016 (212) 340-6266 Training
MCJ-000317
07/01/84—06/30/89
Project Director(s):
Selma Snyderman, M.D.

The primary purpose of this project is to diagnose and treat children with inborn errors of metabolism. While accomplishing this, one fellow will receive indepth training. This project also acts as a referral center for physicians who seek aid in the diagnosis of patients with suspected metabolic disorders.



Children with Special Health Needs

University 5. 7. 1. 2 ded Training Center Westchester County Medical Center 425 Cedarwood Hall Mental Retardation Institute Valhalla, NY 10595-1689 (914) 285-8170

Training
MCJ-009029
07/01/82—06/30/90
Project Director(s):
William Levinson, M.D.

The Mental Retardation Institute was established 36 years ago as the Retarded Children's Clinic at New York Medical College, Flower-Fifth Avenue Hospital in Manhattan. It was the first such clinic for mentally retarded children, and became the prototype for similar services. The institute provides interdisciplinary training, health, and related services in a clinical setting; outreach activities designed to share resources; and expertise through continuing education.

Behavioral Pediatrics Training University of North Carolina at Chapel Hill School of Medicine Chapel Hill, NC 27599 (919) 966-2504 Training MCJ-009089 09/01/86—06/30/91 Project Director(s): Frank A. Loda, M.D.

This project develops and enhances the educational training programs in child behavior for medical students, pediatric residents, behavioral fellows, and practicing physicians in North Carolina by building on existing resources available at the university and its affiliated programs. The project offers two tracks which will allow for scholarly training either in the behavioral management of children with developmental disabilities and dysfunctions, or in investigation and direct service to children in community settings.

University Affiliated Training Center University of North Carolina at Chapel Hill School of Medicine Chapel Hill, NC 27514 (919) 966-1020 Training
MCJ-000916
07/01/65—06/30/90
Project Director(s):
Melvin Levine, M.D.

This project provides interdisciplinary training to health care professionals within the context of the provision of exemplary services and clinical research. Contracts drawn with a number of institutions and agencies extend the training base of the division and provide mechanisms for entering into the service community in a programmatic manner. Currently, the project supports five trainees, two postdoctoral (pediatrics and psychology) and three predoctoral (administration, physical therapy, and nutrition).



Chronic Illness, Disabling Conditions

Appalachian Regional Program for Juvenile Chronic Diseases

Children's Hospital Medical Center Elland and Bethesda Avenues Pavilion 1-29 Cincinnati, OH 45229-2899 (513) 559-4676 MCHIP MCJ-395033 10/01/88—09/30/91 Project Director(s): Daniel J. Lovell, M.D., M.P.H.

This project addresses the identification and management of rheumatic and other chronic childhood diseases in a poverty-stricken, rural, and predominantly Appalachian population. With the cooperation of three universities in two States, and the Kentucky Commission for Handicapped Children, the project will seek to improve the health status of children with chronic diseases by developing secondary level medical care in three rural regions of Kentucky for children with rheumatic diseases and developing secondary level medical care in three rural regions of Kentucky for children with chronic diseases. A comprehensive, community-based, family-centered program will be implemented.

Center for Inherited Disorders of Energy Metabolism

Case Western Reserve University Rainbow Babies and Children's Hospital 2074 Abington Road Cleveland, OH 44106 (216) 844-3661 Training
MCJ-009122
10/01/88—06/30/93
Project Director(s):
Douglas S. Kerr, M.D., Ph.D.

This project will establish a center to provide comprehensive and definitive diagnostic laboratory services for inherited disorders associated with lactic acidosis, abnormal fatty acid oxidation, and altered mitochondrial function. The center will provide postdoctoral training for individuals with career interests in metabolic genetics and will enhance the general understanding of these disorders through postgraduate training for health professionals.

Mental Retardation Training in Interdisciplinary Setting University Affiliated Facility

Ohio State University
The Nisonger Center
1581 Dodd Drive
Columbus, OH 43210-1205
(614) 292-8365

Training
MCJ-000922
07/01/84—06/30/89
Project Director(s):
Vern Reynolds

This project offers an integrated system of comprehensive, interdisciplinary, and specialty clinics which provide diagnosis, assessment, program planning, management, and treatment/intervention services to handicapped clients and their families. The project directs clinical activities toward clients who have particularly complex, difficult, and/or unusual types of handicapping conditions and establishes relationships with health and other community agencies.



Treatment of Metabolic Diseases—Training Setting

Children's Hospital Research Foundation Children's Hospital Medical Center Elland and Bethesda Avenues Cincinnati, OH 45229 (513) 559-4451 Training
MCJ-000427
07/01/84—06/30/89
Project Director(s):
Helen K. Berry, M.A.

The purpose of this project is to provide a regional resource for the diagnosis, treatment, and management of patients with a variety of inherited metabolic diseases, including the preparation of specialized amino acid modified diets for patients with rare disorders for whom commercially prepared diets are not available. Research is conducted on ways to improve diagnosis and better assess prognosis for patients with phenylketonuria and other metabolic disorders.

University Affiliated Training Center

University of Cincinnati Pavilion Building Cincinnati, OH 45229 (513) 559-4621 Training
MCJ-000912
07/01/85—06/30/90
Project Director(s):
Jack Rubinstein, M.D.

This center, now in its 28th year, began with a strong clinical service emphasis with the opening of the Hamilton County Diagnostic Clinic for the Mentally Retarded in 1957 and the Children's Neuromuscular Diagnostic Clinic in 1962. The project operates a satellite program in case management for persons with developmental disabilities. The project has as an objective the provision of interdisciplinary training to approximately 120 trainees, 60 of whom are at the graduate level.

Family Support Project
Oklahoma State Department of Health
P.O. Box 53551

Oklahoma City, OK 73152 (405) 271-4471

MCHIP MCJ-405003 07/01/87—06/30/90 Project Director(s): Nancy Fire, R.N., M.S.

This project seeks to increase support to children with special health needs by addressing the lack of formal support due to fragmentary services in local communities and the lack of identification and utilization of informal support. Project objectives are to: (1) Facilitate local community groups to address formal support system services needs; (2) enable volunteer parents to visit other families in their communities, thereby enhancing informal support systems; and (3) establish a grassroots network of families and community groups across the State.



Training Program in Communication Disorders

University of Oklahoma P.O. Box 26901 Oklahoma City, OK 73190 (405) 271-4214 Training
MCJ-000235
07/01/87—06/30/92
Project Director(s):
Glenda Ochsner

This project provides a multidisciplinary approach to the diagnosis and management of communication problems in children, and offers interdisciplinary training for professional personnel. In addition, the project disseminates information concerning communication disorders to involved professionals throughout the State.

University Affiliated Training Center in Mental Retardation/Developmental Disabilities

Oregon Health Sciences University P.O. Box 574 Portland, OR 97207 (503) 279-8364 Training
MCJ-000920
07/01/84—06/30/89
Project Director(s):
David Macfarlane, M.D.

The goal of this project is to provide interdisciplinary training for a group of specialized professional personnel from health and other relevant disciplines in the management of children and young adults with mental retardation, developmental disabilities, and other chronic conditions. Thirteen disciplines are included within the project structure.

Development of Pediatric Pulmonary Care

Personnel
University of Puerto Rico
P.O. Box 44
Hato Rey, PR 00919
(809) 763-4966

Training
MCJ-000950
07/01/85—06/30/90
Project Director(s):
Pedro Mayol, M.D.

This project provides ongoing training to health care professionals, at both the basic and advanced levels, in pediatric pulmonary care. The center supports the publication and circulation of a bimonthly, medically oriented newsletter, patient information pamphlets, and supplemental educational materials for didactic activities related to pediatric pulmonary care. These products are, for the most part, written in Spanish to meet the needs of the population in Puerto Rico. Concentrated efforts are also being made to meet the educational and clinical needs of health care professionals in the U.S. Virgin Islands (St. Croix, St. Thomas, and St. John).



Children with Special Health Needs

The National Information System for Health-Related Services

University of South Carolina Center for Developmental Disabilities Computer Sciences Division 1244 Blossom Street Columbia, SC 29208 (803) 777-4435 MCHIP MCJ-453511 12/01/84—11/30/88 Project Director(s): Girish G. Yajnik

This project seeks to develop a National Information System (NIS) for Health-Related Services to more effectively match health needs with appropriate services and to promote increased access to information on available services. NIS offers three distinct features: (1) Free access via a 1-800 telephone line for disabled individuals and health professionals; (2) human interaction between consumers and counselors resulting in direct referrals to appropriate service agencies; and (3) periodic followup on referrals to ensure the system's accuracy and effectiveness.

Audiology and Speech Training

Vanderbilt University School of Medicine 21st Avenue South Nashville, TN 37232 (615) 320-5353 Training MCJ-000217 07/01/84—06/30/92 Project Director(s): Fred H. Bess, Ph.D.

This program focuses on developing trainees who have specific expertise in working in medically oriented multidisciplinary settings. It prepares highly competent professionals at Vanderbilt and, through a cooperative agreement, at Tennessee State University to meet the unique and special needs of mothers and children with speech, language, or hearing handicaps.

Postgraduate Training in Children's Dentistry

University of Tennessee at Memphis 875 Union Avenue Memphis, TN 38163 (901) 528-6206

Training MCJ-000907 07/01/53—06/30/89 Project Director(s): Harry Sharp, D.D.S.

This residency training program in pediatric dentistry focuses on the provision of services to handicapped children. The program seeks to establish and enhance communications and linkages among several agencies involved with health services for handicapped children in Mississippi, Arkansas, and Tennessee.



University Affiliated Training Center

University of Tennessee at Memphis Child Development Center 711 Jefferson Avenue Memphis, TN 38105 (901) 528-6511 Training
MCJ-000900
07/01/84—06/30/89
Project Director(s):
Gerald Golden, M.D.

The Child Development Center trains personnel representing 16 clinical specialties that serve mentally retarded and developmentally disabled populations. The center provides training and services in the following areas: Social work, pediatrics, genetics, biochemistry, dentistry, nutrition, nursing, audiology, speech pathology, psychology, special education, occupational therapy, and physical therapy. The center also serves as a central resource for program development, information, continuing inservice education, technical assistance, and consultation in the mid-south area.

Baylor Laboratory Training Program

Baylor College of Medicine Institute for Molecular Genetics 1 Baylor Plaza Houston, TX 77030 (713) 799-5820 Training
MCJ-009121
10/01/88—06/30/93
Project Director(s):
Edward R.B. McCabe, M.D., Ph.D.

This project will provide postdoctoral training in state-of-the-art molecular genetics techniques used in the diagnosis of genetic disease. The program will include interpretation and application of laboratory findings and development and integration of laboratory services as components of systems of genetic care for maternal and child health populations. Activities include an annual workshop on molecular genetics techniques for professional personnel working in clinical laboratories and genetics clinics.

Training of Speech-Language Pathologists

Our Lady of the Lake University at San Antonio 411 Southwest 24th Street San Antonio, TX 78285 (512) 434-6711, ext. 413

Training MCJ-009099 07/01/87—06/30/91 Project Director(s): Earlene Paynter, Ph.D.

This project provides financial assistance to qualified persons interested in working with children, their mothers, and other family members with communication disorders. The ultimate objectives are to increase the number of qualified speech and language pathologists, and to increase the number of persons qualified to identify and habilitate communication disorders in minority populations.



Children with Special Health Needs

Un'versity Affiliated Center

University of Texas Southwest Medical Center at Dallas 200 Treadway Plaza Exchange Park Dallas, TX 75235 (214) 688-7117

Training
MCJ-002000
07/01/85—06/30/90
Project Director(s):
Mark Swanson, M.D.

The purpose of this project is to contribute to the improved health status of mothers and children, particularly children with disabling conditions and chronic illnesses. This is achieved through a coordinated program of advanced, interdisciplinary preservice training, continuing education, and technical assistance for State programs; provision of tertiary services and demonstration of models for improved scope and comprehensiveness of services; applied research; and dissemination. The center serves as the focal point for training and research in child development disabilities in the five States in the region.

Familial Adaptation to Developmentally Delayed

Children
University of Washington
Child Development and Mental Retardation Center
Seattle, WA 98195
(206) 545-1278

Research MCJ-530517 05/01/85—03/31/89 Project Director(s): Keith A. Crnic, Ph.D.

This investigation has two major objectives: (1) To determine whether parents of a developmentally delayed child differ from control parents across measures of parent-child interaction, attitudes, family status, coping resources, and perceived stress; and (2) to identify the degree of stress perceived by these families and the moderating effects of various coping resources on family adaptation. It is hypothesized that families with a developmentally delayed child will report greater stress, and that this stress will adversely impact both the family unit and its individual members.

Family-Centered Nursing for Children with Handicaps

University of Washington Nursing Department SC-74 Seattle, WA 98195 (206) 545-1291 Training
MCJ-000909
07/01/84—06/30/93
Project Director(s):
Patricia Brandt, Ph.D.

The Children with Handicaps Training Project is designed to be responsive to the health care needs of children with handicapping conditions, the health program needs of clinical nurse specialists, and the continuing education and societal needs for graduate nursing education programs. The program prepares nurses at the graduate level for specialization and leadership positions in the health care of these children.



Pediatric Pulmonary Center Training

University of Washington School of Medicine Department of Pediatrics RD-20 Seattle, WA 98195 (206) 543-3200 Training
MCJ-000955
07/01/85—06/30/90
Project Director(s):
David Woodrum, M.D.

This program serves as an interdisciplinary training center for personnel who will be leaders in the development of service, educational, and research programs in the field of pulmonary disease in infants and children and provides a regional resource for short-term, indepth, and continuing education training in the medical and psychosocial aspects of pediatric pulmonary diseases. In addition, the program functions as a model pulmonary disease tertiary care facility for the northwestern region of the United States, and promotes both clinical and laboratory research relevant to the prevention and treatment of pulmonary disease in the pediatric age group.

University Affiliated Training Center

University of Washington
Child Development and Mental Retardation Center
Clinical Training Unit
WJ-10
Seattle, WA 98195
(206) 545-1350

Training
MCJ-000913
07/01/85—06/30/90
Project Director(s):
Clifford J. Seils, M.D., M.P.H.

The Child Development and Mental Retardation Center is an interdisciplinary center dedicated to preventing and ameliorating developmental disabilities by providing advanced professional training, exemplary services, clinical research, community outreach, and technical assistance to the region. The project provides training for approximately 200 students each year, while providing services to more than 2000 clients. The major commitment of the project is to provide training for future leaders in the field.

Interdisciplinary Physical Therapy Training

University of Wisconsin at Madison 2120 Medical Sciences Center 1300 University Avenue Madison, WI 53706 (608) 262-7421 Training
MCJ-009102
10/01/87—06/30/92
Project Director(s):
Kenneth J. Ottenbacher, Ph.D.

The purpose of this project is to educate and train pediatric occupational and physical therapists to provide exemplary service, research, and leadership in dealing with handicapped children and their families. Education and training will occur in the context of an existing interdisciplinary degree. The project will result in the development of an MCH pediatric specialization within the master's degree in therapeutic science. This specialization will include concentrated coursework in pediatric intervention and the development of research and evaluation skills relevant to pediatric occupational and physical therapy practice.

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Children with Special Health Needs

Pediatric Pulmonary Care Training

University of Wisconsin at Madison Clinical Sciences Center 600 Highland Avenue Madison, WI 53792 (608) 263-8555 Training
MCJ-009072
10/01/85—06/30/90
Project Director(s).
Elaine Mischler, M.D.

The emphasis of this pediatric pulmonary center is on interdisciplinary training in a broad range of health-related disciplines in the understanding, approach, and delivery of effective patient care. The program is structured around four critical transition points in pediatric pulmonary care: (1) Transition from delivery in a neonatal intensive care unit to the general pediatric unit; (2) transition of the adolescent with a chronic lung disease from pediatrics to the internal medicine care setting; (3) transition of the chronically ill pulmonary patient to the home setting; and (4) transition of the chronically ill child from the home into the community.

University Affiliated Training Center

University of Wisconsin at Madison 750 University Avenue Madison, WI 53706 (608) 263-7108

Training MCJ-000915 07/01/84—06/30/89 Project Director(s): Raymond Chun, Ph.D.

This program provides interdisciplinary training for persons throughout the university studying in fields related to human development and handicapping conditions, provides health services in a clinical/educational setting to persons with chronic handicapping conditions, and shares its resources and expertise through outreach activities with local, State, and national agencies. Research related to human development and developmental disorders is also conducted.



Chronic Illness, Disabling Conditions

Technology Dependent, Medically Fragile 17

A Model for Home and Community Care for Children Who Are Technology Assisted Coordinating Center for Home and Community Care P.O. Box 613 Millersville, MD 21108 (301) 987-1048 MCHIP MCJ-245023 10/01/87—06/30/90 Project Director(s): Joanne Kaufman

This project develops a model for public/private sector collaboration in financing and case managing home care for technology-assisted children. The project also develops a methodology for educating professionals in case management for family-centered care; identifies and analyzes alternatives to hospitalization; provides family-centered case management services to over 300 Maryland children funded by Medicaid or third-party payers; and publishes monographs on family-centered case management.

