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DEPARTMENT OF COMMERCE

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UNITED STATES DEPARTMENT OF COMMERCE
Office of the Secretary
Washington, D.C. 20230

March 21, 1997

MEMORANDUM FOR: Elena Kagan
Deputy Assistant to the President for Domestic Policy

FROM: Jeffrey A. Hunker
Deputy Assistant to the Secretary

SUBJECT: Department of Commerce's Contribution to the Early Childhood Development Initiative

Below is Commerce's contribution to the Early Childhood Development Initiative.

The Economic Development Administration (EDA) inspired and funded the establishment of multi-county economic development districts (EDDs) all across the country to promote regional cooperation and economic development. Over the past 30 years, almost all of the EDDs have taken on the responsibility for coordinating many other Federal government services in their regions, and their funding has diversified to include funding from many other Cabinet agencies. So, for example, most EDDs coordinate the "Meals on Wheels" programs, day care voucher programs, and other Federal childhood development programs in their multi-county regions.

In addition, from time to time, EDA's public works and infrastructure program has funded the construction of day care centers where the centers were deemed essential for the attraction or retention of jobs and employees in industrial parks.

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HHS

Divider Title: _____

THE SECRETARY OF HEALTH AND HUMAN SERVICES
WASHINGTON, D.C. 20201

MEMORANDUM FOR THE PRESIDENT

I am pleased to submit this report of the Department of Health and Human Services' activities targeting the earliest years of life as requested in your February 24 memorandum. While this report is not an exhaustive compilation of every HHS program and project that serves very young children, it clearly reveals our tremendous commitment to protect and enhance their development.

We look forward to working with you and the First Lady on this extremely important initiative.

Donna E. Shalala

Enclosure

DEPARTMENT OF HEALTH AND HUMAN SERVICES

ACTIVITIES SERVING CHILDREN IN THEIR EARLIEST YEARS: A REPORT TO THE PRESIDENT

MARCH 24, 1997

HHS Activities Serving Children in Their Earliest Years

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Introduction

On February 24, 1997, the President issued a memorandum to all federal departments to report in 30 days on existing and planned projects that target young children in their earliest years of life. This report is a response to the President's request.

The Department of Health and Human Services has been a leader in fostering positive development in our nation's youngest children and their families. The very mission of HHS is to promote health, foster self-sufficiency, and protect children. The Department's programs and activities, therefore, touch every aspect of the protection and promotion of a child's development -- from brain research at our many research labs to disseminating information to parents on safe and healthy care settings. This report is created with this broad vision of early learning and reflects the depth and cross-cutting nature of HHS activities targeted towards children aged zero to three and their families.

Healthy growth and development from pre-conception to early childhood requires the integration of many domains to achieve well-being. Our understanding of child caring and health practices has evolved from a wide investment in and commitment to both basic and applied science. This research serves as the foundation for the programs, services, and messages that we direct to young children and their families.

The earliest years of life are critical to cognitive, emotional, and physical development. For children to develop the proper foundation for learning, working productively, and contributing fully to society, they require emotional nourishment, intellectual stimulation, parental and community support, safe housing, quality child care, good nutrition, and proper health care in their earliest years. While supporting children and parents in their first years of life, HHS's experience and research indicates that learning and developing is a life-long process which does not solely rest on the result of activities in early childhood. Therefore, HHS activities address the entire life span.

This report clearly reveals the tremendous commitment of the Department of Health and Human Services to protecting and enhancing children's development. The report is not an exhaustive list of all our activities on behalf of children thought their childhood years, but it illustrates our commitments in the three areas the President and First Lady will highlight in their April Conference on Early Childhood Development; early childhood services, parenting of very young children, and the health of children ages zero to three.

An outline of activities in each area is followed by more detailed descriptions that include contextual information including funding level and target population where available. Resources and messages, and research are featured in each section, but these often emanate from other activities and programs. Some activities cross over the categories established here and could have been categorized in more than one section, but each is displayed only once. HHS feels that this report is a useful reference, and in the future we plan to publish it in a modified form.

EARLY CHILDHOOD SERVICES

HHS is the administrator of the Child Care and Development Fund--a block grant to States, Territories, and Tribes--that funds child care subsidies and quality activities for low-income families. In addition to this function, HHS has supported research on the effects of child care on young children, and advanced the knowledge of quality child care programs with initiatives around health, safety, and linking with other comprehensive services. HHS also operates the Head Start and Early Head Start programs that provide comprehensive services for children under five. Head Start is the nation's premier early childhood program for low-income children, and is currently expanding to reach more children between the ages of zero to three.

I. Improving the Quality of Care Environments

- Healthy Child Care America Campaign
- The National Center for Health and Safety in Child Care
- University Affiliated Programs/Training Initiative Project
- Administration on Developmental Disabilities Projects of National Significance

II. Head Start and Child Care

- Head Start
- Head Start Training and Technical Assistance
- Early Head Start
- Early Head Start Training and Technical Assistance
- Early Childhood Head Start Collaborative Initiative
- Child Care and Development Fund
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- Head Start - Child Care Partnerships

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- Starting Early - Starting Smart
- Early Head Start Research and Evaluation Project
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- Child Care Policy Research Consortium
- Early Child Care Study of Children with Special Health Needs

IV. Resources and Messages

- Publications: National Health and Safety Performance Standards
- Publications: ABCs of Safe and Healthy Child Care, Action Plan for Child Care Health and Safety
- Other Resources

I. Improving the Quality of Care Environments

Healthy Child Care America Campaign (CCB/MCHB)

Funding level: In 1996, the Maternal and Child Health Bureau, in support of the Campaign, made $2.5 million available to award grants to states to develop strategies for planning health systems in child care. Forty-six grants (to 46 states and territories) of $50,000 each were awarded in October 1996. The grantees are receiving their grants over a period of three years. In addition, the Child Care Bureau and the National Highway Traffic Safety Administration at the United States Department of Transportation have provided $260,000 total of technical assistance.

Target population: Children in child care, their families, and child care providers will be served by this Campaign.

Description: In May 1995, the Child Care Bureau in conjunction with the Maternal Child Health Bureau launched the Healthy Child Care America Campaign. The goal of the Campaign is to promote partnerships between child care and health agencies to ensure that children in child care are safe and have access and receive needed health services. Activities around this initiative include:

- Partnership to Develop and Implement a Child Care Health Consultant Program. MCHB has announced this activity as a priority area under its grant application guidance for Spring 1997 at a funding level of $175,000 per year for a project period of 3 years. The program targets infants and young children in child care programs. The purpose of this activity is to support the health and safety of young children in child care settings through the development and implementation of state based programs to train public and private sector health professionals to serve as health consultants to child care programs. It is hoped that by developing and implementing a standardized training program recognized by health and child care fields, more health professionals will avail themselves of the training and the overall health and safety of young children, and the quality of child care will be enhanced.

- The Health Systems Development in Child Care (HSDCC) grants program was developed by MCHB in collaboration with State and Federal agency members of the Maternal and Child Health/Administration on Children and Families (MCH/ACF) Technical Advisory Group. The program responds to growing concern about the physical, emotional, social and economic status of American children in child care. It parallels national trends in health care and child welfare reform and provides a vehicle for state and community investments in systems development, service integration and child care capacity development. The HSDCC projects are to utilize the child care environment as a focal point for State and community planning to integrate health care, child care and social support services in programs serving children and families. Each project is expected to stimulate and support collaborative, coordinated State-

wide/community-based efforts to ensure safe, healthy and developmentally appropriate child care environments for all children, including children with special health care needs, and their families.

Healthy child care efforts have now been funded in most states. The Maternal and Child Health Bureau is in the final stages of funding the remaining 13 states and territories, expanding the Healthy Child Care America Campaign to every State and Territory in America. MCHB is also launching a new effort to train health professionals to work in child care and issuing a new streamlined set of child care standards that all states and communities could should adopt. Any one of these, or the set together, offer new opportunities to provide visibility to the Campaign. In addition, the volunteer summit in Philadelphia provides a critical opportunity for high-level officials to call upon every doctor and nurse and other child care health consultants in the country to "adopt a child care program."

Contribution to Initiative: The Campaign has raised the awareness about the importance of health and safety in child care. Forty-six states have launched Healthy Child Care America Campaigns at the state and/or community level. The American Academy of Pediatrics has joined the Campaign to provide technical assistance to states and communities and to facilitate health professionals involvement in community-based child care programs. These partnerships between child care and health will ensure that children in child care are immunized, that their learning environments are safe and healthy, and that they have access to on-going preventative health care and education.

The National Center for Health and Safety in Child Care (MCHB)

The Maternal and Child Health Bureau has funded a 4-year grant to the University of Colorado Health Sciences, in Denver, Colorado for the purpose of creating a National Center for Health and Safety in Child Care.

Funding Level: The Center is funded at $350,000 per year for a project period of 4 years.

Target Population: Infants, toddlers, and young children in out of home child care settings.

Description and Purpose: The Maternal and Child Health Bureau's National Resource Center for Health and Safety in Child Care seeks to enhance the quality of child care by supporting state and local health departments, child care regulatory agencies, child care providers, and parents in their efforts to promote health and safety in child care. The Center provides training and technical assistance to support regional, state, and local initiatives; conferences for sharing experiences and knowledge; and development and distribution of resource materials. The Center maintains a computerized database containing the text of *Caring for Our Children. National Health and Safety Standards for Out of Home Child Care* and the text of every states' current child care licensure regulations standards. In 1996, the Center made this information available to a wide variety of potential users by putting the information on its World Wide Web page on the Internet. This accomplishment allows use of the National Health and Safety Standards as a

readily available reference document and the ability to review current health and safety standards from other states.

Contribution to Initiative: The National Resource Center for Health and Safety in Child Care contributes to this initiative by promoting and protecting the health and safety of infants, toddlers and young children in child care. It accomplishes this by the prompt dissemination of new information; training of child care professionals to promote implementation of health and safety standards; and advocacy efforts that strengthen existing state and local health and safety regulations.

University Affiliated Program (UAP)/Training Initiative Project (ADD)

Funding Level: $200,000 per year

Target Populations: 0-3 year olds having a developmental disability or developmental delays.

Description: The University Affiliated Program (UAP) is an ongoing project of 60 programs, with at least one in every State and Territory.Although many of the UAPs provide clinical services and interdisciplinary training in early childhood, the Bronx, NY and South Dakota UAPs are exemplary programs.

- *The Bronx UAP* provides statewide technical assistance to aid the State Department of Health to implement Part H (early intervention program) of the Individuals with Disabilities Education Act (IDEA) which is called EarlyCare in NYS. It has assisted in the development of implementation strategies, enhancing the capacity of the system and developing a satisfactory rate structure. It has worked closely with the NY City lead agency on early intervention. This UAP also provided technical assistance and training in early identification and intervention to local officials and program directors from many NYC agencies. An ongoing effort is personnel preparation training in the area of early childhood; a focus has been on urban community service providers.

- *The South Dakota UAP* has formed a partnership to meet the current and future early childhood personnel needs on Rosebud and Pine Ridge Reservations. It is working in close collaboration with Sinte Gleska University and Oglala Lakota College on the reservations to offer course work and a practicum experience to students and teachers who currently are, or will be working with young children with special needs. The UAP is also preparing materials for these two educational institutions that will enable them to continue teaching these courses on an ongoing basis. These materials will also allow other reservation colleges to begin to establish courses in early childhood/special education at their colleges.

Contribution to Initiative: These activities by the UAPs will contribute to the increased numbers of personnel and para-professionals that will be serving children with special needs in early childhood programs. Their effort in developing training materials and curriculum can be

used by others. Technical assistance provided by the UAPs allows state and local programs to enhance their ability to effectively serve all children in their communities.

Administration on Developmental Disabilities Projects of National Significance (ADD)

Funding Level: Three-year funding of $99,054, $100,000, and $93,158, respectively, per year

Target Population: Training for approximately 500 parents and providers of child care for preschool children with disabilities

Description and Purpose: These three-year grants focus on developing models for training providers and others in the inclusion of children with disabilities in child care settings. They have produced resources and publications, and perform outreach through community forums and message campaigns.

- *"Preschool Inclusion Project,"* University of Miami, Mailman Center for Child Development--links with existing systems, EZ/EC efforts, and community outreach and provides on-site assistance with identified barriers.

- *"Child Care and Early Intervention: Linkage for Successful Inclusion of Young Children with Disabilities,"* Frank Porter Graham Child Development Center, University of North Carolina-Chapel Hill--provides technical assistance to two rural counties, including Latino and Native American populations and an Enterprise Community, by developing training models for implementing the paradigm shift toward family-centered, culturally sensitive, and community-based services.

- *"Child Care Inclusion Project,"* BANANAS, Inc., Oakland, California--works with the Family Resource Network and the Child Care Law Center to establish inclusion as an accepted standard of quality for child care, targeting parents and providers as change agents for a replicable strategy for including children with developmental disabilities from diverse racial, ethnic, and socioeconomic backgrounds.

Contribution to Initiative: These grants represent ADD efforts in the high-priority area of inclusion of children with disabilities in their communities. The support appropriate child care provides for families addresses the social and educational needs of children in their earliest formative years, affords children without disabilities the opportunity to experience the benefits of inclusion of all children, and enables parents to return to or continue work.

II. Head Start and Child Care

Head Start (HSB)

Funding: FY 96, $3.4 billion

Target Population: Low-income children and their families, aged three to five years old. In FY 96, Head Start served over 750,000 children

Description: Head Start is a comprehensive early childhood program for low-income children and their families with the overall goal of promoting the development and social competence of children. The program is designed to maximize the strengths and unique experiences of each child and family. Parents are seen as the principal influence on their child's development and are direct participants and decision-makers in the program. All Head Start staff are expected to work together to support the spirit and philosophy of the Head Start program. Important features of Head Start include:

- Head Start Performance Standards. The performance standards have guided the Head Start program over its 30-year history. These standards and policies specify that Head Start programs must deliver a wide range of services to ensure comprehensive care including health, education, parent involvement, social services, and disability services. The 1994 reauthorization of Head Start required the revision of the performance standards, which will be fully implemented in January 1998. The new standards contain a section on community partnerships, reflecting the goal of Head start agencies to work collaboratively with other community services. This includes the transition of children into and from Head Start. The performance standards also focus on correcting deficiencies in Head Start programs and providing technical assistance.

- Migrant Head Start. The Migrant Head Start program has a unique emphasis on serving infants and toddlers as well as pre-school age children, while their parents are working in the fields. Infants as young as six weeks of age are served in some Migrant Head Start Centers. Migrant centers provide extended day services, usually up to 12 hours a day, and up to 7 days a week during the harvest season to accommodate the working needs of the families they serve. The Migrant Head Start program in FY 96 was funded at a level of $139.4 million, and served over 35,000 children.

Head Start Training and Technical Assistance (HSB).

Funding Level: FY 96 - $74 million.

Description: Head Start has an extensive training and technical assistance (T&TA) system designed to support continuous quality improvement in all Head Start programs. The FY 96 budget for T&TA was $74 million. Fifty percent of the T&TA budget goes to the Head Start grantees to support the provision of local training and technical assistance. The Training and Technical Assistance system consists of:

- Sixteen Technical Assistance Support Contracts who provide training and technical assistance in early childhood education, health, parent involvement, social services and management;
- Twelve Resource Access Projects who provide training and technical assistance in disability services;
- Seven National Training Contracts who develop materials and training guides in the areas of education, health, social services, parent involvement, disabilities, administration and transition;
- Fourteen teaching centers who provide residential training in local exemplary Head Start programs including a migrant and Indian site;
- Indian Health Services which provide technical assistance and training to Indian grantees in health;
- Child Development Associate National Accreditation Project;
- Publications Center; and
- a Data Management Project.

