Maternal and Child Health at the Millennium

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Health Resources and Services Administration
Maternal and Child Health Bureau

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It is with great sadness we report that Vince L. Hutchins, M.D., M.P.H., MCHB director from 1977–1992, died on January 15, 2001. This manuscript was in its final preparation at that time and presents many of the accomplishments of the MCHB for which Vince was responsible. It now becomes one way for us to honor his life, many accomplishments, and leadership in Maternal and Child Health.
MATERNAL AND CHILD HEALTH
AT THE MILLENNIUM
LOOKING BACK, MOVING FORWARD

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Key Words
Children's Bureau, congenital heart disease, history, maternal and child health, mental retardation, newborn screening, nurse practitioners, phenylketonuria, program development, regionalization, rheumatic heart disease, school health, Social Security Act, special education, special project funding, Title V.

Abbreviations
BEH, Bureau for Education of the Handicapped; CCS, Crippled Children's Services; C & Y, Children and Youth projects; CDC, Centers for Disease Control and Prevention; D & E, developmental and evaluation clinics; IDEA, Individuals with Disabilities Education Act; HIV, human immunodeficiency virus; MCH, Maternal and Child Health program; MICA, Maternity and Infant Care projects; MR, mental retardation; NARC, National Association for Retarded Children; NIH, National Institutes of Health; OSERS, Office of Special Education and Rehabilitative Services; PKU, phenylketonuria; PL, public law; RB, reserve B funds; SSA, Social Security Act; TAC, technical advisory committee; UAF, University Affiliated Facility.
ABSTRACT

Since its establishment as the Children's Bureau in 1912, the Federal Maternal and Child Health program, now known as Title V, has used program development to promote and to enhance the health of the Nation's children and families. This paper explains how the program advanced the field of maternal and child health, utilizing a variety of government tools and strategies. Those tools and strategies included special studies and reports; special projects; partnerships with the States, other public agencies, and Congress; formal and informal relationships with evolving Federal health, social, and education programs; and collaboration and partnerships with a variety of entities in the private sector, including professional organizations, voluntary agencies, institutions of higher learning, business and labor, the faith community, and civic and parent groups. This paper also examines four program areas: newborn screening, mental retardation, heart disease, and school health. The examination explores how certain tools and procedures have been used over time in conjunction with special funding mechanisms, consultation, and collaboration to apply new knowledge, institutionalize innovative methods, and educate and nurture categories of professionals specifically to serve these vulnerable populations.

As society moves into the next millennium carrying some of the unresolved problems of its maternal and child population, this population will face new challenges. The Maternal and Child Health/Title V program and its many partners need to review their past history and approaches, modify these approaches for the new era, reaffirm their purpose, and provide the leadership required.
The Maternal and Child Health Bureau believes in a future America in which the right to grow to one's full potential is universally assured through attention to the comprehensive physical, psychological, and social needs of the Maternal and Child Health population. The Maternal and Child Health Bureau strives for a society where children are wanted and born with optimal health, receive quality care, and are nurtured lovingly and sensitively as they mature into healthy, productive adults. The Bureau seeks a Nation where there is equal access for all to quality health care in a supportive, culturally competent, family and community setting.

—Vision, Strategic Plan
Maternal and Child Health Bureau, 1999

As we look to the future America that we are striving to become, it is instructive and inspiring to look back, to reflect on, and to learn from our past in Maternal and Child Health.

The author of this paper, Vince L. Hutchins, M.D., M.P.H., was a pediatrician whose distinguished career spanned much of the story he tells in this paper. His tenure in Government service included the directorship of the Office for Maternal and Child Health from 1977 until 1992. In this document he reviews the major milestones and achievements of the past century. He has documented the development of the unique Maternal and Child Health Federal-State partnership, which dates back to the enactment of Title V of the Social Security Act in 1935, the establishment of the first block grant program in our history, and the foundation on which we are still building Maternal and Child Health services.

This same Maternal and Child Health block grant program has evolved to serve the health of all of America's pregnant women, infants, children, adolescents, and their families, including women of reproductive age, fathers, and children with special health care needs. We face the future with a science base that advances daily, a clear set of goals, and the strong sense of mission to achieve those goals.

Our past is prologue to the America we envision.

Peter C. van Dyck, M.D., M.P.H.
Associate Administrator for
Maternal and Child Health
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An Introduction

Agencies, like people, have certain characteristics, derived from their purpose and molded by their leader.¹

Katherine Bain, M.D., 1962
Deputy Chief, Children’s Bureau
The Federal Maternal and Child Health (MCH) program, throughout the 20th century, has provided a unique partnership in program development among the Federal government, individual States, and local communities to promote the health of children, mothers, and families. This partnership has been implemented through formula or block funds to the States; discretionary grants to various entities involved in maternal and child health; and national leadership in the following areas: consultation, technical assistance, policy development and dissemination, and data collection and analyses.

Part I of this paper provides an overview of the MCH program's evolution in these areas from the time the Children's Bureau was established by Congress in 1912 to the present day. In 1935, when the Social Security Act (SSA) was enacted to combat the serious effects of the Great Depression, Title V of the SSA established the MCH program and assigned it to the Children's Bureau to administer.

Within the context of the organizational and funding history of Title V and its host agency, Part II of this paper uses four selected areas—newborn screening, mental retardation, heart disease, and school health/health of school-age children—to illustrate how the MCH program development principles have continually incorporated scientific and technological advances into promoting the health of the Nation's children and families. Reviewing this history of achievement offers the opportunity to forecast this program's capacity to serve society well in the next century.

Part III of this paper discusses the problems that the MCH program will face in the next millennium, including unresolved problems of the 20th century and new problems, such as those arising from the genome project. The MCH program possesses many tools to confidently meet these challenges in partnership with the States, Congress, families, health care providers, and advocates.
PART I

Program Development and Structure: An Overview
During this century, MCH programs have responded to both the changing needs of the maternal and child health population and the emerging issues. "The legislative history of the Act of 1912, Public Law (PL) 62-116, establishing the Children's Bureau, made it clear it was the intent of the Congress that the findings of its studies and reports should be used to help State and local groups take appropriate action to improve the care of pregnant women and children." With a defined responsibility to all of the Nation's children since the founding of the Children's Bureau ("welfare of children and child life among all classes of our people"), the MCH program has achieved its goals through the use of special studies and reports; special projects; partnership with the States and other health, education, and social service public agencies; and collaboration and partnerships with a variety of entities in the private sector. These entities include professional organizations, voluntary agencies and associations, institutions of higher learning, business and labor, the faith community, and civic and parent groups.

The program's ability to influence the standards of care, the nature of services provided and the health and social conditions addressed, as well as the payment mechanisms employed, has been—and will continue to be—critical to its success.
Evolution of the State and Government Partnership

During the 19th century, States and private agencies assumed responsibility for special groups of children, one of our country's most vulnerable and powerless constituencies. But the concept of a partnership between the States and the Federal government to improve the health of mothers and children did not appear in public debate or Federal law until after the beginning of the 20th century.³

The Federal government's first acknowledgment of its responsibility to promote the welfare of this population occurred in 1912 with the organization of the Children's Bureau. Created "to investigate and report on the status of children and on their common as well as special needs,"⁴ the Bureau interpreted its mandate to mean the establishment of facts for the purpose of stimulating action for children.

In 1921, the Maternity and Infancy (Sheppard-Towner) Act (PL 67-97) was passed and was administered by the Children's Bureau during the Act's existence from 1921-1929. Based on Department of Agriculture legislation, Sheppard-Towner was the first Federal grant-in-aid program to States for health, establishing the principle of public responsibility for child health ("to promote the welfare and hygiene of maternity and infancy"). The Act was controversial and was labeled "radical" and "socialistic" by its critics. The American Medical Association (AMA), the Catholic Church, and the Public Health Service were instrumental in having it repealed eight years after its enactment. Because of a disagreement within AMA over opposition to this legislation, the American Academy of Pediatrics was formed in 1930.

It took the bitter experience of the Great Depression, which demonstrated how tragically dependent children were upon some
kind of protection against economic hazards, to produce the rich harvest of children's programs that came with the SSA in 1935. (See Appendix A: Children's Bureau/Title V Timeline).

Title V of the SSA authorized grants-in-aid to States for MCH programs (Title V, Part 1), including services for crippled children (Title V, Part 2), and child welfare services (Title V, Part 3). The MCH program represented an enhancement and broadening of the educational and preventive element of the Sheppard-Towner Act. In contrast, the Crippled Children's Services (CCS) program was the first program of medical care in U.S. history that was based on the principle of continuing Federal grants-in-aid to the States. CCS was a model of coordination and comprehensiveness—for example, it included case finding and aftercare in its services.

A major legislative reorganization in 1981 consolidated the Title V programs and five other closely allied categorical health programs into the MCH Services Block Grant. By 1988, Congress expressed concern about the lack of information on how Title V funds were used in the States. As a result, amendments to the block grant in 1989 greatly strengthened program accountability. One tenet of the program during its recent history, the strengthening of State authority, is a reflection of the evolution that has occurred in Federal-State relations during the century.

While the 1912 Act directed the Children's Bureau to “investigate and report... upon all matters pertaining to the welfare of children and child life among all classes of our people [emphasis added],” the 1935 legislation was enacted “for the purpose of enabling each State to extend and improve, as far as practicable under the conditions in each State, services [emphasis added].” The 1989
amendments to the block grant were added "to improve the health of all mothers and children consistent with applicable health status goals and national health objectives established by the Secretary of Health and Human Services [emphasis added]."

These three laws are the continuing bases for all authority and activity in the MCH programs.

**Special Projects Authority**

The Children's Bureau pioneered a unique program structure, which contributed to a high quality of service in public programs. With its legislative authority "to investigate and report," the Children's Bureau used its funds to sponsor studies that, according to the words of its first chief, Julia Lathrop, were intended "to serve all children, to try to work out the standards of care and protection which shall give to every child his fair chance in the world." Lathrop continued, "It is obvious that the Bureau is to be a center of information useful to all the children of America, to ascertain and to popularize just standards for their life and development."6

Grace Abbott, the Bureau's second chief, speaking to the National Conference of Social Work in 1932, praised Lathrop's care in selecting the Children's Bureau's first projects: "She held that, as a democracy, the United States must seek continually new ways of insuring the optimum growth and development of all American children. The slow scientific accumulation of fundamental, basic information about children and child life was begun in no narrow or timid spirit by Julia Lathrop."6 In furtherance of the Bureau's mandate, the information in these studies was disseminated to professionals and the public.