Quality Home Care for Chronically III
Children in a Sparsely Populated Area
Utah Department of Health and
the University of Utah
Division of Family Health Services
44 Medical Drive
Salt Lake City, UT 84132
(801) 581-2410

MCHIP MCJ-493629 07/01/85—06/30/89 Project Director(s): Dennis W. Nielson, M.D., Ph.D.

In order to develop a model program for children who require technologically sophisticated care, this project seeks to determine the number of technology-dependent children in home care in the project area and to identify the problems encountered by their caregivers and support service providers. Further activities include developing and implementing protocols, standards of care, and teaching materials; disseminating information; and developing a clinical outreach program.

Benefits of an Interdisciplinary Approach to Feeding Aversion: A Feeding Needs Project University of Wisconsin at Madison 750 University Avenue Madison, WI 53706 (608) 263-6477

MCHIP MCJ-555010 07/01/87—06/30/90 Project Director(s): C.D. Schoenwetter, M.D.

The purpose of this project is to develop a high quality, comprehensive service delivery model for medically fragile children with special needs, their families, and health care providers. Project goals include enhancing all aspects of child development related to feeding; providing an interdisciplinary team as a resource in the home community; developing an interagency linkage system to coordinate services; and developing strategies to prevent feeding aversion in future medically fragile populations.



Technology Dependent, Medically Fragile

Thalassemia Screening and Counseling Project

Association of Asian/Pacific Community Health Organizations 310 8th Street Suite 210 Oakland, CA 94607 (415) 272-9536 Genetics MCJ-061009 10/01/88—09/30/91 Project Director(s): Laurin Mayeno

The goal of this project is to increase access to thalassemia screening, counseling, and education services for Southeast Asian refugee patients at Association of Asian/Pacific Community Health Organizations (AAPCHO) centers. Project activities include developing a screening protocol, developing a computerized tracking system for prevalence rates and followup, developing and implementing plans for each center, and compiling and evaluating existing materials for accuracy and cultural relevance.

Comprehensive Hereditary Anemia Program For Hawaii

University of Hawaii
Office of Research Administration
1540 Maile Way
Box 4C
Honolulu, HI 96822
(808) 948-6834 or 948-6872

Genetics MCJ-153562 01/01/85—09/30/89 Project Director(s): Yujen E. Hsia, M.D.

This project aims to screen diverse Asian populations living in Hawaii for hemoglobin or glucose-6-phosphate dehydrogenase variants in order to determine how best to detect all possible combinations of these variants; estimate their gene frequencies; record their clinical manifestations; and assess the effects of early detection, genetic counseling, prenatal diagnosis, and integrated health management. The program provides education to communities and physicians, written explanations accompanying diagnoses to heterozygotes, and longitudinal comprehensive care to anemic patients in cooperation with their primary physicians.



Comprehensive Care for Cooley's Anemia, Thalassemia

New England Thalassemia Program/Developmental Evaluation Clinic 300 Longwood Avenue Boston, MA 02115 (617) 733-6501 Genetics MCJ-251005 07/01/88—06/30/91 Project Director(s): Allen C. Crocker, M.D.

The overall goal of the New England Thalassemia Program is to improve the quality of treatment for patients with thalassemia. Project objectives are to: (1) Disseminate information and provide community education about thalassemia, (2) identify all patients and carriers in the Region I area, (3) provide comprehensive medical care for Region I thalassemia patients, (4) provide services to promote optimal quality of life, (5) address challenges in providing services to the high-risk Southeast Asian refugee population, and (6) participate in and enhance the implementation of clinical research

South Cove Thalassemia Screening and Education Program

South Cove Community Health Center 885 Washington Street Boston, MA 02111 (617) 482-7555 Genetics MCJ-251004 10/01/87—09/30/90 Project Director(s): Rosalinda Ott, M.D.

This project uses an intradepartmental, multidisciplinary approach to provide screening, case finding, and counseling services. Specific program objectives are to increase identification of patients with thalassemias through blood tests; to provide counseling, education, and support for these patients and for those at risk for trait; and to increase patient and community awareness of the disease and its control through individual and community education efforts.

New York State Cooley's Anemia and Alpha Thalassemia Program

New York State Department of Health and Health Research, Inc.
Laboratory of Human Genetics and Birth Defects Institute
Wadsworth Center for Laboratories and Research Albany, NY 12201
(518) 474-6797

Genetics MCJ-361007 10/01/88—09/30/91 Project Director(s): Ann M. Willc, , Ph.D.

The purpose of this project is to provide expert medical care and counseling for patients with thalassemia and their families; to provide screening and genetic counseling to the general population in order to detect carriers; and to provide education for health professionals and the general public about this group of diseases. Four centers to provide these services have been established, each at an outstanding medical center within the State. Treatment of affected patients includes an intensive transfusion regimen, intensive chelation therapy to remove excess iron, an appropriately timed splenectomy, prevention of infections, treatment of endocrine deficiencies, early detection of other complications, and counseling to promote normal psychological development and planning for survival through mid-life.



Children with Special Health Needs

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Mountain States Regional Hemophilia Center (MSRHC) Program

University of Arizona Health Sciences Center Department of Pediatrics 1501 North Campbell Avenue Tuscon, AZ 85724 (602) 626-6527 Hemophilia MCJ-042002 10/01/85—09/30/90 Project Director(s): James J. Corrigan, Jr., M.D.

Because the Mountain States Region is large in geographic area, a regionalized approach is necessary to solve the problems relating to hemophilia, HIV infection, and AIDS. Using a multidisciplinary team approach, the Mountain States Regional Hemophilia Center Program will work toward the achievement of a series of objectives, including, but not limited to: Assessing the type and severity of hemophilia and other less frequently encountered congenital bleeding disorders; detecting inhibitors; performing periodic comprehensive evaluations; providing HIV screening, medical evaluation, and studies of immune function; teaching home (self-infusion) therapy; providing social, psychiatric, vocational, and genetic counseling; participating in investigative studies relating to hemophilia and its complications; and testing new clotting factor concentrates.

Arkansas Hemophilia Diagnostic and Treatment Center

Arkansas Children's Hospital 800 Marshall Street Little Rock, AR 72202-3591 (501) 271-9192 Hemophilia MCJ-052001 10/01/85—09/30/90 Project Director(s): Morris Kletzel, M.D.

The primary goals of this project are to continue to make comprehensive care available to the adult population, and to provide education for center personnel. Additional objectives include communicating to local physicians who care for patients with hemophilia concerning the service components of the centers and their results; aiding in the development of the Arkansas Chapter of the National Hemophilia Foundation; and continuing efforts toward AIDS prevention by encouraging safe sexual practices, the use of safe blood products, and the prevention of opportunistic infections.

Case Management Demonstration Program,

Los Angeles County

Los Angeles Pediatric AIDS Network California Children's Services Department of Health Services Los Angeles County 2064 Marengo Street Los Angeles, CA 90033 (213) 226-2405

Pediatric AIDS BRH-P09001 08/01/88---07/31/91 Project Director(s): Dale Garell, M.D.

This project will deliver specialized services through a case management system for maternal and pediatric patients with HIV infection. Program objectives include development of an automated case management system, provision of service coordination, provision of a community education program, establishment of a resource bank for community-based services, and the addition of a clinical social worker to provide ambulatory and outreach services.

CHMC-UCSF Northern Coastal California

Hemophilia Program

Children's Hospital Medical Center of Northern California Department of Hematology 747 52nd Street Oakland, CA 94609 (415) 428-3372

Hemophilia MCJ-062008 10/01/86---09/30/90 Project Director(s): Marion Koerper, M.D.

The primary purpose of this center is to provide continued and expanded comprehensive services to all hemophilia and hemophilia-related patients in its catchment area. Project goals focus on the following areas: Patient care services; education; regionalization; relationships with HMOs, PPOs, and State thirdparty programs; participation in the Region IX AIDS Help and Prevention Plan; continued expansion of the center's adult component; and research.

Collaborative Study of the Effects of HIV Development on Hemophilic Children Children's Hospital of Los Angeles 4650 Sunset Boulevard Los Angeles, CA 90027 (213) 660-2450

Research MCJ-060570 05/01/88—04/30/93 Project Director(s): Edward D. Gomperts, M.D.

This study proposes to examine a very important group of children who are infected with HIV. The patients to be studied include children with hemophilia who received repeated infusions of clotting factor concentrate derived from pooled human blood plasma prior to routine screening of the blood supply. A prospective longitudinal study will be conducted to examine changes in neurological and neuropsychological functioning, physical growth and development, and immunological status in children and adolescents with hemophilia who were exposed to HIV and in matched control groups of HIV-negative hemophilia patients and their siblings. The degree of impairment is predicted to be related to the immunologic impairment, age, and hemophilia status of the children.



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Children with Special Health Needs

Hemophilia Center Orthopedic Hospital 2400 South Flower Street P.O. Box 60132 Terminal Annex Los Angeles, CA 90007-2697 (213) 742-1357 Hemophilia MCJ-062006 10/01/86—09/30/90 Project Director(s): Shelby L. Dietrich, M.D.

This program provides comprehensive and expert care services to persons with hemophilia. Services include professional treatment and referral to community resources, annual evaluations and individualized treatment plans, clinical research, patient education for participation in self-care, and medical and support services for HIV-infected patients and their partners or families.

Hemophilia Comprehensive Care Center

Children's Hospital of Los Angeles Division of Hematology/Oncology 4650 Sunset Boulevard Los Angeles, CA 90027 (213) 669-2121 Hemophilia MCJ-062009 10/01/86—09/30/90 Project Director(s): Edward D. Gomperts, M.D.

This center serves as a regional resource designed to support hemophilia care providers in their efforts to meet the growing challenges before them, including: Increasing expertise and resources to deal aggressively with HIV from a medical and psychosocial standpoint; providing effective risk reduction services to prevent further spread of this disease; conducting medical and psychosocial research to learn the most effective ways to combat this disease; and sharing knowledge with other care providers and the community. Four main approaches are being used to meet these challenges: (1) Staff inservice education; (2) consumer education programs; (3) evaluation strategies; and (4) the Peer Support Program.

University of California at Davis (UCD) Northern Central California Hemophilia Program

University of California at Davis UCD Medical Center at Sacramento Department of Pediatrics 4301 X Street Sacramento, CA 95817 (916) 453-2782 Hemophilia MCJ-062007 10/01/86—09/30/90 Project Director(s): Charles F. Abilgaard, M.D.

The UCD Northern Central California Hemophilia Program provides comprehensive diagnostic and treatment services for individuals with hemophilia and von Willebrand disease who live within its catchment area. The goals of the center are to furnish the best medical treatment possible; provide education to patients, families, care providers, agencies, and center staff; cooperate with consumer organizations; and conduct research to benefit the patient population. These goals are being achieved through clinical services, cooperation and consultation, group meetings, individual contracts, mailings, telephone interviews, and videos.



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Mountain States Regional Hemophilia Center (MSRHC)

University of Colorado Health Sciences Center Department of Pediatrics 4200 East Ninth Avenue Box C222 Denver, CO 80262 (301) 394-8471 Hcmophilia MCJ-082002 10/01/85—09/30/90 Project Director(s): William E. Hathaway, M.D.

Because the Mountain States Region is large in geographic area, a regionalized approach is necessary to solve the problems relating to hemophilia, HIV infection, and AIDS. Using a multidisciplinary team approach, the Mountain States Regional Hemophilia Center Program will work toward the achievement of a series of objectives, including, but not limited to: Assessing the type and severity of hemophilia and other less frequently encountered congenital bleeding disorders; detecting inhibitors; performing periodic comprehensive evaluations; providing HIV screening, medical evaluation, and studies of immune function; teaching home (self-infusion) therapy; providing social, psychiatric, vocational, and genetic counseling; participating in investigative studies relating to hemophilia and its complications; and testing new clotting factor concentrates.

Comprehensive Hemophilia Diagnostic and Treatment Center

Children's Hospital National Medical Center Department of Hematology-Oncology 111 Michigan Avenue, N.W. Washington, DC 20010 (202) 745-2140 Hemophilia MCJ-112002 10/01/85—09/30/90 Project Director(s): Craig Kurler, M.D.

The goal of this program is to continue to provide hemophilia comprehensive care and to continue to recruit new patients into existing comprehensive care programs through outreach efforts. In addition, the following HIV/AIDS infection prevention services will be provided: (1) Longitudinal patient education, psychosocial assessment, and counseling services; (2) peer group support and counseling services; and (3) patient-to-patient networking services.

Pediatric AIDS Health Care Demonstration Project, Dade County

Public Health Trust - Dade County 1611 Northwest 12th Avenue Miami, FL 33136 (305) 549-7744 Pediatric AIDS BRH-P04010 08/01/88—07/31/91 Project Director(s): Philip J. Plummer

This project will support multispecialty teams to consult at nine community clinics, and to provide screening services for HIV and special immunology consultations for the comprehensive care of HIV-positive children. The program will also provide continuing education to clinic staff and early intervention services to infants and young children.



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Pediatric AIDS Demonstration Project, Georgia

Georgia Department of Public Resources Division of Public Health 878 Peachtree Street, N.E. Room 217 Atlanta, GA 30309 (404) 894-6622 Pediatric AIDS BRH-P04005 08/01/88—07/31/91 Project Director(s): Virginia D. Floyd, M.D.

Five community components will assist the Division of Public Health in this demonstration project. Each center has its own specific objectives and methods for achieving them. These objectives include establishing models of diagnostic, treatment, referral, and outpatient care for pediatric HIV infection; providing outreach services, education, counseling, and testing for HIV-positive children with hemophilia; providing group support therapy for HIV-positive pregnant women and mothers of HIV-positive infants; and providing outreach to minority adolescents.

Great Plains Regional Hemophilia Center

University of Iowa Department of Pediatrics 2520 Colloton Pavilion General Hospital Iowa City, IA 52242 (319) 356-3422 Hemophilia MCJ-192002 10/01/85—09/30/90 Project Director(s): C. Thomas Kisker, M.D.

This project is designed to address problems occurring at hemophilia centers in Region VII. Specifically, the project will seek to: (1) Persuade inactive hemophilia patients to attend annual comprehensive clinics; (2) continue to provide quality comprehensive health care services despite decreasing funds; (3) increase the knowledge of hemophilia/AIDS and improve the continuity of care; (4) ensure that all hemophilia patients have adequate supplies of treatment products; and (5) reduce the transmission of HIV. Strategies include patient followup, fundraising efforts, educational workshops, discussion of treatment alternatives, and patient counseling regarding HIV risk reduction techniques.

Pediatric AIDS Program in New Orleans

Children's Hospital of New Orleans 200 Henry Clay Avenue New Orleans, LA 70117 (504) 899-9511 Pediatric AIDS BRH-P06030 08/01/88—07/31/91 Project Director(s): Michael Kaiser, M.D.

This project will use a regionalized systems model for providing a child-centered, family-focused program to children with HIV infection. The project will provide direct services at an area clinic for HIV-infected children, and will develop case management plans that are coordinated with maternal care plans. In addition, the program will provide alternative living arrangements, train individuals who interact with pediatric patients, bring psychosocial support to children and their families, reach out to high-risk youth, and develop resource materials.



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Boston Pediatric AIDS Project Dimock Community Health Center 55 Dimock Street Roxbury, MA 02119 (617) 442-8800 or 442-8802 Pediatric AIDS BRH-P01026 08/01/88—07/31/91 Project Director(s): Jackie Jenkins-Scott

A coalition of 16 nonprofit community agencies will work together in this project to provide a full range of medical and supportive services to women and children who have or are at high risk for HIV infection. The project will include a new residential program for pregnant incarcerated women, the first such program in the country.

New England Azea Comprehensive Hemophilia Center (NEACHC)

Worchester Memorial Hospital 119 Belmont Street Worcester, MA 06105 (617) 793-6276 Hemophilia MCJ-252002 10/01/87—09/30/90 Project Director(s): Peter H. Levine, M.D.

The goal of the NEACHC is to continue to provide access to comprehensive care for patients in each of the six New England States, taking into account geographical and travel needs and the unique experience, expertise, and commitment of the staff and facilities to provide comprehensive hemophilia care. The center in Worcester is the core center for Region I. The goals of this center, relating both to the affiliate centers and to the patients, include the following: Maintaining a network of regional comprehensive care centers; collecting data on health outcomes, psychosocial outcomes, and vocational outcomes; providing comprehensive services to patients; providing education and outreach to medical and paramedical staff from New England and other regions; facilitating clinical research efforts which would not otherwise be available in each State; and expanding the regional information system for AIDS, fo both patients and health professionals.

A Model Program for Pediatric AIDS Prevention and Control in Michigan

Michigan Department of Health Center for Health Promotion 3423 North Logan Street P.O. Box 30195 Lansing, MI 48909 (517) 335-8368 Pediatric AIDS BRH-P05032 08/01/88—07/31/91 Project Director(s): Jean Chabut

This project builds a structure for access to specialty medical services, coordinated care, and case management services. An outpatient center will serve both mothers and children at the same site. An attempt will be made to fill identified gaps in existing programs whose resources are being pressed by high and rising caseloads of HIV infection. The overriding purpose of the project to prevent HIV infection by carrying out the recommendations of the State Maternal and Child AIDS Task Force.