Contribution to Initiative: Head Start's Training and Technical Assistance provides valuable guidance, training, and resources to promote quality in Head Start programs.

Early Head Start (HSB)

This is a new service delivery activity funded incrementally over a five year period. It includes a strong research/evaluation component involving 16 research projects which study child, family, program and community variables that affect outcomes.

Funding Level: Total approximately $143 million for FY1996
Number of grantees: 143

Target population: Pregnant women and families with children under age three who meet the income criteria. Number of clients served: 22,248 children

Description and Purpose: Early Head Start was first designed in response to the 1994 reauthorization of Head Start, which established a special initiative setting aside 3 percent of FY 1995 (going up to 5% of FY 98) Head Start funding for services to families with infants and toddlers. The program provides early, continuous, intensive and comprehensive child

development and family support services. This two-generation program provides services that begin before the child is born and concentrate on supporting families during the critical first three years of the child's life. Using the successful Head Start model, Early Head Start offers a basic early education, nutrition, health and family development approach. To meet the unique additional requirements of very young children, the programs will test new services as well, including services to address special health needs for newborns, a three-generational model with grandparents, parents and children, and strong parent-child interaction models.

Contribution to Initiative: Early Head Start is a national laboratory to demonstrate the impact that can be gained when early, continuous, intensive and comprehensive services are provided early on to pregnant women and very young children and their families. Early Head Start addresses maternal and infant health, child development, child-caregiver relationships and community development.

Early Head Start Training and Technical Assistance (HSB)

Funding Level: $4.13 million

Description: An extensive training and technical assistance system exists to support the Early Head Start program by enhancing program quality with emphasis on facilitating each grantee's ability to fully meeting the Head Start Performance Standards.

The system consists of three parts: the Early Head Start National Resource Center (EHSNRC), sixteen Technical Support Contracts (TASCs), and twelve Resource Access Project Contracts (RAPs). The EHSNRC, a consortium comprised of Zero to Three and West Ed, works in partnership with the TASCs and RAPs in providing high quality specialized technical assistance for Early Head Start grantees. The Resource Center provides week long intensive childhood training programs several times a year for grantee staff and Federal staff. The Resource Center also develops and disseminates information, including electronic communication, provides on-site technical assistance visits, and conducts training sessions for trainers for the Infant - Family Network of TASC and RAP Infant Toddler Specialists.

The TASCs provide training and technical assistance through the assignment of a startup consultant to each new grantee. Each TASC has a lead infant - toddler specialist and a pool of consultants with expertise in infant - toddler development and programming, health, parent involvement, social services and management. The RAPs function similarly, with technical assistance focused on enabling grantee staff to integrate children with disabilities into the Early Head Start program.

The system as a whole provides needs assessments, on-site consultation, development of rapid response plans for addressing needs, cluster training and follow-up, use of community resources, materials, workshops and State, Regional and National conferences.

Early Childhood Head Start Collaborative Initiative of the Cherokee Nation, Oklahoma and Indian Health Service (IHS)

Funding Level: The Cherokee Nation Head Start Program for children aged 1 to 2 receives approximately $500,000 from the Head Start Program. The IHS support is included in the direct care funds for health services and cannot be specified.

Description: This is a collaborative activity between the Indian Health Service and the Cherokee Nation Head Start. The Head Start Program provides meals, educational, and social services to low-income Cherokee families. Approximately 76 families will be served in 1997. Parenting skills based on the developmental stages of children are provided to parents and parents and children together when appropriate. Developmental testing is conducted with referrals made for rehabilitative services as needed. The Indian Health Service provides services such as immunization and well child and prenatal care. Nutrition and sanitarian health services are provided to assure a safe and nutritious Head Start Program environment.

Contribution to Initiative: The reduction of infant mortality and enhanced parenting skills and early detection and treatment of developmental delays.

Child Care and Development Fund (CCB)

Funding Level: FY 97 $2.9 billion to States, $59 million to Tribes

Target Population: children under age 13

Description: The newly established Child Care and Development Fund (CCDF) authorized by the Personal Responsibility and Work Opportunity Reconciliation Act of 1996, (PL 104-193), will assist low-income families and those transitioning off welfare to obtain child care so they can work or attend training or education. The Child Care and Development Fund brings together, for the first time, four Federal child care subsidy programs and allows States to design a comprehensive, integrated service delivery system to meet the needs of low-income working families. Additionally, the Child Care and Development Fund sets aside a minimum of four percent of Federal and State funds to improve the quality and availability of healthy and safe child care for all families. Subsidized child care services will be available to eligible parents through certificates or contracted programs. Parents may select any legally operating child care provider. Child care providers serving children funded by CCDF must meet basic health and safety requirements set by States and Tribes. These requirements must address prevention and control of infectious diseases, including immunizations; building and physical premises safety; and minimum health and safety training.

Contribution to Initiative: Affordable, quality child care for low-income families is critical for achieving and sustaining self-sufficiency. The CCDF brings together, for the first time, four federal child care subsidy programs and allow States to design a comprehensive, integrated service delivery system to meet the needs of low-income working families.

Child Care Technical Assistance Project (CCB)

Funding level: FY 96 - $2.3 million

Target population: Child Care Development Fund grantees (States, Tribes and Territories)

Description: The Child Care Technical Assistance Project (CCTAP) seeks to improve and expand the child care delivery systems of State, Tribes and Territories for low-income families. CCTAP provides logistical support for national and regional activities sponsored by the Child Care Bureau for Child Care Development Fund grantees. CCTAP priority issues are providing Federal leadership and establishing linkages, and addressing how welfare reform impacts the accessibility, affordability and availability of quality child care. Information sharing has been a primary objective of CCTAP through sponsoring various national and regional conferences and forums, convening of national work groups, and promoting linkages with several partners to expand resources. Some of these activities are:

- The National Child Care Information Center (NCCIC) disseminates comprehensive child care and early childhood information upon request, publishes and provides resource materials at Child Care Bureau meetings and State and Tribal Child Care Administrators' conferences, leadership forums and technical assistance work groups. NCCIC also responds to requests from parents, community organizations and the general public eager for information on everything from opening a child care center to work and family issues. More than 50,700 people accessed the NCCIC web site and the Center has answered 4,320 requests for information in the past year.

- Leadership Forums and Institutes are held to highlight special issues in child care. Topics include: serving children with special needs in child care, promoting family centered care, improving infant care, expanding school-age care, and innovations in consumer education.

The CCTAP also convenes State and Tribal child care administrators, produces resources on children with special needs, and serves as a locus for collaboration with other federal departments and national organizations.

An additional $4.9 million will be made available to continue and expand the Child Care Bureau's technical assistance activities. This year's technical assistance effort will include seven coordinated initiatives: the expansion of the National Child Care Information System; The expansion of the Healthy Child Care Campaign; the establishment of a special technical assistance effort to promote the inclusion of children with special needs; the establishment of a Public - Private Partnerships technical assistance effort, the establishment of a special technical assistance effort for states to improve data collection and systems development; the continuation of national and regional leadership meetings on emerging child care issues; and the establishment of a Tribal Child Care Technical Assistance Center.

Head Start--Child Care Partnerships

Target population: Low-income families with children under the age of six.

Description: Head Start--Child Care partnerships originated as local efforts across the country to provide comprehensive, quality early childhood education to meet the demands of low-income working families and their children caught in the precarious balancing act of attaining and maintaining self-sufficiency. These collaborations combine full-day, full-year care and education, family social services, health services, and parent involvement, to promote continuous, quality care for young children and their families.

The Administration for Children, Youth and Families' Head Start and Child Care Bureaus are encouraging the development of these partnerships between Head Start and child care programs through the Head Start--Child Care Initiative Project. The goal of this effort is to promote, facilitate and enhance full-day comprehensive services on a national level. A forum of state Head Start Association leaders, project directors, Governor's Offices and other state agencies was held in April, 1996 on Head Start-Child Care Partnerships. The Project will continue to promote the development of new Head Start and child care partnerships, conduct research studies addressing how federal policies and practices can assist local program partnerships, and identify barriers and share model approaches in Head Start--Child Care partnerships.

Contribution to Initiative: Head Start--Child Care partnerships successfully attempt to combine the demands of working and training parents with the acute necessity and complex challenges in finding quality, age-appropriate care for their children.

II. Expanding our Knowledge of the Effect of Early Childhood Programs on Young Children

"Starting Early - Starting Smart" (SAMHSA)

Funding Level: FY 1997, $6.2 million (funds 10 cooperative agreements and a Data Coordinating Center)

Target Population: Families or caregiving units where either the parent, caregiver or their children between the ages of birth to 7, have or are at risk for, substance abuse and/or mental disorders. This program will serve an estimated 3,000 children and their families.

Description: The Starting Early-Starting Smart program is a public - private collaboration which seeks to improve service delivery for young children and their families and caregivers by developing new knowledge, demonstrating what works, and creating community-based partnerships that will sustain improved physical and behavioral health and health care services. Because so many social and economic factors impact children's mental health and their potential for substance abuse, collaboration is an important part of this initiative. HHS is collaborating across its agencies and with the Department of Education and the Casey Family Program. This project will test the effectiveness of integrating substance abuse prevention and treatment services with primary health care service settings and early childhood settings. The data coordinating center will also synthesize the results of this knowledge development effort, and compare it to the usual standard of community care. A long-term goal of this effort is to enable these program settings to serve and be sustained by their communities.

Contribution to Initiative: This effort will support prevention and treatment activities that lead to: the promotion of responsible, informed parenthood; the creation of comprehensive preventive physical and behavioral health care for mothers, fathers and young children; the wider availability of high quality child care and early education; and the expansion of proven state and community-based approaches to reverse current patterns of neglect.

Early Head Start Research and Evaluation Project (HSB)

Funding Level: National Study - $15.4 million, Local Study - $12 million (over a five year period)

Description: Research and evaluation is being conducted by a Consortium of renowned national and local researchers who are conducting cross-site and site specific studies in 16 Early Head Start communities across the country. Nearly 3,400 families are being randomly assigned to Early Head Start programs and comparison groups in these communities. The communities

represent a diversity of Early Head Start settings (rural, urban; various ethnic and racial populations), and the Early Head Start programs represent different types of program auspices and program models. Mathematica Policy Research, in collaboration with Columbia University, is conducting the national study.

This study will evaluate the effectiveness of the program on children, families, staff and communities; explore differential effects for programs and groups of families; and measure program quality and variations. The national study includes an embedded study of child care use and quality by both the project and comparison groups. The sixteen local research studies are being conducted by nationally-known researchers from a variety of disciplines including infant psychiatry, social work, developmental psychology, nursing, pediatric medicine, and others. Local quantitative and qualitative studies focus on emotional regulation, play, language, attachment, children with special needs, culture, substance abuse and other topics. Subgroups of researchers are also conducting policy-relevant studies focused on welfare reform and fathers. The national and local studies will be known as the Integrated Studies on Early Head Start.

Contribution to Initiative: This study will inform our understanding of the impact of Early Head Start on young children's development.

Study of Early Child Care (NIH/NICHD)

Target Population: Newborns, infants, children through age seven, and their families

Description: With more than half the mothers of infants and nearly two-thirds of mothers with children, age three to five, in the workforce, a majority of America's infants and preschool children are in some form of child care. Given this fact, the NICHD started a research program in 1989 to understand how non-maternal day care affects the development of children and their family relationships, and whether different types, quality and time of care influence the outcomes. The Study of Early Child Care has enrolled nearly 1,200 children (and their families) who will be studied from birth to age seven to assess the child care experience and its influence on parental attachment, family relationships, cognitive and social development, health, and school performance. This NICHD study is unique in that diverse child-care settings are being examined: e.g., father care, grandparent care, non-relative care, and center care. In addition, the enrolled families are diverse in terms of race, maternal education, family income and structure, maternal employment status, and the number of hours that children spend in non-maternal care arrangements. Children in this study are now completing their four and a half year assessment, and will be evaluated again at the end of first grade. Beyond this study, NICHD supports research comparing the effects of home versus center-based care on the intellectual development of young children, and the relative importance of quality-of-care versus financial factors in parental decision making concerning child care arrangements.

Contribution to Initiative: The unique NICHD Study of Early Child Care and related research will enable public and policy makers to untangle the myths and better understand the potential impact of day care on child development and parental relationships. As the number of children

in day care increases, this issue must be studied closely and monitored carefully to avoid negative and enhance positive outcomes.

Accomplishments: The first results of the Study of Early Child Care indicate that at age fifteen months, a child's attachment to its mother *was not* adversely affected by the day care experience. Recent intramural studies show that children who spend their preschool years in day care centers perform better intellectually than children who are cared for in their own homes or in family-based day care. Other studies show that parents are more likely to base day care decisions on financial rather than quality-of-care factors.

Planned Activities: Future studies are needed to develop more useful quality-of-care measures to help parents assess day care options, and to examine the impact of child care as it expands to meet the needs of mothers entering the workforce as a consequence of welfare reform, and as Head Start begins to serve younger children. The National Institutes of Health and the Administration for Children and Families are discussing cooperative efforts to address these issues.

Child Care Policy Research Consortium (CCB)

Funding level: In October 1995, $900,000 was made available for three cooperative agreements funded at $300,000 each over a period of three years. This funding will expire in September 1997.

Target population: State and local child care administrators and other policy makers; child care researchers; practitioners and parents; other child care stakeholders.

Description: The Child Care Policy Research Consortium consists of three cooperative agreements funded to examine child care demand, supply and outcomes for low-income families as well as studying the policy issues which affect the delivery of subsidized services. The Consortium partnership clusters are spear-headed by the following organizations:

- National Center for Children in Poverty, Columbia University, NY working in Illinois and Maryland,
- Florida Children's Forum, Tallahassee, FL working in Alabama, Florida, and Massachusetts,
- Regional Research Institute for Human Services, Portland State University, Portland, OR working in Oregon.

These research partnership clusters also include national organizations such as the National Association of Child Care Resource and Referral Agencies, local Child Care Resource and Referral Agencies, and businesses. Initial studies are already yielding information about quality of care from a parent's perspective, the availability of child care for low-income parents, and the employment of parents who receive subsidized care.

Planned Activities: In 1997, $1 million will be made available for up to five new state Child Care Policy Research Partnerships that will be funded for a period of three years (funding expiring in September of 2000). This expansion of funding to new child care research partnership clusters will examine child care needs, opportunities and constraints, and availability, costs and quality in light of the new welfare policies states are adopting.

Contribution to Initiative: Child care represents a crucial factor in public policies designed to enhance economic self-sufficiency and family well-being. Faced with the rapid devolution of responsibility from the federal level, limited funding, and a burgeoning need for child care services, state and local policy makers are under enormous pressure to use their child care dollars effectively in the face of difficult, complex and costly alternatives. Yet, existing data are often limited, out of date, or cannot easily be used in the planning and policy-making process. There is a growing consensus about the critical need for valid, reliable and integrated knowledge to guide the delivery of child care services, inform emerging policy debates, and point the way to more effective, comprehensive and family-focused policy that supports the transition from welfare to work.

Early Child Care Study of Children with Special Health Needs (MCHB)

Funding levels: Year 1: $220,000; Year 2: $220,000; Year 3: 220,000; Year 4: 150,000.

