## The Development of Ambiguous Federal Policy: Early and Periodic Screening, Diagnosis and Treatment (EPSDT)

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This paper examines why Congress's first major program for comprehensive health care to needy children took five years to begin even partial operation. An examination of the 1967 program's legislative history reveals that Congress paid little attention to EPSDT's implications: it was left ambiguous whether health (Title V) or welfare (Title XIX) would administer; costs were never clearly stated; eligibility and scope of services to be provided were left vague. Despite pressure from welfare rights interest groups, these ambiguities delayed the preparation of regulation and guidelines which never did succeed in resolving the question of overlapping jurisdiction and costs. In addition, many states' resistance to paying for the program further held up implementation.

The paper concludes that: (1) Congress's and HEW's unwillingness to face up to the real costs of health programs threatens long-term public and state support for such programs; (2) division of responsibility between health and welfare lessens the impact of a program; (3) grant-in-aid programs give states the power to distort the intent of federal health policies; and (4) where states fail to implement such policies, initiatives may pass to consumer advocacy groups.

In late 1967, the United States Congress passed the Early and Periodic Screening Diagnosis and Treatment (EPSDT) programs of the Social Security Act, potentially the most comprehensive child health care program the government had ever undertaken. However, this program was not implemented immediately; regulations emerged from the Department of Health, Education, and Welfare (HEW) only in November 1971; final guidelines were issued in 1972, and full implementation was deferred until July 1973. Even before that date, it was clear that most states would not comply with HEW's regulations and guidelines, and as of December 1973, HEW (1974) reported that only half the states could be said to be implementing the program state-wide without problems.

<sup>&</sup>lt;sup>1</sup>For example, in March 1973, the National Welfare Rights Organization in a letter to Caspar Weinberger, Secretary of HEW, cited "Massive non-compliance," based on HEW's own reports. See also Tolchin (1973) and Georgetown Law Journal (1971: 976).

This paper will analyze what went on at the federal level to explain why these federal initiatives took so long to be carried out. Issues such as the cost of the program, the administering agency, and the extent of services and children to be served were not clarified in the legislation. The resulting ambiguities left the Department of Health, Education, and Welfare with the difficult, if not impossible, task of drawing up a set of regulations and guidelines which could satisfy administrators, state officials, interest groups, and Congress.

# Background: Health Care for Children Through Government Programs

Part of the ambiguity lay in the almost reluctant way in which the federal government had gotten into the business of providing health services to children. Programs had gradually been added to the federal responsibility and they varied greatly according to their emphasis. Some were concerned with preventive services, others with comprehensive care, still others with diagnosis and treatment of specific crippling diseases.

As Schlesinger (1967) has noted the first federal program to provide care for mothers and children through grants-in-aid to the states was the Sheppard-Towner Act of 1921. Its broad provisions for "promoting the welfare and hygiene of maternity and infancy" did not clarify what services were to be provided. Meanwhile the states and localities had developed on their own preventive care to limited groups of children through well-child conferences run by both voluntary and public agencies.

Screening as a federal policy goal appeared in the 1935 Social Security Act Title V legislation establishing a program for Crippled Children (CC). It sought to enable each state to extend and improve:

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. . . . (Section 511)

To locate such children, some sort of screening procedure is im-

plied. Locating crippled children or children with conditions which might lead to crippling could have taken one of two forms: either a broadly conceived interpretation to set up state-wide screening procedures, or a more narrowly defined one to set up registries of crippled children. The former, today known as "outreach," was not attempted by the states under this program. With the encouragement of the Children's Bureau, which administered the CC program, each state created registries of crippled children to demonstrate how many had been found. These registries proved to be more activity reports than reports on the health status of children and eventually most states dropped the registries.

Preventive care and screening were implicit in an equally important section of Title V, Maternal and Child Health Services, which was a successor to the Sheppard-Towner Act. In many states the legislation's goal of "promoting the health of mothers and children" was understood to mean not only the supervision of maternity clinics and hospitals, but also the promotion of well-child conferences. Thus, two types of screening developed from Title V: through MCH, the well-child conference; and through CC, registries of crippled children. Preventive care was provided by the MCH services through supervision of maternity clinics, through consultations with local health officials, and through the establishment of well-child conferences. Diagnosis and treatment were provided by the crippled children's program. However, by 1955 only 6.5 percent of the nation's children under 21 were reached by these programs (refer to Table 1).

During World War II, the Emergency Maternity and Infant Care program (EMIC) gave the states funds to carry out both curative and preventive services for wives and children of armed forces personnel in the lower pay grades. The well-child conferences of the Title V programs were expanded to care for the additional mothers and children. Despite the program's apparent success, it was nonetheless abandoned after the war with all the other emergency wartime programs (Sinai and Anderson, 1948).

The sixties saw the burgeoning of federally funded health programs for children as well as other age groups. The Title V programs were expanded to include federal grants for local projects: in 1963 the Maternity and Infant Care Projects provided funds for localities to carry out comprehensive maternity and infant care; in 1965 the Children and Youth Projects provided similarly to

TABLE 1

Children Served by Title V Maternal and Child Health and Crippled Children's Programs and the Title XIX Program as a Percentage of U.S. Population Under 21, 1940, 1955, and 1970 (based on data drawn from sources cited below)

	Percentage of U.S. Population Under 21		
	1940	1955	1970
Maternal and Child Health	3.0	5.8	6.9
Crippled Children	.5a	.4	.6
Total Title V Programs	3.5	6.2	7.5
Title XIX Program	_	_	9.4b

<sup>&</sup>lt;sup>a</sup>Data are for 1939 since statistics were not collected for 1940.