Children with Special Health Needs

Region V East Hemophilia Treatment Center and AIDS Risk Reduction Network

Hemophilia Foundation of Michigan 411 Huron View Boulevard Suite 101 Ann Arbor, MI 48104 (313) 761-2535 Hemophilia MCJ-262003 10/01/83—09/30/90 Project Director(s): Sally Crudder, R.N.

The primary goals of this project are to: (1) Maintain a regionalized network of comprehensive and diagnostic treatment services in Michigan, Indiana, and Ohio; (2) maintain multidisciplinary services at treatment centers strategically located throughout the catchment area; (3) provide outreach services to patients, their families, community agencies, and professionals throughout the catchment area; (4) offer AIDS risk reduction services through education and counseling services; and (5) strengthen the network of psychosocial services available for patients regarding hemophilia and HIV infection. The project plan includes provision of nonphysician salary support for nurse coordinators, social workers, and other core treatment center staff so that each center in the catchment area has the capability to offer basic diagnostic and comprehensive hemophilia care.

Comprehensive Hemophilia Care Center

University of Medicine and Dentistry of New Jersey Rutgers Medical School Academic Health Science Center CN 19 New Brunswick, NJ 08903 (201) 937-7679 Hemophilia MCJ-312002 10/01/87—09/30/90 Project Director(s): Parvin Saidi, M.D.

The New Jersey Regional Hemophilia Program (NJRHP) is a statewide program and referral resource for hemophilia and related bleeding disorders. The objective of this project is to continue the NJRHP and to expand its operation in providing high quality care to the more than 800 estimated patients in New Jersey with hemophilia and related bleeding disorders. In addition, the project plans to disseminate accurate and constructive information on AIDS (including ways to reduce the risk of transmission) and to provide psychological support and stress management services for all patients and their families.

Development of a Statewide Health Services
Network for Children with HIV Infection and
Their Families, New Jersey
New Jersey Department of Health
Special Child Health Services
CN 364
Trenton, NJ 08625
(609) 292-5676

Pediatric AIDS BRH-P02011 08/01/88—07/31/91 Project Director(s): Barbara Kem

Hospitalization of children with chronic conditions has been kept to a minimum through the New Jersey Department of Health's efforts to provide comprehensive, coordinated, family-focused services. The goal of this project is to further this work through (1) the development of a statewide network of pediatric HIV treatment centers, and (2) the provision of information, education, and training to other providers and agencies on a local and national basis through the resource center at Children's Hospital of Newark. In addition, a sourcebook on the care of children with HIV infection will be developed and disseminated.

ERIC Full Text Provided by ERIC

Hemophilia/AIDS

Comprehensive Hemophilia Diagnostic and Treatment Center Long Island Jewish Medical Center Lakeville Road New Hyde Park, NY 11042 (718) 470-7380 Hemophilia MCJ-362006 10/01/87—09/30/90 Project Director(s): Richard A. Lipton, M.D.

The Comprehensive Hemophilia Diagnostic and Treatment Center was established as a specialty center for the treatment of hemophilia. The center provides a comprehensive, multidisciplinary program to more than 300 patients. Project objectives include: (1) Identifying all persons with coagulation disorders in the catchment area; (2) assuring the availability and accessibility of quality comprehensive care to all identified patients; (3) educating and addressing the needs of patients, families, health care providers, and the community regarding the condition; (4) managing blood resources, reducing costs, and delivering quality care; (5) collaborating with scientific experts to conduct clinical and basic research of potential benefit to patients; and (6) implementing an AIDS/HIV infection prevention program to reduce the risk and psychosocial impact of AIDS/HIV for patients, families, and providers.

Family AIDS Case Management Program, New York City

Income and Medical Assistance Administration Human Resources Administration 250 Church Street Room 1416 New York, NY 10013 (212) 553-5151 Pediatric AIDS BRH-P02046 08/01/88—07/31/91 Project Director(s): Carol Raphael

This project will provide ongoing case management services to support families with AIDS. A multispecialty team, consisting of a nurse, social workers, AIDS family specialists, and case managers, will interact with health care teams throughout the metropolitan area. Case managers will secure financial assistance, medical care, home care, foster care, and transportation, in addition to providing counseling and home visits to families of HIV-infected patients.

Hemophilia Center - Rochester Region, Inc. Rochester General Hospital 1425 Portland Avenue Rochester, NY 14621 (716) 544-3630 Hemophilia MCJ-362005 10/01/87—09/30/90 Project Director(s): Joyce Strazatosco

The primary goals of this comprehensive program are to control bleeding episodes among hemophilia patients in order to avoid the crippling effects of joint disease and to enable patients to lead normal lives. This will be accomplished through provision of annual comprehensive evaluations, replacement therapy, and psychosocial assessments; and a patient education program supplemented by training and placement on a home care program allowing self-infusion of prescribed blood products. The secondary goals of the project are to reduce the spread of AIDS and to reduce the stress of infected patients and their family members. This will be carried out through individual counseling, HIV testing, group discussions for education and support, and informational mailings.



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Northern Manhattan Women and Children HIV Demonstration Project Columbia University 600 West 168th Street New York, NY 10032 (212) 928-5103 Pediatric AIDS BRH-P02027 08/01/88—07/31/91 Project Director(s): Zena A. Stein, M.D.

This project features the development of a consortium involving the Columbia University School of Public Health, five major Northern Manhattan Medical Centers, and the Upper Manhattan Task Force on AIDS to provide health education, case management, and expanded health care services in Northern Manhattan to children with HIV infection and their families. The goals of this project are to promote regional coordination and planning in addressing the prevention of HIV infection in women and children, and to encourage respite care, foster care, and day care for children with HIV infection in an effort to limit unnecessary hospitalizations.

Regional Comprehensive Hemophilia
Diagnostic and Treatment Center
Mount Sinai Hemophilia Center
Department of Medicine
100th Street and 5th Avenue
New York, NY 10029
(212) 876-8701

Hemophilia MCJ-362004 10/01/87—09/30/90 Project Director(s): Louis M. Aledort, M.D.

The Mount Sinai Hemophilia Center is a specialty center that provides a comprehensive, multidisciplinary program to more than 700 patients. The program includes the services of a hematologist, orthopedist, pediatrician, internist, psychiatrist, physiatrist, genetic counselor, nurse clinician, social worker, HIV risk reduction educator and counselor, physical therapist, dental hygienist, vocational rehabilitation counselor, and financial counselor. The center is part of a network of centers that address issues of regional and national significance and serve as models of care delivery for other chronic conditions. Mount Sinai Hemophilia Center has developed a regionalized approach to care delivery by sharing personnel, resources, and services, and establishing linkages between levels of care with public, private, and voluntary providers.

Comprehensive Diagnostic and Treatment Center Bowman Gray School of Medicine of Wake Forest University Department of Pediatrics 300 South Hawthome Road Winston-Salem, NC 27103 (919) 748-4324 Hemophilia MCJ-372004 10/01/86--09/30/90 Project Director(s): Christine A. Johnson, M.D.

The goal of the hemophilia program is to provide comprehensive hemophilia care through the implementation of HIV testing, educational programs, and counseling services for individuals with hemophilia and their families. Regional AIDS counselors provide formal education and counseling sessions about HIV infection, emphasizing methods for reducing the risk of viral transmission.



Hemophilia/AIDS

Comprehensive Hemophilia Center University of North Carolina at Chapel Hill Center for Thrombosis and Hemostasis

433 Burnett-Womack Building Room 299H Chapel Hill, NC 27514

(919) 966-4419

Hemophilia MCJ-372005 10/01/86-09/30/90 Project Director(s): Campbell W. McMillan, M.D.

The objectives of this project are to: (1) Identify and enroll all persons with hemophilia in the project's catchment area; (2) demonstrate the benefits of comprehensive health care; and (3) collaborate with other health professionals in MCH Region IV regarding specific issues of health care services, training, and clinical research. Additional objectives relating to HIV infection and AIDS are to identify the serologic status and stage of HIV infection in all hemophilia patients enrolled in the center; identify and manage HIV- and AIDS-related stress in center patients; and instruct all center patients and their families regarding current recommended measures for reducing the risk of HIV transmission.

Hemophilia Diagnostic and Treatment Center

Oklahoma State Department of Human Services State of Oklahoma Teaching Hospitals P.O. Box 26307 Oklahoma City, OK 73126 (405) 271-3661

Hemophilia MCJ-402002 10/01/87-09/30/90 Project Director(s): Charles L. Sexauer, M.D.

The main goals of the Oklahoma Hemophilia Diagnostic and Treatment Center (OHTC), directed toward the patient population, are to: (1) Increase access to hemophilia care and HIV infection prevention services; (2) provide genetic counseling to potential carriers of factor VIII and IX deficiency; (3) provide an educational program on human sexuality and HIV infection to adolescents; (4) provide counseling about the risk of perinatal transmission of HIV; (5) educate health care providers and interested groups about hemophilia and HIV infection, and (6) increase communication among patients and families with common hemophilia and/or AIDS-related concerns. Activities during the second project year included establishing a universal information management system for OHTC, establishing three regional task forces, and expanding comprehensive hemophilia care provision and HIV counseling for adult patients with hemophilia.

Comprehensive Hemophilia Diagnostic and **Treatment Center**

Oregon Health Sciences University Cripoled Children's Division P.O. Box 574 707 Gains Southwest Road Portland, OR 97207 (503) 255-8716

Hemophilia MCJ-412002 10/01/87---09/30/90 Project Director(s): Everett W. Lovrien, M.D.

The purpose of this project is to maintain a hemophilia program which will provide regionalized comprehensive care for hemophilia in Oregon, Washington, Alaska, and Idaho. The project goals are to identify hemophilia patients, describe their health problems, and develop a health care plan for each patient. Included in the plan for project activities are assessments of the medical, psychological, vocational, demographic, financial, social, and family impact of hemophilia, patient education; and a treatment plan for anti-hemophilia infusion therapy.



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Comprehensive Care Program for Hemophiliacs

Pennsylvania State University College of Medicine Division of Hematology Milton S. Hershey Medical Center P.O. Box 850 Hershey, PA 17033 (717) 537-8399 Hemophilia MCJ-422004 10/01/85—09/30/90 Project Director(s): M. Elaine Eyster, M.D.

This project focuses on three main objectives: (1) Maintenance of psychosocial programs; (2) coordination and development of AIDS education/RFSR (risk and family stress reduction) counseling programs; and (3) promotion and integration of research activities, including NIH-funded spouse studies and clinical trials, which are essential for the development of effective programs for HIV prevention and therapy. The program has been especially successful in providing psychosocial, educational, and vocational services and interventions to patients with hemophilia.

Regional Hemophilia Diagnostic and Treatment Center

Cardeza Foundation Hemophilia Center Jefferson Medical College Main Building Suite 249 11th and Walnut Streets Philadelphia, PA 19107 (215) 928-7786 Hemophilia MCJ-422005 10/01/85 -09/30/90 Project Director(s): Sandor S. Shapiro, M.D.

The Cardeza Foundation Hemophilia Center and its satellite centers provide medical and psychosocial services for patients with genetic hemorrhagic disorders in eastern Pennsylvania, southern New Jersey, and Delaware. The major goals of the program are to: (1) Provide, in collaboration with the satellite centers, comprehensive medical and psychosocial services to patients with hereditary hemorrhagic disorders; (2) provide AIDS surveillance in patient population; and (3) develop and implement, along with other regional centers, an aggressive AIDS risk reduction program for hemophilia patients, their families, and sexual partners, as well as educational programs for health care providers in the region.

Puerto Rico Pediatric AIDS Demonstration Project

Puerto Rico Department of Health Box 70184 San Juan, PR 00936 (809) 765-6210 Pediatric AIDS BRH-P02044 08/01/88—07/31/91 Project Director(s): Magda Torres, M.D.

This project, developed by the Puerto Rico Department of Health and the Health Department of San Juan, will provide medical and social services to women, infants, and children in San Juan and six municipalities. Prevention will be emphasized through outreach and culturally adapted educational materials. Services to patients with AIDS will promote family unity and home care through a case management approach, using practical help and support services.



Hemophilia/AIDS

FACTS, Family AIDS Center for Treatment and Support

Rhode Island Department of Health 75 Davis Street Providence, RI 02905 (401) 277-2312

Pediatric AIDS BRH-P01012 08/01/88--07/31/91 Project Director(s): Peter Simon, M.D., M.P.H.

This center, developed by a group of medical professionals, social service providers, and religious leaders, provides residential, in-home, and community-based care for families with AIDS-related problems. Program components include an innovative crisis foster care feature to reduce unnecessary hospitalizations and comprehensive care provided through an individual family service plan.

Gulf States Hemophilia Diagnostic and Treatment Center

University of Texas Health Science Center at Houston
University of Texas Medical School
P.O. Box 20780
Houston, TX 77225
(713) 792-5450

Hemophilia MCJ-482004 10/01/87—09/30/90 Project Director(s): W. Keith Hoots, M.D.

This project focuses on three specific aims: (1) To provide all appropriate facets of clinical care to hemophilia patients enrolled in the Gulf States Hemophilia Center and to augment care provision in the Houston satellites to ensure comparable support facilities; (2) to educate and counsel hemophilia patients who have or are at risk for HIV infectic. about the methods available to reduce transmission of the virus; and (3) to facilitate and coordinate regionalization efforts of comprehensive care and AIDS/HIV risk reduction activities in the region. Two local hemophilia task forces will be established to advise and offer direction for these efforts.

North Texas Comprehensive
Hemophilia Center
University of Texas Health Science Center at Dallas
5323 Harry Hines Boulevard
Dallas, TX 75235
(214) 688-3388

Hemophilia MCJ-482003 10/01/84—09/30/90 Project Director(s): George Buchanan, M.D.

The North Texas Comprehensive Hemophilia Center was established in 1983 for the purpose of offering comprehensive diagnostic and treatment services to those children and adults with congenital blood coagulation disorders who reside in North Texas. The continued activities of the center will seek to address the multifaceted problems associated with hemophilia and its most serious complication, HIV infection. These problems will be approached through a closely linked array of clinical, educational, and research efforts carried out by skilled health care professionals who will deal with both pediatric and adult patients. Special efforts will be made to reach the underserved adult patient population.



Pediatric AIDS Health Care Demonstration Project, Texas

University of Texas Health Science Center at San Antonio 7703 Floyd Curl Drive San Antonio, TX 78284-7802 (512) 567-5200 Pediatric AIDS BRH-P06009 08/01/88—07/31/91 Project Director(s): John A. Mangos, M.D.

This project seeks to develop a network of health care delivery and AIDS prevention services through a public education program in Bexar County, and to increase the population served through a care and prevention demonstration clinic in McAllen, Texas. Case management, AIDS prevention programs, education of health professionals, and coordination with selected existing service agencies are integral to the project. Two unique features of the project are the use of Spanish and English to ensure service accessibility and the expansion of services from the metropolitan area throughout rural Southern Texas.

South Texas Comprehensive Hemophilia Center

University of Texas Health Science Center at San Antonio
Department of Pediatrics
7703 Floyd Curl Drive
San Antonio, TX 78284
(512) 691-6197

Hemophilia MCJ-482005 10/01/87---09/30/90 Project Director(s): Richard T. Parmley, M.D.

The overriding goals of the regional hemophilia program are to (1) maximize the quality of life of patients with hemophilia and other congenital coagulopathies; and (2) prevent the spread of HIV infection through patient and community education, while providing psychosocial support for dealing with the stress of this infection. To accomplish these goals, project objectives have been established in the areas of outpatient care, home care therapy and instruction programs, community awareness, counseling for adolescents regarding HIV infection, outreach mechanisms to nearby communities, and coordination of center efforts with other programs addressing similar concerns.

Seattle-King County Pediatric AIDS Demonstration Project

Seattle-King County Department of Public Health 110 Prefontaine Place, South #500 Seattle WA 98104 (206) 296-4677 Pediatric AIDS BRH-P10025 08/01/88—07/31/91 Project Director(s): Kathy Carson

This project will provide education and medical outreach to high-risk, homeless, incarcerated, and "street youth" populations. The project will also provide medical/social case management services for women and children who have, or are at high risk for, HIV infection or AIDS. Improved coordination and collaboration will be encouraged by agencies concerned with AIDS prevention and care for women, children, and youth. Screening, testing, and education services will be delivered under a subcontract with Seattle Youth and Community Services to achieve better outreach to "street youth."



Hemophilia/AIDS 143

Comprehensive Hemophilia Diagnostic and Treatment Center Great Lakes Hemophilia Foundation, Inc. 1725 West Wisconsin Avenue Milwaukee, WI 53233 (414) 344-0772 Hemophilia MCJ-552002 10/01/86—09/30/90 Project Director(s): Janice Hand

This project addresses the need for two forms of care to patients with hemophilia and their families: (1) Treatment for hemophilia and its psychosocial, financial, and school/employment-related complications; and (2) education and counseling toward preventing transmission of the AIDS virus. The goals of this project are to maintain a regional network of hemophilia treatment centers; provide multidisciplinary hemophilia treatment services; develop outreach services to encourage participation by all hemophilia patients and health care providers; reduce the risk of transmission of HIV infection and AIDS within the hemophilia community; and strengthen psychosocial supports to assist families in coping with AIDS and its impact.