This study examines the influence of variations in early child care histories on the development of children with special health care needs. Specifically, the study will test the effectiveness of an intervention model in predicting child outcome as a function of child characteristics, family characteristics, the home environment, and early intervention environment. Very little is known about patterns of child care usage or effects of early child care on special populations. As PL-99-457 is being implemented, case managers, family members, and service providers are being asked to make decisions about alternate care in what is essentially an information vacuum regarding children with disabilities and alternate care environments.

Principal Researcher: Cathryn L. Booth, Ph.D. University of Washington.

Publications: National Health and Safety Performance Standards Guidelines (MCHB)

Target Population: The target population includes infants, toddlers and young children in child care centers and family-child care homes.

Funding Level: The Maternal and Child Health Bureau (MCHB) supported the development of *Caring for Our Children* by the American Public Health Association (APHA) and the American Academy of Pediatrics (AAP) in FY 1989 through FY 1992 at the funding level of approximately 1 million dollars for the 4 year project period. *Stepping Stones* was funded through a cooperative agreement with the National Center for Health and Safety in Child Care.

Description:

Publication: Caring for Our Children. National Health and Safety Performance Standards. Guidelines for Out-Of-Home Child Care Programs. American Public Health Association and American Academy of Pediatrics . The Bureau's support for this project was based on an appreciation of the Bureau's role as a federal agency to encourage the development of new knowledge. MCHB, while recognizing the fact that standard setting was the role of state governments, was also aware through its state Title V needs assessment process and other indicators that an unmet need in many states was the development of the knowledge base from which health and safety standards could be developed for child care settings. The National Research Council in its report, Who Cares for America's Children? Child Care Policy for the 1990's , called for "uniform national child care standards based on current knowledge from child development research and best practice from the fields of public health, child care, and early childhood education--as a necessary condition for achieving quality in out-of-home child care. Such standards should be established as a guide to be adopted by all states as a basis for improving the regulation and licensing of child care and preschool education programs." The MCHB supported the APHA and AAP in their development of this publication in order to make available new knowledge that states could use as guidance in their development of the state standards and licensing regulations they determined to be most needed to promote and protect the health and safety of infants and young children in child care settings.

Publication: Stepping Stones to Using Caring for Our Children: National Health and Safety Performance Standards--Guidelines for Out-of-Home Child Care Programs--Protecting Children From Harm. This publication was developed from the 981 standards contained in *Caring For Our Children,* to identify those standards most needed for the prevention of injury, morbidity and mortality in child care settings. *Stepping Stones* contains 180 standards and can be used by State licensing and regulatory agencies as well as State child care, health and resource and referral agencies, and a variety of other public and private organizations, parents and advocacy groups to promote and protect the health

of young children in child care programs.

Contribution to Initiative: *Stepping Stones and Caring for Our* Children provides state health, child care, license and regulatory agencies with valuable tools to use in their efforts to write policies and regulations which promote and protect the health of young children in child care programs.

Publications: ABCs of Safe and Healthy Child Care, Action Plan for Child Care Health and Safety (CDC)

Publications promoting the health and safety of children in child care centers

Target Population: Child Care Providers

Description: In recent years, the demand for out-of-home child care has surged. Over 7 million children receive child care from a non-relative outside the child's own home. This social and demographic change has resulted in new challenges to maintain healthy and safe child care settings as well as new opportunities to have a positive impact on the health of children. The following are examples of CDC's activities in this area:

- *ABCs of Safe and Healthy Child Care:* Expanding use of child care facilities has contributed to the emergence of infectious diseases that threaten children. These children are at increase risk for enteric infections, respiratory illnesses, and ear infections. CDC published a handbook for child care providers on disease and injury prevention policies and on common childhood diseases and conditions. Also a set of video tapes were produced that may be used in training on diapering and hand washing in child care facilities.

- *Action Plan for Child Care Health and Safety:* The Action Plan was devised as a reference for CDC programs in formulating projects that address needed public health systems, epidemiologic and evaluation research, and public health interventions. The Plan can also be used as a reference by constituencies of the child care health and safety community in planning new projects or in identifying need to be addressed.

Contribution to Initiative: These CDC activities have promoted the need to address the health and safety of children in child care settings.

Other Resources:

Also See: Healthy Child Care America, National Center for Heath and Safety in Child Care, Administration on Developmental Disability Projects of National Significance, Head Start Training and Technical Assistance, Early Head Start Training and Technical Assistance, and the Child Care Technical Assistance Project

PARENTING

HHS's approach to parenting is one of support and education. Grant programs seek to help states prevent unnecessary separation of children and families and preserve families in cases where children's lives are not in danger. Through the Fatherhood Initiative and child support enforcement, HHS seeks to reconnect fathers or non-custodial parents with their young children and involve them in the caring and nurturing of their development.

HHS research has documented the effects of parental separation on young children and found successful intervention models that improve parenting of young children. HHS messages, resources, and campaigns use research in the area of parenting, health and child care to convey important information to parents on their care of their infants and toddlers.

I. Preserving Family Relationships and Encouraging Non-Custodial Parent Involvement

- Fatherhood Initiative
- Family Preservation and Family Support Services
- Paternity Establishment
- Grants to States for Access and Visitation Programs

II. Research

- Parenting and Families
- Study of Home Visitation for Mothers and Children
- Infants after Divorce

III. Resources and Messages

- Dietary Guidelines
- Reducing Mother-To-Infant HIV Transmission
- Video: "Sacred Trust: Protect Your Baby against Fetal Alcohol Syndrome"

I. Preserving Family Relationships and Encouraging Non-Custodial Parent Involvement

Fatherhood Initiative (HHS)

Target Population: Fathers, custodial and non-custodial

Description: HHS has been working to support the role of fathers in a collaborative and coordinated fashion since the President directed all federal departments and agencies to strengthen the role of fathers in families in 1995. HHS activities include sponsoring conferences and research to focus on issues of father involvement, supporting fatherhood in our messages and publications, and being supportive of fathers in HHS's role as employer. Specific activities for very young children include Early Head Start father/male related activities and services, collaboration between Black Colleges and Fraternities and Head Start programs, and new involvement initiatives between school districts, enterprise zones and pre-school programs.

Contribution to Initiative: Encouraging and supporting the involvement of fathers in their young child's lives allows children to form a bond with their fathers, and receive stimulation and support from both parents in the family.

Family Preservation and Family Support Services

Funding: FY 97, $240 million

Description: The primary goals of Family Preservation and Family Support services are to prevent the unnecessary separation of children from their families, improve the quality of care and services to children and their families, and ensure permanency for children by reuniting them with their parents, by adoption or by another permanent living arrangement. Family Preservation and Family Support Services help state child welfare agencies and eligible Indian Tribes establish and operate integrated, preventive family preservation services and community-based family support services for families at risk or in crisis.

Paternity Establishment (OCSE)

Nearly 1.2 million children are born to unmarried parents each year. These births know no socio-economic boundaries. Paternity establishment for children born to unmarried parents, especially voluntary in-hospital paternity acknowledgment for newborns contributes to the healthy development of children. Paternity establishment is an ongoing program that has been strengthened through the Personal Responsibility and Work Opportunity Reconciliation Act (PRWORA) of 1996. The program is a state program administered under the Child Support

Enforcement Program.

Funding: Federal financial participation at the 66% rate is provided to states. Paternity establishment laboratory costs is provided at 90%.

Target Population: Unmarried parents, especially those in hospitals with newborns.

Description: The Clinton Administration has made paternity establishment a top priority. In FY 1996, approximately 1 million paternities were established, an increase of over 50 percent since 1992. In 1993, the Clinton Administration proposed, and Congress adopted, a requirement that states establish a hospital-based paternity programs as a proactive way to establish paternities early in a child's life. Preliminary FY 1996 information indicates that over 277,000 paternities were established through the program.

Under the PRWORA, paternity establishment will be further streamlined, making it easier and faster to establish paternities. It also expands the voluntary in-hospital paternity establishment program and requires a state affidavit for voluntary paternity acknowledgment. In addition, the law mandates that states publicize the availability and encourage the use of voluntary paternity establishment processes.

Contribution to Initiative: Paternity establishment has a number of potential emotional and psychological benefits, including the opportunity for a child to know her family roots, to explore cultural and religious ties, and to establish a father-child relationship and have access to the paternal family. Research shows that children have a healthier development with two parents, even if not both residential.

Grants to States for Access and Visitation Programs (OCSE)

This is a new program to establish and administer programs to support and facilitate noncustodial parents' access to and visitation of their children. Funds are provided to States for activities such as parenting education, mediation (voluntary and mandatory), counseling, development of parenting plans, visitation enforcement and development of guidelines for visitation and alternative custody arrangements. Funds can be granted or contracted through states to local public agencies, non-profit private agencies or the courts.

Funding Level: $10 million per year for all States

Target Population: Includes all ages of children

Description: This is a grant program to enable States to establish and administer programs to support and facilitate non-custodial parents' access to and visitation of their children.

Contribution to Initiative: This can improve parenting of young children through assisting continuing father (or non-custodial mother) involvement in divorced and separated families.

II. Research

Parenting and Families (NIH / NICHD)

Target Population: Parents and families of newborns, infants, and young children

Description: NICHD research aims to understand the dynamics and impact of parenting and families on the well being of infants and young children, from a psychological, sociological, and demographic perspective. Among a range of studies, researchers are assessing how parental interactions affect the development of 1) language and communication; 2) infants and children with disabilities or very low birth weight; and 3) early child behavior, including child discipline or behavior problems. NICHD-supported researchers are also trying to understand how fathers influence a child's well-being. This includes support of activities to collect more uniform and meaningful research data on fathers, as well as studies on such topics as divorced fathers and support payments, the quality of fathers' time spent with children, and discipline styles.

As the composition of households with infants and young children rapidly changes, NICHD research is trying to better define what constitutes a "family unit" and understand how these changes affect child well-being. Through its unique Family and Child Well-Being Network, the NICHD also supports multi-disciplinary research to examine the many social, economic, and psychological factors that influence families. The goal is to understand what factors allow some families to function more successfully than others and to evaluate the effectiveness and impact of an array of public policies and programs. Finally, the NICHD supports an important program to understand differences in Hispanic family dynamics, structure, stability, and their impact on child well-being.

Contribution to Initiative: The Family and Child Well Being Network, along with the other NICHD-supported programs, offer a unique opportunity to examine longstanding myths and give policy makers a firm scientific foundation upon which to build new programs and policies. The cross-cultural nature of many of these studies should also enable programs to better meet the needs of an increasingly diverse preschool population.

Accomplishments:. The NICHD supported Dr. Gary Becker who earned the Nobel Prize in Economics in 1992. Becker's work explains how family and household changes -- social, educational, medical, and work related -- affect overall child well-being and family productivity. The NICHD actively supports the development of novel data sets that are made available to researchers so that they can design and evaluate a range of health, education, and welfare programs. Most recently, the Institute supported the National Survey of Males, which provides ground-breaking data on the child rearing practices of men.

Planned Activities: The NICHD leads a national effort to develop a new panel of indicators to help measure the well-being of the nation's children and families. The annual analysis and publication of this data will help researchers, the Congress, and the public assess the impact of

recent public policy and program changes, such as welfare reform.

Study of Home Visitation for Mothers and Children (MCHB)

Funding levels: Year 1: $350,000; Year 2:$350,000; Year 3: $360,000; Year 4: $275,000

Description: This study seeks to replicate the successful university-based Elmira, New York home visitation study in a low-income, inner-city population in Memphis, Tennessee using city health departments as nurses. As in the original study, the new investigation tests whether prenatal and postpartum nurse home visitation can reduce or meliorate a range of maternal and child health problems in women and children from low-income, inner city, families. The evaluation has been designed to determine whether the nurse home visitation program improved the women's prenatal health habits, infant care giving skills, social support use of community services. For children, the project is designed to determine whether the program prevents prematurity and low birth weight, growth and nutritional problems, and developmental delays. Principal Researcher: David Olds, Ph.D., University of Rochester.

Infants after Divorce (MCHB)

Funding level: Year 1: $150,000; Year 2: $190,000; Year 3: $190,000

Description: The purpose of this study is to identify the factors that should guide decisions regarding access and visitation in cases of divorce for infants in the second year of life. The study will examine how overnight visitation with the father and family relationships influence the social and emotional development of infants in the first two years after divorce. This is the first national study that focus on infants and toddlers in the divorced family. As such, it will provide invaluable information to parents, court personnel, mental health workers, and pediatricians regarding the prevention and recognition of long-term harmful effects of divorce on infant development. Principal Researcher: Judith A. Solomon, Ph.D., Center for Family in Transition.

III. Resources and Messages

In addition to the resources and messages listed below, many of the campaigns mentioned in the areas of health, and child care and early childhood have targeted messages to parents. See also Resources and Messages in those sections.

The Dietary Guidelines for Americans(FDA)

Target Population: All Americans age 2 years and over, including pregnant women.

Description and Purpose: The Dietary Guidelines for Americans provide advice for healthy Americans age 2 years and over about food choices and dietary patterns that promote health and prevent disease. They are issued jointly by the HHS and USDA secretaries and are based on recommendations proposed by a scientific advisory committee which is also managed jointly. The departments update the guidelines every 5 years, as mandated by law. This document serves as the foundation of federal nutrition policy, forming the basis of all dietary guidance issued by the departments.

Contribution to the Initiative: The Dietary Guidelines provide critical information to get children off to a healthy start, including preventing fetal alcohol syndrome and neural tube defects such as spina bifida. The guidelines also help parents of two year olds, so that their children develop healthy eating habits they can maintain for the rest of their lives.

Reducing Mother-to-Infant HIV Transmission (CDC)

Ongoing activities/message to prevent perinatal HIV transmission

Target Population: Women and Newborns

Description: Perinatal (mother-to-infant) transmission of human immunodeficiency virus (HIV), a major cause of illness and death among children in the United States, has infected more than 15,000 children and has already claimed more than 3,000 of their lives. Perinatal transmission is also now virtually the only way children in this country acquire HIV infection.

A landmark event in this epidemic occurred in February 1994 when the National Institutes of Health (NIH) announced the interim results of AIDS Clinical Trials Group Protocol 076 (ACTG 076) demonstrating that zidovudine (AZT or ZDV), administered to a group of HIV-infected women during pregnancy, labor, and delivery, and to their newborns, reduced the risk for perinatal HIV transmission by two-thirds. This dramatic prevention breakthrough offered both the hope of substantially controlling the HIV epidemic in children and the challenge of turning this hope into reality. In response to this challenge, a multifaceted campaign was launched by public and private health organizations, community groups, and individuals to translate the ACTG

076 results into effective prevention measures.

In August 1994, a United States Public Health Service (USPHS) task force led by the NIH and CDC published clinical guidelines on the use of AZT by HIV-infected pregnant women to reduce perinatal HIV transmission, recommending the therapy as a standard of care. In July 1995, USPHS issued recommendations for HIV counseling and voluntary testing for pregnant women and for the use of AZT to reduce perinatal HIV transmission. In addition, several professional medical organizations, including the American College of Obstetricians and Gynecologists and the American Academy of Pediatrics, have adopted policies in support of these guidelines.

Contribution to Initiative: Counseling and educational materials are made available to pregnant women to help them make informed decisions about AZT prophylaxis to reduce the risk of perinatal HIV transmission. To maximize the benefit of these transmission-reduction programs, CDC conducts surveillance and evaluation of these activities are to: (1) ensure that the intervention is effective and reaches women in need, and (2) determine how the intervention or process can be improved.