Source: HEW (1957:7; 1971a:7; 1971b: Tables 7-9, 11; 1972c:1); U.S. Department of Commerce (1940: Table 2: 1956: Table 19; 1970: Table 50); U.S. Department of Labor (1941:40).

selected localities for comprehensive health services for children and youth; in 1968 dental care and intensive infant care projects were also authorized. Localities were also helped to establish health services through the OEO programs which funded neighborhood health centers and provide health services for head start programs.<sup>2</sup>

Medicaid, or Title XIX of the Social Security Act, although not a program aimed specifically at children, rapidly became their largest public medical program after its establishment in 1966. By 1970, expenditures for children under Title XIX were \$968 million compared to \$328 million spent by the Title V programs (Cooper and McGee, 1971: 9). Title XIX of the Social Security Act reimbursed the states for providing health care to welfare recipients and, if the states elected to have such a program, to those who were "medically needy." Each state set its own standards for medical need just as it set standards for eligibility for welfare, but it was intended to include those who were categorically eligible and who

bChildren served by this program may also have received services through Title V programs.

<sup>&</sup>lt;sup>2</sup>For a list of federal, state, and local government health programs for children in 1966, see HEW (1966: Table A-1). Health services administered by the federal government in 1972 are presented in Minnesota Systems (1972: 3-10).

faced high medical expenses although they were not poor enough to receive welfare payments. Children under 21 could also be included in any state's Medicaid program regardless of categorical eligibility, but only 17 states chose this option. Services provided under the 1965 Title XIX legislation included inpatient and outpatient hospital services, and physician's and other remedial services. Preventive care or screening services were not spelled out in the legislation (Social Security Act, Section 1905a). They could be provided, but in practice, most states did not reimburse for them.

Administration of the federal programs were assigned to different federal agencies. All the Title V programs had been assigned to the Children's Bureau and although this bureau moved from one federal agency to another over the years, it remained intact until 1969. In the states, Title V programs were usually administered by health officials. Title XIX, which became the major federal program for health services for children, was administered by a division within the Bureau of Family Services which grew into the Medical Services Administration (MSA) of the Social and Rehabilitation Service (SRS).<sup>3</sup> Most states placed the administration of the program in their welfare departments, although Mississippi set up an independent agency and five states placed it in the health department (HEW, 1970: 395-398).

All federal programs were to be directed toward children who did not have access to regular medical services. In the Title V legislation of 1935 this took the form of directing aid to areas suffering from "economic distress," or to rural areas where no medical care was available (Section 511). The provisions of health services through Title XIX (Medicaid) of the Social Security Act which were expanded by the 1967 amendments to include EPSDT, were directed only to those children eligible through the AFDC Program (Title IV), or classified as "medically needy" by the states (Sections 401-410 and 1905). At no time was the federal law interpreted as having legislated health services for all children. When Congress discussed the Emergency Maternity and Infant Care (EMIC) Act of 1943, it rejected the Children's Bureau's first request for funds

<sup>&</sup>lt;sup>3</sup>Strictly speaking, MSA does not administer Title XIX. It is considered to be a federally assisted state-administered program. However, MSA's duties of monitoring the states' programs and sending policy directives make it look as if it is administering the program, even though states have in the past ignored some of the directives without losing federal funding.

because "there was no requirement of lack of financial ability as prerequisite to the benefits" U.S. Congress, House of Representatives, Report of Committee on Appropriations, February 24, 1943:6, as cited in Sinai and Anderson (1948: 113).<sup>4</sup> Only when Congress was reassured that the program was restricted to needy children did it appropriate the funds. This federal decision to focus programs on poor children rather than on all children was to complicate the administration and implementation of health programs, because it established a two-class system of health care: private for the haves and public for the have-nots, even though well-child conferences had traditionally been open to anyone who wanted to use them without a means test.<sup>5</sup>

## The Beginnings of EPSDT

By 1967 health services for needy children were being carried out by many different federal, state, and local agencies, as well as by voluntary groups and parent-teacher associations. Standards were set by those agencies as well as by the American Academy of Pediatrics, committees of state medical societies, and the American Public Health Association. The time was ripe for a comprehensive plan for preventive health services which would include screening and treatment for children, most particularly those who did not receive care through the private sector. Evidence had been accumulating for years that preventive services would decrease infant and child mortality and lessen the likelihood of crippling diseases, but no government program had yet attempted to provide these services in a comprehensive fashion.

The establishment of a program of preventive services for children confronted the federal government with four major ques-

<sup>4</sup>Various other proposals have been heard from time to time. For example, in 1972. Senator Ribicoff of Connecticut was considering a "kiddycare" bill which would have provided national health insurance for all children the way that Medicare provided a national health insurance for those over 65 regardless of need. Several other members of Congress during its 93rd and 94th sessions were known to have child health insurance bills "in the wings."

<sup>5</sup>The "Bureau of Child Hygiene has been opening child heath centers in various parts of the state where *children of all classes* may be brought for free monthly examination and inspection" (Ingraham, 1926: 115). Emphasis added.

tions which had to be resolved in the course of legislation, administration, and implementation of the program. These questions were: (1) Which children were to be reached? (2) What would be the extent and quality of health services offered? (3) How much could or should be spent on the program? and (4) Through what administering agency was the program to be implemented? The cost would, of course, affect both the extent and quality of care and the numbers of children to be reached. These four questions do not seem to have been addressed in an orderly or exhaustive fashion by those planning the program. As a result, the program that has became known as EPSDT created considerably more controversy during the five years after it was signed into law by President Johnson in 1968 than it did during its eight-month legislative gestation.

The idea for federally sponsored periodic screening for lowincome children first appeared in 1966 in a program analysis prepared in the Secretary's Office of HEW. The case finding was to lift a burden from the population by saving children from handicapping conditions. Three possible programs for the screening and treatment of low-income children were suggested: one program would serve an estimated one million newborn children in health-depressed areas at a cost of nearly \$30 million; another would serve five million children including newborns and those aged one, five, and nine who live in health-depressed areas at a cost of \$150 million; and finally the third would serve all the nation's 104,000 premature infants at a cost of a mere \$5.3 million (HEW, 1966: III. 22). This was the first and last time a federal document put a specific price tag on a specific nationwide screening or preventive care program for specified child populations. As for the administration of this program, it was suggested that "it could be organized as an extension of the present Crippled Children's Program. Funds for such a program could come through the Title XIX 'Medicaid' program. . . . " (HEW, 1966: III, 18), with the suggestion that Title XIX be amended to include diagnostic examinations. The seeds of administrative ambiguity were thus planted in this first report. 6 The

<sup>&</sup>lt;sup>6</sup>Title XIX was barely under way at the time the Program Analysis was written, and its authors may have wanted to hedge their bets since its scope, administration, and direction were unclear. At least one author has said that it was their intention that the program should be administered by Title V with Title XIX acting as a pass-through mechanism (personal communication, George A. Silver, M.D., June 3, 1974).

scope of services was not discussed in any detail.