Adolescent Health

Primary Care/Preventive Health Services Violence/Injury Prevention Youth in Transition



Adolescent Health Training

University of Alabama at Birmingham Division of Adolescent Medicine Department of Pediatrics University Station Birmingham, AL 35294 (205) 934-5262

Training
MCJ-000979
07/01/77---06/30/92
Project Director(s):
Ronald A. Feinstein, M.D.

The goals of this program are to provide comprehensive disciplinary training to health care professionals in adolescent health; maintain clinical programs that provide comprehensive, interdisciplinary health care for adolescents and their families; promote clinical research and the dissemination of information related to adolescent health care; and provide leadership and advocacy for adolescents at the local, State, regional, and national levels. Individual plans for discipline-specific training include clinical practicums, education, research, and leadership training.

Better Health for Rural Teens

Arkansas Department of Health 4815 West Markham Street Little Rock, AR 72205-3867 (501) 663-6812 MCHIP MCJ-053001 10/01/88—09/30/91 Project Director(s): Louise Dennis

The goals of this project are to (1) develop a community-based model to address adolescent health needs, and (2) improve the health of Lake View youth ages 10-19. Four health status improvement objectives have been outlined, based on a preliminary survey of Lake View youth. They are: (1) To reduce the number of youth who engage in unprotected intercourse; (2) to decrease the number of youth who seldom or never wear seat belts; (3) to reduce the number of youth who skip breakfast; and (4) to decrease the number of youth who skip dinner. Approaches to service delivery will include a weekly teen clinic, comprehensive health education, and an after-school teen program to promote physical fitness and positive lifestyles.



Primary Care/Preventive Health Services

Interdisciplinary Adolescent Health Training Project

University of California at San Francisco Division of Adolescent Medicine 400 Parnassus Avenue San Francisco, CA 94143 (415) 476-2184 Training
MCJ-000978
10/01/87—09/30/92
Project Director(s):
Charles E. Irwin, Jr., M.D.

The purpose of this project is to meet adolescent health care needs by training leaders in several health care disciplines within university, community, and regional settings. The overall program goal is that these leaders will continue to develop model comprehensive health care services for youth; create training programs for health professional students and community-based professionals; initiate innovative research; and formulate developmentally sound health policies that will create an environment which fosters successful transition from adolescence to productive adulthood.

YESS Project (Youth Enrichment Support Services)

San Francisco Department of Public Health 101 Grove Street Room 115B San Francisco, CA 94102 (415) 554-2560 MCHIP MCJ-063000 10/01/88—09/30/91 Project Director(s): Geraldine Oliva, M.D.

Balbca High School is an environment where the youth, 95 percent of whom are from minority groups, typically engage in a constellation of high-risk behaviors, such as substance abuse, gang activity, drunk driving, and unsafe sex. The three goals of this project are to: (1) Provide a structure of services which will enable low-functioning adolescents to overcome environmental barriers so that they can successfully negotiate their way to productive adult lives; (2) further elucidate and mitigate the contributing factors which lead to high-risk behaviors; and (3) create a positive environment which will support the positive changes in behavior made by adolescents enrolled in the YESS Project.

Partners in Action for Teen Health (PATH)

Colorado Department of Health 4210 East 11th Avenue Denver, CO 80220 (303) 331-8360 or 331-8372

MCHIP MCJ-083296 10/01/87—09/30/90 Project Director(s): Daniel J. Gossert Barbara Schricker Ritchen

This project seeks to prevent and/or reduce the nine health problems found among Colorado adolescents ages 10 through 19 that were identified in 1986 by the Colorado Department of Health and the Advisory Council on Adolescent Health. Efforts include the development of a model community service system, the collection and analysis of county-specific adolescent health information, and the development of a mechanism for replicating and disseminating the model throughout Colorado, Region VIII, and the United States.



Adolescent Health

Maternal and Child Health Adolescent Network (MCHAN) Hawaii Department of Health Maternal and Child Health Branch 741-A Sunset Avenue Honolulu, HI 96816 (808) 735-3056 MCHIP MCJ-153422 10/01/87—9/30/90 Project Director(s): Lisa A. Simpson, M.D., M.P.H.

This project will develop a health network to improve the health status of youth ages 10 to 19 years. By the end of the grant period, a permanent unit for adolescent health within the Department of Health will be established, a system to coordinate adolescent health services at the State level will be developed, and case management systems will be operating in three counties. The quality and quantity of data on adolescent health will be improved by gathering baseline data and setting minimum reporting requirements for other information.

A Program to Improve the Social/Emotional Functioning of Adolescents with Physical Handicaps

The University of Illinois College of Medicine at Chicago
Center for Craniofacial Anomalies
Department of Pediatrics
P.O. Box 6998-M/C 588
Chicago, IL 60608
(312) 996-7546

MCHIP MCJ-173103 10/01/87—09/30/91 Project Director(s): Kathy Kapp-Simon, Ph.D.

The goal of this program is to improve the social and emotional functioning of adolescents with physical handicaps. Particular emphasis will be placed on decreasing social inhibitions and increasing positive attitudes about appearance, self-awareness, empathetic communication, and the ability to be appropriately assertive in a social situation. These skills will help the youth adapt to their deformity and the stresses of adolescence in order to enhance their desire to go to school, to work, and ultimately, to live independently. Parents will be taught how to reinforce the skills.

Graduate Education in Adolescent Health Care

University of Maryland Walter P. Carter Center 630 West Fayette Street Room 5-686 Baltimore, MD 21201 (301) 328-6495 Training MCJ-000980 07/01/82—06/30/92 Project Director(s): Felix P. Heald, M.D.

This project is designed to train medical, nursing, nutrition, social work, and psychology students to deliver comprehensive health care to adolescents and to develop skills which will allow them to assume leadership positions in the field of adolescent health care. The program provides continuing education, consultation, and technical assistance to State and other agencies, conducts research on adolescent health service delivery, and advocates on behalf of adolescents.



Primary Care/Preventive Health Services

Adolescent Health Training Program University of Minnesota

Box 721 UMHC

Box 721 UMHC Harvard Street at East River Road Minneapolis, MN 55455 (612) 626-2820 Training
MCJ-000985
10/01/79—06/30/92
Project Director(s):
Robert W. Blum, M.D., M.P.H., Ph.D.

The goal of this program is to improve the status of American youth by developing leadership capabilities among those who will assume responsibility in the adolescent health care field, in both the academic community and in the public sector. The project seeks to recruit and train health care professionals from the fields of medicine, nursing, nutrition, psychology, and social work who wish to have an impact extending beyond individual patient care, and those whose work efforts will benefit the field of adolescent health care through the training of others, the development of service models, applied research, and other creative efforts relating to adolescent health care.

Interdisciplinary Training Program in Adolescent Health Care

University of Cincinnati College of Medicine Children's Hospital Medical Center Division of Adolescent Medicine Elland and Bethesda Avenues Cincinnati, OH 45229 (513) 559-4681 Training MCJ-000964 10/01/77—06/30/92 Project Director(s): Joseph L. Rauh, M.D.

This program is constructed around dual curriculums, an interdisciplinary core curriculum and a discipline-specific curriculum. The three goals of the project are to: (1) Maintain an interdisciplinary faculty and training program in adolescent health care for the instruction of health science and health care trainees from six disciplines—medicine, nursing, psychology, social work, nutrition, and special education; (2) maintain an exemplary service base which serves as a national model for the delivery of adolescent health care as well as a clinical setting for multidisciplinary trainees; and (3) develop the Adolescent Center for Education, which will produce and distribute printed and audiovisual educational materials for professionals, patients, and adolescents at a regional and national level.

Pilot Project for the Establishment of a Health Services System for Llorens Torres High Risk Youth San Juan Health Department Box 21405 Rio Piedras, PR 90928

(809) 763-6560

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MCHIP MCJ-723455 10/01/87—09/30/90 Project Director(s): Carmen Feliciano, M.D.

The overall goal of this project is to develop strategies which improve the physical, emotional, and mental health of Llorens Torres high-risk adolescents and which can be replicated in other metropolitan areas. Activities include the development of a multiservice, community-based health services system and the establishment of a multidisciplinary health team for the screening, evaluation, and treatment of youth enrolled in the project.

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Adolesc**ent Heal**th

Adolescent Health Training Project

University of Washington
Division of Adolescent Medicine
Child Development and Mental Retardation Center
WJ-10
Seattle, WA 98915
(206) 545-1249

Training MCJ-000970 10/01/77—06/30/92 Project Director(s): James A. Farrow, M.D.

This project has two principal goals. The first goal is to provide comprehensive health care and intervention services to adolescents and their families in the greater Seattle-King County area. The second goal is to provide local, regional, and national leadership in the identification of major adolescent health issues; the development of effective intervention strategies to meet the specialized health needs of adolescents; and the development of effective methods for training health care personnel in the skills required to meet those needs. The program provides supervised training in 12 settings, including school-based clinics, Children's Hospital and Medical Center, and the Residential Treatment Center for Juvenile Offenders.



Primary Care/Preventive Health Services

Break the Chains of Violence

Contra Costa County Health Department Prevention Program 75 Santa Barbara Road Pleasant Hill, CA 94523 (415) 646-6511 MCHIP MCJ-063220 10/01/87—9/30/90 Project Director(s): Nancy Baer Larry Cohen

The two major goals of this project are (1) to reduce the incidence of suicide, of assault and homicide, and of dating violence; and (2) to improve the coordination of violence prevention services in order to ensure the adoption of multifaceted prevention strategies over single focus interventions. The project serves adolescents in three communities. The central concept involved in reaching these goals is that the community must become involved in prevention activities at several concurrent levels in order to effect positive changes.

Risk-Tasking Behavior in Adolescents: Impact of Puberty

University of California at San Francisco School of Medicine Third and Parnassus Avenues

San Francisco, CA 94143 (415) 476-2184 Research MCJ-060564 12/01/87—11/30/90 Project Director(s): Charles E. Irwin, Jr., M.D.

The purpose of this study is to examine the relationships between the timing of physiological development and three risk-taking behaviors: Sexual activity, substance use, and accident-related behaviors. The underlying hypothesis driving this research is that the timing of physiological maturation predisposes adolescents to engage in certain risk-taking behaviors which fulfill critical developmental needs, both psychosocial and physiological, during the second decade of life.

Health Promotion Program for Urban Youth—Violence Prevention Project

Trustees of Health and Hospitals of the City of Boston, Inc.
Nurses Education Building 112
818 Harrison Avenue
Boston, MA 02118
(617) 424-5196

MCHIP MCJ-253420 10/01/87—9/30/90 Project Director(s): Alice Hausman

This project seeks to reduce the incidence of negative health outcomes of violence by making the clinical setting more responsive to the needs of youth at risk of, or engaged in, violent behavior. The project also seeks to link primary and secondary prevention services in order to generate a comprehensive approach to the problem.



Native American Adolesce Injury Prevention Project New Mexico Health and Environment Department P.O. Box 968 Santa Fe, NM 87504-0968 (505) 827-0192 MCHIP MCJ-353717 08/01/85—07/31/89 Project Director(s): Lydia Pendley

This project seeks to reduce the rate of unintentional injuries and deaths among Native American adolescents in New Mexico and throughout the Southwest Activities include collecting data on unintentional injuries among Native American teens, developing youth-oriented injury prevention methodologies, supporting local implementation of adolescent injury prevention strategies, and supporting policies and political emphasis on adolescent injury prevention.

Longitudinal Program to Reduce Drinking-Driving Among Adolescents University of Washington Division of Adolescent Medicine WJ-10 Department of Pediatrics Seattle, WA 98195 (206) 545-1249 MCHIP MCJ-533704 09/01/85 —11/30/88 Project Director(s): James A. Farrow, M.D.

This project aims to reduce the number of alcohol- and drug-related automobile accidents among 16-to 19-year-old drivers. Activities include the development of a questionnaire to be used to identify those students at highest risk for drinking and driving, the development of a state-of-the-art curriculum designed to deter this behavior, and the provision of specialized programming for those students thought to be at high risk for driving while intoxicated.



Adolescent Health

Youth in Transition—The Alabama Experience

Division of Rehabilitation and Crippled Children Services 2127 East South Boulevard Montgomery, AL 36199 (205) 288-0220 MCHIP MCJ-013630 07/01/85—06/30/89 Project Director(s): Delia T. Kenny

This project aims to design, develop, implement, monitor, and evaluate a community-based, outcome-focused service model in order to assist physically disabled and/or chronically ill adolescents who are at risk in their transition to maturity. The program will create an administrative structure at the State level and two pilot sites for the provision of an integrated continuum of health and education services. In addition, the program will provide training to enable service providers to coordinate service planning for youth at each site and to enable the adolescents and families to function as their own "case managers."

The Development of a Prevocational Training

Children's Hospital National Medical Center 111 Michigan Avenue, N.W. Washington, DC 20010 (202) 745-5483 MCHIP MCJ-115011 07/01/88—06/30/90 Project Director(s): Patience H. White, M.D.

The goals of this project are to determine if early vocational guidance can improve vocational readiness in adolescents with rheumatic disease and to expand the project to encompass children with chronic illnesses. The program includes prevocational assessment and counseling; an employment resource guide; outreach to children, families, and employers in the region; and a computerized data base with prevocational data.

National Center for Youth with Disabilities

University of Minnesota Adolescent Health Programs D-136 Mayo Memorial Building
Box 721 UMHC
Harvard Street at East River Road
Minneapolis, MN 55455
(612) 626-2825

MCHIP MCJ-273616 10/01/85—09/30/89 Project Director(s): Robert W. Blum, M.D., M.P.H., Ph.D.

The goals of this project are to expand the health and health-related knowledge and involvement of individuals, agencies, and programs providing services to youth with chronic illnesses and disabilities; to demonstrate service system models which allow adolescents to improve their growth, development, work, and participation in the community; and to support the design and implementation of State and community programs which deliver services to youth. Project activities include developing a computerized resource network to facilitate retrieval of information related to adolescents with chronic illnesses or disabilities.



Youth in Transition

Implementation and Evaluation of Psychosocial Services for Adolescents with Genetic Diseases

New York State Department of Health Bureau of Child and Adolescent Health Empire State Plaza Corning Tower Room 780 Albany, NY 12237 (518) 474-2749 Genetics MCJ-361005 10/01/84—09/30/90 Project Director(s): Barry Sherman, Ph.D.

This project aims to develop a model support program for the coordination and integration of psychosocial support services in order to meet the special needs of genetically affected adolescents and their families. An interdisciplinary team approach to care coordination and management will be used which emphasizes individual, family, and community resources for a more comprehensive and holistic response to the needs of these adolescents and their families.

Networking Services for Adolescents with Sickle Cell Disease: An Interdisciplinary

Demonstration Project

Sickle Cell Disease Research Foundation of Texas, Inc.

Box 8095 2410 Hamilton Suite 210 Houston, TX 77288 (713) 651-8071

(804) 924-2345

Genetics MCJ-481003 10/01/87—09/30/90 Project Director(s): Dolores M. Dodd

This project will develop a network of coordinated psychosocial community services designed to address the unmet psychosocial needs of adolescents with sickle cell disease and to assist these individuals in preparation for a productive adulthood. The program will focus on enhancing the self-concept and self-esteem of the adolescents enrolled in the program.

The Family Autonomy Program University of Virginia Medical Center Kluge Children's Rehabilitation Center 2270 Ivy Road Charlottesville, VA 22901 MCHIP MCJ-515019 10/01/87—09/30/90 Project Director(s): Sharon L. Hostler, M.D.

The goal of this project is to ensure the successful transition to adulthood of adolescents with physical disabilities or chronic illnesses by means of interventions with families, with the health care team, and with the adolescents themselves. The project seeks to encourage the involvement of families in planning for the health care of their children, to modify staff behaviors and institutional practices to promote family autonomy, and to broaden treatment goals so that they include health maintenance and future planning for adolescents with special needs.



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Adolesce. t Health

University of Washington Adolescent/Young Adult Transition Program

University of Washington Adolescent Clinic Division of Adolescent Medicine CDMRC WJ-10

Seattle, WA 98195 (206) 545-1273

MCHIP MCJ-535032 10/01/88—09/30/91 Project Director(s): James A. Farrow, M.D.

This program focuses on three main goals: (1) Improvement in care for chronically ill adolescents and young adults who are in need of transition to adult care; (2) assessment of health care costs in order to understand and facilitate the transition process and its financial impact on institutional and community health care systems; and (3) development of a transition model applicable to community general hospitals allowing maintenance of the health status of patients in their local communities. The program will establish a core interdisciplinary transition team to carry out various components of the transition program and to disseminate training organizational materials in two regional hospitals.



Youth in Transition

General Program Concerns

State Staff Development
MCH/Public Health Professional Development
Program Coordination and Networking
Financing
Data and Information
Overcoming Ethnocultural Barriers to Genetic Services



Section of l'amily Health Staff Development

Grant

Alaska State Section of Family Health 1231 Gambell Street Anchorage, AK 99501 (907) 274-7626 MCHIP MCJ-023711 10/01/87—09/30/89 Project Director(s): Rita A. Schmidt, M.P.H.