Video: "Sacred Trust" (IHS)

Resource titled, "Sacred Trust: Protect Your Baby Against Fetal Alcohol Syndrome."

Funding Level: Estimated $200,000 of predominantly US Department of Agriculture (USDA) funds.

Target Population:: American Indian and Alaska Native Women of Child Bearing Age. This video was distributed to all Women, Infants, and Children (WIC) Programs of the USDA, Supplemental Food Programs Division (SFPD) that serve American Indians and Alaska Natives and to all service sites of the Indian Health Service (IHS).

Description and Purpose: A story-telling approach of a family preparing for an Indian Pow Wow is used to emphasize the importance of preserving the strength of Indian people and culture through healthy children by not drinking alcohol during pregnancy. The purpose of the video is to prevent fetal alcohol syndrome (FAS) and fetal alcohol effects (FAE). This award-winning video was developed using a collaborative approach between the USDA, SFPD and the IHS, Nutrition Program. An interagency agreement transferred USDA funds to the IHS for conducting a needs assessment and focus groups of women in three rural reservations and one urban center. The American Indian Health Care Association was contracted to gather information about why women choose to drink or abstain during pregnancy, barriers to stopping the behavior, and acceptable ways to communicate motivating messages. The information gathered was reported to the IHS and USDA and was used in developing the video. This resource received the 1996 Golden Eagle Award of the Council on International Non-Theatrical Events. The video has received high praise from American Indian women.

Contribution to Initiative: Although FAS is an alcohol problem and not just a concern for this

population, an educational resource was designed to meet their special needs. Babies with FAS are mentally retarded and babies with FAE have short attention span and poor coordination. The video uses the phrase "Not Now" as a slogan for refusing alcohol during pregnancy. A copy of this video and companion pamphlet and poster are provided.

HEALTH

HHS iscommitted to providing States and communities with the resources they need to ensure healthy outcomes for their young children and promote optimal conditions for children with disabilities or developmental delays. HHS has many grants that are aimed at State health agencies or community organizations that provide information and services to pregnant women, parenting women and children directly. Our information allows parents to make informed decisions on how to care for their infants and toddlers, and our health services are directed to some of the country's most vulnerable populations such as the homeless and low-income individuals. HHS has been particularly supportive of maternal and child health services, encouraging immunizations and prenatal care, reducing environmental risks, and identifying and treating children who are drug and alcohol exposed or at-risk for mental health problems.

These services and initiatives build on a wide range of research and evaluation projects that have informed our thinking about early learning and child development and led to dramatic progress in fighting and preventing disease and disability. HHS has used this research to train health professionals, produce practical resources for parents and providers, and provide effective direct services to young children.

I. Supporting States and Communities in Their Efforts to Maintain and Promote Healthy Outcomes for Young Children

A. Overall Maternal and Child Health

- Children's Health Initiative
- Healthy Start Initiative
- "Healthy People 2000": National Health Promotion and Disease Prevention Objectives
- Healthy Tomorrows Partnership
- Breast-Feeding Initiative
- Maternal and Child Health Block Grant
- Newborn Hearing Screening
- Maternal and Child Health Epidemiology Program
- Early and Periodic Screening, Diagnosis and Treatment Program
- "Put Prevention into Practice" Campaign
- Minority Community Health Coalition Demonstration Grant Program
- Outreach and Primary Health Services for Homeless Children
- Ryan White Title III Early Intervention Services

B. Immunization

- Childhood Immunization Initiative
- Immunization Program for Alaska Native Children
- "Together for Tots": Immunization Initiative in Community and Migrant Health Centers

C. Prenatal Care

- Folate Fortification Initiative
- Humanitarian Device Exemption - Treatment for Urinary Tract Obstruction

- Prenatal Smoking Cessation Program
- Prevention of Congenital Syphilis

D. Environment

- Childhood Injury Prevention Program
- Lead Poisoning Prevention and Screening
- Child Health Initiative

E. Substance Abuse and Mental Health

- Residential Substance Abuse Treatment Grants for Women and Children
- Prevention and Treatment Block Grant Set-Aside for Pregnant Women and Women with Dependent Children
- Model Projects for Pregnant and Postpartum Women and Their Children

II. Enhancing the Care of our Practitioners, Providers, and Professionals

- Bright Futures
- Leadership Education Projects to Support Training of Professionals working with Young Children
- Bilingual/Bicultural Service Demonstration Grant Program

III. Direct Service

- Community and Migrant Health Centers
- Indian Health Service

IV. Building the Research Base to Improve Health Care and Promote Healthy Development

A. Tracking and Measuring Health Status and Quality

- Children's Health Surveillance Activities
- Infant Nutrition
- Medical Expenditure Panel Survey
- MCH Model Data Sets
- Effects of Early Discharge Policies
- Regulatory Disorders and Development Outcomes
- Validity of Neurobehavioral Symptoms Reported in Children with Traumatic Brain Injury
- Pregnancy Risk Assessment Monitoring Systems
- Quality Measurements and Improvement in Child Health Care

B. Prevention Research

- Childhood Infectious Disease Research
- Prenatal and Perinatal Research
- Vaccination Research

- Prevention of Birth Defects / Centers for Birth Defects Prevention Research
- Prevention of Fetal Alcohol Syndrome / Prevention Strategies
- Research Projects to Close the Racial Disparity in Infant Mortality
- Low Birth Weight and Other Perinatal Outcomes Research

C. Interventions and Developmental Practices

- Evaluation of Hawaii's Healthy Start Program
- Planned Research Projects on Preventing Developmental Delays
- The Physical and Developmental Environment of the High Risk Infant
- Pediatric Health Supervision to Promote Literacy
- Evidence Based Practice Centers

D. Basic Science Research

V. Resources and Messages

- National Hispanic Prenatal Hotline Project
- Handbook: Participant-Driven Managed Supports - Breaking New Ground
- Resources on HIV, Sickle Cell Disease, Otitis Media with Effusion, and Pain
- Publication: Substance using Pregnant and Postpartum Women - Treatment Protocols
- Publication: From the Source: A Guide for Implementing Perinatal Addiction, Prevention and Treatment Programs
- Forthcoming Resources on Medical Management of Detoxification of Pregnant Women and Neonatal Assessment
- Other Resources and Messages

I. Supporting States and Commmunities In Their Efforts to Maintain and Promote Healthy Outcomes for Young Children

A. Overall Maternal and Child Health

Children's Health Initiative (HHS)

Target Population: uninsured children, especially Medicaid eligible children

Description: As part of the Administration's attempt to increase the number of children who are insured, HHS is working with other federal partners, states, communities, the private sector, managed care organizations and others to enroll Medicaid-eligible children through enhanced outreach and other targeted efforts. In addition, the Administration is proposing to expand health care coverage for children by providing grants to states for children not eligible to receive Medicaid benefits; by providing states with the option to allow continuous coverage to children for one year after eligibility is determined without redeterminations; and by providing temporary premium assistance to families with workers between jobs.

Contribution to Initiative: This effort to insure children will increase access to health care, and allow more children to receive preventive care that will protect can their health.

Healthy Start Initiative (MCHB)

Funding Level: 558 million has been invested since 1991 in support of the Healthy Start Initiative to reduce infant mortality. Fifteen projects were awarded funds in 1991 and seven additional projects were added in 1994. Currently there are Healthy Start projects in 22 communities, urban and rural. Approximately 30 new communities will be added in 1997.

Target Population: Women of child bearing age--especially those with high risk factors-- infant, and their families

Description: The purpose of the Healthy Start Initiative is to identify and operationalize a broad range of community driven strategies and interventions which could successfully and significantly reduce infant mortality. During the demonstration phase (Phase A), the Healthy Start Initiative supported 22 urban and rural communities across the country, 15 since 1991, and seven additional since 1994. All projects have an infant mortality rate at least 150% of the national average.

Healthy Start brings to focus the need to strengthen and enhance community systems of maternal and infant care. Healthy Start challenges communities to fully address the medical, behavioral and psychosocial needs of women and infants. The principles guiding the planning and operation

of the program are innovation, community commitment and involvement, increased access, service integration, and personal responsibility. An additional principle, sustainability, was added in 1996. A unique hallmark of the projects is the development of strong coalitions of consumers from the project area, local and State governments, the private sector, schools, religious groups, and neighborhood organizations.

The Healthy Start Initiative features an aggressive national and local public service information and education component to raise awareness of infant mortality, and promote perinatal care and other healthy behaviors. In Healthy Start the term perinatal refers to the care given to both mother and infant through the age of one. An extensive outcomes and process-oriented national evaluation of the 15 original projects will expand knowledge, and assess diverse interventions and their effectiveness across distinct populations. The national evaluation addresses the impact of the demonstration on reduction of infant mortality; it is anticipated that the nation evaluation will be completed in 1998.

A total of nine categories of infant mortality reduction strategies have emerged from Phase I of the Healthy Start Initiative. These models are: 1) Outreach and Client Recruitment; 2) Care Services; 3) Family Resource Centers; 4) Enhanced Clinical Services; 5) Risk Prevention and Reduction; 6) Training and Education; 7) Adolescent Programs; 8) Facilitating services; and 9) Community-Based Consortium.

The FY 1997 funds provide the opportunity to begin the Replication Phase (Phase II) of the Healthy Start Initiative. The purpose of Phase II is to operationalize successful infant mortality reduction strategies and to launch Healthy Start projects in new urban and rural communities. The FY 1997 funds also provide for: maintenance of a level of support to Phase I grantees for continued implementation of successful strategies; and for utilizing these grantees to provide peer mentoring to new Healthy Start communities and other health care providers.

Contribution to Initiative: The Healthy Start Initiative has reduced infant mortality rates, low birth weight infants, improved access and coordination of care and services for women and infants. The collaborations have increased awareness and participation of entire families in early and regular perinatal care for giving babies a healthy start, and helped communities to address the problems facing these families and their local health system. Many service provider share improved both the quality and availability of their services from participation in Healthy Start.

Healthy People 2000 (OPHS)

National Health Promotion and Disease Promotion Objectives

Target Population: All Americans, including young children and pregnant women

Description: Healthy People 2000, the national prevention initiative to improve the health of all Americans is a product of cooperation among government, voluntary and professional organizations, business, and individuals. The cornerstone of this effort is a set of national health

promotion and disease objectives for the year 2000. Healthy people 2000 sets three broad public health goals for the 1990s: 1) Increase the span of healthy life for Americans: 2) Reduce health disparities among Americans: and 3) Achieve access to preventive services for all Americans. To achieve these goals 22 priority areas have been defined, each containing objectives for improving health status, reducing health risks, and increasing the delivery of preventive services and protective actions.

Objectives that are relevant to children age zero to three include the following: 16 objectives with attendant sub-objectives aimed at improving maternal and infant outcomes, including low birth weight and infant mortality; objectives targeting unintentional injuries, such as reducing drowning death to no more than 2.3 per 100,000 children aged 4 and under (1987 baseline was 4.2); and other targeting the prevention of chronic disabling conditions, such as increasing to 80% the proportion of providers of primary care who routinely refer or screen infants and children for impairments of vision, hearing, speech and language, and assess other developmental milestones as part of well-child care.

Contribution to Initiative: Healthy People 2000 sets benchmarks for the Nation for young children in the areas of health promotion, health protection, and preventive services. These benchmarks provide guidance to communities about how to target their efforts to improve the well being of young children and allow for ongoing tracking of how we are doing nationally and locally where they have been adopted and the data is collected. This ensures that in the health arena we are forming the solid foundation for the future promoted by the initiative.

Healthy Tomorrows Partnership (MCHB)

Target Population: children, parents and families, especially those with limited access to quality health services.

Description: *The Healthy Tomorrows Partnership* began in 1989 as a collaborative venture between the Maternal and Child Health Bureau and the American Academy of Pediatrics. Its purpose is to stimulate innovative programs that prevent disease and disability and promote health and access to health care services for children nationwide. The program supports innovative and cost-effective approaches to provide community-defined preventive child health and development services, particularly for vulnerable children and their families with limited access to quality health services. It requires cooperation among community organizations, individuals, and agencies; Federal, State, and local governments; professional organizations; foundations; corporate leaders; and families to share their knowledge and expertise and commit the necessary resources for mutual problem solving. In addition, it forges partnerships of pediatricians and other pediatric primary care professionals, educators, social service providers, local government and business to build self-sustaining programs to assure healthy children.

The *Caring Program for Children* in Pittsburgh, Pennsylvania, is an outstanding example of the HTPCP Partnership. The Caring Program changed the health care system to work to meet the health care needs of America's children and families by overcoming traditional proprietary

boundaries and conventional thinking, and forging new alliances with the private sector, public sector, community organizations and health professionals. Project Caring has led the way for children to gain vital access to needed health services for over 80 new families and children each year in Pennsylvania. In addition, by replicating their efforts in an additional 26 States, Project Caring has benefited countless numbers of children and families across America.

Contribution to Initiative: Since the "Healthy Tomorrows" project began in 1989, the program has served more than 40,000 children, parents, and families in 36 states, the District of Columbia and Puerto Rico. To date the "Healthy Tomorrows" program has funded and supported 85 projects at a total program commitment of $21 million (over the 12-year period of the initiative) resulting in more than $62 million invested by communities. The issues addressed included interventions for health promotion through risk reduction in families (e.g., health education and literacy, attention deficit treatment, parent-pediatric partnerships for strengthening families to make the vulnerable invincible, preventive primary services for substance-abusing, technology-dependent children's services, family-focused strategies for reducing premature and unprotected sexual activity among minority youth in school-based health clinics, first steps primary prevention program on child abuse, healthy beginnings, collaborative developmental clinic, rural partnerships for children, fostering improved health status for foster care children, family growth center pilot project, primary care for children in homeless shelters, improving health care access for Hispanic families, infant and family follow up program, and innovative interventions and care coordination services for children with special health needs, such as child care for ventilator dependent children).

Breast-Feeding Initiative (MCHB)

Funding Level: MCHB grants and contracts over 10 years totaling approximately 10 million

Target Population: Health providers, pregnant women, and parents of newborns and infants

Description: Since the publication of the *Surgeon General's Report on Breast-feeding* in 1984 MCHB has been implementing these recommendations. MCHB has supported training, research, and service projects. MCHB is an active partner in national coalitions, as Healthy Mothers, Healthy Babies and the National Association for Breast feeding Advocates (NABA). MCHB is actively involved with their Federal partner, the USDA, WIC program.

A report entitled "*The Medical Contraindications to Breast-feeding*" was developed by Dr. Ruth Lawrence under contract with MCHB in response to the GAO recommendations from their review of the WIC Program. MCHB with Best Start Inc., are developing a Health Provider Breast-feeding Promotion support kit. This will be in conjunction with the USDA Consumer Breast-feeding Promotion campaign. This kit will be part of Building Bright Futures initiative and contain the following items: provider pamphlet, pocket reference guide, question and answer sheet, patient letter, resource guide, patient pamphlets and posters. MCHB is supporting an AAP Breast feeding Coordinator training meeting to be held in April 1997. MCHB and UCLA are planning a national media Breast-feeding promotion conference.