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In 1936, Congress stipulated its initial Title V appropriations language that half of the formula grant funds allotted to the States—Fund A—would be matched dollar for dollar by the individual States. The other half—Fund B—would require no State matching. The Fund B provision took into account the per capita income of each State; therefore, the poorer States would receive a larger, proportional share of Fund B than the richer States. Fund B was initially included only in Part 1 of Title V (MCH), but in the 1939 amendments, it was also added to Part 2 (CCS).

Profoundly affecting the progress and quality of MCH and CCS was the early decision to “reserve” a portion of Fund B (the half of the appropriation States did not have to match) to provide for “special projects of regional and national significance”—a phrase that would reappear in the 1981 Maternal and Child Health Services Block Grant legislation. As a method of disbursing funds, special projects have an advantage over formula funds in being more flexible and more readily targeted to issues or areas of particular need. Title V Reserve Fund B (RB) made it possible for States to explore new methods and to develop new and exciting programs. The value of this form of program stimulation, which the Children’s Bureau developed, is reflected in its subsequent incorporation into programs of other agencies.

An emphasis on training strengthened the impact of the MCH program. The Children’s Bureau was the first to use Federal funds for this purpose, beginning in 1922 when it provided training for nurses under the Sheppard-Towner Act. In 1947, the Bureau made the first training grant to a school of public health, a special project grant for teaching maternal and child health. As a corollary, in its health programs the Bureau has always encouraged States to be liberal in their policies on training and to encourage the maximum use of funds for training of health personnel in all fields. All States used their formula funds in this way in the earliest
With increasing demands on the formula funds over the years, States decreased their funding of staff education.

As the MCH program matured, the special-project grant authority and appropriations were broadened substantially to assist the maternal and child health field as new challenges appeared. During the 10-year period beginning in 1957, Congress increased the appropriation and earmarked $1 million for demonstration clinical programs for children with mental retardation (MR). MR funds were used for discretionary projects to educate the public and the professions and to sponsor Developmental and Evaluation (D & E) Clinics. In 1963, responding to President John Kennedy’s “President’s Message Relative to Mental Illness and Mental Retardation,” Congress increased the MCH and CCS appropriation, earmarking part for special project grants to clinical programs for mentally retarded children; authorized Maternity and Infant Care (MIC) grants; and authorized a new research project grant program under Title V.

In 1965, amendments to Title V authorized both project grants for comprehensive health services for children and youth (C & Y projects) living in areas with concentrations of low-income families and a new grants program for training projects. The 1967 amendments earmarked 6 percent of the MCH appropriation for family planning services and authorized three new types of medical care project grants: infant care (neonatal intensive care), family planning, and dental care. To support the new program activities, 50 percent of the annual appropriation was allotted for formula grants to States (including

Establishment of a Birth Registration Area (10 States and the District of Columbia)
set-aside funds for various RB and MR projects), 40 percent for direct project grants such as MIC and C & Y, and 10 percent for research and training. The research and training grants, in addition to the earlier established RB and MR grants, required no match; the “program of projects”—MIC, C & Y, neonatal, family planning, and dental care—required a 25 percent match by the grantee.

The Title V program was converted to a block grant as part of the Omnibus Budget Reconciliation Act (OBRA) of 1981, PL 97-35. Categorical programs consolidated under the MCH Services Block Grant included maternal and child health and services for children with special health care needs; supplemental security income for children with disabilities; lead-based paint poisoning prevention programs; genetic disease programs; sudden infant death syndrome programs; hemophilia treatment centers; and adolescent pregnancy grants.

The contemporary MCH Block Grant features two major funding components familiar to students of the program: (1) 85 percent of the appropriated funds is allotted to the States in formula grants, and (2) about 15 percent is set aside for discretionary grants, referred to as Special Projects of Regional and National Significance (SPRANS)—a phrase that had its origin in 1939.

Sweeping amendments enacted under OBRA 1989, PL 101-239, introduced stricter requirements for the use of funds and for State planning and reporting. The 1989 Title V amendments provided for a second Federal set-aside program to promote the development of statewide networks of comprehensive, community-based systems of services that could ensure family-centered, culturally competent, coordinated care for all children and their families. Funded with 12.75 percent of the annual appropriation above $600 million, these Community Integrated Service Systems (CISS) special...

Sheppard-Towner Act established national policy that the people, through their Federal, State, and local governments, share responsibility for helping to provide community services that children need for a good start in life.
projects were encouraged to use one of six strategies in their programming, including home visiting and one-stop shopping models. Congress added a separate Abstinence Education program (Section 510, Title V) as part of the 1996 welfare reform legislation, PL 104-193, the Personal Responsibility and Work Opportunity Reconciliation Act. The 5-year (1998-2002) capped entitlement program was authorized to receive $50 million annually.

Government Tools, Activities, and Strategies
The Sheppard-Towner Act of 1921 introduced to the field of human services the concept of grants-in-aid, which are essentially payments made by the Federal government to State and local governments in support of action advancing a Federal objective. The grants-in-aid tool allowed the Federal government to become involved in a wide array of program fields without displacing the role of States and without arousing fears of an activist Federal government. Consequently, the Federal government was seen to function less as a substitute for State and local action than as a subsidizer and stimulator of State and local action.

Grants-in-aid were a government tool borrowed from a practice of the U.S. Department of Agriculture, a fact that humorist Will Rogers was well aware of when he made the following comment: "I am mighty glad so many people in America are taking up children work. Being a ranchman and farmer, and also a child owner, I have often wished that when one of my children got sick, I could wire or call up some government expert and have him come and look after them, like I can do if my cows or pigs get some disease."

In the decades after the Sheppard-Towner Act—a period of considerable inventiveness in the

Sheppard-Towner Act lapses due to significant opposition from the Catholic Church, the Public Health Service, and the American Medical Association
technology of government action—various government programs, including Title V, developed different instruments or tools of public action. Examining these tools illuminates the number of distinctive means by which many government programs now operate.10

Many of the tools, activities, and resultant strategies used by the MCH/Title V program are discussed below. One of the tools sparingly used by the program is regulations. Regulatory programs essentially function by imposing restrictions. MCH issued few regulations until the mid-1970s, when the new organizational structure required it. Instead, the program functioned for several decades with the distribution of policy and administrative bulletins in a loose-leaf health policy manual. Currently, the basic structure of the MCH/Title V program provides the following broad array of government tools:

- Grants-in-aid to States to enable or assist them with defining needs, setting standards, planning and policy formulation, providing or arranging health care, and related activities
- Discretionary grant funds available to States, institutions of higher learning, and others for special projects to do the following: conduct research, identify and define problems, demonstrate new or improved methods for delivery of care, disseminate new information, support specialized services or resources not otherwise available, and educate health professionals about the special health and related needs of mothers and children
- Interagency agreements with other Federal agencies or non-Federal entities—using funds from any of the agencies or from all—to promote mutual objectives or interests
- Federal staff to provide program administration, professional consultation, and technical assistance to the States; to serve as a catalyst for

Dissident group of pediatricians resign from AMA in protest and form the American Academy of Pediatrics
interactions between and among the States, the professional communities, the voluntary organizations, families, and others concerned; and to formulate national policy

None of these attributes is unique to the MCH program. What is unique is the integration and centrality of purpose, the shared philosophy and resources, and the common focus on improving the health status of a defined population of women and children.

The following hypothetical scenario illustrates how this integration of government tools, activities, and strategies works:

- A problem is identified
- Research grants are funded to further define the problem and to develop efficacious ways of resolving or ameliorating it
- Demonstration grants are funded to field test and refine what has been learned in the laboratory
- Conferences, workshops, and other forms of continuing education are supported to disseminate the new information and/or teach necessary skills
- Publications are disseminated
- Relevant information and techniques are incorporated into pre-service, in-service, and continuing education programs
- Appropriate services or methodologies are incorporated, with the assistance of program consultation, into the basic State service program and/or the private sector

Table 1 illustrates how these tools of government were utilized in the fields of injury prevention and maternal nutrition beginning in the 1960s. Clearly, not all program development follows this structure and sequence. That it can—
and sometimes does—demonstrates the supportive interaction of the MCH's program's components.

Interagency Collaboration

Title V's relationship with Title XIX (Medicaid) has been problematic. Both are siblings in the Social Security Act, along with Title XVI (Supplemental Security Income [SSI]) and Title XXI (State Children's Health Insurance Program [CHIP]). Both share the same congressional authorization committees and, often, the same SSA amendments. Both programs, through legislative language, have required or implied cooperation between them, usually carried out by interagency agreements at the Federal and State levels.

In recent years, Technical Assistance Groups (TAGs) have been formed to promote interagency collaboration. These TAGs have been composed of Federal, regional, and State officials from both programs and frequently others, such as professional organizations. Title XIX, since its enactment in the mid-1960s, has been seen as the payer of services, and Title V as the arranger/provider of services. With a responsibility for all, Title V programs have traditionally helped finance or provide basic health services for children, pregnant women, and women in their child-bearing years who did not have any other form of health insurance.

At the State and community level, Title V has helped meet the need for services not covered by health insurance, such as home visiting, outreach, care coordination, and prevention services. Not an entitlement program, Title V has more flexibility in its use of funds (although with a capped budget, this flexibility is limited by the resources it has available). The flexibility has permitted Title V to improve

Birth Registration Area included all states

1933
other needed functions of the health care system, such as enabling services, population-based activities, and infrastructure support. MCH/Title V programs have used these broad functions and expertise at Federal, State, and community levels to assist in the planning and implementation of the new CHIP legislation.¹⁵

MCH Leadership

The MCH program's ability to react, to focus resources, to mingle various types of program action, to initiate new activities, and to phase out those that have achieved their purpose or are no longer needed (e.g., rheumatic fever prevention projects, pediatric radiology training projects) is the real strength of the program. As legislative changes have been made, as administrative and organizational changes have emerged, and as Federal-State relationships have evolved, none of these changes has altered the basic philosophy and mission of the MCH program.