President Johnson, in his address to Congress on the Welfare of Children on February 8, 1967 (U. S. Congress, 1967a) recommended that increased funds for the care of needy children be doubled to a total of \$221 million. He also asked that the number of needy children being seen and treated under the Crippled Children's program be doubled to one million. Whether these increased appropriations and expanded legislation were aimed at the same populations was not clear from the President's message.

### EPSDT Legislation—H.R. 5710

Some clarification appeared eight days later when the President's ideas were incorporated in legislation introduced by Representative Wilbur Mills. The Social Security Amendments of 1967, or H.R. 5710, provided broad-ranging changes in the Social Security Act programs, of which the child health provisions formed only a small part. When the House Ways and Means Committee invited comment from interested parties, the bill was described as including "revisions in the Old-Age, Survivors and Disability Insurance; provisions relating to health care for the aged and others (Title XVIII and Title XIX); provisions relating to public assistance; tax provisions relating to senior citizens, etc." (U. S. Congress, 1967b). Only those who already knew that nearly half of those eligible for care under Title XIX were under 21 would have noticed that the hearing could have anything to do with children.

The provisions for Early and Periodic Screening, Diagnosis and Treatment (EPSDT) of needy children consisted of three amendments: two to Title XIX and one to Title V, of the Social Security Act. The major amendment to Title XIX (now frequently referred to as the EPSDT amendment) was worded as follows:

... effective July 1, 1969, such early and periodic screening an diagnosis of individuals who ar eligible under the plan and are under the age of 21—to ascertain their physical or mental defects, and such health care, treatment, and other measures to correct or ameliorate defects and chronic conditions discovered thereby, as may be provided in regulations of the Secretary. [Sec. 301 (b) (1)]

The intent of this legislation was to encourage staes to extend their coverage of care for children to preventive ervices. At the time,

only seven states specifically provided for this care in their state plans (HEW, 1967: 44).

The other amendment to Title XIX called for cooperation between the Title XIX and the CC and MCH programs of Title V. This amendment provided for the state Title XIX agency to enter into agreements with any agency receiving payment for part or all of its costs under Title V; that it use such an agency in furnishing care and services; and that it make provision for reimbursing such an agency for the care and services furnished. This agreement of cooperation was not new to Title XIX. When Medicaid was passed in 1965, it had included a provision for the state Title XIX agencies to enter into agreements with the state agencies responsible for administering or supervising health services and vocational rehabilitation. The novelty was that the Title V agencies were specifically mentioned, the agreement was to include reimbursement and the Secretary of HEW would write regulations clarifying the scope of the relationship [Section 1902 (a) (11) (A) and (B); (A) was the original statement; (B) was the 1967 addition].

The third amendment, an amendment to Title V, said that state health plans with regard to the Crippled Children's program must:

... effective July 1, 1967, provide for early identification of children in need of health care and services, and for health care and treatment needed to correct or ameliorate defects or chronic conditions discovered thereby, through provision of such periodic screening and diagnostic services, and such treatment, care, and other measures to correct or ameliorate defects or chronic conditions as may be provided in regulations of the Secretary. [Section 301 (a) (2)]

This mandate to carry out preventive care replaced the weaker langage in the earlier Crippled Children's provisions for locating crippled children. Authorizations for the program were to be increased from \$55 to \$65 million (U. S. Congress, 1967b: 93). In its explanations of the act's provisions, HEW said that the amendment to Title XIX plus the "proposed increase of \$15 million [sic] in the authorization for 'Crippled Children's Services' and the requirement . . . that such services include periodic screening and diagnosis would greatly strengthen the nation's programs for children" (U. S. Congress, 1967b: 26). HEW had not mentioned how the program was to be administered or how many children were to be served.

These three amendments constituted what has become known

as EPSDT, the Early and Periodic Screening, Diagnosis and Treatment Program. EPSDT went through three phases in its legislative history: as H.R. 5710 when it was discussed in hearings before the House Ways and Means Committee in March and April 1967; as H.R. 12080 when in August it emerged from the Ways and Means Committee Report; and still as H.R. 12080 in hearings before the Senate Finance Committee during August and September of the same year. During each phase, the issues of program cost and administration were taken up while the questions of scope of services and eligible population were more frequently ignored.

## The First Public Discussion—H.R. 5710 Hearings

Hearings on H.R. 5710, held before the Ways and Means Committee during March and early April 1967, extended for nearly 3,000 pages of testimony of which child health amendments formed only a small part. More individuals or organizations commented on the costs of the program than on any of the other three issues that would determine the shape of the future program. However, those testifying were confused as to who was to foot the bill, Title V or Title XIX. HEW had suggested \$100 million extra for Title XIX earmarked for children and \$15 million extra for Crippled Children under Title V. Some of the Title XIX money (or perhaps much of it) was supposed to go toward encouraging states to expand their programs to include any kind of services to children, not just the preventive ones (U. S. Congress, 1967b: 125-126). George Meany welcomed the President's proposals for "an increase of \$100 million in federal financial participation for needy children," but added that the amounts authorized for child health were the "absolute minimum required" (U. S. Congress, 1967b: 584-585). The American Parents Committee (U. S. Congress, 1967b: 2006) and the American Academy of Orthopedic Surgeons (U. S. Congress, 1967b: 2351) supported the \$10 million increase (presumably for crippled children), which would pay for additional case finding and increased medical costs. Other organizations were less certain that the amounts asked for would be adequate to carry out the additional case finding and payment for increasing medical costs. The American Cerebral Palsy Association (U. S. Congress. 1967b: 2237) said that \$18 million extra was needed. The Foundation for the Blind (U. S. Congress, 1967b: 2242) and the State of Illinois Commission on Children (U. S. Congress, 1967b: 2416) both objected that CC is closed-ended funding and would limit the kinds of services that could be provided. Title XIX funding is openended. The strongest request for additional support for the CC program came from those who administered it, the Association of State and Territorial Health Officers. Under a 1965 law the CC programs would have to pay "reasonable cost" for hospital services and without the provision of additional federal funds, this "greatly increased cost is working a tremendous hardship on these programs. . . . There is every possibility that they will result in a reduced amount of care given" (U. S. Congress, 1967b: 2263).