The Indian Health Service is also promoting the benefits of breast-feeding in their services. *The Breast-Feeding Program of the Gallup Indian Medical Center*, which targets mothers and newborns of the Navajo Nation, highlights a multi-disciplinary approach of nutrition, nursing, and physician staff to coordinate education of mothers-to-be on the advantages of breast-feeding. New mothers do not receive gift-pack formula at the time of post-delivery hospital discharge. Breast-feeding of infants in the special care nursery is maintained by hospital policy with obstetrical nurses assisting the new mothers in pumping and storing the breast milk. The community nutrition and nursing services provide support to breast-feeding mothers after discharge from the hospital.

Contribution to Initiative: Breast-feeding benefits infant growth and development, prevention of SIDS, and is a natural form of immunization. Disseminating this information will provide parents with the information they need to make informed choices on protecting their baby's health and development.

Maternal and Child Health Block Grant (HRSA)

The Maternal and Child Health Block grant is administered as a Federal-State partnership to improve the health of all mothers, children and adolescents consistent with the national health objectives for the year 2000.

Funding Level: Funded at $681 million in FY 1997.

Target Population: Approximately 17 million women, infants, children, adolescents, and children with special health care needs are provided services under this program.

Description: The population served by the Maternal and Child Health Block Grant is threatened by many medical, social and economic epidemics such as increases in child poverty, violence, and injury, coupled with insufficient access to health care resources. Program funds are used to:

- Improve the health status of mothers and children in perinatal health indices (infant death, fetal death, maternal mortality, low birth weight, very low birth weight) and increased access for selected services (prenatal care, Early Periodic Screening, Diagnosis and Treatment, Immunization, Children with Special Health Needs).

- Improve access for mothers and children to systems of integrated community health services systems by increasing the number of State MCH programs that have written cooperative agreements with State Medicaid, WIC, and social service agencies.

- Strengthen the responsiveness of health systems in meeting the needs of special MCH populations by building the capacity of consumers, providers, State agencies and managed care plans in each State to integrate and culturally adapt services for vulnerable populations of Children with Special Health Care Needs (CSHCN), including cultural minorities. HIV/AIDS, hemophilia and genetic services are linked into primary and

routine community care and into managed care.

Contribution to Initiative: The Block Grant makes a major difference in the lives of all families and to low-income recipients in particular, for whom access to comprehensive health services requires more than financing mechanisms. The MCH Block Grant provides leadership in strengthening and reshaping the system of care and linking Federal/State/local and private programs to improve the health of mothers and children, thereby creating an environment that encourages the reduction of risk behaviors, promotion of optimal growth and development, prevention of disease and disability, and achievement of the *Healthy Children 2000* objectives.

Newborn Hearing Screening (CDC)

Planned activity to prevent hearing loss in children

Target Population: Newborn infants

Description:. Approximately one in every 1,000 children are born with a moderate to severe bilateral hearing impairment. Many more are born with less severe or unilateral impairments. Still other children develop hearing impairments during early childhood. Without early identification and treatment, it is difficult for children with hearing impairments to acquire fundamental language, social, and cognitive skills that provide the foundation for later success in school and society.

Recognizing the importance of identifying hearing loss during infancy, and given the demonstrated success of recently developed technologies and procedures for conducting hospital-based universal hearing screening programs, the Health Resources and Services Administration, the National Institutes of Health, and the Centers for Disease Control and Prevention have agreed that a coordinated effort among the respective agencies is needed to expedite the implementation of newborn hearing screening system. The three agencies are planning to work with the Office of Special Education and Rehabilitative Services to facilitate the integration of screening, assessment, diagnosis and intervention services.

Contribution to Initiative: In 1989, C. Everett Koop, then Surgeon General of the United States, set as a goal that all infants with significant hearing loss would be identified before 12 months of age. This goal is one of the National Health People 20000 Objectives. Although there has been impressive progress in the last few years, there is still a great deal of work which needs to be done. In fact, only about 10% of all newborns are currently screened for hearing loss before leaving the hospital, and only abut 5% of all infants are born in hospitals with universal newborn screening programs. This effort will move the nation toward universal screening as a standard of care.

Maternal and Child Health Epidemiology Program (CDC)

Funding Level: FY 96 - $1.6 million

Target Population: Women and Infants (less than 12 months)

Description: The Maternal and Child Health Epidemiology Program (MCHEP), a collaborative effort between CDC and the Health Resources and Services Administration (HRSA), provides support to State maternal and child health programs. Its primary objectives are: 1) to assist States in identifying and collecting the data needed to assess and protect the health of mothers and infants; 2) to conduct epidemiological analyses of maternal and infant health service and policy issues essential for State program planning, policy development and priority setting; and 3) to support State efforts to use information effectively to make decisions about the health of mothers and infants.

Contribution to Initiative: Numerous examples exist to document the improvement in programs and changes in policy that resulted from this epidemiological support. Through this program, the State of Georgia evaluated the efficacy of prenatal care case management funded by Medicaid and found that it does get high risk women into care earlier. This evaluation influenced the State to continue providing case management services.

The Early and Periodic Screening, Diagnosis, and Treatment (EPSDT)Program (HCFA/MB)

A preventive and comprehensive child health program for Medicaid-eligible individuals.

Funding Level: Medicaid spending in FY 1995 on children ages 0 to 3 was approximately $10.5 billion (federal and state funds - federal share approximately $6 billion.)

Target Population: Medicaid eligible individuals under age 21. Estimated 6.5 million children zero to three received benefits in FY 95.

Description and Purpose: The EPSDT program is a comprehensive and continuous child health program required by law. It assures the availability and accessibility of specific health care resources. It assists Medicaid recipients and their parents or guardians effectively use them. Mandatory services include screening, vision, hearing, dental, and other necessary health care and diagnostic services and treatment to correct or ameliorate defects and physical and mental illnesses and conditions discovered by the screening services.

Contribution to Initiative: The EPSDT program continues to be one of the most effective and comprehensive child health programs for children up to age 21. Benefits include: Assessment of health needs through initial and periodic examinations; assurance that health problems are diagnosed and treated early, before they become more complex and their treatment more costly; and healthier children at an early age ready to learn.

"Put Prevention into Practice" Campaign (OPHS)

Target Population: All Americans, including young children and pregnant women.

Description: Put Prevention into Practice is a campaign to improve the deliver of preventive care by primary care provider to improve the health of all Americans. Such care includes immunizations, screening tests, chemoprophylaxis, and counseling interventions provided by clinicians to prevent disease or to detect disease in its earliest, most treatable stages. The program is a research-based team approach using a kit of materials. The Put Prevention into Practice *Education and Action Kit* includes materials for the provider, the clinic staff and systems, and the health care consumer. Components directed at young children include the *Child Health Guide* to inform parents of the care their children need and give them a place to record those services, appointment reminder cards for staff to send to parents, child preventive care flow sheets for clinicians to chart services delivered to children, a section of the *Clinician's Handbook of Preventive Services on* appropriate preventive services for children, and a *Child Preventive Care Timeline: Recommendation of Major Authorities* poster.

Contribution to Initiative: The Put Prevention into Practice Program provides a system to reinforce the delivery of critical preventive services for young children such as full childhood immunization by age 2 and developmental screening. It also addresses the needs of pregnant women to get children off to a healthy start.

Minority Community Health Coalition Demonstration Grant Program (OPHS)

Funding Level: In FY 96, 14 grants were awarded totaling $1.8 million

Target Populations: Projects funded under this demonstration program may target any age group(s) as recipients for services. In FY 96, 5 of the projects specifically identified prenatal activities and included infants in their targeted population.

Description: The Minority Community Health Coalition Demonstration Grant Program provides support to community health coalitions to develop, implement, and conduct demonstration projects which coordinate integrated community-based screening and outreach services, and include linkages for access and treatment to minorities in high risk, low income communities.

Outreach and Primary Health Services for Homeless Children (HRSA)

Funding Level: 10 grantees received at total of $2.3 million in FY 1996.

Target Population: Grantees treat children ages 0-18.

Description and Purpose: The Stewart B. McKinney Homeless Assistance Act was enacted on

July 22, 1987 and established the Health Care for the Homeless (HCH) Program. HCH grantees provide comprehensive health care services to homeless children and adults. Title VI of the McKinney Act as amended in 1992, adding Section 340(s), which authorized additional Federal funding to provide outreach and primary health services for homeless children (the Homeless Children Program). As a result of Section 340(s), 10 Homeless Children grants were funded. To receive data and other information related to homelessness, including homeless children, inquirers may call Policy Research Associates, which operates an Information Resource Center supported by the Bureau of Primary Health Care. Their toll free number is 888-439-3300.

Contribution to Initiative and Significance: A key component of the Homeless Children programs is the establishment of a "medical home" to ensure the provision of comprehensive primary health care and outreach services to homeless children.

Ryan White Title III Early Intervention Services (HRSA)

Funding Level: FY 1997 appropriation: $69.6 million. Currently 151 programs located in 34 States, the District of Columbia and Puerto Rico receive Title III grant support.

Target Population: Prenatal to adults
FY 1995 data indicate that 1,181 clients under age 2 received primary care services, and 784 clients between the ages of 2 and 4 clients received primary care services.

Description and Purpose: The Title III Early Intervention Services (EIS) program of the Ryan White CARE Act provides grant support for outpatient HIV early intervention and primary care services for low-income, medically underserved people in existing primary care systems. The continuum of care provided by Title III EIS programs and supported with grant funds, extends from prevention of HIV infection to clinical care for individuals with AIDS-defining illnesses. Prevention services include risk reduction counseling and testing, partner involvement in risk reduction, and transmission prevention. Services provided for HIV positive clients include testing to determine the extent of damage to the immune system, anti-retroviral therapies, prophylaxis for opportunistic infections, and standard and investigation therapies for clinical manifestations of HIV infections/ malignancies as part of ongoing medical and psychosocial care. Nutritional, oral health, mental health, and case management services are also provided.

B. Immunization

Childhood Immunization Initiative (CDC)

An ongoing program to increase and sustain childhood immunization rates.

Funding Level: FY 1996 - $747 million

Target Population: Children ages 0 -2 years old

Description: In 1993, The Childhood Immunization Initiative (CII) was one of the earliest priorities of the Clinton Administration. In response to disturbing gaps in the immunization rates for young children in America, the Administration designed a comprehensive CII. The Administration and Congress committed substantial new resources for immunization, including budget increases for service delivery improvements and for purchase of vaccine to be made available to needy children under the Vaccines for Children Program.

CII is working to build a comprehensive vaccination delivery system. It integrates efforts of the public and private sectors, health care professionals and volunteer organizations. The goals are: 1) to ensure that at least 90 percent of all two-year-olds receive each of the initial and most critical doses and to reduce most diseases preventable by childhood vaccination to zero; and 2) by 2000, ensure that at least 90 percent of all two-year-olds receive the full series of vaccines, and that a system is in place to sustain high immunization coverage.

Contribution to Initiative: Activities included in the CII have contributed to the unprecedented decline in vaccine-preventable diseases. In 1995, record lows were reported for measles, mumps, rubella, diphtheria, tetanus, polio, and invasive *Hemophilus Influenzae* (see below) in children less than 5 years of age. For example, 309 measles cases were reported, down from more than 27,000 cases at the peak of the measles resurgence in 1990.

As part of this initiative, several agencies have set the goal of eliminating Hemophilus Influenzae Type B (Hib) Meningitis by the year 2000. This form of meningitis causes acquired mental retardation and deafness in infants and young children. Collaborative vaccination research by the Food and Drug Administration, The Centers for Disease Control and Prevention and the National Institutes of Health has led to breakthrough vaccines against the infection that has nearly eliminated the disease.

Immunization Program for Alaska Native Children (IHS)

Target Population: Alaska Native newborns and children to age 2.

Funding Level: $1.5 million

Description : The purpose of the activity is to prevent the morbidity and mortality associated with childhood disease preventable by immunization. Major accomplishments include:

- Prevention and Control of Viral Hepatitis: The Viral Hepatitis Program (VHP) is now recognized as the national and international leader in the prevention and control of Viral Hepatitis. Since 1982, the VHP has reached all the high-risk villages in Alaska and has the potential for eradicating Hepatitis B; by 1988, the majority of Alaska Natives were immunized against Hepatitis B; more than 96 percent of Alaska Native newborns receive a dose of Hepatitis B vaccine before their hospital discharge; the annual incidence of acute symptomatic Hepatitis B infection has decreased from 215 per 100,000 prior to 1982, to 5 per 100,000 in 1996. The 1-year case fatality rate for primary liver cancer has decreased from 100 percent to 50 percent in the same time period.

- Increased Immunization Rates: Increased 2-year old immunizations rates in Alaska Natives from 49-73 percent in 1990 to 76-96 percent in 1996; more than 90 percent of 2-year old children were fully immunized against Hemophilus Influenzae Type B.

- Utilization of Immunization Tracking Systems: The number of tribal programs utilizing the Registration and Patient Management System immunization package for immunization tracking has increased from none in 1990 to 7 programs in 1996.

Contribution to Initiative: These immunizations efforts have improved the health of young Alaska Native children by preventing viral hepatitis and Hemophilus Influenzae Type B.

"Together for Tots" (HRSA)

An activity to improve immunization rates in underserved high risk children who use Community and Migrant Health Centers for their health care. The program is administered by the Health Resources and Services Administration.

Funding Level: In September of 1995, the NIP/BPHC partnership provided $450,000 to fund Together for Tots initiatives in 8 states. In September of 1996, the NIP/BPHC partnership increased the funding to $600,000 to continue the initiative in the original 8 states and to fund 2 additional states, Maine and Utah.

Target Population: Children 12-35 months old.

Description: As part of the HRSA Bureau of Primary Health Care's effort to meet the Childhood Immunization Initiative goal of 90 percent coverage by 2 years of age, HRSA is

collaborating with the Centers for Disease Control and Prevention's National Immunization Program. The mission of the initiative is to guide national immunization efforts toward excellence by building both State-based and community health center systems that implement continuous quality improvement strategies and by expanding partnerships at the local, State and national levels. The project team consists of Community and Migrant Health Centers, State Primary Care Associations, Clinical Networks, the National Association of Community Health Centers, Inc., the Health Resources and Services Administration's Bureau of Primary Health Care, the Centers for Disease Control and Prevention's National Immunization Program, and State Health Departments in the participating States. Expected outcomes of the initiative include (1) to build infrastructure at the local, State and national levels for a comprehensive, integrated approach to improving preschool immunization rates, and; (2) to apply total quality management concepts and tools to project planning, implementation, and evaluation.

This program uses a State-based approach where additional resources are provided to State and Regional Primary Care Associations to provide on-site assistance to health centers, through a dedicated clinical expert, in measuring, analyzing and improving clinical outcomes. This approach has successfully reinforced the concept of quality improvement efforts through local leadership. The participants are the Primary Care Associations in Arizona, Colorado, Connecticut, Maine, Utah, Missouri, New York/New Jersey, North Carolina, and Ohio.

Contribution to Initiative: This immunization initiative fosters long term partnerships dedicated to improving the clinical care and health outcomes of over 150,000 medically underserved and high risk children.

C. Prenatal Care

Folate Fortification Initiative (FDA)

Target Population: Pregnant Women and their Children

Description: Under the new FDA rules, specified grain products will be required to be fortified with folic acid. CDC estimates that there are approximately 4,000 pregnancies each year, including 2,500 live births, that are affected by spina bifida and other neural tube birth defects. In 1991, research by CDC and others showed that the vitamin folic acid could prevent 50% - 70% of the U.S. cases of neural tube defects.