To investigate and report, to advocate, to research and train, to allocate funds, to direct and redirect special funds, and to assist as time and circumstance require are the main strengths of the MCH program. These strengths are exemplary of the leadership shown by MCH/Title V program staff throughout this century. Without the basic State programs MCH helped to conceive and to support, the discretionary projects would have limited purpose and diminished efficacy. Without the discretionary projects, the State programs would not have become the comprehensive, responsive systems of advocacy and care that they are today.¹⁶

Department of Labor's Annual Report recommends 3 major programs: (1) aid to dependent children, (2) welfare services for children needing special care, and (3) maternal and child health services including services for crippled children.
Summary

Beginning in 1912 as the Children's Bureau, a small, focused Federal agency, the MCH program evolved into a Federal-State partnership in 1935 with the adoption of Title V of the Social Security Act. It then was transformed into a State-Federal partnership in 1981: the Maternal and Child Health Services Block Grant. Innovative funding mechanisms for special projects were developed within each period of program history.

In 1969, the program's remarkable stability was disrupted when administrative responsibility was shifted out of the Children's Bureau to the Public Health Service. After a bumpy bureaucratic journey, the MCH program steadied in 1990 and took a small organizational step upward in organizational visibility as a bureau. The 1990s have witnessed continuing efforts to bring accountability to the program for its performance and to establish uniform data collection and reporting on progress toward fulfilling its mission.5
PART II

Program Development in Specific Areas
Part II of this paper discusses the evolution of the MCH program in several important areas: newborn screening, mental retardation, heart disease, and school health/health of school-age children. It also demonstrates how MCH program efforts spurred a more permanent State-Federal role in these areas.
Newborn Screening
Special projects funding supported both (1) research projects on
developing inexpensive and reliable screening tests for low
prevalence metabolic diseases in newborns and (2) demonstration
projects for rapidly implementing the screening tests in State MCH
formula fund programs. Population screening for these “inborn
ers errors of metabolism” soon became statewide and routine. Special
project funds were then used for monitoring, training, and
proficiency testing.

Phenylketonuria
The beginning, 4 decades ago, of the development of screening
tests for metabolic conditions ushered in a new era in prevention.
Phenylketonuria (PKU) was the first metabolic disorder for which a
screening test was developed. With early diagnosis, the severe
mental retardation associated with PKU can be prevented or
favorably modified by special dietary management, if treatment is
begun in the first few weeks of life.

A Technical Advisory Committee (TAC) to the Children’s Bureau
recommended urine screening for PKU in 1958. During 1960,
many of the States cooperated in a plan to test infants during the
first 6 weeks of life to determine the presence of PKU through a
simple diaper test. At least 25 infants were found to have PKU and
were placed on a diet before they became retarded.17

In 1961, Guthrie reported the results of his new inhibition assay
screening test, one that used a
few drops of dried blood to detect
PKU. In the same year, on the
basis of Guthrie’s research on the
accuracy and usefulness of blood
screening, the TAC
recommended that the Children’s

Title V Legislation enacted as part
of Social Security Act and
administered by Children’s Bureau

1935.
Bureau shift from urine screening to a nationwide blood screening program. By 1962, 32 State MCH programs were participating in the trial, more than 400,000 newborns had been tested, and 37 confirmed cases of PKU were diagnosed. The National Association for Retarded Children (consisting largely of parents) conducted an extensive grassroots lobbying effort to establish mandatory PKU screening legislation. Legislation making PKU screening compulsory was swiftly adopted across the country; 43 States had such statutes by 1973.  

In 1967, the Technical Committee on Clinical Programs for Mentally Retarded Children initiated a Children's Bureau-funded, 17-center collaborative study to monitor the program and to address questions arising from the screening program, such as how long to continue the low-phenylalanine diet and how to clarify the results of treatment. The study continued into the 1980s, following the children into their early school years.

In the late 1970s, a study reported that most women of childbearing age with PKU who were no longer on their special diets faced daunting reproductive risks of nearly 90 percent for adverse pregnancy outcomes. These women had been taken off their special diets between ages 7 through 10 years and follow-up had been discontinued. The MCH program convened a group of experts in 1979 to discuss these findings and to make recommendations. With the National Institute of Child Health and Human Development, MCH funded studies to locate, study, and counsel these women. In the mid-1990s, MCH funded special projects in Seattle and Boston to provide outreach and dietary management to the affected women who were planning pregnancies.

The MCH program also supported early studies on developing and implementing screening tests for congenital hypothyroidism.

Recommendations 2 & 3 (Department of Labor Report) were enacted into law as Title V of the Social Security Act, administered by Children's Bureau, Department of Labor.
congenital adrenogenital syndrome, cystic fibrosis, and some chromosomal disorders. By 1971, as a training, monitoring, and counseling support to these State screening programs, 21 projects supported by Title V funds were in operation to provide cytogenetic and biochemical laboratory services as extensions of clinical services at hospitals or medical schools. These laboratory grants continued into the mid-1980s. Through interagency agreements with the Centers for Disease Control and Prevention (CDC) and through individual grants to laboratories, MCH has supported many of the metabolic and hematological disorder proficiency-testing programs that have become part of State programs.

Sickle Cell Screening

In the early 1970s, several States passed laws requiring sickle cell screening of newborns, school-age children, or marriage license applicants. Congress passed the National Sickle Cell Anemia Control Act in 1972, which MCH administered beginning in the mid-1970s. MCH also administered the National Sickle Cell Anemia, Cooley’s Anemia, Tay-Sachs, and the Genetic Diseases Act (PL 94-278) that Congress, growing weary of single-disease legislation, passed in 1976. In the Genetic Diseases Act, Congress incorporated the previous sickle cell and Cooley’s Anemia legislation and named 11 genetic conditions to be covered, although a legislative clarification in 1978 (PL 95-626) stated these 11 named conditions were only meant to be examples. As a result, education, diagnostic, and counseling services became available to populations remote from tertiary genetic centers. Treatment was not included in the Act. Title V played a significant role in promoting the development of regionalized

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Emergency Maternity and Infant Care enacted (PL 78-156)
systems of genetic services as part of the rule-making and implementation of the National Genetic Diseases Act. Regionalization of genetic services in many States preceded regionalization of perinatal services. This legislation and its programs were incorporated into the Maternal and Child Health Services Block Grant in 1981.

To enhance the rapid implementation of newborn screening for sickle cell anemia and other hemoglobinopathies, Congress in 1986 added funds to Title V to fund such projects. All States and the District of Columbia now screen infants for genetic and metabolic disorders and treat or refer for treatment those with a confirmed diagnosis. Screening for PKU and congenital hypothyroidism is virtually universal. Screening and follow-up for galactosemia and sickle cell disease and for other hemoglobinopathies is nearly universal. (See Table 2 for national estimates of 4 selected conditions, including numbers of newborns screened, confirmed, and referred for treatment in 1997, the latest year for which data is available.) Many States also screen for several very rare metabolic conditions: maple syrup urine disease, homocystinuria, histidinemia, and biotinidase deficiency.

Newborn Hearing Screening

One in every 1,000 infants born in the United States is deaf at birth or has a severe hearing disorder. Yet for many years, fewer than half of these infants were recognized as being hearing impaired until later in childhood, when their condition had already compromised speech and language development. In 1989, working with the MCH program, Surgeon General C. Everett Koop challenged parents, physicians, State agency staff, and researchers to work together to find better ways of identifying very young children with hearing impairments. Dr. Koop set a Year 2000 goal that all children with significant hearing impairment would be identified before 12 months of age.
Beginning in 1990, the Maternal and Child Health Bureau and the Office of Special Education and Rehabilitative Services in the U.S. Department of Education collaborated on several research and technology transfer projects that established the feasibility of universal newborn hearing screening as a standard of practice in newborn nurseries. A National Institutes of Health Consensus Development Conference recommended in March 1993 that all babies be screened for hearing loss before discharge from the hospital. Since that time, hundreds of hospitals have implemented universal newborn hearing screening programs. However, many hospitals have not yet implemented such programs, and only about 20 percent of all babies born in this country are screened for hearing loss before being discharged from the hospital.

In 1998, the Maternal and Child Health Bureau developed a performance measure for the States on newborn hearing screening (Appendix B) and drafted Objective 33 of Healthy People 2010, to increase to 100 percent the proportion of newborns screened for hearing loss by 1 month of age (Appendix C).

Of further concern, an informal survey in 1999 made the following estimates: in 39 percent of the States, Medicaid does not reimburse hospitals for newborn hearing screening; in 26 percent of the States, Medicaid pays only for screening done on an outpatient basis; and in 13 percent of the States, Medicaid pays only for screening at-risk infants—though research shows half of all infants with congenital hearing loss do not have risk factors (letter, Karl R. White, Ph.D., Department of Psychology, Utah State University, 1999).

Groups that collaborated on the issue of newborn hearing screening witnessed a major step forward in early 1999. In February, the American Federal Security Agency becomes the Department of Health, Education, and Welfare.
Academy of Pediatrics published a policy statement recommending that "universal [newborn hearing] screening has a goal that 100 percent of the target population, consisting of all newborns, will be tested using physiologic measures in both ears. A minimum of 95 percent of newborns must be screened successfully for it to be considered effective." Guidance was also provided for hospitals, tracking, follow-up, and evaluation elements of a universal newborn hearing screening program.24

The Future
The future holds two goals for the MCH program and newborn screening. The first goal is to overcome obstacles to implementing universal, newborn hearing screening programs nationwide, thereby reducing the average age at which children with hearing loss are identified. Objective 31 of the draft of Healthy People 2010 Objectives ensures that all newborns will be screened by State-sponsored programs to detect PKU, congenital hypothyroidism, galactosemia, and hemoglobinopathies. Objective 33 will increase to 100 percent the proportion of newborns who are screened for hearing loss by 1 month of age (Appendix C). The second goal is to collaborate closely with the Human Genome Project as it increases our ability to identify the genetic basis for diseases.