The goal of this project is to improve the health status of women, children, and families by improving the planning and administrative capabilities of the Section of Family Health of the State of Alaska. Project activities include establishing a procedural plan that will lead to improved perinatal health care services for the women of Alaska and improving the data collection efforts of the Section of Family Health.

Training and Staff Development of MCH

Personnel

American Samoa Department of Health Pago Pago, AS 96799 (684) 633-1222, ext. 138 MCHIP MCJ-603501 10/01/87—09/30/89 Project Director(s): Tofiga Liaiga, M.D.

The purpose of this project is to provide training/technical assistance to MCH staff in reviewing local needs and problems of the target population and to provide assistance in dealing with these needs. The project will fund consultants with public health expertise to provide training in data management and health education to MCH staff, or will send key personnel off the island for training in these areas.

MCH Management Information System

Arizona Department of Health Services
Division of Family Health Services
1740 West Adams
Phoenix, AZ 85007
(602) 255-1223

MCHIP MCJ-043861 10/01/87---09/30/89 Project Director(s): Kate Zipenis, M.P.H.

The goal of this project is to develop and pilot-test an integrated MCH data base, which is linked to related data bases within the Division of Family Health Services and to other important data bases. Data entry will occur at the local level, where it can also be manipulated to meet local needs. Program objectives include reducing paperwork at the State and local levels, enhancing the ability for local data entry and manipulation to mee local needs, improving the ability at the State level for MCH programs to review contractor's performance and ensure quality assurance and contract compliance, and enhancing the management and planning capabilities of MCH program managers at the State level.



State Staff Development

Quality Assurance in Arkansas Maternity Clinics

Arkansas Department of Health Section of Maternal and Child Health 4815 West Markham Little Rock, AR 77205 (501) 661-2251 MCHIP MCJ-053521 10/01/87—09/30/89 Project Director(s): Deborah Bryant, M.D.

This project seeks to ensure the delivery of quality clinical care that is consistent with current prenatal standards. A maternity nurse practitioner will be hired to revise public health nurse protocols, develop quality assurance testing protocols for local health departments, establish a management information system as a data base for administrative tracking of clinical quality assurance activities, and conduct inservice training sessions and quarterly clinical conferences for public health nurses in each region.

Continuing Education in Maternal and Child Health

San Diego State University Foundation 6505 Alvarado Road Suite 205 San Diego, CA 92120 (619) 594-4493 or 594-4667 Training
MCJ-009079
10/01/87—09/30/89
Project Director(s):
Allan Oglesby, M.D.

The purpose of this project is to update and improve the knowledge and leadership skills of the State MCH directors and their key interdisciplinary professional staff in all States in the United States. The first component of the project focuses on leadership skills. The second, more advanced component deals with managerial and programmatic issues for middle and upper level management staff. The third component is an introductory course covering the purpose, philosophy, history, and legislation of State Maternal and Child Health Programs for inexperienced State MCH staff.

Staff Development Project - Breastfeeding Initiative

Commonwealth of the Northern Mariana Islands
Department of Public Health and Environmental Services
P.O. Box 409 CK
Saipan, MP 96950
(607) 234-8950

MCHIP MCJ-693250 10/01/88—09/30/89 Project Director(s): Jose T. Villagomez, M.D.

This project addresses the need for a mechanism by which to integrate available resources to conduct a breastfeeding campaign. The goal of the project is to provide training for management and key staff in the planning, implementation, evaluation, and continuation of a model statewide lactation program, including community outreach. The project's objective is to increase the knowledge and skills of professionals, paraprofessionals, and families concerning the need for and art of breastfeeding.



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General Program Concerns

Tri-Regional Education and Networking
Development System (TRENDS for MCH/CSHN
Nurse Leaders)
University of Delaware
345 McDowell Hall
Newark, DE 19716
(302) 451-8373

Training
MCJ-009054
10/01/84—09/30/89
Project Director(s):
Edith Anderson, Ph.D.

This project aims to develop and offer a series of continuing education courses for nurse consultant leaders in Department of Health and Human Services Regions I, II, and III. The focus of the program is to increase leadership skills among State MCH/CSHN nurses; develop a nursing network among States; and assist nurse leaders in developing new skills in planning State continuing education efforts.

MCH Staff Development

Guam Department of Public Health and Social Services P.O. Box 2816 Agana, GU 96910 (671) 734-2931, ext. 216 MCHIP MCJ-663666 10/01/87—09/30/89 Project Director(s): Laurent S.F. Duenas

This project seeks to continue to improve the effectiveness of health services and service personnel who directly or indirectly serve the families in the project area by evaluating the present services, developing a comprehensive quality assurance program, and improving the health information system.

Continuing Education in Maternal and Child Health

University of Kentucky College of Nursing Rose Street Lexington, KY 40536 (606) 233-5237 or 233-6533 Training
MCJ-000969
10/01/84—09/30/89
Project Director(s):
Carolyn Williams, D.N.S.

The purpose of this project is to increase the leadership competence of nurses functioning as State nursing consultants and/or administrators in Title V MCH and CSHN Programs in Regions IV and VI. Activities include providing continuing education courses, establishing a nursing consultant communication network, and developing continuing education guidelines.



State Staff Development

Kentucky Outreach Project for Handicapped Children's Services

Kentucky Commission for Hand: Capped Children 982 Eastern Parkway
Louisville, KY 40217

MCHIP MCJ-213801 10/01/88—09/30/89 Project Director(s): Sylvestor J. Nitzken

The Kentucky Commission for Handicapped Children (KCHC) is a State government health care program that provides diagnostic evaluations, medical followup, prosthetic devices, and rehabilitative therapy for eligible children and youth under the age of 21. KCHC provides care, management, screening, and/or referral services for approximately 45,000 children annually. An additional 39,000 physically handicapped children and youth are in need of services, however. The Kentucky Outreach Project is designed to provide the necessary marketing and outreach services to enable KCHC to promote a greater statewide awareness of its programs and activities; specifically, to disseminate training, information, and education services.

Radio Communication System, Outer Island Dispensary System

Trust Territory of the Pacific Preventive Health Services Republic of the Marshall Islands P.O. Box 16 Majuro, MH 96960 MCHIP MCJ-753763 10/01/85—9/30/89 Project Director(s): Arata Nathan

The goal of this project is to develop and establish a high frequency radio communication network to serve the outer island medical system. This radio system will provide daily contact with the dispensaries and 24-hour per day access to physician consultation for the outer island health assistants.

Missouri MCH Staff Development Grant

Missouri Department of Health Division of Maternal, Child, and Family Health 1730 East Elm P.O. Box 570 Jefferson City, MO 65102 (314) 751-6174 MCHIP MCJ-293720 10/01/88—09/30/89 Project Director(s): Deanna Severance

This project will help develop an evaluation program and train staff to be able to conduct evaluations. Professional consultants will be hired to develop a resource allocation plan and an evaluation mechanism for the MCH Block Grant so that State staff can evaluate existing programs to determine funding needs and existing program effectiveness.



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Montana MCH Staff Development Grant

Montana Department of Health and Environmental Sciences
Family/MCH Bureau
Cogswell Building
Helena, MT 59620
(406) 444-4740

MCHIP MCJ-303304 10/01/88—09/30/89 Project Director(s): Sidney C. Pratt, M.D

This project addresses the lack of a comprhensive, current statement of objectives for maternal and child health in Montana by facilitating the establishment of a process for planning which goes beyond a single document. This process will allow periodic revision, encourage extension of the objectives into direct service planning, serve as an impetus for designing data systems, and provide a tool for presenting budget requests. The Montana MCH Program will hire a public health coordinator to plan with State MCH staff, key local health departments and hospitals, and others to develop meaningful goals and objectives, determine MCH needs, and plan generally and specifically to meet these needs.

Improve Capacity to Deliver MCH/Health Department Services

Nebraska Department of Health
Division of Maternal and Child Health/Nutrition
301 Centennial Mall South
P.O. Box 95007
Lincoln, NE 685(*)
(402) 471-2781

MCHIP MCJ-313444 10/01/87—09/30/89 Project Director(s): Georgia Bihr

This project seeks to address the Department of Health's needs in the areas of evaluating health data, developing comprehensive data bases and management systems, coordinating and enhancing planning activities, and integrating existing resources across the State. Efforts will include hiring an outside MCH consultant and organizing an MCH advisory council.

Project to Increase Capacity of CSHN Program

Nevada State Health Division MCH-CSHN Title V Program 505 East King Street Room 205 Carson City, NV 89710 (702) 885-4800 MCHIP MCJ-323404 10/01/87—09/30/89 Project Director(s): Ann R. Malone, M.S.N., C.N.A.A.

The purpose of this project is to enhance the capacity of Nevada's CSHN Program to increase community awareness through outreach, public education, professional training, and the formation of a family health services advocacy council. The program objectives are to establish a family health services advocacy council; develop outreach and education programs for the public and professionals; provide educational programs related to family health; and develop data collection systems to record pertinent client information.



State Staff Development

New Hampshire Birth Defects Data Base Project

New Hampshire Division of Public Health Services 6 Hazen Drive Concord, NH 03301 (603) 271-4596

MCHIP MCJ-333222 10/01/87—09/30/89 Project Director(s): Jane M. Hybsch

This project seeks to design and implement a statewide surveillance system to gather information on adverse reproductive outcomes and the incidence/prevalence of congenital malformations in children. A computer program will be implemented to match four existing data bases containing essential baseline data for comparative purposes.

Children with Special Health Care Needs Continuing Education Institutes

Children's Hospital 700 Children's Drive Columbus, OH 43205 (614) 461-2352 MCHIP MCJ-393375 10/01/83—09/30/89 Project Director(s): Antoinette P. Eaton, M.D.

The purpose of this institute is to maintain and strengthen leadership capabilities for medical, nursing, and administrative personnel in programs providing services to children with special health care needs. One introductory institute and one advanced institute are given each year. The introductory institute offers orientation for new staff concerning the history, organization, funding, purposes, and functions of CSHN programs. The advanced institute attracts senior CSHN program officers who discuss current issues, develop problem-solving strategies, and forecast future trends in health care services for children with special health care needs.

Child Health Reporting System Project

Oklahoma State Department of Health Maternal and Child Health Services P.O. Box 53551 Oklahoma City, OK 73152 (205) 271-4471 MCHIP MCJ-403234 10/01/87---09/30/89 Project Director(s): Edd Rhoades, M.D., Ph.D.

The goals of this project are to build a new and efficient multifunctional reporting system; obtain current and complete child health data for program management; provide a uniform automated billing system for the EPSDT agency; and provide immediate access at the county level to local program data. The project is divided into two phases. During the initial phase, planning and development of the model system software were conducted; during the second phase, the model system software programming is being carried out.



General Program Concerns

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Staff Development Initiative Brought Down to Earth Phode Island Department of Heal

Rhode Island Department of Health Division of Family Health 75 Davis Street Room 302 Providence, RI 02908 (401) 277-2312 MCHIP MCJ-443144 10/01/87—09/30/89 Project Director(s): William Hollinshead, M.D.

This project aims to develop an onsite program at the Department of Health that will provide needed instruction in quantitative management skills. It is anticipated that this instruction will aid staff in improving their skills in writing quantitative objectives, standards, cooperative agreements, and evaluation protocols. The program will also identify and develop the necessary skills for working efficiently as a team.

Proposal for the Provision of Technical Assistance, Staff Development, and Marketing Strategies

South Dakota Department of Health 523 East Capitol Pierre, SD 57501 (605) 773-3737

MCHIP MCJ-463302 10/01/88—09/30/89 Project Director(s): Debra Erickson-Louchart

South Dakota is one of the few States whose community health nurses (CHNs) are employees of the State as a part of the Community Health Nursing and Maternal Child Health Programs. This organizational structure causes difficulty in attempting to find the best possible manner of addressing the technical assistance and staff development needs of the nursing staff. To upgrade the skills of the CHNs to function as quality case managers of high-risk pregnant women, the South Dakota Department of Health will provide technical assistance in four designated locations in the State. To market newly available high-risk pregnancy case management services, public service announcements will air on local television stations during key times of the day.

Improved Third-Party Reimbursements

Utah State Department of Health Family Health Services Division P.O. Box 16650 Salt Lake City, UT 84116 (801) 538-6161

MCHIP MCJ-493400 10/01/87—09/30/89 Project Director(s): Peter C. van Dyck, M.D., M.P.H.

The goal of this project is to develop and implement a plan which would correct identified weaknesses and problems and further develop the successful aspects of the system of third-party reimbursement. Through close monitoring of activities and specific measures of success (i.e., improved third-party collection rates), the division expects to eventually increase collections by as much as 25 percent from this source, thereby increasing resources to support maternal and child health services.



State Staff Development

Maternal and Child Health Staff Development

Vermont State Department of Health P.O. Box 70 Burlington, VT 05402 (802) 863-7280 MCHIP MCJ-503404 10/01/87—09/30/89 Project Director(s): Roberta Coffin, M.D.

The goal of this project is to establish a process for planning which allows periodic revision, encourages extension of the objectives into direct service planning, serves as an impetus for restructuring of the data systems, and provides a tool for presenting budget requests. The result of this process will be increased ownership by the MCH staff of the planning process evaluation.

State Program and Staff Development to Improve Nutrition Services for School-Age Children with Handicapping Conditions

Virginia Department of Health Children's Specialty Services 109 Governor Street 6th Floor Richmond, VA 23219 (804) 786-3691 MCHIP MCJ-513305 10/01/88—09/30/89 Project Director(s): Willard R. Ferguson, M.D. Janet W. Horsley, M.P.H., R.D.

This project provides an interagency approach to program and staff development between the Virginia Department of Health and Virginia Department of Education to develop nutrition services for handicapped children, ages 2-21, who are enrolled in public schools. The purpose of the project is to: (1) Increase the awareness and knowledge of nutritionists, school staff, and families about the nutritional needs of chronically ill children; (2) create networ' ong families of handicapped children, school systems, and community nutrition resources; and (3) initiate ongoing nutrition programs for school-age handicapped children.

Region X Nursing Training Network

University of Washington School of Nursing Room 212 S CDMRC WJ-10 Seattle, WA 98195 (206) 543-9200 Training
MCJ-009074
10/01/85---09/30/89
Project Director(s):
Kathryn Barnard, Ph.D.

The goal of this project is to enhance MCH and CSHN programs over a 3-year period by establishing a network mechanism among public health nurse leaders in Region X. This network will be composed of the nursing representatives for the Association of State and Territorial Directors of Nursing from the region, the State MCH and CSHN nursing consultants, and nursing educators representing MCH training programs in the region, and will serve to develop and implement nursing standards and protocols to be used in these programs.



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Maternal and Child Health Development

Program

University of Alabama at Birmingham Tidwell Hall Room 231 Birmingham, AL 35294 (205) 934-7161

Training MCJ-009040 10/01/83—06/30/89 Project Director(s): Christiane Hale, Ph.D.

The primary purpose of this project is to continue the development and operation of MCH academic training and continuing education in the School of Public Health. Other goals are to further develop the program's capacity to provide technical assistance and consultation to public and community agencies serving mothers, children, and families; and to conduct MCH-focused research linked to communitybased services.

Behavioral Pediatrics Training Program

Children's Hospital of Los Angeles 4650 Sunset Boulevard Los Angeles, CA 90027 (213) 669-2110

Training MCJ-009091 10/01/86—06/30/91 Project Director(s): Barbara M. Korsch, M.D.

This program provides training in behavioral, developmental, and psychosocial aspects of pediatrics for faculty, fellows, residents, and medical students. The program encourages the development of optimal doctor-patient relationships, communication skills, and receptiveness to learning psychosocial issues.

Maternal and Child Health **Development Training**

San Diego State University Foundation 6505 Alvarado Road Suite 205 San Diego, CA 92120 (619) 594-4493 or 594-4667

Training MCJ-009044 10/01/83—06/30/89 Project Director(s): Allan Oglesby, M.D.

This program prepares a variety of health-related professionals for leadership roles in Federal, State, regional, local, and international programs providing health services for mothers and children. The project is structured to accommodate a total of six postdoctoral trainees per academic year, in addition to providing ongoing continuing education and research efforts. Currently, the university offers several joint programs with the University of California at San Diego.



Occupational Therapy Training in Pediatrics

University of Southern California 1975 Zonalave KAMB34 Los Angeles, CA 90033 Training
MCJ-009048
07/01/84—06/30/92
Project Director(s):
Florence Clark, Ph.D.

This project provides occupational therapy students enrolled in a master's program with training that emphasizes the building of leadership skills in adolescent and pediatric treatment. The program places strong emphasis on issues related to functioning on interdisciplinary teams and in the community to contribute to the field through research related to the delivery of occupational therapy services in MCH settings.

Training in Maternal and Child Health Care

University of California at Berkeley Regents Office M-11 Wheeler Hall Berkeley, CA 94720 (415) 642-6482 Training
MCJ-000103
07/01/84—06/30/89
Project Director(s):
Frank Falkner

The purpose of this program is to prepare professionals for leadership roles in public health programs for mothers and children and to provide other students in the School of Public Health with information about the field of MCH practice. In addition to serving students from California, Nevada, and Oregon, this program has received students from many other States and territories, thereby providing a regional and national resource for leadership training.