The concerns for the funding of this new program stemmed from confusion over whether it was a Title V or Title XIX program, or rather, whether it was a health or a welfare program. At the federal level, Title XIX was administered by the Medical Services Administration (MSA) of the Social and Rehabilitation Service (SRS); Title V by the Children's Bureau, which at the time was part of SRS but was soon to be dismantled and transferred to the newly created Health Services and Mental Health Administration (HSMHA). This separation was paralleled at the state level, where the Title XIX programs were usually administered by welfare departments and Title V programs by health departments. The confusion was not clarified in commentary on the administrative framework for the program. HEW Secretary John Gardner (U.S. Congress, 1967b: 98) called for agreements between the Title XIX and Crippled Children (Title V) agencies. Martha M. Eliot (U. S. Congress, 1967b: 2267), former head of the Children's Bureau, "heartily" approved of this relation. The American Nursing Association (U. S. Congress, 1967b: 2229) felt that the purpose of the legislation was to broaden the base of the Children's Bureau Title V programs, and ignored the role of the Title XIX agency. Representative James A. Burke (U. S. Congress, 1967b: 1964) of Massachusetts was the only one to comment on the ambiguity, saying: "it is a program that should be administered by the Department of Public Health. . . . It is not a welfare program. It is a health program." The issue of whether health or welfare should implement a health program for welfare children was not resolved during these or subsequent hearings; it has continued to plague all those charged with implementing the program.

The issue of which children were to be served or which ones were eligible for the proposed program also received scant attention and produced conflicting points of view. Secretary Gardner (U. S. Congress, 1967b: 190), like the President, had suggested that 500,000 additional children would be screened furing the first year of operation, and within three to five years, the program would extend to five million children. Whether these were children to be served under the CC or the Title XIX program was not clear. The American Parents Committee (U. S. Congress, 1967b: 2007) also picked up this 500,000 children figure and assumed the case finding for these low-income or medically indigent children would take place within the context of the CC program. Not only was there question of how many children would or could be served, but who would be eligible for the new program. There was pressure to expand state CC services to include children with vision or hearing problems and there was concern that specialized services not available through the private sector would no longer be available to middle-income families if the present program were carried out. Under the Title XIX program economic eigibility was the only criterion. The repercussions of this unresolved conflict would be felt down to the implementation of the programs within the state.

Except for the comment that vision and hearing screening should be included, no one testified at these or at later hearings on the scope or extent of screening or preventive care to be carried out in the proposed program. These details were to be prescribed by the Secretary.

## Phase 2—Same Provision; New Bill

The three EPSDT amendments remained essentially unchanged when the Social Security amendments of 1967 were incorporated into H.R. 12080, which was reported out of the Ways and Means Committee in August 1967. The many major changes which affected the rest of the Social Security Act affected EPSDT only in-

<sup>&</sup>lt;sup>7</sup>During 1968 before EPSDT, the CC program served 475,000 children while Medicaid served 5,574,000 children. The CC program had been serving over 400,000 children since 1964. No data are available on the children served by Medicaid during its first two years, 1966 and 1967 (HEW, 1971a: Table 1; HEW, n.d.: Table 2).

directly.<sup>8</sup> One of the changes was to consolidate all the funding for Title V into one authorization of \$250 million, of which half was to go for Maternal and Child Health and Crippled Children's Services combined. If the shares were divided equally, the CC program would receive an authorization of \$62.5 million, a few million dollars less than had been proposed in H.R. 5710.<sup>9</sup>

The date on which screening was to become effective, July 1, 1967, was removed from the EPSDT amendment to Title V because the date was already past. July 1, 1969, remained as the effective date for the program in the Title XIX amendment. With the EPSDT amendment to Title V written into a new consolidated Title V, the two EPSDT amendments to Title XIX were called "conforming amendments.<sup>10</sup>

The question of administrative authority was immediately raised in the Ways and Means Committee's report which emphasized that the EPSDT provisions were to bring about more aggressive case-finding by the CC programs; however, the committee then obscured its intent: (U. S. Congress, 1967c: 127)

Organized and intensified case-finding procedures will be carried out in well baby clinics, day care centers, nursery schools, Headstart centers in cooperation with the Office of Economic Opportunity, by periodic screening of children in schools, through follow-up visits by nurses to the homes of newborn infants, by checking birth certificates for the reporting of congenital malformation and by related activities. Title XIX (Medical Assistance) would

<sup>8</sup>One major issue debated throughout the 1967 Social Security Amendments was whether the eligibility levels for medically needy should be limited to 133 ½ percent of the public assistance levels under the categorical programs. Both the states and the federal government were anxious to cut Medicaid costs by limiting the number of people who would be eligible for the medically needy category. Congress decided to apply this limitation only to the AFDC program. Consequently the number of children eligible for EPSDT through Title XIX was curtailed by this action.

<sup>9</sup>In fact, the MCH and CC shares, as they were allocated by the HEW Secretary, were not quite equal. The CC program received slightly more than the MCH program.

<sup>10</sup>SRS administrators later, when writing regulations for Title XIX, wondered whether the Title V amendment took precedence because the Title XIX amendments were "conforming." They were reassured by HEW General Counsel that juridically this had no meaning and they could proceed with regulations for Title XIX.

be modified to conform to this requirement under the formula grant program.

The legislative mandate was only for the CC and Title XIX programs, but the committee was suggesting that all other federal, state, and local programs be asked to cooperate as well, with neither the funding nor the administrative framework provided for them. Much of the screening work around the country was at the time being supported by the MCH program, but it was not mentioned in the commentary.