Mental Retardation
"The fact that there is at present no special provision for this unfortunate class ['feeble-minded persons'] is a matter of concern to many public-spirited citizens," stated the 1915 letter of transmittal from the Chief of the Children's Bureau to the Secretary of Labor that accompanied the 13th Children's Bureau publication, Mental Defectives in the District of Columbia. The primary focus of this early study was on two problems: (1) clearly defining mental retardation and distinguishing it as a separate issue from illiteracy and poverty and (2) determining what kinds of services were needed for mental retardation.25 The study reported a
probable incidence of "feeblemindedness" in the District of Columbia of 1 in 200, with 54 percent at large in the community under varying conditions of helplessness and neglect, with only 12 percent receiving proper care. The Bureau’s national plan, based on the report, “moved toward the direction of protecting these individuals from the community and protecting the community from them.”

*Early Years*

In the ensuing years, services for the mentally retarded were developed, primarily at the State level. A considerable expansion of residential institutions occurred, with many of them still focusing on efforts to provide the kind of training that would make the "subnormal," normal. This early period saw the development of special classes for the retarded in community schools, prevocational schools, sheltered workshops, foster homes, and guidance centers. During this time, research on MR also stimulated prevention strategies. However, these services reached only a portion of those who needed them. In 1923, a Children's Bureau study of the work histories of minors who had been pupils in special classes for "mental defectives" was published. This study pointed a new direction for program development by indicating that there was a place in industry for these "subnormal young men and women."26

*The 1950s:*

Several forces converged in the 1950s to create a new approach to services for the mentally retarded. Separate groups of parents joined together in 1950 to form the National Association for Retarded Children (NARC). Grover Powers, chair of pediatrics at Yale, challenged pediatricians in 1953 to develop skills "to help parents [of these children] in their hour of black despair... and..."
give them insight into community resources." Toward the end of 1954, Children’s Bureau Chief Martha May Eliot, in a report to Congress titled “Conditions of Mothers and Children in this Nation,” designated the mentally retarded as one of four groups of children deserving special emphasis within Bureau programs. Mental retardation became a departmental priority in 1955 with the establishment of the Secretary’s Committee on Mental Retardation, which developed a plan for both Federal and State agencies. The committee assigned responsibility for developing clinical services to the Title V agency.

In 1955, the Children’s Bureau made four grants for special demonstrations of clinical services for the mentally retarded. The approach of these clinics included pediatric direction (a cornerstone of other MCH programs and a move away from the traditional psychiatric direction of these clinics), management responsibility, and a multidisciplinary team (pediatrician, public health nursing consultant, medical social worker, clinical psychologist, nutritionist, and speech and hearing consultants).

NARC proposed an array of program services to Congress in early 1956. In the Appropriations Act for 1957, Congress pulled together the concepts of NARC, the departmental committee, and Eliot’s four demonstration projects into a department-wide program of appropriations. It earmarked $2 million of the Title V appropriation for the development of MR clinical services: $1 million to the States as part of the MCH formula grants and $1 million for special projects for mentally retarded children. MCH was selected primarily because a sizable number of CCS agencies by law or regulation excluded children from service for conditions that otherwise were eligible if the child was retarded or had an IQ below 75. The States’ MCH units and parent groups responded promptly, and new diagnostic,
consultation, and education clinics (D & E clinics) were rapidly established. Throughout the years, a consistent ratio of approximately one in three children referred as mentally retarded were found not to be mentally retarded.30

The 1960s
By 1960, it was obvious that to further spread the concept of the D & E clinics, it would be necessary to train more professionals to serve the mentally retarded. Congress, therefore, gave the Children’s Bureau authority to make direct grants to institutions of higher learning to promote this training. This new authority of the Social Security Amendments of 1960 (PL 86-778) amended the Maternal and Child Health and Crippled Children's provisions of Title V to provide that "special project grants, up to 12.5 percent of the total amount appropriated, may be made to State agencies and also directly to public or other nonprofit institutions of higher learning for special projects of regional or national significance [emphasis added]."

The 1960s brought the new influence of NARC and the leadership of President John F. Kennedy who, in 1961, appointed a panel on mental retardation "to appraise the adequacies of existing programs and the possibilities for utilization of current knowledge."31 Those recommendations relating to Title V were included in the President’s Message Relative to Mental Illness and Mental Retardation, which stated, “The relationship between improving maternal and child health and preventing mental retardation is clear.” The presidential panel’s recommendations were enacted by Congress in PL 88-156.32-34

The Social Security Amendments of 1965 (PL 89-97) authorized Title V to provide "grants to institutions of higher learning for the training of professional personnel for health and related care of..."
crippled children, particularly mentally retarded children and children with multiple handicaps." This amendment was intended primarily for assistance in staffing the health component of the University Affiliated Facilities (UAFs), which were being constructed under PL 88-164, stemming from the presidential panel's recommendations. UAF program grants (known later as the University Affiliated Programs or UAPs and known today as Interdisciplinary Leadership Education in Neurodevelopmental and Related Disabilities or LEND projects) provide interdisciplinary training for physicians, psychologists, social workers, dentists, nurses, physical and occupational therapists, nutritionists, geneticists, and others who care for children with multiple handicaps.35

PL 89-97 resolved an important policy conflict. The earmarking of special project funds for mentally retarded children in the CCS program presented an interesting congressional challenge to eight States, which at that point, by law or regulation, still included the phrase "of normal intelligence" in their definition of crippled children. These States could not use the new funds for mentally retarded children as long as this language was retained. All eight States, shortly after the passage of this Act, quickly removed the exclusion from their laws and regulations.3

Later Years
By 1973, as a result of the events of the preceding 2 decades, more than two-thirds of some 250 D & E Clinics were operating in the States with all or some of their support from Title V. These clinics provided care to children at an earlier age, with 30 percent of the children younger than 5 years of age and 76 percent younger than 10 years. In addition, 43 States had laws requiring all newborns to be screened for PKU; Title V training funds were supporting 19 UAF interdisciplinary programs; 21 cytogenetic and biochemical laboratories were providing services; and 56 Maternity
and Infant Care projects were providing services in low-income areas of the nation.36

These projects, for the most part, grew out of legislation enacted in the 1950s and 1960s. By the late 1960s and early 1970s, Title V was the focus of little new legislation. The country had moved on to the philosophy of the Great Society, with an emphasis on funding categorical programs and communities and bypassing official State agencies. Many States were perceived as recalcitrant and unresponsive to a large percentage of their internal populations. The countervailing philosophy of the "new Federalism" became stronger during the 1970s, with an increased emphasis on State authority that resulted in the block grants of the early 1980s.

With the enactment of the Education of the Handicapped Act of 1975 (PL 94-142) and its focus on expanded services for children in special education, including the concept of "mainstreaming," there was a new demand for interagency collaboration. In 1976, the MCH program joined the Bureau for Education of the Handicapped (BEH) in inviting the leadership of the State directors of special education and the State directors of Title V programs to advise on how the two Federal programs could work together to meet the States' needs. The directors requested the two Federal agencies to fund selected States in an implementation demonstration. Beginning in 1977, BEH and MCH, using special project funds, developed six State collaborative projects to foster the implementation of PL 94-142 across agency lines at State and local levels. Serving both preschool and school-age populations, mainly at the community level, the six projects developed productive interagency agreements and increased contact and cooperation among health and education professionals and agencies.
After the 1986 amendments to the Education of the Handicapped Act (PL 99-457), MCH collaborated with BEH's successor agency, the Office of Special Education and Rehabilitative Services (OSERS), in a number of projects, workshops, and other activities that stemmed from Part H of the new Act. Collaborators included other Federal agencies, State agencies, professional organizations, nonprofit entities, and parent groups with an interest in services and issues for infants, toddlers, and their families. These intense collaborative efforts continue with the revision of the program as the Individuals with Disabilities Education Act in 1997.

The Future
During the past 40 years, interwoven efforts such as advocacy by parent groups, innovative and administrative leadership by Federal and State Title V agencies, and congressional appropriations for formula and special project grants have developed and institutionalized programs of prevention, diagnosis, treatment, and rehabilitation in the field of childhood mental retardation. Methods have varied from the provision of clinical services by multidisciplinary teams to newborn screening, professional education, and efforts to change public attitudes. The future will require a continuing interest in healthy pregnancies; programs for infants, preschoolers, and their parents; attention to environmental risks; and strong interagency and inter-sector collaboration.

Heart Disease and Expanded Crippled Children's Services
Special projects in heart disease have had an impact on the State CCS in two ways: (1) they initiated the broadening of the diagnostic categories in the State programs, and (2) they introduced the concepts of quality assurance, subspecialty training for the care of children, and regionalization of care for the diagnosis and treatment of low prevalence conditions.
Rheumatic Heart Disease

In the early years of Title V, during the 1930s and the 1940s, the predominant conditions seen in State CCS programs were orthopedic. Such crippling conditions accounted for more than 80 percent of the children receiving services. The U.S. Interdepartmental Committee to Coordinate Health and Welfare Activities reported in 1938 that in northern parts of the nation about 1 percent of all school children suffered from rheumatic heart disease, which required extended treatment, including both intensive and convalescent care. The committee, at a subsequent conference, proposed an increased appropriation for CCS for "care of children who are suffering from heart disease."37

In 1939, at the request of the American Academy of Pediatrics, Congress increased the appropriation for the CCS, with the understanding that part of the funds would be used to assist some States to include children with rheumatic fever and congenital heart disease. The Children's Bureau used RB funds to develop demonstration programs for the care of children with rheumatic fever in limited geographic areas in nine States. Eventually, special projects awards were made to 29 States. When the demonstration phase was over a decade later, children with rheumatic fever and congenital heart disease were included in almost all State CCS programs.