Training Nurse Midwives

Georgetown University 3700 Reservoir Road, N.W. Washington, DC 20057 (202) 687-4772 Training
MCJ-009032
07/01/83—06/30/93
Project Director(s):
Judith S. Melson, C.N.M.

This program is designed to train nurse midwives to provide perinatal care for women and newborn infants. It also equips these professionals to provide leadership in the design, implementation, and management of health care for women and infants in public and private programs; to serve as advocates for women and infants in promoting optimal health (especially for the poor and disadvantaged); and to conduct research in the field of maternal and child health.

Nurse-Midwifery in the Public Sector

Emory University Nell Hodgson Woodruff School of Nursing Atlanta, GA 30322 (404) 727-6918 Training MCJ-009115 07/01/88—06/30/93 Project Director(s): Elizabeth S. Sharp, Dr.P.H.

The purpose of this project is to increase the number of certified nurse-midwives who are prepared to assume leadership positions in the provision of services to women and their newborns in public health settings.



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Training in Maternal and Child Health

University of Hawaii 1960 East-West Road Biomed C105M Honolulu, HI 96822 (808) 948-8832 Training
MCJ-000156
07/01/65—06/30/89
Project Director(s):
Gigliola Baruffi, M.D.

This program's goal is to develop leadership, knowledge, and innovative solutions to individual and community MCH problems through instruction, community service, and research. The program also provides consultation in needs assessment, program planning and evaluation, and staff development.

Advanced Competencies in MCH for Occupational Therapies

University of Illinois at Chicago
Department of Occupational Therapy
College of Associated Health Professions
1919 West Taylor Street
Chicago, IL 60612
(312) 996-6901

Training MCJ-009101 10/01/87—06/30/92 Project Director(s): Mary Lawlor, Sc.D.

This project provides postprofessional education programs for occupational therapists and members of other professions providing MCH services. The goals are to produce more scientific practitioners, to enhance the body of knowledge supporting the efficacy and cost-effectiveness of occupational therapy services to mothers and children, and to create and maintain an interdisciplinary network of pediatric scientists and clinicians.

Maternal and Child Training Program

University of Illinois at Chicago P.O. Box 6998 Chicago, IL 60680 (312) 966-5951 Training MCJ-009041 10/01/83—06/30/89 Project Director(s): Naomi Morris, M.D.

This program focuses on health needs and multidisciplinary interventions in a spectrum of substantive areas while preparing students to assume leadership or middle management positions. Activities include evaluating the effects of services on the health status of specified groups; improving the structure, process, and content of services through application of the latest scientific theories and practices; and developing effective policies.



Public Health Nutritionists for Maternal and Child Health

Tufts University School of Nutrition Frances Stern Nutrition Center New England Medical Center 750 Washington Street Box 783 Boston, MA 02111 (617) 956-5273 Training
MCJ-009120
10/01/88—09/30/93
Project Director(s):
Johanna T. Dwyer, D.Sc.

The goal of this project is to improve and expand the leadership training of public health nutritionists at the master's level with a specialization in maternal and child health to address national priorities in the field. The program expands the usual internship/master's program to provide increased emphasis on quantitative skills, epidemiology, administration, MCH nutrition, and child welfare.

Public Health Training in Maternal and Child Health

Harvard School of Public Health 677 Huntington Avenue Boston, MA 02115 (617) 732-1080 Training
MCJ-000102
07/01/88—06/30/89
Project Director(s):
Isabelle Valadian, M.D.

This program seeks to educate health professionals about the specific health needs and services required by mothers and children and to conduct and stimulate relevant research in these areas. The scope of the teaching covers concepts and methods, studies of natural phenomena and of policy development, and issues of implementation and evaluation.

Public Health Nutrition Training Program

University of Minnesota Harvard Street at East River Road Box 721 UMHC Minneapolis, MN 55455 (612) 626-2820 Training MCJ-009118 07/01/88—05/^^/93 Project Director(s): Mary T. Story, Ph.D.

The overall goals of this training program are to improve and enhance the nutritional health of mothers, children, and adolescents, and to develop, expand, and improve delivery of nutrition services to these groups through leadership training of nutritionists who hold or will hold positions of responsibility within academic and public health sectors. The educational program will focus on acquisition of appropriate knowledge bases, skills, and attitudes which will facilitate leadership in the field of maternal and child nutrition.



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Training in Maternal and Child Health

University of Minnesota School of Public Health 420 Delaware Street, S.E. Minneapolis, MN 55455 (612) 625-3660 Training
MCJ-000111
07/01/85---06/30/89
Project Director(s):
Barbara Leonard, Ph.D.

This program provide raduate training to health professionals pursuing careers in public health with a concentration in main and child health. It also provides technical assistance, consultation, and support to MCH agencies within Region V and to the area west of Minnesota.

Conference on Brain/Behavior in Pediatric AIDS

New York State Institute for Basic Research in Developmental Disabilities 1050 Forest Hill Road Staten Island, N° 10314 (718) 494-5117 Training MCJ-009, 24 10/01/88—06/30/89 Project Director(s): Peter Vietze, Ph.D.

The purpose of this projec is to support an interdisciplinary conference on brain and behavior in pediatric AIDS. This conference will provide training to professionals from various disciplines in the management of pediatric AIDS patients. It will also serve as a platform for the exchange and discussion of information, experiences of health professionals, and latest developments in this field. The main focus is on the neurological complications of pediatric AIDS and their diagnosis, management, and treatment/therapy.

Maternal and Child Health Training

Columbia University 80 Haven Avenue, B-3 New York, NY 10023 (212) 257-7527 Training
MCJ 109042
10/01/83—(> ^'89
Project Dir. ()):
Rosemary Barber-Madden, Ed.D.

This program is designed to train professionals to address and analyze the health problems of women, children, and families and to develop effective and cost-efficient responses. Efforts are aimed at expanding and improving the four components of the program: Degree training and continuing education, research and evaluation; consultation and technical assistance; and advocacy in the professional and public arenas.



Social Work Training in
Maternal and Child Health
Columbia University School of Social Work
622 West 113th Street
New York, NY 10025
(212) 854-5061

Training
MCJ-002027
07/01/84—06/30/92
Project Director(s):
Alex Gitt, man, Ed.D.

The goals of this program are to prepare social work students to provide direct and indirect health services to children, mothers, and families; to provide staff development programs for currently employed professionals; and to develop curriculum content and case materials for graduate and continuing education courses.

Nutrition Training
University of North Carolina at Chapel Hill
315 Pittsboro Street
Chapel Hill, NC 27599-7405
(919) 966-3432

Training
MCJ-000965
10/01/77—06/30/93
Project Director(s):
Mildred Kaufman, R.D.

The goals of this project are to provide a comprenensive education program for public health nutritionists, to provide technical assistance and continuing education for practicing public health professionals, and to conduct basic and applied research that will improve the practice of public health nutrition.

Postgraduate Programs in Maternal and Child Health Occupational Therapy/Physical Therapy

University of North Carolina at Chapel Hill Division of Physical Therapy Chapel Hill, NC 27599 (919) 966-4708 Training
MCJ-000149
07/01/65—06/30/92
Project Director(s):
Joyce Sparling

This project provides educational experiences for physical therapists, occupational therapists, medical students, and members of other professions involved in maternal and child health care. An additional goal is enhancement of the minority presence in MCH programs.

Training Program in Maternal and Child Health

University of North Carolina at Chapel Hill 407 Rosenau Hall Chapel Hill, NC 27599-7400 (919) 966-5981 Training
MCJ-000107
()7/01/84—06/30/89
Project "virector(s):
Milton Kotelchuck

This program seeks to train health professionals to assess community health needs, plan and evaluate programs, provide services, and administer agencies relating to maternal and child health. It also serves as a source of support for the region in providing vital technical assistance and consultation, as well as hosting an annual MCH regional conference.



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General Program Concerns

Education to Improve Services to Mothers and Children Case Western Reserve University 2121 Abington Road Cleveland, OH 44106 (216) 368-3231 Training MCJ-000140 07/01/67—06/30/93 Project Director(s): Janice Neville, R.D.

The purpose of this project is to improve and extend the education of persons providing care for mothers and children so that nutrition services of an appropriate kind and quality are provided through public agencies and facilities. The major focus of the program is on the education of public health nutritionists with special expertise and experience in maternal and child nutritional care.

Training in Behavioral Pediatrics

Columbus Children's Hospital 700 Children's Drive Columbus, OH 43205 (614) 461-2352 Training
MCJ-009053
09/01/84---06/30/91
Project Director(s):
Antoniette Eaton, M.D.

The overall purpose of this project is to refine, evaluate, and disseminate a model curriculum for the preparation of subspecialists in behavioral and developmental pediatrics who will assume academic and professional leadership positions and function as role models by providing exemplary patient care, demonstrating a commitment to research, and exhibiting quality teaching.

Joint Public Health/Social Work Training

University of Pittsburgh 130 Desoto Street Pittsburgh, PA 15261 (412) 624-3102 Training
MCJ-000114
07/01/82—06/30/92
Project Director(s):
Gerald St. Denis, r.i.D.

This project supports advanced social work training in public health by means of an interdisciplinary curriculum in public health and social work.

Nurse Midwives in Regional Maternal and Child Health Planning

University of Pennsylvania 420 Service Drive Philadelphia, PA 19104 (215) 898-4335 Training
MCJ-009051
07/01/84—06/30/93
Project Director(s):
Joyce Thompson, C.N.M., Dr.P.H.

This program has as its primary purpose providing tuition to selected students in the graduate nurse-midwifery program who are committed to providing MCH services under Title V and other publicly funded programs for low-income women. The total experience is directed toward preparing students to become leaders in the field in order to bring about the changes necessary to meet the needs of mothers and babies.



MCAIPublic Health Professional Development

Training in Maternal and Child Health Care

University of Puerto Rico Department of Human Development Maternal and Child Health Program G.P.O. Box 5067 San Juan, PR 00936 (809) 758-2525 or 758-1445 Training MCJ-000161 07/01/67—06/30/89 Project Director(s): Ana Navarro, M.D.

The purpose of this program is to develop the highly trained professionals needed to serve the educational, research, and service needs of the community and to previde the health services required by mothers and children. The program conducted six major continuing education activities during the past year which primarily addressed issues of nutrition and pregnancy.

Maternal and Child Health Training

University of South Carolina College of Social Work Columbia, SC 29208 (803) 777-5291 Training MCJ-009097 07/01/87—06/30/92 Project Director(s): Patricia Conway, Ph.D.

The goals of this 5-year project are to prepare social workers to assume leadership roles in the health field with a special emphasis on maternal and child health, to provide ongoing education for social workers currently working in MCH positions, and to disseminate state-of-the-art information regarding social work practice and education in maternal and child health.

Graduate Training in Public Health Nutrition

University of Tennessee 404 Andy Holt Tower Knoxville, TN 37996-0140 (615) 974-6241 Training
MCJ-000110
07/01/84—06/30/93
Project Director(s):
Betsy Haughton, Ed.D.

This program seeks to educate and train students and practitioners to enable them to meet an increasing demand for qualified personnel in the field of maternal and child nutrition. It also provides continuing education to practitioners in Region IV and long-term master's level graduate education.

Behavioral Pediatrics Training

Virginia Commonwealth University Children's Medical Center Box 514 MCV Station Richmond, VA 23298 (804) 786-6493 Training MCJ-009095 10/01/86—06/30/91 Project Director(s): Joseph Zanga, M.D.

This program will train individuals to assume positions of leadership in the academic community. These individuals will be prepared to provide services to families in need, to supervise pediatricians and pediatric trainees in the provision of these services, to educate professionals in behavioral pediatrics, to make new contributions to the field, and to contribute to the empirical data base necessary for the scientific advancement of behavioral medicine.

ERIC

Full Text Provided by ERIC

General Program Concerns

Leadership Training in Pediatric
Physical Therapy for the Pacific Northwest

University of Washington
Department of Rehabilitation Medicine
RJ-30
Seattle, WA 98195
(206) 543-3600

Training
MCJ-009103
10/01/87—06/30/92
Project Director(s):
Marjoric E. Anderson, Ph.D.

The purpose of this project is to provide a dual-track, graduate level, postprofessional training program in order to prepare a group of 20 pediatric physical therapists to assume leadership positions in the delivery and improvement of services in community-based programs providing health care for mothers and children. Coursework will consider differing social, cultural, and health practices of diverse ethnic groups and will promote education in effective management and policy formation.

Maternal and Child Health Development

Program
University of Washington
School of Public Health
Seattle, WA 98195
(206) 543-8827

Training
MCJ-009043
10/01/83—06/30/89
Project Director(s):
Irvin Emanual, M.D.

The purpose of this project is to continue the operation of a formal Maternal and Child Health Program in the School of Public Health and Community Medicine. In addition to the standard full-time program, part-time study for graduate students who are currently employed is offered.

Graduate Training in Pediatric Nursing University of Wisconsin at Madison 600 Highland Avenue

Madison, WI 53792 (608) 263-5282

Training MCJ-009052 07/01/84—06/30/93 Project Director(s): Karen Pridham, Ph.D.

This program seeks to maintain and strengthen the existing option in child and adolescent nursing in the patient-child area of the master of science program. Goals include strengthening the curriculum related to care for chronically ill or handicapped children, providing students with opportunities to learn about the needs of these children, and providing opportunities for preparation in administrative and consultative roles in Title V and other programs for children and adolescents.



Development of Areawide Genetic Service Program of Education, Counseling, and Testing Health Officers Association of California 926 J Street Sacramento, CA 95814 (916) 443-9076 Genetics
MCJ-061007
10/01/87—09/30/92
Project Director(s):
George C. Cunningham, M.D.

This network is directed by genetic services representatives from California, Hawaii, Nevada, and a coordinating council of providers and Title V representatives. The goals of the project are to: (1) Identify genetic services needs for the region; (2) identify and develop resources to meet these needs; (3) establish standards for services to ensure high quality and public protection and confidence in genetic services; and (4) increase professional and public knowledge of genetic conditions and their prevention. Activities include publishing a quarterly newsletter, sponsoring conferences for all health professionals, collecting data and developing a data base, reviewing laboratory quality control procedures, and providing continuing education.

Mountain States Regional Genetic Services Network (MSRGSN)

Colorado Department of Health 4101 East 11th Avenue Denver, CO 80220 (303) 331-8373 Genetics
MCJ-081002
10/01/84—09/30/92
Project Director(s):
Robert S. McCurdy, M.D.

This network is a consortium of States, including Arizona, Colorado, Montana, New Mexico, Utah, and Wyoming, created to provide more comprehensive and better coordinated genetic services to the populations of these States. The goal of the project is to increase the communication, coordination, and collaboration efforts of the Mountain States Region for the delivery and enhancement of genetic services.

Maternal and Infant Health Collaboration

The American College of Obstetricians and Gynecologists 409 12th Street, S.W. Washington, DC 20024 (202) 863-2579

MCHIP MCJ-115018 10/01/88—09/30/91 Project Director(s): Janet Chapin

This project addresses the need to make current information on obstetric and gynecologic health available to the directors of State Maternal and Child Health Programs in a timely fashion. The following project objectives have been established to reach this goal: (1) Facilitate communications between and among State MCH directors and private sector and academic sector OB/GYNs; (2) encourage the involvement of OB/GYNs in the development of public policy regarding the reduction of infart mortality and the provision of perinatal services to all women; and (3) devise strategies to increase OB/GYN participation in Medicaid and services provided through other public programs.



Program Coordination and Networking

State Maternal and Child Health Development

Project

Association of Maternal and Child Health Programs (AMCHP)
2001 L Street, N.W.
Suite 308
Washington, DC 20036
(202) 775-0436

MCHIP MCJ-113805 10/01/88—09/30/91 Project Director(s): Catherine A. Hess

This project is intended to establish a centralized resource for State Title V MCH and Children with Special Health Care Needs program directors which can provide technical guidance on the array of Federal programs that provide services to mothers and children. To achieve this goal, the project will: (1) Develop an analysis of the statutory and regulatory framework defining the structure and authority of Title V Programs and Title V's role vis-a-vis other key programs devoted to maternal and child health; (2) identify and undertake an analysis of the significant Federal assistance programs that intersect with Title V; and (3) develop guidelines on how the laws might be favorably interpreted or implemented to improve services to Title V beneficiaries.

Development and Maintenance of Communication and Coordination
Network for the Delivery and Enhancement of Genetic Services within HHS Region IV
Emory University School of Medicine
Pediatrics/Medical Genetics
2040 Ridgewood Drive
Atlanta, GA 30322
(404) 727-5840

Genetics
MCJ-131002
10/01/83—09/30/90
Project Director(s):
Louis J. Elsas, III, M.D.