Although administration was to be in the hands of the CC program, case finding would also be carried out by the Title XIX program. A dual system of administration was being proposed, with the Title XIX agency expected to provide reimbursement to the Title V agency (U. S. Congress, 1967c: 195). CC's funding for this massive expanded program was limited to about \$7.5 million more than its previous authorization, while there was no mention of the funding to be available to Title XIX for the program. Thus the program was not likely to open the way for increased services by the MCH and CC programs (usually the health departments) in the states. The open-ended funding of Title XIX gave that program greater flexibility.

Finally, the committee did not mention the number of children to be helped by this expanded program nor the extent of services to be provided.

When H.R. 12080 passed the House in August and was sent to the Senate, the cost of EPSDT, the eligible population, the extent of care and how the program was to be administered, had not been clarified. The latter two questions were left for the Secretary of HEW to prescribe in regulations. Presumably, the Senate hearings would provide insight into the intent of the legislation, but this was not to be.

## Phase 3—Senate Hearings and Passage

Hearings were held before the Senate Finance Committee during August and September 1967. The EPSDT provisions were unchanged from the hearings before the Ways and Means Committee on H.R. 5710, so most of those who testified did so on other controversial issues without reference to EPSDT. No special mention

of EPSDT was made by either HEW Secretary Gardner or Under-Secretary Wilbur Cohen. Nor did senators raise questions. Among the hundreds of witnesses and communications that were incorporated into these hearings, only one witness, Dr. Donald C. Smith of the American Academy of Pediatrics, stressed the need for preventive health measures in childhood and asked that the high quality of CC programs be maintained. He therefore recommended an amendment that would require cooperation between state agencies administering Crippled Children's Programs and those administering Title XIX programs (U. S. Congress, 1967d: I, 201). No such requirement was added. Congress retained the more ambiguous wording of the amendment that state Title XIX agencies provide for "entering into agreements" with Title V and other agencies.

H.R. 12080 was a complex bill with titles relating to Public Assistance, Medicare, Medicaid, and Child Welfare. The Child Health Act of 1967 was only eight and a half of the 112 pages, and EPSDT took up only the three paragraphs described earlier. Provisions on AFDC stimulated the most comment. Early periodic screening and treatment, if not ignored, at least was not uppermost in people's minds. In retrospect, this lack of concern seems odd because so much time and energy during these hearings were devoted to restricting the costs of Medicaid. This new program would greatly increase Medicaid costs. Perhaps those who proposed the program were aware of its high potential cost and also of the jurisdictional dispute it would engender and therefore deliberately underplayed financing and administration.

The three amendments which became known as EPSDT passed the Senate unchanged from the House version. After a Senate-House conference, they then passed the two houses as part of the Social Security Amendments of 1967 or PL 90-248, and were signed into law by President Johnson on January 2, 1968.

The United States had just enacted its first policy mandating preventive health services for needy children, a kind of health insurance for the poor. All states with Title XIX programs<sup>11</sup> would have to provide such services for all eligible children. In addition, the Crippled Children's Program would also have to carry out early periodic screening for those who were eligible under its plans. Yet, despite the broad mandate, during its eight-month legislative his-

<sup>&</sup>lt;sup>11</sup>By 1970, this would include all states but Alaska and Arizona.

tory, EPSDT's details were scarcely touched on. The scope of screening and the eligible population were hardly mentioned. Estimates of cost were applied separately for the CC and Title XIX programs with no public discussion on how these costs would be worked out. Nor was it discussed whether health or welfare agencies were to be responsible for this health-welfare program. Thus, the Secretary's office was faced with a formidable task in understanding legislative intent when it came to writing regulations.

## Development of Regulations and Guidelines<sup>12</sup>

Although the EPSDT provisions had become law in January 1968 with the stipulation that they be implemented by July 1, 1969, final regulations and guidelines did not appear for four and a half years. Proposed regulations were issued in December 1970; after lengthy discussions final regulations appeared in November 1971 and final guidelines in June 1972. Meanwhile, the final implementation date for all age groups had been deferred until July 1, 1973. This fourand-a-half-year period was filled with discussions within HEW as to what direction rule making should take. Many people were involved—administrators and planners for the Title V and Title XIX programs in Washington, senators, representatives, Congress as a whole, the state Title XIX and Title V agencies, which were for the most part welfare and health departments, the HEW regional offices, the National Welfae Right Organization (NWRO), the Medical Assistance Advisory Council (MAAC), and professional groups such as the American Optometric Association. The law was interpreted and reinterpreted; the scope of services under EPSDT was broadened, narrowed, and then broadened again. Opposing forces used HEW as a battleground for issues which had not been resolved during the program's legislative history. The administrative framework, costs, eligibility, and scope of the program all had to be clarified before regulations and guidelines could be published and the program implemented.

<sup>&</sup>lt;sup>12</sup>I am grateful to the many officials of the Social and Rehabilitation Service and the Maternal and Child Health Services who generously gave of their time to provide much of the information upon which the following pages are based. Their generosity should not be confused with responsibility for the way their information has been used.

### Regulations and Guidelines—Administering Agency

Congress had given EPSDT both to Title XIX and to the CC program of Title V, without clarifying which agency was to administer the progrm. The CC program which was administered by the Maternal and Child Health Services (MCHS) was not asked by HEW Secretary Wilbur Cohen to develop regulations, even though the legislation called for them. This charge was giveninstead to Medical Services Administration (MSA) in the summer of 1968. <sup>13</sup> Even though MSA wondered at first what the implication was of the dual administration in the legislation, it worked out a draft whereby the state agencies would make firm agreements with one another, and this approach was coordinated with Dr. Arthur Lesser, the director of MCH Services. MSA proceeded to draft regulations and assume its role as the administrator for the EPSDT program, while using MCHS as consultants.

After proposed regulations for the EPSDT program were published in December 1970, states began to question how this cooperation would work.<sup>14</sup> The Medicaid program was to provide for (U. S. Federal Register, 1970b: 18879):

... identification of those eligible individuals who are in need of medical or remedial care and services furnished through Title V grantees, and for assuring that such individuals are informed of such services and are referred to Title V grantees for proper care and services, as appropriate.