Congenital Heart Disease

Research developments for the diagnosis and treatment of congenital heart disease moved rapidly in the decade after Gross reported, in 1939, the first successful surgical treatment of a patient with patent ductus arteriosus.85-44 In the beginning, few diagnostic and surgical teams were trained to care for children with this problem; thus, new technology available to
treat them was limited to a few teaching hospitals. Guided by the principle that new surgical advances should be translated into benefits for children, State CCS agencies began to arrange care for children whose disabilities were amenable to treatment by these new procedures.

The success of the Blalock-Taussig operation in 1944 for a common type of congenital heart disease—tetralogy of Fallot—brought hundreds of children from many States to Johns Hopkins Hospital for this treatment. The problem and cost of their care became so acute that the hospital sought assistance from the Maryland State Department of Health, which in turn approached the Children's Bureau. The Bureau gave a special project grant of RB funds to the Maryland State Department of Health in 1949 to pay for the care of children coming to Baltimore from other States for this purpose. This grant, which antedated the establishment of regional congenital heart centers, was the model for the centers.

Regional Congenital Heart Centers
Concerned that the new technology was not available to children in many States and influenced by a consultation with the Technical Advisory Committee on Programs for the Care of Children with Rheumatic Fever and Heart Disease, the Children's Bureau, beginning in 1951, set aside $100,000 of RB funds for support of regional congenital heart centers. Criteria for selecting a medical center included a record of successful cardiac surgery; the capacity to serve an additional number of children; a location to easily serve adjoining States, and the willingness and ability of the CCS agency in the State to administer a regional program. By this administrative procedure of providing grants to State agencies to arrange and pay for care at designated regional congenital heart centers, children living in States that for a time lacked the necessary resources were able to obtain promptly what was for many a life-saving treatment.
Special project grants similar to Maryland’s were made to State agencies in California (with centers in San Francisco and Los Angeles), Illinois (Chicago), and Texas (Dallas) for out-of-state children. The later development of open-heart surgery at the University of Minnesota made possible effective treatment of additional kinds of congenital heart disease at additional centers in Minneapolis and Rochester, Minnesota.\textsuperscript{46,47} By 1956, five regional centers were in existence, designated to serve the States nearest each center. These centers provided tertiary services for a multi-state area and, concurrently, funded the preparation of personnel, both pediatric and surgical, to perform these new procedures. Thus, concepts of long-term and continuing education were formally added to the regionalization models.

In addition, many States had developed their own centers.\textsuperscript{5} The most serious problem continued to be the inadequacy of funds to meet the demand for service. Congress granted the Children’s Bureau’s request for $1.5 million in supplemental funds to be used during 1958-1959 to finance the program.

During the next 2 decades, pediatric cardiac diagnostic and treatment services became widespread. These services, combined with an expanding availability of private and public funding for health care, led to a decreasing need for regional congenital heart centers supported by the Bureau. The centers began to be phased out in the 1970s.

\textit{The New England Regional Infant Cardiac Program}

The Regional Infant Cardiac Program in New England, established in 1968 as a Children’s Bureau research project, developed out of the conviction that not all babies with congenital heart disease were diagnosed.
sufficiently early to allow a hopeful plan of treatment. The program included all New England hospitals engaged in the definitive diagnosis and treatment of these infants. Nearly 1,800 children who survived critical congenital heart disease in infancy were followed for up to 5 years to learn the "survival, residual cardiac disability, and psychologic development of these children. In addition to services, this program accumulated valuable information for the entire field of infant cardiac disease. The program became self-sufficient after a decade of special project support.

Quality Assurance
The regional cardiac program in Minnesota, which served the midwestern States (including the sparsely populated northern plains States of North Dakota, South Dakota, and eastern Montana), continued into the late 1970s. Central and regional Federal MCH staff discussed the future of the program with Minnesota center faculty and the participating State CCS directors in 1979. A decision was made to shift the emphasis to the evaluation of care at cardiac centers. A special project grant was funded to support this new activity during its formation. A nonprofit corporation that eventually became the Pediatric Cardiac Care Consortium (PCCC) was formed with five institutions. A data collection, analysis, and reporting system was developed and a database formed to allow centers to compare their results with the norms from the combined data. (An adjusted mortality model was used to compare the expected number of deaths with the number of observed deaths.) PCCC became self-sufficient in the mid-1980s and continues without special project funds. From the original five participating centers, the program has expanded to include 39 centers that are submitting data: 35 in the United States (21 States), 2 in Canada, 1 in Scotland, and 1 in Costa Rica.

Expanded Crippled Children’s Services
The initiatives started in 1939 and 1940 for rheumatic fever and congenital heart disease were the forerunners of many types of special
projects that extended and strengthened the CCS program immeasurably. As appropriations were increased, special project grants were provided for programs for children with such conditions as cerebral palsy, epilepsy, and hearing impairments and for graduate training and institutes in specialized subjects. By 1958, orthopedic conditions constituted a little less than 50 percent of the reported diagnoses.

Summary
During the past 6 decades, as advances have occurred in the diagnosis and treatment of heart disease, the Federal MCH program has utilized congressional appropriations to meet the challenges and to improve the care of affected infants and children. Through the creative interplay of funds to States and funds for special projects, program development techniques permitted the early demonstration of new procedures that later were incorporated into State CCS programs.

School Health/Health of School-Age Children
School health, like elementary and secondary education, is a local issue, funded with local and State funds. The role of the Federal MCH program in school health has been essentially limited to publishing reports and standards and sponsoring leadership conferences. Special projects have been used for these functions. Demonstration projects in school health services have been funded infrequently.

The roots of school health can be traced back to the Industrial Revolution and to the beginning of compulsory education. Two late 19th-century changes contributed to the development of school health services: the public health movement defining the content of school health services and the public education movement defining the population to be served. Medical inspection of school

 Researchers perfect a prenatal test for detecting sickle cell disease, an inherited blood disorder.

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Provided by the Maternal and Child Health Library, Georgetown University
children started in the late 1800s. Most States began school medical examination programs that basically had the same goals: (1) exclusion of contagious diseases, where possible; (2) detection of the most obvious physical disabilities of school children, and (3) correction of these disabilities by the municipality. School nurses were added just after the turn of the century. In 1902, at the request of the New York City Health Department, a staff nurse from the Henry Street Visiting Nurse Association was lent to public schools. This effort was so successful that more nurses were added, and the practice of public health nurses in schools was developed.

Children's Bureau

After-school attendance became compulsory, concern about the spread of communicable diseases became one of several child-oriented social and public health activities of the late 19th century. Although these social and public health activities led to the establishment of the Children's Bureau, school health was not high on the bureau's priority list in its early years. Early studies and reports were more concerned with infant and maternal mortality, child welfare, preschool health, juvenile justice, child labor, special populations such as "mental defectives," and children deprived of parental care. No standards were developed for school health, but "physical minimums" were developed for working children. The early interest in education, exemplified by the back-to-school drive of 1919, was more a measure to decrease child labor. A 1918 publication does state: "When the infant grows up and enters school, his physical health is still a matter of grave concern. . . . The school physician finds these [physical] defects. . . . but it is the public health nurse who follows the child into the home and sees that the needed hygienic care or medical treatment are actually secured." Standards for the health of the school child appeared in the proceedings of a 1919 conference on child welfare standards.
During the 1920s and the 1930s, a wave of State legislation established school health services to prevent the conditions revealed by the health assessments of the military inductees in World War I. School health developed into a triad of health services, health education, and health of the school environment.

The MCH Program

The Federal MCH program has been involved in school health for many years. School health services were among the mechanisms used to reach children with the formula funds allocated to States in 1936 by the new Title V/MCH legislation. States used both Federal formula funds and State/local matching funds in school health (e.g., funds for Pennsylvania’s school health program were designated as the State’s total matching funds into the late 1970s). A report on the first 4 years of the Bureau’s MCH program stated: “Most State departments of health are responsible for school health service, especially in rural areas, as part of the maternal and child health program and are cooperating with State departments of education in developing programs of school health education.” The Public Health Service’s Office of Child Health reported from a late 1970s survey that health departments funded and supervised school health in one-third of the States; education departments funded and supervised school health in another third; and the remaining third had mixed funding and supervision.

In 1945, representatives of Federal health and education and other professional associations met to consider the health needs of school children and ways of meeting them. The conferees expressed concern that the health assessments for World War II, as for World War I, continued to reveal physical and mental health conditions that could have been prevented in early childhood. As a result,
a Committee on the School-Age Child, including representatives of the Office of Education, the Public Health Service, and the Children’s Bureau, was established. The committee met regularly and published a 1951 report emphasizing preventive health measures and the development of local resources for diagnosis and treatment. It expressed concern with impaired hearing, defective vision, and epilepsy and stated the need for safe drinking water, adequate toilet facilities, and accident prevention.\textsuperscript{56} During these years, school health became primarily a nursing service of documentation, case finding, and referral to community physicians; of dental screening; and, in what became its most important function, of health education based either in the classroom or in physical education.\textsuperscript{57}

Because communicable diseases had almost disappeared and children’s needs were being replaced by the new morbidities, pressures to change school health programs began to mount in the 1960s and 1970s.\textsuperscript{58} In his February 1963 Message to Congress on Our Nation’s Youth, President Kennedy requested “the Secretary of Health, Education, and Welfare to put a high priority on the Department’s studies of school health programs.”\textsuperscript{59} The Secretary’s letter, transmitted in a Children’s Bureau report on “Health of Children of School Age,” spelled out the inadequacies in the quantity and quality of medical care received by children in many low-income families.\textsuperscript{3} Discussion began to shift from school health, per se, to the health of the school-aged child. Lynch’s often quoted remark, “There is no health in school health,” reflected the view that school health had failed to keep up with the changing needs of the school population.\textsuperscript{56}

Secretary of Health, Education, and Welfare Joseph Califano, in his message to an MCH-sponsored National School Health Conference in Minneapolis in 1977, said: “Perhaps, the single most
important contribution school health programs can make to promote health is to emphasize the importance of life styles, and the environment, and to teach children how to use the health system. A unanimous resolution of that conference stated: "School health in all of its manifestations is seen as a mechanism through which the two major institutions in the life of the child—the family and the school—may be assisted in accomplishing their responsibilities." In 1982, another MCH-sponsored conference, "Health of School-Age Children," hosted by the University of Colorado School of Nursing, built on these themes, stating: "There is increasing awareness of children as products of the society in which they live and of the influence of environmental, social, and economic changes, such as single-parent families, working mothers, low income, [urbanization, and violence] on the health of children." The conferees summarized: "The health of school-age children should become a community-wide concern and not be viewed as the sole domain of any single part of the system. Responsibility ... devolves upon children themselves, their families, physicians, schools, health agencies, community organizations and groups, and many others.