This project carries out the functions of the Southeastern Regional Genetics Group (SERGG), serving Alabama, Florida, Georgia, Kentucky, Louisiana, Mississippi, North Carolina, South Carolina, and Tennessee. Activities include identifying regional resources, goals, and needs; developing a registry of regional genetics resources; creating quality control programs; providing information to parents and professionals: reviewing third-party reimbursements; and providing a forum for the discussion of ethical and legal issues in genetics.

Great Lakes Regional Genetics Group (GLaRGG)

Indiana State Board of Health Genetics Disease Section Maternal and Child Health 1330 West Michigan Street Indianapolis, IN 46206-1964 (317) 633-0644 Genetics MCJ-181003 10/01/88—09/30/91 Project Director(s): Diane Downing, M.S.N.

The purpose of the Great Lakes Regional Genetics Group is to continue an established genetics network for Federal MCH Region V, which includes Illinois, Indiana, Michigan, Minnesota, Ohio, and Wisconsin. The network provides a forum for sharing resources and developing cooperative efforts toward improving the quality and quantity of services related to genetic diseases. Project goals include improving communication and coordination within Region V, establishing and implementing laboratory quality assurance programs, developing a uniform data base system, and improving financial support for genetic services.



General Program Concerns

Future Directions of Services for Children with Special Health Care Needs

University of Iowa National Maternal and Child Health Resource Center College of Law Iowa City, IA 52242 (319) 335-9046 MCHIP MCJ-193790 08/01/85—07/31/89 Project Director(s): Josephine Gittler, J.D.

The overall goal of this project is to delineate future directions of services to children with special health care needs and their families. The project is addressing future directions of services from the perspective of public programs, particularly the State Programs for Children with Special Health Needs. Activities include the provision of educational and training activities, special initiatives regarding subjects which are important in promoting the development of a family-centered, community-based system of comprehensive services, and coordination of preliminary testing of a new reporting form for State Programs for Children with Special Health Needs.

Great Plains Genetics Service Network (GPGSN)

The University of Yowa Department of Pediatrics Division of Medical Genetics Iowa City, IA 52242 (319) 356-2674 Genetics MCJ-191002 10/01/83—09/30/90 Project Director(s): James W. Hanson, M.D.

This project seeks to address the current lack of coordination of information and resources, which results in duplication of services, inefficient use of resources, and decreased impact on the delivery of genetic services. The Great Plains Genetics Service Network serves to coordinate resources; review reimbursement systems; develop a teratology information service; develop systems of data collection and analysis; develop and implement a quality control program; and provide genetics education to teachers, health professionals, and the public.

Council of Regional Networks for Genetics Services (CORN)

Greater Baltimore Medical Center Department of Pediatrics 6701 North Charles Street Baltimore, MD 21204 (301) 828-2780 Genetics MCJ-241005 10/01/86—09/30/90 Project Director(s): R. Stephen S. Amato, M.D., Ph.D.

This coalition provides a means for communication between genetic services networks, coalitions of consumer groups, and other professional groups whose activities may relate to the provision of genetics health care. Activities include data collection and analysis, a quality assurance program, genetics education for the public, and policy and advocacy programs for persons with genetic disorders.



New England Regional Genetics Group (NERGG)

Massachusetts Health Research Institute, Inc. 101 Tremont Street Suite 600 Boston, MA 02108 (617) 426-6378 Genetics
MCJ-251003
10/01/85—09/30/90
Project Director(s):
Allen C. Crocker, M.D.
Richard W. Erbe, M.D.
Stacey T. Kacoyanis, M.D.

The purposes of this network are to provide a forum for the discussion of regionwide concerns regarding the provision of optimal services in medical genetics, to promote the availability of high quality genetic services, to ensure that providers and consumers have the opportunity to discuss issues of mutual interest, and to encourage active genetics education throughout New England. Activities have included the establishment of an external laboratory quality control program for maternal serum alphafetoprotein testing, the development of a partnership among several centers to produce improved risk tables for Down syndrome, collection of data on the utilization of amniocentesis in New England, and establishment of a regional fragile-X parents' organization.

New England SERVE: A Planning Network for Children with Special Health Care Needs Massachusetts Health Research Institute, Inc. 101 Tremont Street Room 615 Boston, MA 02108 (617) 574-9493 MCHIP MCJ-253878 10/01/86—09/30/89 Project Director(s): Susan G. Epstein, M.S.W. Ann B. Taylor, Ed.D.

This network fosters collaboration among State Programs for Children with Special Health Care Needs in New England. Activities include documenting quality assurance and monitoring activities; reviewing existing standards of care and developing new standards; facilitating interagency and public/private cooperation; and publishing the New England Status Report, which covers legislation and program initiatives.

PATHFINDER: A Project to Improve Systems of Care for Children with Chronic Health Conditions
Park Nicollet Medical Foundation
5000 West 39th Street
Minneapolis, MN 55416
(612) 927-3393

MCHIP MCJ-273929 11/01/86—09/30/89 Project Director(s): William F. Henry

This project has two principal goals The first is to facilitate national and regional public policy development to augment the provision of comprehensive, community-based services to children and youth with chronic illnesses or disabilities. The second is to enhance the capability of professionals and agencies throughout the region to provide more effective care for children and youth with chronic illnesses or disabilities. Activities include conducting an annual, invitational, state-of-the-art workshop; providing community network consultation/technical assistance; publishing a national newsletter; maintaining a continuing education center; and publishing guidelines entitled *How to Develop a Community Network*.



General Program Concerns

New Mexico Genetics Outreach Project
New Mexico Health and Environment Department
MCH Bureau
Health Services Division
P.O. Box 968
Santa Fe, NM 87504-0968
(505) 277-5551

Genetics MCJ-351002 10/01/85—09/30/89 Project Director(s): John Aase, M.D.

This project seeks to establish a coordinated, university-based system for the delivery of genetic services throughout the State by establishing satellite genetics clinics in already existing sites, expanding the number of clinic sites within the State, and hiring the necessary personnel to provide these additional services. Additional goals are to provide increased and more accessible genetic services to the State's medically indigent genetics fund; to provide outreach and educational activities on genetics issues to health providers and consumers; and to determine the need and feasibility of establishing a statewide maternal serum alpha-fetoprotein screening program.

Coordination and Communication Network for Genetics Services in New York State

New York State Department of Health and Health Research, Inc.
Wadsworth Center for Laboratories and Research Laboratory of Human Genetics
P.O. Box 509
Albany, NY 12201
(518) 474-6796

Genetics MCJ-361004 10/01/84—09/30/92 Project Director(s): Ann M. Willey, Ph.D.

The purpose of this project is to ensure that all individuals affected with or at risk for transmitting a genetic disorder are able to make informed health decisions and are provided access to diagnostic, counseling, and preventive services. Achievements to date include the expansion of GENES (Genetics Network of the Empire State); development of a data base of genetic services contacts; newborn screening followup reorganization, including tracking of infants diagnosed with galactosemia, PKU, and hypothyroidism; provision of technical assistance to other regions; and coordination of new State appropriations for expanded services to sickle cell patients.

Pacific Northwest Regional Genetics Group (PacNoRGG)

Oregon Health Sciences University Crippled Children's Division P.O. Box 574 Portland, OR 97207 (503) 279-8342 Genetics MCJ-411002 10/01/84—09/30/92 Project Director(s): Victor D. Menashe, M.D.

This project seeks to develop a coordinated system to assure high quality genetic services and educational program: in Alaska, Idaho, Oregon, and Washington. The project goals are to: (1) Provide a communications natwork among the various genetics groups in the Northwest; (2) to make genetic services more easily accessible to all residents in the four States; (3) to provide educational programs to professionals and the public; and (4) to assure the quality of genetic services within the four States. The program is carried out through the work of volunteers, who generate activities they feel are important for improving communication, services, and education in the genetics field.



Program Coordination and Networking

In reasing Numbers of Southeast Asians Receiving Comprehensive Health Services (INSEARCH)

Rhode Island Department or Health Division of Family Health 75 Davis Street Providence, RI 02908 (401) 277-2312 Genetics MCJ-441002 10/01/88—09/30/91 Project Director(s): Peter R. Simon, M.D., M.P.H.

The goal of this project is to enhance the availability, accessibility, and utilization of genetic and other maternal and child health care services for the Southeast Asian (SEA) populations residing in Rhode Island. The main objective in reaching this goal is the development, implementation, and evaluation of a comprehensive followup and case management tracking unit at the health centers serving the majority of the SEA populations. This unit will assist members of the primary and secondary care teams in meeting the specific health care needs of this population, will train SEA interpreters concerning maternal and child health care concepts, and will educate health care providers concerning specific cultural differences.

Comprehensive Genetics Center

Meharry Medical College 1005 David Todd Jr. Boulevard Nashville, TN 37208 (615) 327-6399 Training
MCJ-000440
07/01/84—06/30/89
Project Director(s):
Dharmdeo Singh, Ph.D.

This project is part of the Tennessee Statewide Genetic Screening Program, which provides medical services, training, and education. The program is designed to accomplish the following goals: (1) To reduce the recurrence of mental retardation and genetic and/or birth defects; (2) to educate the public about the facts, causes, and prevention of genetic and/or birth defects; (3) to provide access to diagnostic testing; (4) to refer the individual and/or family for medical followup; (5) to provide genetic counseling; and (6) to coordinate the resources available for individuals who may have a genetic disease.

The Delta Project: A Model Program Designed to Promote Regional Otologic Health Care University of Tennessee at Memphis Memphis Child Development Center 711 Jefferson Avenue Memphis, TN 38105 (901) 528-6511

MCHIP MCJ-473808 10/01/86—10/01/89 Project Director(s): Gerald S. Golden, M.D. Kevin T. Kavanagh, M.D.

This project seeks to improve medical and rehabilitative services for children with hearing, speech, or language disorders in Arkansas, Mississippi, and Tennessee. Activities include developing and maintaining a referral network; identifying barriers to access for rural, indigent, and culturally diverse populations; and developing a failed appointment notification and rescheduling system.



General Program Concerns

A Proposal to Establish a Genetics Network for Texas 1968

Texas Department of Health 1100 West 49th Street Austin, TX 78756-3199 (512) 458-7111 Genetics MCJ-481005 10/01/88—09/30/92 Project Director(s): Walter P. Peter, Jr., M.D.

The goal of this project is to decrease significantly the incidence of genetic disease in Texas, and to alleviate the suffering and anxiety of patients and their families due to the threat or presence of genetic disease. The major objectives of the program are to: (1) Establish a well coordinated statewide network of human genetic services; (2) maintain and expand the newborn screening and adult carrier screening programs; (3) collect data on the provision of genetic services; (4) coordinate the laboratory diagnostic capacity of existing genetics groups in the areas of biochemistry, cytogenetics, and prenatal diagnosis; (5) develop human genetics educational program; (6) review and improve sources of funding; and (7) expand patient care in the underserved areas of Texas.

Expanding Resources and Improving Genetics Services Using the Mid-Atlantic Regional Human Services Network: A Seven State Consortium

The University of Virginia Medical School Department of Pediatrics Division of Medical Genetics P.O. Box 386 Charlottesville, VA 22902 (804) 924-2665 Genetics MCJ-511002 10/01/88—09/30/90 Project Director(s): Thaddeus E. Kelly, M.D., Ph.D.

The goal of the Mid-Atlantic Regional Human Genetics Network (MARHGN) is to increase the access to and the quality of genetic services. This will be achieved through cooperative interchange among the seven member States. The program involves education of the public and of providers of genetic services; quality control of genetics laboratories; data collection and analyses of genetic services; and special projects.

Development of a Statewide Genetic Services

Wyoming Department of Health and Social Services
Division of Health and Medical Services
Hathaway Building
4th Floor
Cheyenne, WY 82002-0710
(307) 777-7941

Genetics MCJ-561001 10/01/87—09/30/91 Project Director(s): Larry Goodmay, M.S., M.B.A.

This project will provide comprehensive genetic services (clinical, educational, and laboratory) to the residents of Wyoming, as well as educational and informational services to health care providers, teachers, and the general public. Wyoming will contract for clinical genetics personnel services from adjacent regional medical centers; these physicians will travel on a scheduled basis to several clinic sites located throughout the State to provide genetic services.



Improving Health Insurance Coverage for Adolescents

University of California at San Francisco Institute for Health Policy Studies 1326 Third Avenue Box 0936 San Francisco, CA 94143 (415) 476-3896 MCHIP MCJ-063500 10/01/87—09/30/90 Project Director(s): Harriette B. Fox Margaret McManus Paul W. Newacheck

The goal of this project is to improve access to appropriate health care services for adolescents, especially for those adolescents with special health care needs, by removing or alleviating existing financial barriers to health care services. Activities include assessing the adequacy of group, individual, and commercial health insurance policies for adolescents; identifying alternative mechanisms for removing or alleviating existing financial barriers; and preparing state-of-the-art reports on these issues.

Training for Reimburgement for Genetic Services

University of Connecticut Health Center 263 Farmington Avenue Farmington, CT 06032 (203) 679-2676

Training
MCJ-009107
10/01/87—09/30/89
Project Director(s):
Robert Greenstein, M.D.

This project seeks to update and improve the knowledge and skills of health professionals in programs serving mothers and children and to increase the overall awareness of genetic services. The project will develop a set of standardized definitions of genetic services that may be uniformly implemented by providers, consumers, and third-party payers in order to improve the effectiveness of reimbursement, with the goal of stabilizing the availability and affordability of services. Training materials about genetic services will be developed and will include information about professional services, procedures, laboratory tests, and consumer needs and resources.

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Financing

Project on Families in the Changing Health Care Marketplace
Center for Public Representation
520 University Avenue
Madison, WI 53703
(608) 251-4008

MCHIP MCJ-555002 07/01/87—06/30/90 Project Director(s): Nina L. Camic

The goal of this project is to assist in the formation of a collaborative effort involving the government, providers, private payers, and families in order to reconcile the operational difficulties of achieving health care cost containment while retaining quality, access, and family-centeredness. The project will seek to develop approaches to health care financing that are sensitive to the needs of families with children with special health care needs, to assist families with special health care needs in dealing with financial problems which pose barriers to obtaining appropriate health services, and to disseminate information regarding financing of care for children with special health care needs.



Health and Nutritional Status of Mexican-American Children Stanford University Stanford, CA 94305 (415) 723-3095 Research MCJ-060518 04/01/88—03/31/91 Project Director(s): Reynaldo Martorell, Ph.D.

This study analyzes data from the National Health and Nutrition Examination Surveys I and II and the Hispanic Health and Nutrition Examination Survey to identify and quantify the major health and nutritional problems of Hispanic children and adolescents in the United States. Specifically, the project plans to assess the level of severity of health and nutritional problems for these population groups; identify far tors related to poor health and nutrition; assess the functional implications of identified health problems; and determine how these problems are being addressed by health care programs.

Delaware Automated Tracking and Information System

Delaware Department of Health and Social Services Division of Public Health P.O. Box 637 Dover, DE 19905 (302) 736-4767 MCHIP MCJ-103303 10/01/88—09/30/82 Project Director(s): D. Clendaniel T. Zimmerman, Ph.D.

The primary goal of this project is to begin to provide the State of Delaware with a fully operational, statewide method of tracking clients known to the various maternal and child health/handicapped children programs. Specific objectives are to survey program staff to determine data elements needed by each program and to contract with a technical assistant to facilitate surveys of programs, determine hardware needs, develop the necessary software, and train staff in its use.



Data and Information

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Developing Policies to Promote Healthy and Strong Pamilles: A Focus on Promotion of

Adolescent Health

AAMC (AAMFT Research and Education) Foundation Family Impact Seminar

1717 K Street, N.W.

Suite 407

Washington, DC 20006

(202) 429-1825

MCHIP MCJ-113002 10/01/88—09/30/92 Project Director(s): Theodora Ooms

The goal of this project is to improve family involvement in adolescent health through providing the best information available about the family's role, exemplary program models, and supportive policies to staff at the Federal and State levels. The program will include three separate but related activities conducted over 3 years: (1) Federal policy seminars, (2) background state-of-the-art reports, and (3) replication of seminars in selected States. An estimated 500 Federal and 1000 State policy staff will benefit directly from the project's activities.

Healthy Mothers, Healthy Babies

The American College of Obstetricians and Gynecologists 409 12th Street, S.W. Suite 309 Washington, DC 20024-2188 (202) 863-2458

MCHIP MCJ-113566 02/01/85---01/31/89 Project Director(s): Janet Chapin

The Healthy Mothers, Healthy Babies Coalition seeks to develop MCH networks for sharing information, promote public awareness of preventive health habits for pregnant women, distribute public education materials on topics related to improving maternal and child health, and assist in developing State coalitions. The coalition has 95 members, representing voluntary and professional organizations and Federal agencies. Through meetings, conference exhibits, press conferences, surveys and reports, publications, and a quarterly newsletter, the coalition reaches thousands of individuals each year with information and strategies for improving maternal and child health.

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

MCHIP MCJ-111006 10/01/84---09/30/89 Project Director(s): Robert C. Baumiller, S.J., Ph.D.

The goal of this project is to contribute to the maintenance and improvement of the health status of mothers and children by providing comprehensive and current MCH-related information services and technical assistance to all Federal and State agencies, voluntary organizations, and individuals involved with maternal and child health. The project maintains the MCH Reference Collection, a SPRANS data base, and information on over 1000 MCH organizations. Pub" ations include a variety of directories and annotated bibliographies.