U.S. food manufacturers will add the nutrient folic acid to most enriched breads, flours, corn meals, pastas, rice and other grain products according to the FDA fortification rule. Folic acid, or folate, reduces the risk of neural tube defects, such as spina bifida, when consumed in adequate amounts by women before and during early pregnancy.

Contribution to Initiative: This fortification initiative can potentially prevent 2000 cases of spina bifida and anencephaly from occurring in infants in the United States.

Humanitarian Device Exemption (FDA)

Target Population: Pregnant women carrying babies with urinary tract obstruction (affecting fewer than 4,000 unborn babies a year).

Description: The FDA granted the first approval of a medical device under the new Humanitarian Device Exemption (HDE) regulation on February 14, 1997. The exemption makes it easier and less costly to bring to market products for rare conditions or diseases. The device is a fetal bladder stent created to treat urinary tract obstruction in unborn babies. Under the new HDE regulation, the manufacturer is now approved to market the product commercially. Until now the primary way to treat urinary tract obstruction was by inserting a needle into the baby's bladder every couple of days to withdraw urine. The new fetal bladder stent can be implanted into the baby's urinary tract, allowing urine to drain from the baby's bladder without any further invasive procedures.

Contribution to Initiative: This exemption removes disincentives to researching and developing treatments that affect a small minority of the population. Rare diseases and conditions in children are therefore more likely to be treated.

Prenatal Smoking Cessation Program (CDC)

Funding Level: FY 96 - $0.9 million

Target Population: Women and Infants

Description: Smoking during pregnancy has been identified as the most important potentially preventable cause of low birth-weight in the United States. It is estimated that perhaps 25 percent of low birth-weight in the United States can be attributed to maternal smoking. The purpose of CDC's Prenatal Smoking Cessation program is to develop and enhance the capacity of maternal and child health programs to reduce the effects of smoking among women of reproductive age and their families.

Contribution to Initiative: Since 1986, CDC has provided funding and technical assistance to State health departments in the development, implementation and evaluation of prenatal smoking cessation interventions. Since 1993, CDC also has collaborated with the Association of Maternal and Child Health Programs (AMCHP) to promote smoking cessation during pregnancy.

Prevention of Congenital Syphilis (CDC)

Funding Level: FY96 - $31.4 million

Target Population: Women and Newborns

Description: Syphilis and congenital syphilis are important sentinel health indicators of populations at significant risk for multiple health and socioeconomic problems, including HIV infection. Syphilis has been nearly eliminated from many industrialized countries, yet the United States continues to have relatively large numbers of cases reported annually (68,953 total reported cases in 1995). In 1995, an estimated 1,548 infants were treated for congenital syphilis caused by their mothers' untreated or inadequately treated syphilis during pregnancy. At least 124 pregnancies ended due to syphilitic stillbirths. Nearly all infants born with syphilis required prolonged hospitalization for antibiotic treatment. As recently as 1986-1990, a major epidemic of syphilis occurred across the United States.

CDC's Division of STD Prevention (DSTDP) supports 65 STD Prevention programs through grants to 50 states, 7 territories, the District of Columbia, and Puerto Rico. State and local programs use these resources to develop and support preventive health services for STDs, including primary prevention activities, screening programs, surveillance systems, counseling as appropriate, and notification of sex partners.

Contribution to Initiative: Between 1994 and 1995, the overall rate of congenital syphilis decreased from 55.6 to 39.0 cases per 100,000 live births. In 1995, the rate of congenital syphilis in African-Americans was 162.2 per 100,000 live births and 49.7 in Hispanics. This represents a 30% decrease among African-Americans and a 35% decrease among Hispanics. In 1995, twelve states had congenital syphilis rates that exceeded the revised Healthy People 2000 objectives of 40 cases per 100,000 live births.

D. Environment

Childhood Injury Prevention Program (CDC)

An ongoing program to reduce the leading causes of injury in children

Funding Level: FY 1996 - $1.7 million for children (not limited to ages 0-3)

Target Population: Children - ages 0 -21 years old

Description: Unintentional injuries are the leading cause of deaths and disabilities among children ages 1 to 19. Research shows that the greatest toll of injuries among children include motor-vehicle-related injuries, drownings, fires, poisoning, falls, and violence. CDC monitors trends in childhood injuries, conducts research to better understand risk factors, and evaluates

strategies to prevent these injuries.

The following are examples of injury prevention activities targeted that involve children:

- Prevention of Motor Vehicle Injuries: CDC and the National Highway Traffic Safety Administration work to apply the public health approach to making road travel safer for children and all Americans. For example, child safety seats reduce the risk of death for infants by 69 percent and for toddlers by 47 percent. CDC funds and assists in the evaluation of interventions such as: a campaign to educate parents of the value of child safety seats and how to use them; and a program that distributes free child safety seats to families served by WIC clinics; a program for high school students to increase seat belt use. Studies have also been funded to look at improved closure designs on child safety seats and the effectiveness of laws requiring use of seat belts.

- Fire and Burn Prevention: The mortality rate from fires is higher in the United States than in any other industrialized country. The most common cause of these deaths is residential fire. Although smoke detectors reduce the risk of a house fire roughly by half, about one quarter of American homes do not have a detector or have one that is not functional. CDC sponsored a smoke detection distribution program that successfully reduced fire-related deaths in a high-risk area of Oklahoma City. Four years after the initial distribution program, 45 percent of the distributed detectors were still functional. Over this period, the fire-injury rate within the target area dropped by 80 percent, and the injury rate per 100 fires decreased by 74 percent.

Contribution to Initiative: Currently, CDC childhood injury prevention research funds are awarded to 12 states, which conduct demonstration projects that measure the prevention effectiveness of their programs and interventions Previous cost-effectiveness analyses have indicated that, for example, every dollar spent on child safety seats saves society $32, every dollar spent on bicycle helmets saves society $30, and every dollar spent on smoke detectors saves society $65. CDC will continue to work with partners to describe and track the problems related to childhood injuries, determine the causes of the injuries, and ascertain effective strategies for preventing injuries.

Lead Poisoning Prevention and Screening (CDC)

Ongoing program to prevent lead poisoning in children

Funding Level: FY 1996 $36.2 million - for all children (not limited to 0-3)

Target Population: Children - ages 1- 4

Description: Childhood lead poisoning is a major preventable environmental health problem in the United States. About 1.7 million children from 1-4 years of age have elevated blood lead levels. All high risk children need to be screened and receive follow-up care. Although much

progress has been made, many children remain at high-risk for lead exposure, especially children in areas with high prevalence of elevated blood lead levels.

CDC provides financial and technical assistance to 40 state and local health departments to improve or expand their capacity to support: childhood lead screening; referral of children with elevated levels for treatment and environmental intervention; educating the public, health professionals and policy makers about childhood lead poisoning; and capacity building for state laboratory-based surveillance of childhood lead poisoning. CDC is in the process of revising its screening guidelines which are expected to improve public and private sector efforts to identify high-risk children with lead poisoning.

Contribution to Initiative: CDC was instrumental in the initiation of Federal action to reduce lead in gasoline which brought about declines in average blood lead levels in the U.S. population as a whole. CDC efforts - and monitoring through the National Health and Nutrition Examination Survey - has made it possible to chart the nation's progress against this disease. CDC has documented a 70% drop in blood lead levels of children aged 1-5.

In FY'96, CDC's grant-supported programs screened more than 1.8 million children for lead poisoning and identified about 45,000 with elevated blood lead levels.

Child Health Initiative (CDC/ATSDR)

Ongoing research and program activities to promote the environmental health of children who live near hazardous waste sites.

Target Population: Children - ages 0-21

Description: Children who live near hazardous waste sites often have greater exposures, greater potential for health problems, and less ability to avoid hazards. Exposure to hazardous substances can cause learning disabilities and growth and development problems in children. Recognizing these special vulnerabilities, the Agency for Toxic Substances and Disease Registry (ATSDR) has launched an initiative to emphasize child health in all agency programs and activities. ATSDR's findings, from more than ten years of public health assessments, toxicologic investigations, epidemiologic studies and reviews by expert workgroups, demonstrate the special vulnerabilities of children who live near hazardous waste sites.

Contribution to Initiative: ATSDR's external Board of Scientific Counselors appointed a Child Health Workgroup, composed of nationally recognized experts in child health and environmental medicine, to examine available data (from ATSDR and other sources) on the impact of hazardous waste sites on children's health, identify key information gaps, and propose further prevention activities.

E. Substance Abuse and Mental Health

Residential Substance Abuse Treatment Grants for Women and Children (SAMHSA)

Funding Level: Pregnant and Postpartum Women and Children (PPW) FY 97- $18.6 million
Women and Children (RWC), FY 97 - $ 33.2 million

Target Population: PPW served approximately 1,200 infants and children in FY 96.
RWC served approximately 1,800 children (38% below the age of 3) in FY 96.

Description: SAMHSA has two treatment programs dedicated to pregnant and postpartum women and their children and women with children. They were developed to provide support for comprehensive substance abuse treatment services in residential settings for women and their children. The program elements include housing that permits children to live with their mothers in a nurturing, supportive, and drug-free environment.

- Pregnant and Postpartum Women and Children: The goals of this program related to infants and children are to: promote safe and healthy pregnancies and perinatal outcomes; reduce infant mortality rates; increase the proportion of infants born drug-free and of normal birth weight; increase the proportion of infants receiving primary health care services; and interrupt the substance abusing lifestyle of women in order to promote the well-being of their children. Services for the infants and young children include specialized newborn care, pediatric care including screening and ongoing assessment for alcohol and other drug related birth defects, screening for infectious diseases, and ongoing baby care.

- Women with Children: The goals of this program for children are to enhance the physical, mental, and social health and well-being of children with intra-uterine or environmental exposure to alcohol and other drugs; increase access to primary health care for children; and improve family and social functioning. Services for mothers and children include primary health care, pediatric health care, mental health services, substance abuse prevention, therapeutic interventions such as pediatric screening and a full range of services, developmentally appropriate interventions to foster healthy physical, social and cognitive development, parenting skills training, health education, vocation and educational training; and education and counseling related to HIV/AIDS, STDs, domestic violence, sexual, physical, and emotional abuse.

Contribution to Initiative: It is well documented in the literature that infants and children exposed to parental substance abuse and conditions of poverty at an early age (birth to three years) are deemed "at-risk' for developing problems later in life such as substance abuse, mental illness, delinquency, low academic achievement, inter-personal violence, and unemployment. These programs address these risk factors and support families breaking the cycle of alcohol and other drug abuse.

Substance Abuse Prevention and Treatment Block Grant Set-Aside for Pregnant Women and Women with Dependent Children (SAMHSA)

Funding Level: 5% of base, or approximately $43 million in FY 1994

Target Population: Pregnant women and women with dependent children.

Description: The Substance Abuse Treatment Prevention and Treatment Block Grant to States set-aside establishes new or expands existing treatment capacity for pregnant women and women with dependent children. Funds from the set-aside provide substance abuse treatment and prevention services, as well as gender-specific wrap-around services such as child care and prenatal care.

Contribution to Initiative: The State Block Grant set-aside for pregnant women and women with dependent children was implemented in 1993 and insured that a minimum of five percent of State Block Grant funds were used to meet the substance abuse prevention and treatment needs of this population in States where this minimum was not being spent. It is applicable to all States and territories.

Model Projects for Pregnant and Postpartum Women and Their Infants (SAMHSA)

Funding Level: There were 147 programs funded between 1989 - 1992, but all of the PPWI are due to end in 1997. There are two programs which will receive a combined total of $0.9 million, which will continue to the end of the fiscal year.

Target Population: Women of childbearing age who are pregnant and parenting and who abuse substances or are at risk for abuse. This program also focuses on children zero to three years of age.

Description: This CSAP demonstration grant program supports comprehensive, community-based prevention programs to help women of childbearing age (especially low-income women) to avoid the use of alcohol and other drugs during pregnancy. Early intervention and treatment strategies are also developed for substance abusing pregnant and parenting women and their infants.

Program goals are to: promote the involvement and coordinated participation of multiple organizations in providing comprehensive services; increase the availability and accessibility of prevention, early intervention, and treatment services; decrease the incidence and prevalence of drug and alcohol use among pregnant and postpartum women; reduce the incidence of abuse and neglect among children of substance abusing women; reduce the severity of impairment among children born to substance using women; improve provider recognition of co-occurring mental and addictive disorders; and increase the availability, accessibility, and coordination of comprehensive mental health and substance abuse programs.

Contribution to Initiative: Lessons learned from implementing projects for substance abusing pregnant and postpartum women and their children address prenatal care issues, substance abuse treatment for substance abusing women, services for drug exposed infants, parenting skill building among others. Each project has an evaluation component which measures the achievement of program goals and objectives. In addition, the program supported a cross-site evaluation of the first 115 projects, and currently supports a second, more rigorous cross-site evaluation of 10 projects whose cross-site design includes standardized instruments and comparison groups. An implementation manual, *From the Source*, was developed from the first cross-site evaluation. This manual provides guidelines for community based service providers who are developing programming for pregnant and parenting women. In addition, findings from the final reports of these grants will be maintained in the High Risk Populations Findings Bank.

II. Enhancing the Care of Our Practitioners, Providers and Professionals

Bright Futures (MCHB)

Target Population: Health Professionals, children and families

Funding: MCHB has developed a unique public - private partnership with Georgetown University, Harvard University, and Pfizer, Inc. to assist in the development of *Bright Future* materials and messages to health professionals and families through various publications and an interactive Web site.

Description: Health promotion and preventive strategies aimed at children in the context of families and communities are essential for addressing the "new morbidities" that plague our children from their earliest days. *Bright Futures* is a partnership that strives to promote and improve the health, education, and well-being of children, families and communities for the 21st century. It is based on the science, parent perspectives, and the experience of national experts, representing the key health and family organizations of America. *Bright Futures* is a set of developmentally-based multi-disciplinary guidelines that promote health and address the preventive needs of all children and their families within the communities they live.

Using the *Bright Futures* guidelines as a cornerstone, *Building Bright Futures*, the implementation phase of the program is currently focusing on three goals: improving the overall health of children and families, changing the way health professionals practice, and changing the way families view preventive care in order to enhance their participation. A series of implementation guides that focus on such key areas of child health oral health, nutrition, mental health are being developed to provide health professionals and families with specific tools and strategies to bring the *Bright Futures* recommendations "home" to the health care setting, to communities, and to families.

Contribution to Initiative: *Bright Futures* is changing the organization of health supervision by increasing collaboration among health disciplines and between families, health professionals and communities. With more than 20 national organizations support, the multi-disciplinary Bright Futures guidelines have been incorporated into policies, programs and health practices throughout the United States--the State of Florida adopting them as state-wide standards being one example. Publications include: *Bright Futures Guidelines for Health Supervision for Infants, Children and Adolescents; Bright Futures Pocket Guide; Bright Futures in Practice: Oral Health; Bright Futures Anticipatory Guidance Cards; Bright Futures Oral Health Quick Reference Cards; Bright Notes Newsletter (Quarterly); Bright Futures in Practice: Nutrition (in preparation); Bright Futures in Practice: Mental Health (in preparation); Bright Futures for Families Series (in preparation); video tele-conference with Parent Network--Bright Families, Bright Consumers, Bright Futures.*

Leadership Education Projects to Support Training of Professionals Working with Young Children (MCHB)

Target Population: Health Professionals

Description: Well-educated health professionals can assure that infants and children, including those with special health care needs, achieve their full potential. MCHB has developed leadership education projects to support the training of professionals in disciplines such as pediatrics, nursing, nutrition, social work, psychology, audiology, speech pathology, occupational therapy, physical therapy, pediatric dentistry, and health administration, and through provision of continuing education, technical assistance and consultation.