Two concerns of the 1960s, adolescent pregnancy and the limited role of school nurses, led to new initiatives: one, a series of special projects, and the other, a new role for nurses.

Adolescent Pregnancy

In the 1960s, during a period of rapid changes in U.S. society, national attention was focused on the problem of adolescent pregnancy. The Children's Bureau, reporting to the House Appropriations Committee in 1961, reported that the number of births out of wedlock had risen appreciably in recent years. Concern was expressed by
physicians, who drew attention to the increased health risks for the adolescent mother and her infant and the complications of too-early pregnancy and childbearing; from educators, who noted that adolescents who became pregnant dropped out of school and did not complete high school; and from medical social workers, who worried about the many life problems these young people experienced.

An early response to these needs was the Webster School Project in Washington, D.C.—a Children’s Bureau-funded research demonstration program. Like most school districts at that time, the District of Columbia excluded pregnant girls from regular schools. In the early 1960s, the personnel and financial costs of increasing numbers of requests for homebound instruction of pregnant girls caused school administrators to reevaluate their policies. The D.C. Superintendent of Schools formed a committee of school personnel and representatives of community agencies and organizations. After 2 years of study, the committee recommended that a separate, specialized, full-day program for pregnant girls be established to meet their educational, medical, and social needs.

The Webster School, funded as a result of these recommendations, clearly demonstrated that special services to meet the needs of girls during pregnancy can be successfully provided through comprehensive program planning. Webster School became a national model for comprehensive centers for adolescent pregnancy. Replication quickly began. The Consortium on Early Childbearing and Childrearing, supported by Bureau special project funds and continuing into the early 1970s, was established as a research utilization-and information-sharing project to disseminate findings from these demonstration programs. By then several hundred programs were in existence, and the movement began to
incorporate services into regular school settings. Among the earliest of these were School No. 1 in Baltimore and Lulu Mae Nix's statewide program in Delaware.

Nurse Practitioners and School-Based Clinics

Training programs for nurse practitioners began at the University of Colorado in the mid-1960s. These programs, most initiated in pediatric departments, offered registered nurses an additional year of training in physical examination, diagnosis, treatment, and patient management. By the 1990s, most of these programs had become master's degree tracks in nursing schools. Nurse practitioner training, coupled with its recognition in the State nurse practice acts, made possible the expansion of primary care services in schools.65

Innovative models for reorganized health services in schools began to appear. Phil Porter consolidated all child health programs in Cambridge, Massachusetts, in 1967. During the following 15 years, Porter nurtured and developed a program in Cambridge that replaced traditional school nurses with "clinical nurses" and eventually pediatric nurse practitioners as they became available, to create comprehensive school-based clinics.66 In the late 1960s, the C & Y Project of Parkland Memorial Hospital in Dallas, Texas, opened a comprehensive health center at the local high school; a year later, the St. Paul/Minneapolis, Minnesota, MIC Program opened its first school-based health center in a local high school. Both clinics were staffed by nurse practitioners, physicians, and mental health professionals.

Continuing development of school-based clinics has been assisted by the Robert Wood Johnson Foundation (RWJF) over many years through the leadership of Julia G. Lear, as she has worked with

National Parent Resource Center survey documented family participation

1992

Provided by the Maternal and Child Health Library, Georgetown University
universities and local and State health agencies. The RWJF grantees were not permitted to hire health professionals directly but had to contract with hospitals, health departments, or other suitable providers. Thus, health services provided at the school were a unit of a larger health care institution.67

Annette Lynch, while in the Pennsylvania Department of Health, designed and implemented a similar program in that State in the late 1970s. The Department of Health made part of their Title V grant-in-aid funds available to schools of nursing at the University of Pennsylvania and the University of Pittsburgh, as supplements to their MCH-funded graduate nurse training programs, to train school nurses from a selected school district as nurse practitioners. The local school district provided salary support for the school nurse through two semesters of training; the nurse attended a summer session on her own. The nonprofessional activities of the school nurse (screening tests and health room activities, such as first aid, triage, referral, and clerical work) were assumed by a trained non-professional aide supervised by the school nurse. The recently trained school nurse practitioner, now with additional time, assumed the duties of the school physician and added the following new services: (1) expanded health assessment by history, neurological examination, and developmental assessment; (2) improved problem management, using the problem-oriented record and broadened anticipatory guidance; and (3) more expert handling of acute inter-current illness and injury. School physicians, no longer needed for screening physical examinations, were employed for fewer hours as consultants to the school nurse practitioner. The success of the pilot program led to its spread throughout much of the State.51

In the 1980s and 1990s, threats of drugs, violence, and human immunodeficiency virus (HIV) infection inspired additional school-based service programs. Though limited by local community attitudes toward many teenage risk behaviors, several Federal agencies...
provided an infusion of funds to combat these threats. CDC also provided health education funds with an emphasis on reducing tobacco use and increasing physical activity. The MCH program supported the development of school nurse consultants at the State level and created a special grant program to train school-based health professionals in multidisciplinary teaming. MCH also encouraged State MCH offices to use their MCH State block grant funds to support school-based health centers. MCH block grant funds were a key supporter of most of the early school-based health centers; a 1994 national survey found that $12 million in block grant funds had been allocated to school-based centers by 25 States in the 1994 fiscal year. The Bureau of Primary Health Care and the Health Care Financing Administration, through Medicaid funds, also were contributing substantially to the school-based centers.

The Future

By 1998, 1,154 schools around the country had school-based health centers offering a comprehensive array of services. States currently provide some degree of financial support to one of every two school-based health centers in the United States. In 1996, 34 States allocated $41.9 million in State general funds and Federal block grant dollars to fund the centers. Recent changes in health care, particularly the spread of managed care and the development of integrated health service networks, have reawakened mainstream interest in school health service and created the possibility for strengthening the model’s efficiency and effectiveness.

Title V Information System

established by MCHB

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Summary

The integration of government tools, activities, and strategies, described in Part I and displayed in Table 1, as a process of program development was also used in the four program areas of Part II. The development of these four program areas, described in some detail in the text, are summarized in Table 3. The strategies in Table 1 are found again in Table 3, with the addition of Standards and Training. Most of the strategies and their accompanying tools are used in each of the four program areas.

This examination of the four program areas has explored how certain tools and procedures have been used over time in conjunction with special funding mechanisms, consultation, and collaboration to enhance program development within the MCH/Title V national program. The Federal role encompassing problem identification, consultation, collaboration, information dissemination, and directed funding has permitted Federal leadership to work with State leadership over many years and in a variety of organizational settings to promote the health of the Nation's children and their families. The careful interplay of the grants-in-aid funds and the set-aside funds allows the program to apply new knowledge, institutionalize innovative methods, and educate and nurture categories of professionals specifically to serve vulnerable populations of women and children.
PART III

Moving Forward
At the 1982 Surgeon General's Workshop on Children with Handicaps and Their Families, John MacQueen, reflecting on over 30 years of experience in MCH program development, commented:

Those of us from state programs are not surprised that a new type of medical problem—that of the ventilator-dependent child—has been identified and that a proposal is made to provide services for the children so involved. The Federal-State public health programs for mothers and children have been developed over the years to provide new services for what were then new problems. The early regional programs to provide care for congenital heart disease, rheumatic fever prevention, cleft-palate, PKU identification, development of pediatric intensive care, hemophilia, and genetic programs were created when new problems were identified for which a form of treatment was available. Each of these programs was originally introduced at some type of meeting or conference similar to the one that we attend today.

Those of us from agencies involved with providing services for handicapped children also recognize that the services needed by the ventilator-dependent child are in many ways similar to those needed by hundreds of thousands of other disabled children in the nation. . . . The proposed programs providing services for the ventilator-dependent child differ from the current ones only in the technical nature and complexity of the services needed to address problems unique to these children.
The nation faces new and unresolved problems in women's health; the role of the family in the community; increasing ethnic and cultural diversity; the health and welfare of immigrant children; the health of incarcerated youth; the growing need for integrated services and interdisciplinary education; concerns for adequate quality child care; large numbers of children, including those with disabilities, living in poverty; and millions of children uninsured or underinsured, even with the new Title XXI State Children's Health Insurance Program (CHIP).

And new problems and issues will emerge. The implication of the work on the human genome is one problem. Identification of infants (and even fetuses) with specific genes thought to be predictive of disease raises issues of ethics, stigmatization, the involvement of parents, mandatory versus voluntary screening, insurance coverage, accuracy of prediction, and the difference between having a genetic disease and one's ability to function in society. These issues are well known to Title V. Safety and effectiveness must be established before these tests are routinely used within State newborn screening programs. Providers will also have to be trained to perform educational and counseling functions with a full understanding of the ethical, legal, and social implications of genetic testing and follow-up.

Will Title V be at the geneticists' table as these issues are discussed? It will be a test of Title V's tools of program development. Title V has gained much knowledge from working for the past 2 decades with the genetic diseases program, and it must put some of the tools at its disposal to work to infuse the field with this knowledge and institutionalize it. The ethics of the genetic diseases field is calling for analysis and action.
MacQueen's remarks on MCH's history of program development give us some encouragement as we move forward into the new millennium. During the 1990s, increased accountability has returned to the MCH program. Uniform data collection and reporting on progress is being established for both the State block programs and SPRANS, and performance measures are now required. We have the same tools that we used in the past to meet the challenges of the future: investigating and reporting; advocating; establishing research and training programs; allocating and reallocating funds; demonstrating new and innovative approaches; providing technical assistance and consultation; partnering and collaborating with diverse agencies, organizations, individuals, and families; and interacting with the basic State programs and discretionary projects.