In most states, Title V agencies were in health departments while Title XIX agencies were in welfare departments. The greatest con-

<sup>13</sup>Writing regulations was a new procedure for MSA. Prior to 1968, Title XIX programs had provided all guiding material to the states through its *Handbook of Medical Assistance—Supplement D*. Since these guidelines gave no way for the public or interested parties to be heard, and since several different agencies had been placed together during the 1968 reorganization of HEW, their policies were standardized and regulations had to be written. H.R. 12080 required that regulations be written for use of skilled nursing homes as well as for EPSDT, and both these regulations were several years aborning.

<sup>&</sup>lt;sup>14</sup>Proposed regulations for cooperation between Title V and Title XIX agencies had been published earlier that year but had elicited little comment from the states, possibly because the states did not know what the scope of the program would be (U. S. Federal Register, 1970a: 8664).

cern was duplication of effort between the two agencies, but one state official pointed out that this relation would result in more competition and misunderstanding between the programs than already existed. Neither Congress nor HEW had taken into account that these two agencies might not work well together on the state level. The MCHS pressed for greater details on the relationship in the guidelines, while state and regional officials asked why other agencies, such as Visiting Nurses Associations and home health agencies, had not been mentioned.

The question of reimbursement provided the major conflict and source of confusion for the Title XIX and Title V agencies. Early in 1970, MSA had received the legal opinion that the regulations called for total reimbursement for all Title V services and the Title XIX agency would have no control over the numbers of children screened, or the amount of reimbursement except as these items might be covered in the written agreements, nor could reimbursement be limited to children referred by the Title XIX agency. But the confusion persisted, perhaps because the state Title XIX agencies were not happy that they would be paying for Title V services which hitherto had been free to recipients. The following year MSA had to issue another clarification, slightly weakened by this time, that Title XIX payment could include both diagnostic and treatment services "as appropriate." It noted that responsibilities for payment were program decisions rather than those of legal prerogative. MSA was trying to force the states to work out their own relationships, but the state Title V and Title XIX agencies kept appealing to their respective HEW agencies for support. The next year another memorandum reiterating the previous position was sent out. The reimbursement issue was particularly difficult because in many states the Title V programs provided the major public screening services through child health conferences, and the major public diagnostic and treatment services through the Crippled Children's program. However, their funding had not increased and consequently they had trouble maintaining their programs.

Between 1968 and 1972, MSA gradually clarified its role as the sole administrator of the EPSDT program, while MCHS took a more and more consultative role. 15 MSA's involvement in its new

<sup>&</sup>lt;sup>15</sup>Regulations for the Title V EPSDT amendment were finally issued in 1974 (U.S. Federal Register, 1974).

role of providing for health services was so strong that by 1973 it was letting contracts for EPSDT program evaluations and for the development of screening standards. These contracts, which were part of MSA's surveillance and evaluation responsibility, did not differ much from contracts which were let by MCHS for evaluation of its programs. Meanwhile, the MCHS were not entirely pleased to see MSA moving into the field of health services. This tension at the federal level was reflected within the state agencies, either because of the existence of an MSA and an MCHS encouraged their state counterparts to square off against one another, or because the two federal agencies could not control them. One MSA administrator wondered at the time whether MSA had a policy of encouraging interagency relations, because the guidelines did not reflect this. The issue always came to a head over whether Title XIX would reimburse Title V for its services. States were hard hit by inflation and were looking for ways to avoid spending money. When these issues had to be settled, Title V agencies (usually the health department) and Title XIX agencies (usually the welfare department) would buck the issue up to the federal level. The administrative issue had been resolved in one sense, but as soon as the states began implementing the program, all the tension between a health agency and a welfare agency which was running a health program erupted, and this ambiguity continued to plague all those charged with implementation.

## Regulations and Guidelines—Costs and Funding

The administrative decision which made EPSDT a Title XIX program resolved the issue of who was to pay for it. Title XIX reimburses from 50 to 83 percent of states' costs. Theoretically no limits existed for the development of the EPSDT program, but experience with Title XIX had shown that generally states like California and New York took advantage of the program, while smaller, poorer states did not. As Stevens and Stevens noted (1970: 365-378), when states did spend a great deal of money, as New York and California did in the early years of Medicaid, then Congress got upset because costs were too high.

<sup>&</sup>lt;sup>16</sup>In 1969, these two states alone accounted for 45 percent of Medicaid expenditures (HEW, 1972b: Table 7).

During the first two years of regulation drafting, cost estimates were not made because, according to MSA and state officials, available data were so poor. However, by August 1970 someone had come up with a first-year cost of \$45 million. This large sum must have alarmed HEW, for by December of that year it had advised the Senate Finance Committee that it had delayed issuance of regulations for EPSDT because of the "great cost" it would entail for both the federal and state governments. HEW then asked Congress for legislation to phase in the program slowly (U. S. Congress, 1970: 169), but Congress refused. Meanwhile, Senator Abraham Ribicoff and the Medical Assistance Advisory Council (MAAC) continued to press for regulations.

When proposed regulations were published in December 1970, the states responded vehemently and very rapidly on the question of cost. Eighteen out of the 22 states responding said the program would place a financial burden on the state beyond its capacity. In case HEW should miss the point, one southern state had its entire congressional delegation send letters of alarm. Part of the reason states could not estimate costs was that the federal guidelines were still not available.<sup>17</sup>

During the spring of 1971, the Nixon administration had committed itself to a reduction of federal Medicaid costs for fiscal 1972, <sup>18</sup> and by May HEW, following suit, decided it would allow states to implement the program in phases starting first with children under six in order to soften the financial impact on the states. The softened financial impact on the federal government was implicit. Costs continued to concern HEW; one official estimated EPSDT would cost \$400 million by 1973 and this would create a sizable drain on the Treasury. HEW decided to narrow the scope of services and also to concentrate on slowly phasing in children by age groups. In September, HEW decided that the program would cost only \$25 million the first year. When this sum was approved by the Office of Management and Budget in the fall of 1971, the final regulations could be published.

<sup>&</sup>lt;sup>17</sup>One small midwestern state which had looked more carefully at costs than others estimated they would have 15 to 20 children eligible for kidney dialysis at \$30,000 each.

