TITLE V OF THE SOCIAL SECURITY ACT
AND
STATE PROGRAMS FOR
CHILDREN WITH SPECIAL HEALTH CARE NEEDS

LEGISLATIVE HISTORY *

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I. 1935 Enactment of Title V of the Social Security Act

Title V of the Social Security Act, "Grants to States for Maternal and Child Welfare," was enacted in 1935. Title V authorized three separate programs of grants to the state.

The Act authorized federal grants to states for "Services for Crippled Children (CCS)." The Act stated that these grants were:

For the purpose of enabling each State to extend and improve (especially in rural areas and in areas suffering from severe economic distress), as far as practicable under the conditions in such State, services for locating crippled children, and for providing medical, surgical corrective, and other services and care, and facilities for diagnosis, hospitalization, and aftercare, for children who are crippled or who are suffering from conditions which lead to crippling....

The state programs receiving grants for this purpose became known as the State Crippled Children’s Services (CCS) Programs, or State Crippled Children’s (CC) Programs. Since the Act did not define the term “crippled children,” the State CCS Programs had flexibility in determining the population to be served based on an assessment of the particular needs of this population in their states.

* This paper presents a brief overview of the legislative history of Title V of the Social Security Act and the State Programs for Children with Social Health Care Needs (CSHCN Programs). The paper was prepared for the targeted Technical Assistance for State Title V CSHCN Programs Work Group established by the Division of Services for Children with Special Health Needs (DSCSHN) of the Maternal and child Health (MCH) Bureau. A more detailed legislative history of Title V of the Social Security Act is in the process of being prepared by the National Maternal and Child Health Resource Center at the University of Iowa, College of Law and will be available from the DSCSHN of the MCH Bureau.
Title V also authorized grants to states for “Maternal and Child Health (MCH) Services.” The state programs receiving grants for this purpose became known as the State Maternal and Child Health (MCH) Programs.

Finally, Title V authorized grants to states for “Child Welfare (CCS) Services.” Title V contained an authorization for grants for states for child welfare services until 1967 when the authorization was repealed, and authorization for federal financial assistance to the states for child welfare services was placed in Title IV of the Social Security Act.

During the four and one-half decades following the enactment of Title V, there were a series of other amendments to Title V of the Social Security Act, and some of these amendments resulted in significant changes in the provisions of the legislation related to the state CCS Programs.

II. The Omnibus Budget Reconciliation Act of 1981

A. Creation of the Maternal and Child Health Services Block Grant

The Omnibus Budget Reconciliation Act of 1981 (OBRA ’81) amended Title V of the Social Security Act so as to substitute the heading “Maternal and Child Health Services Block Grant” (MCH Block Grant) for the heading “Maternal and Child Health and Crippled Children Services.” OBRA ’81 retained Title V as the basis for a separate block grant for health services for mothers and children, including crippled children. The Title V CCS Program and the Title V MCH Program were consolidated with several other programs. The consolidated programs included the Supplemental Security Income Disabled Children’s Program.

B. Mission and Functions of State Crippled Children’s Services Programs

OBRA ’81 retained authorization for federal financial assistance to the states for the State CCS Programs. Title V, as amended by OBRA ’81, continued to authorized federal assistance to the states for the specific purpose of enabling each state “to provide services for locating and for medical, surgical, corrective, and other services, and care for and facilities for diagnosis, hospitalization and aftercare for children who are crippled or who are suffering from conditions leading to crippling.” OBRA added a provision to Title V authorizing federal assistance to the states for the specific purpose enabling each state “to provide rehabilitation services for blind and disabled individuals under the age of 16 receiving benefits” under the Supplemental Social Security Income Program.
C. Earmarking of Funding for State CCS Programs

Prior to the OBRA '89 amendment, Title V earmarked a designated portion of the funds annually allocated to the states for the State CCS Programs and earmarked a designated portion of these funds for the State MCH Programs. OBRA '81 eliminated the explicit earmarking of funds allocated to the states for these two programs.

D. Administration of State CCS Programs at State Level

OBRA '81 required that the state health agency be responsible for administering the State CCS Program as well as the State MCH Program at the state level. However, a “grandfather clause” allowed a State CCS Program that was being administered by an agency, other than the state health agency, to continue to be separately administered by that agency.

III. Consolidated Omnibus Budget Reconciliation Act of 1985

The Consolidated Omnibus Budget Reconciliation Act of 1985 amended Title V of the Social Security Act so as to change the terminology used in the Act from crippled children to children with special health care needs (CSHCN). The Act substituted the term “children with special health care needs or who are suffering from conditions leading to such status for the term “children who are cripples or who are suffering from conditions leading to crippling;” it substituted the term “services for children with special health care need” for the term “crippled children’s services,” and it substituted the term “programs for children with special health care needs” for the “crippled children’s programs.”

IV. The Omnibus Budget and Reconciliation Act of 1989

A. Mission and Functions of State CSHCN Programs

The Omnibus Budget and Reconciliation Act of 1989 (OBRA '89) significantly amended Title V of the Social Security Act. It retained the authorization of federal financial assistance to the states for State Programs for Children with Special Health Care Needs (State CSHCN Programs). However, it redefined the mission and functions of the State CSHCN Programs.

The Act, as amended by OBRA '89, specifically authorizes funding for the purpose of enabling each state:
To provide and to promote family-centered, community-based, coordinated care (including care coordination services...) for children with special health care needs...