MCH/Title V has developed a strong working relationship with its primary partners—the States. Starting in the political scene of the mid-1960s, especially with its MIC and C & Y projects, Title V has also had communities as a focus of program development. A number of SPRANS efforts have used program development tools for community development. The development of the Children with Special Health Care Needs program's theme of family-centered, community-based, culturally competent, coordinated care is an expression of Title V's vital interest in the places where families live. Supporting MCH units in city health departments over the last decade and a half and assisting them to develop a national organization—CityMatCH—is one example. Developing and supporting Fetal Infant Mortality Review programs at the community level in partnership with the American College of Obstetricians and Gynecologists and the CDC is another. The CISS projects have expended much of their energy in community development in the past decade. With the recent philosophy of devolution from the Federal to the State level and the subsequent devolution of authority to the community level, this Title V
experience is appropriate to the current emphasis on community. The challenges and opportunities for the health of the children in the community are here.

Nearly 25 years ago, Saad Z. Nagi, a sociologist experienced in MCH programs, cautioned: "It is difficult to discern future trends in maternal and child health care. In a democratic society, interests are articulated through constituencies and leaders whose opinions help indicate future directions. The once visible constituency concerned with children has been divided and considerably weakened . . . . In the absence of effective constituencies and leaders to point the way, the prognosis is guarded."

Since then, the Title V program has provided leadership and strengthened its ties to the broad MCH constituency through program initiatives, collaborations, and consultations on both continuing and emerging issues. Looking back at the progress of the MCH program as it met the challenges through program development—partnering with the States, Congress, families, health care providers, and advocates—should inspire confidence in the program as it moves forward into the next millennium.
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27. Powers GF. The retarded child and his family as a challenge to pediatric practice, research and education (Howland Award Address). Pediatrics. 1953;XII:219-226


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41. Blalock A, Taussig HB. The surgical treatment of malformations of the heart in which there is pulmonary stenosis or pulmonary atresia. JAMA. 1945;128:189


46. Lillehei CW, Cohen M, Warden HE, Ziegler N, Varco RL. The results of direct vision closure of ventricular septal defect in eight patients by means of controlled cross circulation. Surg Gynecol Obstet. 1955;101:446-466


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68. States choose a comprehensive model. ACCESS [newsletter of the George Washington University Making the Grade program]. Summer 1997


Problem 2: Maternal Nutrition

Problem 1: Injury Prevention

An increasing cause of death in childhood is identified as injuries. Injury prevention is not seen as a public health function of state health departments.

Research suggests that pregnant women do not need to restrict their weight gain to 20 pounds.

Research grants are funded to further define the problem and to develop efficacious ways of resolving or ameliorating it.

The National Research Council (NRC) is awarded a contract to support a subcommittee of the NRC's Food and Nutrition Board to review the research on maternal nutrition.

Demonstration grants are funded to field test and refine what has been learned in the laboratory.

State departments of health in California, Massachusetts, and Virginia are awarded demonstration grants to develop public health programs in childhood injury prevention.

Conferences, workshops, and other forms of continuing education are supported to disseminate the new information and/or teach necessary skills.

Consultation provided to the American Academy of Pediatrics' (AAP) Injury Prevention Committee.

MCH regional staff and the American College of Obstetricians and Gynecologists (ACOG) are informed of NRC findings and publications on maternal nutrition.

Publications are disseminated.

Materials developed by three demonstrations are shared with AAP.


Relevant information and techniques are incorporated into pre-service, in-service, and continuing education programs.

AAP Committee uses materials to develop The Injury Prevention Program (TIPP).

NAS's report is used in developing a publication by ACOG: *Nutrition in Maternal Health Care*.

Appropriate services or methodologies are incorporated, with the assistance of program consultation, into the basic state service program and/or the private sector.

A contract is funded to hold regional workshops for all state health departments on childhood injury prevention. Grant to AAP assists implementation of TIPP into a national AAP program.

District ACOG chairs and federal regional office staff hold workshops for maternal care providers on new recommendations.

<table>
<thead>
<tr>
<th>Strategies</th>
<th>Problem 1: Injury Prevention</th>
<th>Problem 2: Maternal Nutrition*</th>
</tr>
</thead>
<tbody>
<tr>
<td>A problem is identified.</td>
<td>An increasing cause of death in childhood is identified as injuries. Injury prevention is not seen as a public health function of state health departments.</td>
<td>Research suggests that pregnant women do not need to restrict their weight gain to 20 pounds.</td>
</tr>
<tr>
<td>Research grants are funded to further define the problem and to develop efficacious ways of resolving or ameliorating it.</td>
<td>The National Research Council (NRC) is awarded a contract to support a subcommittee of the NRC's Food and Nutrition Board to review the research on maternal nutrition.</td>
<td></td>
</tr>
<tr>
<td>Demonstration grants are funded to field test and refine what has been learned in the laboratory.</td>
<td>State departments of health in California, Massachusetts, and Virginia are awarded demonstration grants to develop public health programs in childhood injury prevention.</td>
<td></td>
</tr>
<tr>
<td>Conferences, workshops, and other forms of continuing education are supported to disseminate the new information and/or teach necessary skills.</td>
<td>Consultation provided to the American Academy of Pediatrics' (AAP) Injury Prevention Committee.</td>
<td></td>
</tr>
<tr>
<td>Publications are disseminated.</td>
<td>Materials developed by three demonstrations are shared with AAP.</td>
<td></td>
</tr>
<tr>
<td>Relevant information and techniques are incorporated into pre-service, in-service, and continuing education programs.</td>
<td>National Academy of Sciences' (NAS) publication, <em>Maternal Nutrition and the Course of Pregnancy: Summary Report</em> is widely distributed.</td>
<td></td>
</tr>
</tbody>
</table>

*A similar series of events occurred in the mid-1980s, resulting in NAS's twin publications in the early 1990s: *Nutrition during Pregnancy* and *Nutrition during Lactation*. 

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Provided by the Maternal and Child Health Library, Georgetown University
### TABLE 2. Number and Percentage of Newborns and Others Screened, Confirmed, and Treated by Selected Condition: Estimated National Data, 1997*

<table>
<thead>
<tr>
<th>Condition</th>
<th>Total Births by Occurrence</th>
<th>Receiving at Least One Screen</th>
<th>No. of Presumptive Positive Screens</th>
<th>No. of Confirmed Cases</th>
<th>Needing Treatment that Received Treatment</th>
</tr>
</thead>
<tbody>
<tr>
<td>PKU</td>
<td>3,882,632</td>
<td>3,855,252</td>
<td>99.3</td>
<td>4,092</td>
<td>235</td>
</tr>
<tr>
<td>Congenital hypothyroidism</td>
<td>3,882,632</td>
<td>3,855,245</td>
<td>99.3</td>
<td>107,416</td>
<td>1,399</td>
</tr>
<tr>
<td>Galactosemia†</td>
<td>3,882,632</td>
<td>3,560,877</td>
<td>91.7</td>
<td>9,447</td>
<td>98</td>
</tr>
<tr>
<td>Sickle cell anemia‡</td>
<td>3,882,632</td>
<td>3,674,116</td>
<td>94.6</td>
<td>13,549</td>
<td>1,891</td>
</tr>
</tbody>
</table>

*Use occurrence births as denominator.
†Report only those from resident births.
‡Use number of confirmed cases as denominator.
§Three states not reporting.
¶Five states not reporting.
*From Title V Information System, National Center for Education in Maternal and Child Health, Maternal and Child Health Bureau.

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### TABLE 3. Program Development Strategies Used in Four Program Areas

<table>
<thead>
<tr>
<th>Strategies</th>
<th>Newborn Screening</th>
<th>Mental Retardation</th>
<th>Heart Disease</th>
<th>School Health</th>
</tr>
</thead>
<tbody>
<tr>
<td>Problem identification</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
</tr>
<tr>
<td>Research</td>
<td>✓/✓</td>
<td>✓/✓</td>
<td>✓/✓</td>
<td>✓/✓</td>
</tr>
<tr>
<td>Demonstrations</td>
<td>✓/✓</td>
<td>✓/✓</td>
<td>✓/✓</td>
<td>✓/✓</td>
</tr>
<tr>
<td>Workshops/collaborations</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
</tr>
<tr>
<td>Publications</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
</tr>
<tr>
<td>Interagency agreements</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
</tr>
<tr>
<td>Consultation</td>
<td>✓</td>
<td>✓/✓</td>
<td>✓</td>
<td>✓/✓</td>
</tr>
<tr>
<td>Standards</td>
<td>✓/✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
</tr>
<tr>
<td>Training</td>
<td>✓/✓</td>
<td>✓/✓</td>
<td>✓</td>
<td>✓</td>
</tr>
</tbody>
</table>