<sup>&</sup>lt;sup>18</sup>The administration was at the time proposing the ill-fated Family Health Insurance Plan (FHIP), and EPSDT was held up while HEW studied how they fit together. Officials in the secretary's office even considered getting legislation to eliminate EPSDT altogether.

The states through their concern for their own costs had managed to stave off for nearly three years the implementation of a law passed by Congress. 19 The power of the states in this case illustrated the limitations of federal aid programs. Since the incentive was not great enough, and since financial needs were sufficiently pressing, the states did what they could to hinder implementation. HEW was caught between the congressional groups which had favored EPSDT and the state welfare agencies who were its clients. HEW deferred making a choice by offering the states a few years' respite by phasing in the program slowly. This respite was only temporary, and eventually the states would have to come to terms with the financial burden of EPSDT, unless they could convince Congress to repeal it completely.

## Regulations and Guidelines—Eligibility

The eligibility issue was also resolved when EPSDT became solely a Title XIX program. Under Title XIX any child who was eligible under the state plan was eligible for EPSDT. However, state plans varied considerably. By 1971, 48 states had Medicaid programs under which all children receiving AFDC welfare payments were eligible. In addition, 25 states offered Medicaid services to any low-income child who fell within the income guidelines (HEW, 1971c: 2-3). Arizona and Alaska had no Medicaid services. However, states varied considerably in their eligibility requirements. For example, in 1968 while New York was providing medical payments for 206 children per 1,000 inhabitants, South Carolina was providing for only two per 1,000 (HEW, n.d.: Table A). In all it was estimated that approximately 10 million children would have been eligible for EPSDT, or 12 percent of the United States child population of 80 million.

During the development of regulations and guidelines restrictions on eligibility arose from the need to cut back costs and one way to do this was to cut down on the eligible population and to allow states to serve first children under six years and not serve older children until 1973. This phasing-in approach met at first with some skepticism from the HEW general counsel, but it was finally ac-

<sup>&</sup>lt;sup>19</sup>Two states, Virginia and Mississippi, were exceptions and had supported the program and were implementing the program before February 1972.

cepted. The eligibility restriction was supposed to be temporary but states were in fact slow to phase in the over-six population.

## Regulations and Guidelines—Scope of Services

From the earliest drafts of the regulations, MSA understood that the amount, duration, and scope of services was to be comprehensive and this thinking was reflected in the proposed regulations published in 1970 (U. S. Federal Register, 1970b: 18879; emphasis added).

Effective January 1, 1971 (or earlier at the option of the State), that early and periodic screening and diagnosis to ascertain physical and mental defects, and treatment of conditions discovered regardless of the limits otherwise imposed under the State plan on the type and amount of such care and services. . . . will be available to all eligible individuals under 21 years of age.

In the 48 states with Medicaid programs at the time, state plans were by no means comprehensive. All states included the five basic services: inpatient care, outpatient care, laboratory and Xray services, skilled-nursing home services for those over 21, and physician services, but here the similarity ended. One state, Minnesota, provided the full range of services available; others like Kansas, Nebraska, North Dakota, and New York provided all but one or two services; still others like Mississippi and Missouri offered only three additional services. Eighteen states did not provide dental services and 18 did not provide eyeglasses; eight states did not provide prescribed drugs (HEW, 1971d). In fact, in five states the content of Medicaid programs was determined by state statutes, and since screening for eye defects or provision of eyeglasses, as well as other services, were not included, the above regulation would require a change in law. Thus to be comprehensive any federal regulation would have to go outside the bounds of state plans.

The states objected vigorously to providing unlimited amounts of services for unlimited periods regardless of the limits of the state plan. They said the regulations were contrary to the intent of Title XIX and federal-state grant programs because they took away from the state control over the scope of their programs. Some state officials also said that the state simply did not have the medical

manpower to carry out such a comprehensive plan, implying that government should not try to provide services to low-income people until resources are available. Another state official suggested more directly that periodic screening was an outmoded concept largely abandoned by public health and the medical profession.

Strong support for the regulations came from the director of the National Legal Program on Health Problems of the Poor, who also lobbied effectively with other groups, particularly welfare rights groups, to support the EPSDT program. He asked that the regulations specify the types of care included, such as eyeglasses and hearing aids, and dental fillings.

During the long period between the proposed and final regulations, state and federal concern for EPSDT costs was rising. The result was that MSA regretfully curtailed the scope of services required of the states under EPSDT. The final regulations asked the states to provide EPSDT "within the limits of the state plan on the amount, duration and scope of care and services" (U. S. Federal Register, 1971: 21410). This constituted a major blow to the comprehensiveness of the treatment segments of the EPSDT services. As mentioned before, states were uneven in their provisions for treatment. The welfare rights lobby had had some effect, however, for the regulations included three treatment services which had to be included by states regardless of the limits of state plans:

. . . eyeglasses, hearing aids, and other kinds of treatment for visual and hearing defects, and at least such dental care as is necessary for relief of pain and infection and for restoration of teeth and maintenance of dental health.

These three treatment services, plus early and periodic screening, thus became the EPSDT program as it emerged from the federal regulations.

In writing guidelines, MSA tried to help states develop as comprehensive a program as possible. The MCHS which over the years had developed a body of information on quality health services for children provided valuable consultation. Other groups like the American Optometric Association, speaking in the interests of its own profession, asked specifically that visual screening and restorative services be included. The final guidelines reflected these interests, and detailed the case-finding procedures, screening tests to be performed, and diagnosis, treatment, and therapeutic services to be made available to eligible children (HEW, 1972a).

All these services, however, had to be carried out within the limits of the state plan.

To those who had viewed EPSDT as a major innovative comprehensive health program for needy children, the regulations were a disappointment. Treatment was not comprehensive. To those with a "toe-in-the-door" philosophy of federal policy making, it was an encouraging first step for the care of children. Certainly more poor children would get more types of care under this program than they had before. In one state, where the scope of the program had the potential of being comprehensive, an official commented wryly that the same services were not available to middle-income children.