The term “care coordination services” referred to above is defined as:

services to promote the effective and efficient organization and utilization of resources to assure access to necessary comprehensive services for children with special health care needs and their families.
42 U.S.C. §701 (b)(3).

The Act, as amended by OBRA ’89, also specifically authorized federal funding for the purpose of enabling each state:

To facilitate the development of community-based systems of services for such children [children with special health care needs] and their families...

It should be noted in this regard that OBRA ’89 incorporated by reference the National Health Promotion and Disease Prevention Objectives for the Year 2000 issued by the U.S. Department of Health and Human Services (HHS), and Objective 17.20 calls for all states to establish and maintain systems of comprehensive, community-based, coordinated, and family-centered services for children with or at risk of chronic and disabling conditions. See supra discussion at page 5.

In addition, the Act, as amended by OBRA ’89, specifically authorizes federal funding for the purpose of enabling each state:

to provide rehabilitation services for blind and disabled individuals under the age of 16 receiving benefits under Title XVI, to the extent medical assistance for such services is not provided under Title XIX...

B. Mission and Function of State MCH Programs

OBRA ’89 retained the authorization of federal assistance to the states not only for the State CCS Programs but also for the State MCH Programs. Title V, as amended by OBRA ’89, basically defines the mission and functions of the State MCH Programs as they had been previously defined.
Title V, as amended by OBRA ’89, specially authorizes federal funding for the purpose of enabling each state
to provide and to assure mothers and children (in particular those with low income or with limited availability of health services) access to quality maternal and child health services; [and]

... to reduce infant mortality and incidence of preventable diseases and handicapping conditions among children, to reduce the need for impatient and long-term care services, to increase the number of children (especially preschool children) appropriately immunized against disease and the number of low income children receiving health assessments and follow-up diagnostic and treatments services, and otherwise to promote the health of mothers and infants by providing prenatal, delivery, and postpartum care for low income, at-risk pregnant women, and to promote the health of children by providing preventive and primary care services for low income children;
42 U.S.S. §701(a)(1)(A)&(B)

C. Earmarking of Funding for State CSHCN Programs

Title V, as amended by OBRA ’89, require that a minimum of 30% of a state's allotment of funds be used for services for children with special health care needs. It permits, but does not require, that more than 30% be used for children with special health care needs. The Act, as amended by OBRA ’89, provides:

In order to be entitled to payments for allotments... of this title for a fiscal year, a State must prepare and transmit to the Secretary an application... that---

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(3) except as provided under subsection (b) of this section, provides that the State will use...
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(B) at least 30 percent of such payment amounts for services for children...

D. Annual State Application for Block Grant Funds

Title V, as amended by OBRA ’89, requires that the annual State applications for block grant funds contain information concerning needs of
CSHCN and goals/ objectives/ activities to meet the needs of CSHCN. The legislation, as amended, provides:

In order to be entitled to payments for allotment... of this title for a fiscal year, a state must prepare and transmit to the Secretary an application... that---

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(1) contains a statewide needs assessment (to be conducted every five years)... that shall identify (consistent with the health status goals and national health objectives)... the for---

(C) services for children with special health care needs...

E. Annual State Reporting Requirements

Title V, as amended by OBRA '89, requires each state to prepare and submit an annual report on its activities. The legislation provides that the annual report shall include certain specified information and states that for this purpose CSHCN "shall be considered to be a separate class of individuals." 42 USC §706(2)(A).

V. Objective 17.20 of the National Health Promotion and Disease Prevention Objectives

A. OBRA and National Health Promotion and Disease Prevention Objectives

As it has been pointed out, the OBRA '89 Amendment to Title V of the Social Security Act incorporated by reference the National Health Promotion and Disease Prevention Objectives for the Year 2000 related to children with special health care needs and their families. The Act, as amended by OBRA '89 includes the general statement that appropriations are being authorized under the Act:

To improve the health of all mothers and children consistent with the applicable health status goals and national health objectives established by the Secretary under the Public Health Service Act for the year 2000....

The Act provides that the required state applications for MCH Block Grant funds must contain "a statewide needs assessment... that shall identify
consistent with the health status goals and national health objectives).... the need for ... services for children with special health care needs (emphasis added)”. 42 U.S.C.§705(a)(1)(C). The Act also provides that the required annual reports of the States must include “information... necessary... to describe the extent to which the state has met... the national health objectives (emphasis added).” 42 U.S.C. §706(a)(1).

B. Systems Development Objective


Objective 17.20 states:

Increase to 50 the number of States that have service systems for children with or at risk of chronic and disabling conditions, as required by Public Law 100-239.

C. Elements of Service Systems to be Developed

Commentary to Objective 17.20 describes service systems for such children as:

organized networks of comprehensive, community based, coordinated, and family-centered services.

D. Reference to Title V MCH Block Grant Legislation

Commentary to Objective 17.20 makes reference to the Title V MCH Block Grant legislation, and it makes reference to Part H of the Education of the Handicapped Act (now known as the Individuals with Disabilities Education Act). It states:

The concept of service systems is reflected in recent Federal legislation. The Title V Maternal and Child Health Services Block Grant legislation of 1989 mandates State Programs for Children with Special Health Care Needs to promote the building of such service systems, and Part H of the Education of the Handicapped Act (P.L.-457) establish a discretionary program to build statewide systems for comprehensive, community-based, coordinated, family-centered
services for infants and toddlers with, or at risk of, chronic and disabling conditions.