- Developmental Specialist in Pediatric Practice. The MCHB supported an effort with ZERO TO THREE/ National Center for Clinical Infant Programs to investigate issues related to a specially trained non-medical infant/child development specialist as a vehicle for providing assessment and care to families in primary care pediatric practice focusing on advancing parental and child development. ($25,000 contract)

- Professional education in behavioral pediatrics. The MCHB supports leadership education to enhance the behavioral, psychosocial and developmental aspects of general pediatric care by preparing fellows in behavioral pediatrics to be educators, investigators and clinicians and through providing pediatric practitioners, residents and medical students with essential biopsychosocial knowledge and clinical expertise ($1 million per year).

- Multiple disciplines caring for children with neurodevelopmental disabilities. The MCHB also supports Interdisciplinary Leadership Education in Neurodevelopmental and Related Disabilities (LEND) aimed at improving the health and developmental potential of infants and children with, or at risk for, neurodevelopmental and related disabilities, including mental retardation, neurodegenerative and acquired neurological disorders, and multiple disabilities. The LEND program prepares health professionals to assist children and their families to achieve their developmental potential by forging a community-based partnership of health resources and community leadership. ($17.5 million/year supports 34 programs throughout the U.S.)

Contribution to Initiative: With the advances in the science of human growth and development, it is critical to translate these new exciting findings into practice. This requires leadership education for health professionals, training of the infant child care providers, and education for parents. By focusing on the importance of health promotion, prevention and the benefits of coordinated health care, families and practitioners, working as partners within their communities, are able to develop creative approaches for improving the health of infants and children, including those with special health care needs, and for addressing the health problems of vulnerable groups whose needs are not currently being met by our systems of care. MCHB efforts are designed to improve access to health care for the Nation's children, while improving the quality and reducing the overall long-term costs of health care in America through leadership

education.

Bilingual/Bicultural Service Demonstration Grant Program (OPHS)

Funding level: In FY 96, 14 grants were awarded totaling $1.17 million

Target Population: Projects funded under this demonstration program may target any age group(s) for services. In FY 96, 9 of the projects specifically identified prenatal activities and included infants in their targeted population.

Description: The Bilingual/Bicultural Service Demonstration Grants Program provides support to improve the ability of health care providers and other health care professionals to deliver linguistically and culturally competent health services to limited English proficient populations.

Contribution to Initiative: The programs of the Office of Minority Health focus on health problems identified as being the leading causes of "excess deaths" among minority populations, including infant mortality. This program supports activities which reduce social, cultural, and linguistic barriers between providers and clients with limited English proficiency, and improves their access to good health care. Activities include linguistic and cultural competency training for health care professional; development of health promotion information in the native language of the target populations(s); interpretation services, increased use of case managers and outreach workers from the racial and ethnic communities being serviced; and counseling, mentoring, and support group programs for clients who speak limited English.

III. Direct Services

Community and Migrant Health Centers (HRSA)

Community- based primary care providers serving medically underserved people nation-wide. This ongoing program is administered by the Health Resources and Services Administration under Section 330 of the Public Health Service Act.

Funding Level: Funded at $802 million for fiscal year 1997.

Target Population: Medically underserved, disadvantaged populations including: minorities, women of child bearing age, infants, persons with HIV/AIDS, substance abusers and/or homeless individuals and their families. In fiscal year (FY) 1995, the Community and Migrant Health Centers (CHC) Program served 8 million clients. Of this total, approximately 75 percent were pregnant women, infants, children and youth up to 19 years old.

Description: To provide access to case-managed, family-oriented preventive and primary health care services for people living in rural and urban medically underserved areas. CHCs are located in areas throughout the country where there are financial, geographic, or cultural barriers to primary health care for a substantial portion of the population. CHCs seek to improve access by supporting local, community-based health care systems and providers. They bring care to alternative sites where people live or work including schools, homeless shelters and migrant camps. They empower their communities, generate jobs, assure the presence of health professionals and facilities and utilize local suppliers.

CHCs provide comprehensive primary medical care services with a culturally sensitive, family oriented focus. These medical services include: preventive health and dental services; acute and chronic care services; and appropriate hospitalization and specialty referrals. CHC services are prevention-oriented and include such children's services as immunizations, well baby care, and developmental screenings. CHCs also provide essential ancillary services such as laboratory tests, X-ray, environmental health and pharmacy services. In addition, many centers provide such enabling health and community services as transportation, health education, nutrition, counseling, and translation services. Case management--the coordination of the center's services with community services appropriate to the needs of the patient (social, medical, or economic)--is emphasized.

Contribution to Initiative: Provision of case-managed, family-oriented preventive and primary health care services to over 8.1 million medically underserved people, including children, nationwide.

Indian Health Services (IHS)

Funding Level: $1.7 billion for health services.

Target Population: The Indian Health Service is responsible for providing Federal health services to American Indians and Alaska Natives (AI/AN) who live on or near reservations that are within the funded scope of IHS programs. In FY 1996, the IHS service population of AI/AN was approximately 1.4 million children and adults.

Description: The services provided vary from community to community and are determined by medical priorities, the level of appropriated funds, and what services are available from other resources in the local area. The health services are delivered through 540 direct health care delivery facilities including 49 hospitals, 195 health centers, 8 school health centers, 289 health stations and clinics, and 152 Alaska Village clinics. Some of these facilities and programs are tribally managed.

The health status of AI/AN people has improved dramatically since 1973 as measured by reduced mortality rates. Contributing to this improvement are widespread immunization programs, improved sanitation, and better access to primary care. Prenatal and well-child care have produced a 60% and 75% decrease in infant and maternal mortality rates respectively. The injury prevention program has produced a 73% reduction in injuries since 1972-74. The IHS has established major health initiatives and emphasis in domestic violence and child abuse prevention, Indian children and youth, and injury prevention to increase the chances that young children will increase their chances of leading healthy and productive lives.

Contribution: Improved infant and maternal mortality rates.

IV. Building the Research Base to Improve Health Care and Promote Healthy Development

A. Tracking and Measuring Health Status and Quality

Children's Health Surveillance Activities (CDC)

Funding Level: FY 1996 - $13.3 million for children (not limited to age 0 -3)

Target Population: Children ages 0 -21 years old

Description: CDC conducts several surveys that produce a broad range of data on the health status of children. The following is a list of the surveys that include children age 0-3 years old:

-National Health and Nutrition Examination Survey
-National Hospital Discharge Survey
-National Survey of Ambulatory Surgery
-National Ambulatory Medical Care Survey
-National Hospital Ambulatory Medical Care Survey
-Natality Statistics from the National Vital Statistics System
-Mortality Statistics from the National Vital Statistics System
-Fetal Death Statistics from the National Vital Statistics System
-Linked Birth/Infant Death Data Set from the National Vital Statistics System
-1991 Longitudinal Follow up to the National Maternal and Infant Health Survey
-1993 NHIS Access to Care Survey
-The National Health Interview Survey on Disability
-National Health Interview Survey
-National Immunization Survey
-National Immunization Provider Record Check

Contribution: These childhood surveillance activities provide the information needed to monitor the health and well-being of children, particularly in this critical time of dramatic change in health and human services.

Infant Nutrition (FDA)

Target Population: Infants, Parents

Description: FDA strives to ensure the nutritional soundness of infant formulas for proper growth and development. Several contractual activities underway with the Life Sciences

Research Office of the Federation of American Societies for Experimental Biology are to 1) provide an up to date review of nutrient requirements for infant formulas for full term infants and 2) an up to date review of energy and macro nutrient requirements of pre-term infants in infant formulas for pre-term infants.

Contribution to Initiative: This review of infant formulas seeks to ensure that infants are receiving proper nutrition. Good nutrition plays an important part in the normal and healthy development of infants.

Medical Expenditure Panel Survey: Data on Children (AHCPR)

The Agency for Health Care Policy and Research's (AHCPR's) Medical Expenditure Panel Survey (MEPS) will begin to make data available in March of 1997.

Target population: MEPS contains data on 7,000 children ages 0 to 17, including 1,500 children ages 0 to 3.

Description and purpose: MEPS is a nationally representative survey that collects detailed information on the health status, health services use and costs, health insurance coverage, employment, income and job characteristics of individuals and families in the United States. Specifically MEPS data will be able to answer questions regarding children's access to insurance and care, their use of health care services, and their family's health care expenditures. MEPS data will also be used to make comparisons over three decades (1970s, 1980s, and 1990s).

Contribution to Initiative: Children ages 0 to 3 have been shown to benefit from certain health services (e.g., timely immunizations), and to suffer when certain health services are not available. Health insurance coverage is an important predictor of access to services. MEPS data will allow us to understand whether and how coverage for young children has changed over time, and the relationships among childhood disorders, conditions, and preventive interventions, family income, insurance coverage, expenditures and health status.

MCH Model Data Sets (MCHB)

Funding: The direct MCHB support of the entire project is about $325,000 over a period of three years. This estimate includes the cost of two large meetings of data and MCH content experts in Washington, D.C., plus regular participation of a smaller group of developers with the breadth of expertise required for this task.

Description: The MCH Model Data Sets are a collection of indicators of 1) the health of infants, children, adolescents and women of reproductive age and 2) key factors that contribute to the health status of these populations. There are separate data sets for each of the populations listed above. The data set includes core indicators to serve such diverse functions as needs assessment, policy and program development, evaluation, resource allocation, monitoring, quality assurance,

and accountability. This multi-purpose set of indicators will be a blueprint for state and local development of MCH data bases and a foundation for development of more detailed and specialized data sets at the national, state and local levels.

The model data set will be disseminated widely on hard copy, diskettes, and via the Internet. A detailed dissemination plan has not yet been developed. However, the intent of this project is to produce a set of indicators that all providers and monitors of MCH services will be encouraged to collect and use. Data for the indicators will be collected primarily at the individual person level. They can be calculated, therefore, locally, at the state level, and nationally. Dissemination will be aimed at potential users at all of these levels.

Contribution to Initiative: These data sets will allow provide quality indicators of health status to researchers examining the health of our youngest children.

Effects of Early Discharge Policies (MCHB)

Funding: The cost for FY 97 (year two of a four year project) is $230,000.

Description: Efforts are being made to establish a coordinated national strategy to obtain timely information and promote its translation into effective, humane, and cost-conscious policy on the first primary care services received by newborns and mothers. There is currently widespread public and professional concern regarding early maternal-newborn discharge. Although there have been many publications on this topic, scientific evidence is currently unavailable to guide clinical or reimbursement policies not only on hospital length of stay but also on the services needed immediately following discharge for the general maternal-infant population. Clinicians, hospitals, program managers, third party payers, the public, and policy-makers need reliable information to guide both the hospital and community-based primary care services received by most mothers and newborns in the first days of life and parenting.

Contribution to Initiative: The coordinating center team at the University of California at San Francisco is nationally recognized for its research on perinatal health services. The multi-disciplinary maternal and child health services research team has expertise in Epidemiology, statistics, outcomes research, cost-effectiveness analysis, and research on socio-economically and ethnically diverse populations. This team has published extensively in medical journal on early discharge. In addition they provide technical assistance to other researchers interested in early discharge, providing direct scientific coordination and promotion of national collaboration.

Regulatory Disorders and Development Outcomes (MCHB)

Funding level: Year 1: $155,000; Year 2: $150,000; Year 3:$150,000: Year 4: $150,000; Year 6: $150,000

Description: This investigation proposes to test the efficacy of an assessment battery of tests

designed to predict those infants who will develop behavioral and emotional problems by three years of age. Many of the children who develop behavioral and emotional disorders are not identified until after two years of age. Some problems may not be detected until the child enters school.
Principal researcher: Stephen W. Porges, Ph.D. University of Maryland.

Contribution to Initiative: If successful, the assessment battery being tested by the study will have immediate application as it will aid clinical researchers and clinicians in developing effective preventive strategies to address infant vulnerabilities.

Validity of Neurobehavioral Symptoms reported in Children with Traumatic Brain Injury (MCHB)

Description: Headaches, inattention, poor memory, and other behavior complaints are common sequelae of traumatic brain injury (TBI) in children. In the present study, 68 children with moderate to severe TBI, together with 53 children with orthopedic injuries only, were followed prospectively from the time of hospitalization. Post-injury behaviors symptoms and other child and family outcomes were assessed at a baseline evaluation conducted soon after the injury and again at a 6-month follow-up. Overall, study findings support the utility of neurobehavioral symptoms as markers of injury severity and predictors of child and family sequelae.

Contribution to Initiative: This research furthers our understanding of symptoms associated with TBI and indicators of its presence and severity, and provides insight into how to help and treat children affected by TBI.

Pregnancy Risk Assessment Monitoring Systems (CDC)

Funding Level: FY 96 - $8.9 million

Target Population: Women and Infants

Description: The Pregnancy Risk Assessment Monitoring System (PRAMS) is a surveillance system designed to identify and monitor selected maternal behaviors and experiences that occur before, during, and after pregnancy. In particular, PRAMS was designed to supplement data from vital records and to generate data for planning and assessing perinatal health programs in participating States. States select a sample of mothers who are asked about behaviors and experiences such as access to, and use of, prenatal and infant care, alcohol use, smoking, and violence during pregnancy.

Contribution to Initiative: PRAMS data are used to enhance understanding of maternal risk factors and their relationship with adverse pregnancy outcomes and aid in the development and assessment of programs designed to identify high-risk pregnancies and reduce adverse outcomes, including low birth-weight and infant mortality.

Quality Measurements and Improvement in Child Health Care (AHCPR)

The Agency for Health Care Policy and Research (AHCPR) is applying knowledge learned from the scientific research base in early childhood health to development of tools to measure and improve the quality of child health care.

Description: Several current projects suggest the extent of AHCPR's commitment to building quality measures, and improving quality of health care, for children.

- Consumer Assessments of Health Plans Study (CAHPS). AHCPR is funding a 5-year project to help consumers identify the best health care plans and services for their needs. The goals of the Consumer Assessments of Health Plans Study (CAHPS) are to (1) develop and test questionnaires that assess health plans and services, (2) produce easily understandable reports for communicating survey information to consumers, and (3) evaluate the usefulness of these reports for consumers in selecting health care plans and services. In addition to core items, CAHPS includes pediatric (families with children) items.

- CONQUEST 1.0. CONQUEST 1.0 is a computerized Needs-Oriented quality Measurement Evaluation system. It is a prototype system for collecting and evaluating clinical performance measures. CONQUEST 1.0 includes two interlocking databases with a user-friendly interface to help users find measures to fit their needs. It summarizes information on approximately 1,200 clinical performance measures developed by public- and private-sector organizations. Included in these performance measures are childhood immunization records, measures of prenatal care, numbers of cesarean sections per all deliveries, low birth weight measurements, and a gauge of the rates of infant mortality. All of these measures can then be used to develop quality guidelines and initiatives or to measure whether appropriate and adequate care for children.

AHCPR is also involved with efforts of the National Committee on Quality Assurance to build additional HEDIS measures for children, and convened a meeting in January 1997 to provide expert advice on this topic. AHCPR is also co-sponsoring the May 1997 research agenda conference on pediatric quality of care, also cosponsored by the Centers for Disease Control and Prevention, the National Institutes of Health, the Health Resources and Services Administration, the Health Care Financing Administration, the David and Lucille Packard Foundation, and Pfizer, Inc. The purpose of the conference is to create and disseminate a research agenda on quality of care measures for children and to bring attention to issues that require attention in the research community and from policy makers.