General Program Concerns

Primary Care Assis ance and Accountability

Project

Association of Materna! and Child Health Programs (AMCHP) 2001 L Street, N.W. Suite 308 Washington. DC 20036 (202) 775-0436 MCH1P MCJ-113400 10/01/87—09/30/90 Project Director(s): Catherine A. Hess

This project's goals are to improve the capacity of State MCH agencies to: (1) Make high quality, comprehensive primary care available and accessible to all children and youth; (2) measure and document the needs of children and youth; (3) assess the adequacy of the primary care system in meeting these needs; and (4) measure and document the use of Title V MCH funds. Project activities include assessing current State efforts in areas related to primary care, needs assessment and planning, and the use of data systems and reporting; conducting surveys; identifying resources for technical assistance, potentially useful data systems, and reporting formats; and developing and delivering resources and technical assistance to MCH State agencies.

Voluntary State Reporting System on MCH Services

The Public Health Foundation 1220 L Street, N.W. Suite 350 Washington, DC 20005 (202) 898-5600 MCHIP MCJ-510477 08/31/88—08/31/91 Project Director(s): James T. Dimas

This project seeks to provide an analysis of the Public Health Foundation's ASTHO (Association of State and Territorial Health Officials) Reporting System FY 1987-88 data related to services and expenditures of the Nation's State MCH and CSHN Programs, and to prepare reports about these data. In addition, the foundation publishes information on the Nation's public health agencies and responds to special data requests from the U.S. Public Health Service, Congress, State and local health agencies, and other public health organizations.

Working Group on the Measurement of Child Health Status and MCH Services

Child Trends, Inc. 2100 M Street, N.W. Suite 411 Washington, DC 20037 (202) 223-6288 MCHIP MCJ-113794 05/01/86—04/30/89 Project Director(s): Barbara Starfield, M.D.

This project seeks to identify the state of the art concerning the measurement of child health status; reach a consensus on the most appropriate and useful existing measures; develop an instrument that can be used to monitor the health of U.S. children and evaluate MCH programs; and promote adoption of this instrument by Federal and State statistical agencies, clinicians, and public health researchers. Activities include publishing an annuted bibliography on child health status measures, participating in conferences, and working to have portions of the child health status instrument developed and incorporated into State and Federal health surveys.



Data and Information

Pacific Basin Maternal and Child Health Resource Center

University of Guam P.O. Box 5143 UOG Station Mangilao, GU 96923 (671) 734-4717 MCHIP MCJ-663490 09/01/87—08/31/90 Project Director(s): Augusta Rengiil

The goal of this project is to provide assistance to the maternal and child health programs in the Pacific Basin in their efforts toward improving the health status of women and children. The project maintains an MCH resource center, makes culturally relevant materials available to health service providers, and develops publications which address special concerns of Pacific Basin populations or which present information in various island languages.

IDEALS (Idaho Data Exchange and Linkage System)

Idaho Bureau of Maternal and Child Health 450 West State Street Boise, ID 83720 (208) 334-5962 MCHIP MCJ-163303 10/01/88—09/30/89 Project Director(s): Thomas L. Bruck, D.D.S., M.P.H.

The goal of this project is to improve the health status of women, children, and families by improving the Bureau of Maternal and Child Health planning and management capabilities to serve these populations. State staff of the Bureau of Maternal and Child Health, with the assistance of the Bureau of Systems Management, will develop, design, and implement an information system linking all Maternal and Child Health (MCH) and Developmental Disabilities (DD) Programs.

American Nurse-Midwifery

Rush-Presbyterian-Saint Luke's Medical Center 1653 West Congress Parkway Chicago, IL 60612 (312) 942-6604 MCHIP MCJ-173928 10/01/86—09/30/89 Project Director(s): Constance J. Adams

Important information about certified nurse-midwives (CNMs) and the nature of their clinical practice was obtained from a survey conducted on behalf of the American College of Nurse Midwives in 1982. The major focus of this project is to determine what changes have taken place in selected characteristics of CNMs and the nature of their clinical practice between 1982 and the present. Comprehensive information is being obtained about the specific services provided by CNMs and the magnitude of their involvement with malpractice suits.



General Program Concerns

Midwest Maternal and Child Health Data

Improvement Project
University of Illinois at Chicago
School of Public Health
2035 West Taylor Street
Chicago, IL 60612
(312) 996-5951 or 996-0719

MCHIP MCJ-173450 10/01/88—09/30/91 Project Director(s): Joan Kennelly, R.N., M.P.H. Naomi M. Morris, M.D., M.P.H.

The Midwest MCH Data Improvement Project seeks to improve the health outcomes of the MCH populations in Regions V and VII by designing, testing, and implementing a biregional MCH data system to enhance the States' capacities to formulate policy and programmatic strategies. The project will work to correct the current fragmentation of health system data by creating the infrastructure necessary to develop and maintain uniform minimum data sets and program/health outcome indicators for MCH populations and programs; define and test a system for transferring data from the States to the central data base; and field-test selected indicators using a sample from the multistate MCH data base.

Assuring Comprehensive Health Care Using the Iowa Profile of Problems and Goals

University of Iowa Hospitals and Clinics Child Health Specialty Clinics Department of Pediatrics Hospital School 247 Iowa City, IA 52242 (319) 356-1118 MCHIP MCJ-195022 10/01/87—09/30/90 Project Director(s): Richard P. Nelson, M.D.

The Iowa Profile of Problems and Goals (IPPG), a clinical descriptive tool used to characterize the functional status of the child or family according to required special services or assistance, will be used in this project to obtain detailed analyses of selected populations of children receiving Child Health Specialty Clinics services. The project will determine the usefulness of the IPPG as an objective method of describing the populations of children receiving the services of State Title V Programs, and the applicability of the IPPG as a case management method in tracking.

Region III Perinatal Information Consortium

Johns Hopkins University
School of Hygiene and Public Health
Department of Maternal and Child Health
624 North Broadway
Baltimore, MD 21205
(301) 955-636

Training
MCJ-009110
10/01/87—09/30/90
Project Director(s):
Greg Alexander, D.Sc.

This project seeks to improve the health and survival of infants and their mothers by supporting the technical perinatal information management and utilitation capacities of State MCH/CSHN Programs for planning, coordinating, targeting, advocating, promoting, and evaluating health services. This will be accomplished by assisting State agencies in the identification of data acquisition and utilization needs and the development of strategies to address these concerns, and by providing technical assistance and educational support to State agencies to enhance their capacities to collect, analyze, and disseminate data.



Data and Information

A Planning Proposal for a National Survey of Children with Special Health Needs Albert Einstein College of Medicine 1300 Morris Park Avenue Bronx, NY 10461 (212) 430-5301 MCHIP MCJ-117007 10/01/88—03/31/91 Project Director(s): Ruth E.K. Stein, M.D.

The purpose of this project is to establish and implement a planning mechanism for a new population-based survey of children in the United States who have special health needs. It will involve designing, planning, and piloting a national cross-sectional survey that will provide the data base and framework for the development and monitoring of a system of regionalized and community-based service. This will allow for the addition of longitudinal and/or sequential cross-sectional surveys in the future.

Development of a Child and Adolescent Health Profile Welfare Research, Inc. 112 State Street 10th Floor Albany, NY 12207 (518) 432-2564 MCHIP MCJ-363753 08/01/85—07/31/89 Project Director(s): Linda Simkin, M. Phil.

This project seeks to increase the access of State and local planners and decision-makers to recent child and adolescent health data. Project objectives include: (1) Developing a prototype statistical report of key indicators of child and adolescent health status; (2) preparing a directory of State data sources for child and adolescent health; and (3) producing a manual on the development of a statistical health profile and disseminating it to MCH directors, planners, and administrators in other States.

Expanding and Institutionalizing the Region IV
Network for Data Management
and Utilization
University of North Carolina at Chapel Hill
Health Services Research Center
Chase Hall 132-A
CB 7490
Chapel Hill, NC 27599

MCHIP MCJ-373915 10/01/86—09/30/89 Project Director(s): Priscilla A Guild, M.S.P.H.

This project seeks to identify factors contributing to high infant mortality in Region IV (Alabama, Florida, Georgia, Kentucky, Mississippi, North Carolina, South Carolina, and Tennessee) and to provide technical assistance to the State MCH Programs which address these factors. Activities include the annual publication of the *Perinatal D-tta Book*, which summarizes 40 perinatal indicators (by race) and 22 public health service figures for each State, the region, and the Nation; an annual workshop (carrying continuing education credit) for MCH program and State statistical staff; and at least four annual technical assistance site visits to address State-specific problems.



General Program Concerns

(919) 966-7117

Health and Education Collaboration for Children with Handicaps

University of North Carolina at Chapel Hill Department of Maternal and Child Health 407 Rosenau Hall CB 7400 Chapel Hill, NC 27599 (919) 966-5979

MCHIP MCJ-375031 10/01/88—09/30/91 Project Director(s): Anita M. Farel

The purpose of this project is to promote interagency collaboration and coordination among State programs for children with special health care needs, P.L. 99-457, Part H lead agencies, and State education agencies in DHHS Region IV by improving the collection and use of data that will support program planning, monitoring, and evaluation. Specifically, the objectives of this project are to: (1) Develop an Infants and Toddlers Model Data Set to improve the ability of State programs for children with special health care needs to identify children in need of services; (2) design a protocol for sharing data among State programs for children with special health care needs in order to monitor the health and developmental status of the target population; and (3) promote interprogram communication regarding data collection and use among State programs and improved reporting and information management systems.

Maternal and Child Health Studies

Information Sciences Research Institute 8027 Leesburg Pike Suite 102 Vienna, VA 22180 (703) 448-1143 MCHIP MCJ-510536 07/01/86—06/30/89 Project Director(s): Margaret W. Pratt

This project collects and publishes MCH data which can be used for program planning and evaluation. As its primary activity, the project has used both historical and current data to provide uniform and consistent annual information, as well as trend data, for the United States, each State and county, selected major cities, and other defined areas. The project has prepared many onetime reports and has also developed a series of publications for making mortality and natality data available for use by managers of MCH and CSHN Programs.

Teratogen Information System (TERIS)

University of Washington School of Medicine Seattle, WA 98195 (206) 543-2465 Genetics
MCJ-531C01
10/01/87—09/30/89
Project Director(s).
J. M. Friedman, M.D., Ph.D.
J.E. Polifka
Thomas H. Shepard, M.D.

The goal of this project is to make current, authoritative information on the teratogenic effects of drugs and other environmental agents more readily available to clinicians and, through them, to pregnant women. To do this, the project will expand the TERIS data base to include all agents listed in the *Physician's Desk Reference* as, well as 50-100 other agents that are commonly encountered by women during pregnancy. Other activities include developing microcomputer-based versions of the data base and of *Shephard's Catalog of Teratogenic Agents* and conducting a national workshop to devise a strategy for improving clinical teratology services.



Data and Information

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A Community-Based Genetics Services Network for Native Americans of the Southwest

University of Arizona College of Medicine Arizona Health Sciences Center Section of Genetics/Dysmorphology Department of Pediatrics Tuscon, AZ 85724 (602) 795-5675 Genetics MCJ-041003 10/01/87—09/30/90 Project Director(s): H. Eugene Hoyme, M.D.

This project seeks to increase the utilization of genetic services by Native Americans throughout the Southwest by providing clinics and professional and community education. Project goals include developing a definition of the incidence of congenital anomalies and genetic disorders and investigating their societal impact in the target population; reducing the number of genetic disorders and congenital anomalies in the target population; and creating a heightened awareness by Native Americans and their health care providers of the role of genetics in health care and disease.

Hepatitis B Screening Access Program for Southeast Asians

Asian American Health Forum 835 Jackson Street Suite 407 San Francisco, CA 94133 (415) 391-8494 Genetics
MCJ-061008
10/01/88—09/30/91
Project Director(s):
Tessie Guillermo

The goal of this project is to increase access to hepatitis B screening and immunization for Southeast Asian pregnant women and their newborns. The primary objectives for the first year include identifying sites in which the project will be implemented; screening and counseling up to 400 Southeast Asian pregnant women and immunizing their newborns as needed; gathering screening results and immunization data; and establishing a relationship with a pharmaceutical supplier in order to obtain vaccines by donation.



Overcoming Ethnocultural Barriers to Genetic Services

San Francisco General Hospital (SFGH) Perinatal Genetics

University of California at San Francisco
Department of OB/GYN and Reproductive Sciences
3rd and Parnassus Avenue
Room U262
San Francisco, CA 94143
(415) 821-3133

Genetics
MCJ-061005
10/01/87—09/30/90
Project Director(s):
William R. Crombleholme, M.D.
Mitchell S. Golbus, M.D.

The goals of this project are to (1) lower the barriers to accessing appropriate genetic counseling and testing interventions faced by the SFGH perinatal system patients, and (2) develop a model system for the delivery of genetic counseling interventions to underserved populations and disseminate the knowledge gained through the program's efforts. To achieve these goals, the program will employ genetic counselors and bilingual, bicultural counseling aides, maintain appropriate protocols for services and referrals, integrate the genetics program into the existing SFGH Perinatal System, and maintain a satellite prenatal diagnosis center at SFGH which will offer amniocentesis and maternal serum alphafetoprotein followup.

Demonstration of an Innovative Approach to Genetic Counseling Services for the Deaf Population
Gallaudet University
800 Florida Avenue, N.E.
Washington, DC 20002

(202) 651-5258

Genetics MCJ-111005 10/01/84—09/30/9^o Project Director(s): Kathleen Shaver Amos, Ph.D.

The purpose of this project is to overcome the barriers to genetic counseling services that are currently encountered by the deaf population. To achieve this goal, the project will: (1) Prov. a comprehensive model genetics program for hearing-impaired individuals and their families at Gallaudet University; (2) integrate and coordinate the provision of genetic services to deaf clients with those provided by the District of Columbia, Commission of Public Health, Genetics Services Program; and (3) initiate extensive information dissemination and outreach education to geneticists, deafness professionals, medical professionals, and deaf consumer groups.



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General Program Concerns

Proposal to Extend and Enhance the Utilization of Existing Genetic Services by Overcoming Ethnocultural Barriers

University of Medicine and Dentistry of New Jersey Medical School Division of Human Genetics 185 South Orange Avenue Newark, NJ 07103 (201) 456-4477 Genetics MCJ-341004 10/01/88—09/30/91 Project Director(s): Franklin Desposito, M.D.

The purpose of this project is to improve the medical care of immigrant populations in Atlantic City, Camden, and Trenton, New Jersey, who face numerous barriers posed by their ethnocultural, language/communications, and financial backgrounds. A detailed system of strategies involving educational materials which are linguistically and culturally sensitive, audiovisual aids, bilingual genetic screening forms, translator selection, training, and utilization, and intercultural workshops has been developed to assist the local genetic services programs in overcoming these barriers to access.

Proposal to Increase the Utilization of Genetic Testing and Counseling Services by Hispanic and Immigrant Populations New Jersey State Department of Health Special Child Health Services 363 West State Street CN 364
Trenton, NJ 08625

(609) 292-5676

Genctics MCJ-341002 10/01/85—06/30/89 Project Director(s): Barbara P. Kern

This project seeks to develop and test strategies to increase the utilization of genetic services by Hispanic and immigrant populations in five counties in the northeastem region of the State of New Jersey. The project will provide inservice training, workshops, and audiovisual and printed materials to genetic services providers in order to assist these providers in communicating more effectively with their non-English speaking clients and in providing culturally sensitive services.

Oklahoma Native American Genetic Services

Program
Oklahoma State Health Department
Division of Maternal and Child Health
P.O. Box 53551
Oklahom. City, OK 73152
(405) 271-4476

Genetics MCJ-401002 10/01/87—09/30/90 Project Director(s): Edd Rhoades, M.D., M.P.H.

This project seeks to develop a coordinated network of genetic services that is culturally acceptable and financially accessible to Native Americans in Oklahoma in order to increase their utilization of genetic services. Program objectives include establishing genetic clinical services at seven selected Indian Health Services hospitals and clinics; increasing identification and referral of Oklahoma Native Americans at risk for genetic disorders or birth defects; collecting and analyzing epidemiological data on the incidence and prevalence of birth defects and genetic disorders; and developing collaborative liaisons among the genetics team, Indian Health Services, and related programs.

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Overcoming Ethnocultural Barriers to Genetic Services

Comprehensive Genetic Services and Education Program for the Deaf and Hearing Impaired Saint Christopher's Hospital for Children Section of Medical Genetics 5th and Levigh Avenue Philadelphia, PA 19133 (215) 427-4430

Genetics MCJ-421007 10/01/88—09/30/91 Project Director(s): Kathleen E. Toomey, M.D.

The purpose of this program is to provide genetic evaluation, diagnosis, and counseling services, developmental assessments, and vocational counseling to the deaf and hearing-impaired community of the Greater Delaware Valley. Project goals will be met through the activation of a team composed of geneticists, a counselor, and an education specialist fluent in manual communication who will conduct clinical services and implement a program of education and literature dissemination to the target population.



General Program Concerns

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