#### Conclusion

The advent of EPSDT legislation provided the United States with the first major federally sponsored program for comprehensive health services for 12 percent of America's children. It could have been a prototype for health insurance for all children, but congressional intent for the program was so ambiguous that considerable energy had to be exerted to resolve the questions it posed. During the development of regulations and guidelines interest groups used what leverage they could to accomplish their ends. These conflicting interests used HEW as a battleground and compounded the task of program implementation. Some individuals and groups, such as community organizations, the MAAC, and the National Legal Program on Health Problems gave fairly steady, general support to the program, but factions tended to cluster around particular issues: administration, costs, and scope of services.

MSA emerged as the administrator of the EPSDT programs and found itself providing for health services for children, something that had been the province of MCH services. The factions within HEW managed to adjust to these new roles, but implementation of the program would create new tensions between health and welfare agencies at the state level. Ambiguity in legislative intent gave no one federal or state agency full responsibility for carrying out the program. Thus, the administering agencies were unable to build a bureaucratic constituency behind the program. Responsibility was divided between health and welfare agencies

with most going to the latter. On the federal level, MSA showed yet greater commitment than MCHS. In the states, neither health nor welfare agencies could become committed and build up the solidarity needed to carry out the program.

Costs were another issue which brought several factions into conflict over a program variously described as costing anywhere from \$15 to \$400 million. President Nixon had pledged not only to reform the welfare system, but also to cut costs, yet he had inherited one of the most far-reaching health programs the nation had ever undertaken. Congress, although also committed to lowering welfare costs, and particularly Title XIX costs, managed to live with its ambivalence toward the EPSDT program and mandated its implementation while attempting to cut back on other programs. The states were the hardest hit by the program's staggering potential (though never defined) costs. During the development of regulations and guidelines they tried to discourage HEW from asking them to carry out the program, and when they had to implement, they moved very slowly. States were angered by the heavy costs and lack of lead time they had been given. One state official suggested that states should have been given the same amount of time for implementation as HEW had had to write regulations.

While most of those who grouped around the issue of costs wanted to cut back or eliminate the program, those concerned with the eligible population and scope of services strongly favored the program's development. County and national welfare rights organizations, with the support of MCH services, had shown their strength by the well-thought-out and comprehensive array of tests and screening mechanisms that became available to low-income children (at least those eligible for Title XIX under state plans). However, the states and federal government in their concern for costs succeeded in cutting back the scope of services available under the program.

The absence of discussion surrounding EPSDT's intent is not unique in the history of federal health policy. Title V when presented to Congress in 1935, received scant notice because attention was drawn to the major provisions of the Social Security Act. EPSDT's predecessor and umbrella program, Medicaid, slipped into the 1965 Social Security Amendments to fill the gaps left by Medicare. When it was passed, it was called the "sleeper" of the Amendments because no one had foreseen that the costs of this

program would rise from \$2 billion to nearly \$9 billion in a few years and that by 1971 it would be serving nearly 20 million people.

The experience of Title V, Medicaid and EPSDT exemplify the toe-in-the-door procedures of federal policy making. Congress seems to assume that once a worthy policy is passed, its implications can be worked out later, and the program expanded when necessary or desirable. This had not always been the case. Title V was never expanded. Its funds were increased over time, but the program never became a national program for child health services. Since the sixties other programs such as Head Start and Neighborhood Health Centers and, of course, EPSDT have been added to supplement Title V rather than integrated. Medicaid was viewed as a stop-gap measure for those not eligible for Medicare. It did expand, but its unexpected high costs did little to endear to the American public the principle of publicly financed medical care. To compound the problem of poorly thought-out policy, EPSDT was added to Medicaid before its implications were studied.

What can one learn about ambiguous toe-in-the-door policy making from the experience of EPSDT and its four-and-a-half-year delay in implementation? First, that Congress and the executive agencies are unable or unwilling to come up with reliable cost estimates for health and welfare programs. One wonders whether accurate cost estimates were actually unavailable to Congress or whether no one in Congress or HEW was willing to face the costs the program would entail. At any time Congress or HEW could have gone back to the 1966 Program Analysis and discovered that the cost of screening five million children was \$150 million. It may be true that no politician can sell an expensive health program to his constituents, but unrealistic costing leads to a public that may become increasingly disenchanted with federal health programs which cannot live up to the expectation placed on them by Congressional and Executive rhetoric.

Second, ambiguity in administrative assignment lessens bureaucratic solidarity and thereby a program's chances for success. Had Congress given responsibility for EPSDT to one single agency, it would have been easier to build bureaucratic solidarity behind the program to smooth its implementation. The division of responsibility between health and welfare split the program between agencies with differing philosophies and goals.

Third, establishing federal child health policies through the mechanism of federal-state grant-in-aid programs increases the am-

biguity of the final policy. Medicaid and EPSDT are officially state programs. And the states can put up formidable barriers to their implementation. They can protest vigorously to HEW as they did when the proposed EPSDT regulations were issued. In addition, they can refuse to implement the program at all; they can limit eligibility; or they can limit the scope of the state plan. Since states in fact have used all of these ways to limit the economic impact of the Medicaid and EPSDT programs, it is not an encouraging precedent. Even the threat of lawsuits and federal penalty have failed to move some states.

Finally, the role of health and welfare interest groups in urging HEW to carry out EPSDT should be noted. The welfare rights groups lobbied to get regulations to emerge from HEW. The continued role of these groups in bringing lawsuits against states for failure to implement EPSDT indicates that such groups may be taking the leadership which states have been unwilling to exercise in implementing federal policy.

Congressional intent in EPSDT legislation, as in much legislation which is born in compromise, had resulted in ambiguity. If Congress was ambiguous in its intent for EPSDT in 1967-68, it continued to be so. While trying to cut welfare and Medicaid costs on the one hand, in 1972 it reaffirmed its intent to maintain the EPSDT program by adopting a penalty for states which failed to carry out the program. This ambiguity encouraged many groups to work for the program's early demise. Compromises made during the development of regulations and guidelines placated, at least temporarily, the states, interest groups, and administering agencies, and thereby assured the program of a continued, albeit tenuous and unsatisfactory existence.

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