Contribution to Initiative: In order to assure that their dollars are buying high quality health care for covered children and parents-to-be, purchasers, including the Federal government, need valid measures of health care quality.

B. Prevention Research

Childhood Infectious Disease Research (CDC)

Ongoing research projects to control infectious disease in children

Funding Level: FY 1996 - $4.4 million for children (not limited to ages 0-3)

Target Population: Children - ages 0 -21 years old

Description: Infectious diseases increasingly threaten public health and contribute significantly to the escalating costs of health care. CDC works to prevent illness and death from infectious diseases in children by: Epidemic investigation; surveillance of infectious diseases; Epidemiologic and laboratory research; and formulating, disseminating, an evaluating prevention and control strategies. The following are examples of CDC's infectious disease control activities targeted to children ages 0 -3:

- *Meningitis prevention:* During the early 1980s meningitis caused by Hemophilus influenzae type b (Hib) was a leading cause of morbidity and mortality in the U.S., affecting one out of every 200 children less than 5 years of age. CDC worked on the evaluation of the new conjugated Hib vaccines. Since the introduction of routine infant immunization to prevent Hib infection, the incidence of invasive Hib has fallen over 95 percent. As a result of this success, CDC has targeted invasive Hib disease for eradication in the U.S. by the year 2000.

- *Antibiotic Resistance Educational Material:* In response to the growing problem of antibiotic resistance in treating infectious diseases, CDC developed materials (pamphlet, posters, disease-specific fact sheets; videotape) to educate parents on the threat of antibiotic resistance and the association of resistance with overuse of antibiotics.

Contribution: CDC is working with its many partners to address the challenges of controlling preventing infectious diseases in children.

Prenatal and Perinatal Research (NIH / NICHD)

Target Population All pregnant women and their newborns

Description: NICHD pre- and perinatal research aims to improve pregnancy outcomes to reduce infant morbidity and mortality. Despite impressive strides, nearly 11 percent of the over 4 million infants born each year are premature or have very low birth weights. To focus on this problem, NICHD supports several major research efforts: the goal of the Maternal Fetal Medicine Units Network is to improve the management of high risk pregnancies, and prevent complications of labor and delivery including preterm labor; the D.C. infant mortality initiative is

another large effort, examining different models of prenatal care to assess their impact on birth outcomes, especially among high risk, minority populations.

NICHD also supports the Neonatal Intensive Care Unit Network to develop new and improved ways to prevent or treat the immediate disorders associated with prematurity, such as neonatal respiratory distress, severe eye problems, brain hemorrhage, and severe jaundice (which can lead to brain damage). NICHD supports a range of studies to understand and prevent nutritional deficits and intrauterine growth retardation, as well as intramural research to develop vaccines against infections that are particularly devastating to infants. The Pediatric AIDS Clinical Trial Group (PACTG), and other HIV-related studies reviewing obstetric and nutritional interventions, seek improved ways to prevent HIV transmission from the mother to the fetus or newborn. Most recently, the PACTG began planning to test protease inhibitors in infected pregnant women and newborns.

Contribution to Initiative: Since 1962, research in this area has helped to reduce the infant mortality rate by 70 percent, virtually eliminated several major causes of morbidity, and enhanced the chances for children to develop free of physical defects, visual or learning impairment, or mental retardation. Continuing this research holds promise for further improving the chances for infants to be born and remain healthy through infancy.

Accomplishments: Many achievements have emerged from these NICHD-supported and collaborative research efforts, including the overall improvement of pregnancy outcomes; RhoGAM™ to prevent Rh hemolytic disease; the identification and use of prenatal folic acid to reduce the risk of neural tube defects; surfactant to prevent respiratory distress syndrome; the *Hemophilus influenza* type b (Hib) vaccine to prevent Hib meningitis and mental retardation, the Back-to-Sleep campaign to reduce SIDS; the identification of bacterial vaginosis and group B strep vaginal infections as potentially causing premature delivery; and, the approval and use of AZT to prevent the vertical transmission of HIV.

Planned Activities: The NICHD will expand its efforts to identify the specific causes of and improve methods to prevent premature labor, including new clinical trials testing the use of antibiotics to treat women at high risk of bacterial vaginosis.

Vaccination Research (FDA)

Target Population: All US children

Description: The Center for Biologic Evaluation and Research through its Office of Vaccines Research and review and its Office of Establishment Licensing and Product Surveillance has on-going programs in the regulation of pediatric vaccines. The purpose of CBER's activities are to ensure that the highest quality vaccines are made available to children in a timely manner.

Activities under these programs include; 1) the licensing of new pediatric vaccines (recent examples include two acellular pertussis vaccines and the chicken pox vaccine); 2) the review of

Investigation New Drug application for future pediatric vaccines (examples include vaccines for rotaviral or Group B streptococcal infections); 3) safety and potency testing of pediatric vaccines; 4) monitoring of demonstrated or potential vaccine adverse events; 5) inspection of manufacturers of pediatric vaccines for, *inter alia*, compliance with current good manufacturing practices to ensure consistent, high quality vaccines; 6) research programs to study demonstrated or potential vaccine adverse events, including improved methodologies for safety monitoring; 7) research programs to develop new or improved childhood vaccines; 8) interaction with other governmental and non-governmental agencies to help ensure the most appropriate use of childhood vaccines.

Contribution to Initiative: This activity directly benefits the health and welfare of children through the elimination of childhood diseases and their attendant mortality and morbidity.

Prevention of Birth Defects / Centers for Birth Defects Prevention Research (CDC)

Ongoing research projects to prevent birth defects

Funding Level: FY 1996 - $6.1 million

Target Population: Children - prenatal to newborns

Description: Birth defects are the leading cause of infant mortality in the United States and the primary cause of nearly 7,000 or 20 percent of all infant deaths each year. Each year, factors in the periconceptional and prenatal environment result in major birth defects that affect 120,000 babies. We know the causes of about 25 percent of these birth defects, and as a result, prevention is possible in some cases. CDC works to monitor trends in birth defects, developmental disabilities, and genetic diseases, in link these health outcomes with the factors in the environment that increase risk; and identify effective means of reducing that risk.

Contribution to Initiative: CDC has established Centers for Birth Defects Prevention Research in 6 States which have initiated unique national collaborative research into the causes of birth defects. The role of environmental pollutants, drugs, specific behaviors, or genetic susceptibilities in causing birth defects, developmental disabilities, or other adverse reproductive outcomes is being explored. These new Centers will accelerate the process of finding the causes and risk factors for birth defects.

Prevention of Fetal Alcohol Syndrome / Prevention Strategies (CDC)

Ongoing program and research activities to prevent fetal alcohol syndrome

Funding Level: FY 1996 - $6.3 million

Target Population: Children - prenatal to newborn

Description: Heavy prenatal alcohol use can result in fetal alcohol syndrome (FAS), one of the leading known causes of mental retardation and birth defects. In addition to FAS, studies have documented other growth and neurodevelopmental deficits among children whose mothers drank at lower thresholds during pregnancy. Estimates of the rate of FAS range from .67 to 2.2 per 1000 live births.

CDC is working to design, implement, and evaluate prevention strategies for specific high-risk groups to prevent occurrence of FAS and other alcohol-related birth defects. In addition, CDC is developing methodologies for improving FAS case detection and surveillance and for using existing data collection systems to estimate the incidence of FAS and perform descriptive Epidemiology.

Contribution to Initiative: Through these activities CDC will further understanding of women who give birth to children with FAS, increase the ability to identify high-risk women, and better define the spectrum of outcomes and needs of children exposed to alcohol in-utero.

Research Projects to Close the Racial Disparity in Infant Mortality (CDC)

Funding Level: FY 96 - $2.2 million

Target Population: Women and Infants (less than 12 months)

Description: Pre-term delivery, the termination of pregnancy before completion of 37 weeks of gestation, together with low birth-weight, is the third leading cause of infant mortality in the United States. The percent of pre-term births has risen steadily from 9.4 in 1981 to 11.0 in 1994. Black women experience twice the risk of pre-term delivery as white women. In 1994, the percentage of black and white infants that were born pre-term was 18.1 percent and 9.6 percent, respectively. Risk factors for pre-term delivery include low socioeconomic status, low pre-pregnancy weight, inadequate weight gain during pregnancy, previous pre-term delivery, a history of infertility problems, vaginal spotting or light bleeding during pregnancy, antepartum hemorrhage and abnormal placental implantation , alcohol consumption before the third trimester of pregnancy, negative attitude about the pregnancy, smoking, multiple gestation, cervical factors, myometrial factors, problems with the fetal membranes and decreased utero placental blood flow.

The reasons for the disparity in pre-term delivery between black and white women remain unexplained. Therefore, CDC has begun to examine psychological, social, cultural, and environmental factors that may contribute to pre-term delivery using a community participatory approach in Harlem and Los Angeles. Full participation by the community is a necessity in improving the understanding of both risk and protective factors influencing maternal health and pregnancy outcomes. The community helps decide what questions should be asked, how prevention efforts should be conducted, and how the results should be interpreted. Additionally, because high levels of exposure to such factors as stressful life experiences put African-American women at increased risk for adverse reproductive outcomes, CDC is

examining the validity and reliability of stressful life event scales in African-American women.

Contribution to Initiative: This community-based prevention research project in an innovative approach to prevent infant mortality in communities that still have an excess burden of infant deaths.

Low Birth Weight and Other Perinatal Outcomes Research (AHCPR)

AHCPR has undertaken various projects, grants, and initiatives to help build the science base for health care in perinatal care. Selected examples include a Patient Outcomes Research Team (PORT) regarding prevention of low birth weight and other research on perinatal services.

Funding Level: The combined funding level for these projects totals $24 million (cumulative total funding for active projects).

Target Populations: Pregnant women and infants.

Description and Purpose:

- Low birth-weight PORT: Low birth weight is a substantial risk factor for infant mortality and early childhood illnesses. Nearly 70 percent of all infant mortality and approximately one-third of all handicapping conditions are associated with low birth-weight. After extensive scientific review of the literature on the multiple causes of low birth-weight, AHCPR developed a comprehensive 5-year research project that focuses on areas where there is a wide variation in obstetrical practice and other practices to reduce low birth-weight, but little scientific evidence supporting these practices. The project, which is now in its last year, has already yielded several key findings.

- Other Perinatal projects: Beyond the PORT research the Agency has funded other projects regarding high-risk infants and their care. Two studies, which began in fiscal year 1996, focus on guidelines for care of low birth weight infants. One study will provide strategies for clinical care and for establishing policy, and the other research project focuses on chronic lung disease (CLD) and home care interventions necessary to control neonatal ICU costs. Other perinatal care studies are listed on the attachment.

Contribution to Initiative: The low-birth-weight project has already made several substantial contributions to the science base on perinatal care and prevention of low birth-weight. For example, it found a strong relationship between bacterial vaginosis in pregnancy and pre-term delivery, especially in African American women; the effectiveness of zinc supplementation for improving birth-weight in African American women; that de-regionalization of perinatal services can have a negative effect on neonatal mortality; that antenatal corticosteroids are effective in improving outcomes of pre-term newborns; and no evidence for the effectiveness of bed rest in preventing pre-term delivery and a variety of pregnancy problems. Taken together, these and other findings begin to provide the scientific basis for designing a more cost-effective package of prenatal and perinatal services. As they are replicated, individual findings can be

used to improve clinical practice and the organization of care, and to develop performance measures for health plans that deliver services to pregnant women.

C. Interventions and Developmental Practices

Evaluation of Hawaii's Healthy Start Program (MCHB)

Description: This is a five-year study designed to provide a comprehensive process and outcome evaluation of Hawaii's Healthy Start program (HSP), an established screening and outreach program for environmentally at-risk children and their families. In the HSP's early identification component, population-based screening and assessments are used to identify at-risk families of newborns. In the home visiting component, trained paraprofessionals provide direct support and education services to assure access to pediatric primary care and other community resources in the child's first five years of life.
Principal Researcher: Cal Cia, M.D., University of Hawaii.

Contribution to Initiative: This evaluation provides insight into the efficacy of models of social services service delivery to at-risk families and infants.

Planned Research Projects on Preventing Developmental Delays (CDC)

Funding Level: FY 96 - $3.5 million

Target Population: Children - Birth to five
(No children are being served at this time)

Description: CDC is planning a set of quality scientific studies designed to provide policy oriented research data regarding "what works" in early intervention. These research studies will be directed at children and/or their families to prevent or remedy a wide variety of developmental delays or problems. CDC has joined with local research partners in multiple communities throughout the United States. Our local research partners will coordinate with existing community resources and services to conduct the study .

The interventions to be studied will occur between the prenatal period and the child's fifth birthday. They will be designed to assess whether the services provided will facilitate parent/child relationships, promote the development of the child and enhance family functioning. It will also examine whether these services, delivered during the preschool years can: 1) promote better relationships and more stable family patterns; and 2) prevent adolescent and adult problems such as school failure, illiteracy, teen pregnancy, substance abuse, unemployment, poverty, and welfare dependence.

The research goal of this study is to provide scientific data for state and national policy makers

and providers of services for young children and their families in order to determine: 1) What interventions are effective to promote child development; 2) What are the characteristics of children and families who benefit most from the intervention; and 3) What are the costs and benefits of intervention.

Contribution to Initiative: There is a continued need for solid scientific research on societal or community interventions that benefit young children and their families. It is important that these research efforts be long-term longitudinal studies. These studies are urgently needed to provide quality data to influence state and national policies and services for young children and their families. Not only will the immediate benefit of the interventions be determined, but the longitudinal data collected will enable researchers to address the long term impact of the interventions such as its effect on grade retention, special education, and teen pregnancy.

The Physical and Developmental Environment of the High Risk Infant (MCHB)

Funding: $156,000 , FY 97

Description: Contemporary neonatal intensive care units are intensely busy places caring for seriously ill babies. The care environment is replete with high technology machines, generating significant noise in units that know no difference between morning and evening. Lights generally blaze 24 hours a day. Care must be immediate and deliberate given the high vulnerability of the infants. New treatments and new technology are often instituted without the full appreciation of their consequences. Retinopathy of prematurity (retrolental fibroplasia) is a classic example where premature low birth weight infants required oxygen to sustain life but were at-risk for blindness because too little oxygen would cause brain damage and too much would damage the retina. Early availability of oxygen therapy in the 1950's tragically resulted in an epidemic of retinopathy of prematurity, where the over reaction to this consequence--too little oxygen, resulted in a concomitant occurrence of brain injury known as cerebral palsy.

The Physical and Developmental Environment of the High Risk Infant project has brought together an interdisciplinary group of national experts and parents to systematically review the scientific literature--both human and animal-- examining the biological basis of growth and development of the fetus and newborn, particularly as it affects brain development and functioning. They have convened several work groups and national symposia to investigate the basic biophysiological and biopsychosocial science relating to the newborn in order to make recommendations to achieve an optimal therapeutic environment and establish a science of caring.
Principal Researcher: Stanley Graven, M.D., University of South Florida

Contribution to Initiative: To date they have explored 28 domains and over 345,503 references and have identified highly significant practices for professionals and parents that enhance and promote fetal and neonatal growth and development, especially for at risk-low birth weight infants. As a result of this effort, many neonatal intensive care units in the U.S. have become family friendly, where parents are no longer considered visitors but are involved in the