Note: ✓=low level of activity.
✓/✓=high level of activity.
<table>
<thead>
<tr>
<th>Date</th>
<th>Event</th>
<th>Legislation</th>
<th>Organization</th>
</tr>
</thead>
<tbody>
<tr>
<td>1909</td>
<td>First White House Conference on the Care of Dependent Children</td>
<td></td>
<td></td>
</tr>
<tr>
<td>1912</td>
<td>Children’s Bureau established</td>
<td>PL 62-116 CB, Dept. of Labor &amp; Commerce</td>
<td></td>
</tr>
<tr>
<td>1913</td>
<td>Department of Labor &amp; Commerce split</td>
<td></td>
<td>CB, Dept. of Labor</td>
</tr>
<tr>
<td>1915</td>
<td>CB publishes Mental Defectives in DC</td>
<td></td>
<td></td>
</tr>
<tr>
<td>1921</td>
<td>Sheppard-Towner (S-T) Act Grants-in-aid to states</td>
<td>PL 67-97</td>
<td></td>
</tr>
<tr>
<td>1922</td>
<td>Nurses training funded with S-T funds</td>
<td></td>
<td></td>
</tr>
<tr>
<td>1929</td>
<td>S-T repealed</td>
<td></td>
<td></td>
</tr>
<tr>
<td>1935</td>
<td>Social Security Act, Title V enacted</td>
<td>PL 74-271</td>
<td></td>
</tr>
<tr>
<td>1939</td>
<td>Rheumatic fever &amp; heart disease funds</td>
<td></td>
<td></td>
</tr>
<tr>
<td>1945</td>
<td>Committee on the School-Age Child</td>
<td></td>
<td></td>
</tr>
<tr>
<td>1947</td>
<td>SPH training grant</td>
<td></td>
<td></td>
</tr>
<tr>
<td>1949</td>
<td>MD/Hopkins, first regional heart center</td>
<td></td>
<td></td>
</tr>
<tr>
<td>1957</td>
<td>MR services earmark of Title V funds</td>
<td></td>
<td></td>
</tr>
<tr>
<td>1960</td>
<td>Special project grant authority</td>
<td>PL 86-778</td>
<td></td>
</tr>
<tr>
<td>1962</td>
<td>PKU state trials</td>
<td></td>
<td></td>
</tr>
<tr>
<td>1963</td>
<td>MCH, research grant authority</td>
<td>PL 88-156</td>
<td></td>
</tr>
<tr>
<td>1965</td>
<td>C &amp; Ys, training grant authority</td>
<td>PL 89-97</td>
<td></td>
</tr>
<tr>
<td>1967</td>
<td>Neonatal, dental, &amp; FP projects</td>
<td>PL 90-248</td>
<td></td>
</tr>
<tr>
<td>1968</td>
<td>The Webster School Project</td>
<td></td>
<td></td>
</tr>
<tr>
<td>1969</td>
<td>CB dismantled, Title V to PHS</td>
<td></td>
<td>MCHS, HSMHA, PHS, DHEW</td>
</tr>
<tr>
<td>1971</td>
<td>Cytogenetic &amp; biochemical labs funded</td>
<td></td>
<td></td>
</tr>
<tr>
<td>1973</td>
<td>MCHS split into OMCH and DCS, which is responsible for Title V set-aside projects</td>
<td></td>
<td>OMCH, BCHS, HSA, &amp; DCS, BCHS, HSA, DHEW</td>
</tr>
<tr>
<td>1975</td>
<td>Education of the Handicapped Act</td>
<td>PL 94-142</td>
<td></td>
</tr>
<tr>
<td>1976</td>
<td>National Sickle Cell Anemia, Cooley’s Anemia, Tay-Sachs, and Genetic Diseases Act</td>
<td>PL 94-278</td>
<td></td>
</tr>
<tr>
<td>1978</td>
<td>Health Service and Centers Amendments of 1978</td>
<td>PL 95-626</td>
<td></td>
</tr>
<tr>
<td>1979</td>
<td>Pediatric Cardiac Care Consortium</td>
<td></td>
<td></td>
</tr>
<tr>
<td>1981</td>
<td>MCHS Block Grant</td>
<td>PL 97-35</td>
<td></td>
</tr>
<tr>
<td>1982</td>
<td>Health of School-Age Children Conference OMCH and DCS recombined into DMCH</td>
<td></td>
<td>DMCH, BHCDA, HRSA, DHHS</td>
</tr>
<tr>
<td>1986</td>
<td>Newborn screening for sickle cell anemia &amp; other hemoglobinopathies</td>
<td>PL 99-509</td>
<td></td>
</tr>
<tr>
<td>1989</td>
<td>DMCH reorganized into OMCH, BMCHRD, HRSA, DHHS</td>
<td></td>
<td>OMCH, BMCHRD, HRSA, DHHS</td>
</tr>
<tr>
<td>1990</td>
<td>Accountability, CISS projects</td>
<td>PL 101-239</td>
<td></td>
</tr>
</tbody>
</table>

continued next page
### APPENDIX A: Children’s Bureau/Title V Timeline (continued)

<table>
<thead>
<tr>
<th>Date</th>
<th>Event</th>
<th>Legislation</th>
<th>Organization</th>
</tr>
</thead>
<tbody>
<tr>
<td>1990</td>
<td>Maternal and Child Health Bureau established Newborn hearing screening projects</td>
<td></td>
<td>MCHB, HRSA, DHHS</td>
</tr>
<tr>
<td>1990</td>
<td>Individuals with Disabilities Education Act</td>
<td>PL 101-476</td>
<td></td>
</tr>
<tr>
<td>1996</td>
<td>Personal Responsibility and Work Opportunity Act: Abstinence Education</td>
<td></td>
<td></td>
</tr>
<tr>
<td>1997</td>
<td>Performance measures for states</td>
<td></td>
<td></td>
</tr>
<tr>
<td>1997</td>
<td>Balanced Budget Act of 1997, SSA, Title XXI (CHIP)</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

**Abbreviations:**
- BCHS, Bureau of Community Health Services
- BHCD, Bureau of Health Care Delivery and Assistance
- BMCHRD, Bureau of Maternal and Child Health and Resources Development
- CHIP, State Children’s Health Insurance Program
- CB, Children’s Bureau
- CISS, Community Integrated Service Systems
- C & Y, Children and Youth projects
- DCS, Division of Clinical Services
- DHEW, Department of Health, Education, and Welfare
- DHHS, Department of Health and Human Services
- DMCH, Division of Maternal and Child Health
- FP, Family Planning
- FSA, Federal Security Agency
- HRSA, Health Resources and Services Administration
- HSA, Health Services Administration
- HSMHA, Health Services and Mental Health Administration
- MCHB, Maternal and Child Health Bureau
- MCHS, Maternal and Child Health Service
- MIC, Maternity and Infant Care projects
- MR, mental retardation
- OMCH, Office for Maternal and Child Health
- PHS, Public Health Service
- PKU, phenylketonuria
- SPH, schools of public health
- SSA, Social Security Act
- S-T, Sheppard-Towner Act

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Appendix B: Maternal and Child Health
National “Core” Performance Measures, 1997

<table>
<thead>
<tr>
<th>Performance Measure 10</th>
<th>Percentage of newborns who have been screened for hearing impairment before hospital discharge.</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Goal</strong></td>
<td>To reduce the morbidity associated with hearing impairment through hospital discharge.</td>
</tr>
<tr>
<td><strong>Measure</strong></td>
<td>Percent of newborns screened for hearing impairment before hospital discharge.</td>
</tr>
<tr>
<td><strong>Definition</strong></td>
<td><strong>Numerator:</strong> The number of infants in the State whose hearing has been screened before hospital discharge by either tests of otoacoustic emissions or auditory brainstem responses. <strong>Denominator:</strong> The number of births in the State in the calendar year.</td>
</tr>
<tr>
<td><strong>Healthy People 2000 Objective</strong></td>
<td><strong>Objective 17.6</strong> Reduce significant hearing impairment to a prevalence of no more than 82 per 1,000 people. <strong>Objective 17.16</strong> Reduce the average age at which children with significant hearing impairment are identified to no more than 12 months.</td>
</tr>
<tr>
<td><strong>Data Sources and Data Issues</strong></td>
<td>State birth certificates, new born hearing registries, tests of otoacoustic emissions and auditory brainstem responses.</td>
</tr>
<tr>
<td><strong>Significance</strong></td>
<td>The advantages of early detection of hearing impairments are indisputable and include necessary follow-up of free and appropriate enrollment in habilitation and education programs.</td>
</tr>
</tbody>
</table>
Appendix C: The Healthy People 2010 Objectives, Draft #2 (1998)

Chapter 12. Maternal, Infant, and Child Health

31. (Developmental/Formerly 14.15) Ensure that all newborns are screened by state-sponsored programs to detect phenylketonuria (PKU), congenital hypothyroidism, galactosemia, and hemoglobinopathies.
   31a. All are screened at birth.
   31b. There is follow-up diagnostic testing for screening positives within appropriate time period.
   31c. Enrolled in appropriate service interventions for infants with diagnosed disorders within appropriate time period.

Potential Data Source: Title V Performance Measures, HRSA, MCHB

33. (Developmental) Increase to 100% the proportion of newborns who are screened for hearing loss by 1 month of age, have diagnostic follow-up by 3 months and are enrolled in appropriate intervention services by 6 months.
   33a. Hearing screening by 1 month.
   33b. Follow-up diagnostic completed by 3 months.
   33c. Enrolled in appropriate services by 6 months.

Potential Data Source: Title V Performance Measures, HRSA, MCHB
MATERNAL AND CHILD HEALTH BUREAU

Mission
The mission of the Maternal and Child Health Bureau (MCHB) is to provide national leadership and to work in partnership with States, communities, public-private partners, and families to strengthen the maternal and child health (MCH) infrastructure, assure the availability and use of medical homes, and build knowledge and human resources, in order to assure continued improvement in the health, safety, and well-being of the MCH population. The MCH population includes all of America’s pregnant women, infants, children, adolescents and their families, including women of reproductive age, fathers, and children with special health care needs (CSHCN).

Values
- Affordable and accessible high quality care for all.
- Accountable, regularly monitored and evaluated evidence-based quality care.
- Preventive, protective health care that addresses an individual’s physical, psychological, and social needs.
- Comprehensive, coordinated care in medical homes that includes direct and enabling services.
- Consumer-oriented, family-centered, and culturally competent care linked to community services.
- Continually improving health care based on research, evaluation, training/education, technical assistance, and the dissemination of up-to-date information.

Goals and Objectives
The Maternal and Child Health Bureau (MCHB) provides leadership to improve access to comprehensive, culturally sensitive, quality health care for all pregnant women, infants, children, adolescents, and their families, including women of reproductive age, fathers, and children with special health care needs (CSHCN). The Bureau has set the following goals and objectives for the year 2003, which are consistent with the Health Resources and Services Administration (HRSA) Strategic Plan and the Healthy People 2010 objectives.

GOAL 1. Eliminate barriers and health disparities
To eliminate health disparities in health status outcomes through the removal of economic, social, and cultural barriers to receiving comprehensive, timely, and appropriate health care.

GOAL 2. Assure Quality of Care
To assure the highest quality of care through the development of practice guidances, data monitoring, and evaluation tools; the utilization of evidence-based research; and the availability of a well-trained, culturally-diverse workforce.

GOAL 3. Improve the Health Infrastructure and System
To facilitate access to care through the development and improvement of the MCH health infrastructure and systems of care to enhance the provision of the necessary coordinated, quality health care.