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ABSTRACT

The purpose of this booklet is to provide answers to basic questions about the Medicaid Early and Periodic Screening Diagnosis, and Treatment (EPSDT) program. The first section argues that the need for EPSDT is evidenced in statistics on the health status of needy children. Provision of health care for many needy children depends on their elegibility for Medicaid; however, Medicaid is not available to all disadvantaged children in need of health services. Section Two argues that because its mandate covers all eligible poor children, the EPSDT program is able to meet the health needs of all youth from low income families. The program status, screening effectiveness, program design, inter-agency relationships and related benefits of the program are discussed. Section Three explores aspects of program implementation including states' roles, cost and quality of EPSDT services, and program administration. Section Four briefly overviews program eligibility, confidentiality of records, and client's choice of service provider. The final section summarizes EPSDT experiences in attempting to provide health services and lists problems likely to be faced by any comprehensive health care program. (Author/RH)

EPSD&T:

The Possible Dream

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FOREWORD

Early and Periodic Screening, Diagnosis, and Treatment (EPSDT), one of the least understood and least publicized of the Department of Health, Education and Welfare's (HEW) health care programs, is expected to serve an estimated 2.25 million children in FY 1977, at a Federal cost of about $150 million—a fraction of the more than $10 billion in total Federal Medicaid costs. More Medicaid-eligible needy children will be served under EPSDT than all the other Federally-supported health care programs combined. In four years, more than five million health screening examinations—plus the necessary diagnosis and treatment—will have been performed. This reaches a significant portion of the approximately 11.5 million EPSDT-eligible children. In the process, EPSDT has made significant observations about the health care system of the country—particularly as it impacts on the poor and dependent people. The magnitude of the program and the scope of its activities make EPSDT a major experience in the process of developing a national preventive and comprehensive health care system.

Yet, even with implementation under way in all but one State (Arizona has no Medicaid program), basic questions about the program are still raised: Is it a necessary service? An effective one? Does it set up a system of second-class medicine for the poor? Is it a manageable program? Is the provision of EPSDT services a reasonable expenditure of public funds? At a reasonable cost to the public?

This paper is an attempt to address these questions. It is the conviction of those who have worked to get EPSDT under way that the problems this program faces in implementation and the problems it has uncovered in the health care system are problems that must be faced no matter what the administrative arrangements, the fate of EPSDT, or the final shape of National Health Insurance.

It is in that spirit that this publication is presented.

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I. Needy Children and the Health Care System

The need for EPSDT is clear from the statistics on the health status of needy children. It is a story that has been told in great detail many times in the past decade, from the 1966 Program Analysis of Maternal and Child Health[1] that resulted in the creation of EPSDT, to the November 1976 report by the Office of Child Health Affairs (OCHA).[2] The details differ, but in 1976, just as in 1966, the available facts make the same case: that needy children suffer disproportionately from ill health and yet lack the necessary treatment. The OCHA reported, among other things, that poor children:

- — suffer 23% more hearing impairment
- — do not grow as tall as other children
- — are more likely to have low hemoglobin values during their years of growth
- — suffer a higher incidence of impetigo, gastrointestinal diseases, parasitic diseases, and urinary tract infections, and those in urban areas are more often the victims of lead paint poisoning, and insect and rodent bites

Among minority children, the conditions of ill health were found to be particularly acute. Other studies in recent years have made some of the same points: the National Nutrition Survey, the reports of the National Center for Health Statistics (NCHS), and local studies[3] all confirm these findings. From the Health Interview Surveys conducted annually by the National Center for Health Statistics and special studies, we also know that poor children are likely to have twice as many hospitals stays, more days in bed, and more days lost from school than children who are not poor, as well as more impairment from chronic disease.

Because EPSDT is a program exclusively for needy children, it can be expected to find these same things—and it does. Among the children screened through the program, 45% require follow-up referrals for an average of over two conditions:

- —50% are found to be inadequately immunized
- —25% are found to have severe dental problems

— 10% have vision problems
— 12% have low hemoglobins
— 8% suffer from upper-respiratory problems
— 7% suffer from genitourinary infections
— 9% in urban areas have elevated blood lead levels
— 8% have hearing problems[4]

Detailed statistical reports from the States show that roughly 50% of the screening referrals were for conditions other than vision, hearing, dental, and lead poisoning problems.[5] Children with previously undetected conditions as severe as cancer, epilepsy, and congenital defects are coming to medical attention through EPSDT, and are being started on their way to treatment.[6] EPSDT, by offering care that is not readily available to poor children, is identifying conditions not being detected otherwise.

Some needy children simply are not getting any health care and others are not getting adequate care. Medical professionals themselves are learning from EPSDT that even children under a physician's care sometimes have undetected conditions in need of treatment. In Baltimore, for example, physicians from the University of Maryland became involved in a project to screen children living close to the University who had been using its health facilities. Among the 361 children screened, 335 had a total of 331 referrable conditions. Physicians in the project found this a " . . . profound experience in preventive medicine. Not one of these conditions would otherwise have been recognized so early in its course for these children."[7]

Specially monitored EPSDT demonstration projects found that fewer than 1% of the 7,426 children screened had had a previous examination comparable to what is called for by the EPSDT program. Sixty to 80% of the health problems found in these children were previously unknown and untreated, even though 80% were considered to be chronic.[8]

Medical practitioners themselves provide part of the answer to why this should be so. Dr. Phillip Porter, who treats needy children in Cambridge, Massachusetts, observes that such children were being treated only for presenting symptoms and injuries before they were enrolled in his clinic. Periodic lead poisoning testing, auditory and visual screening, hematocrits, physical examinations, and developmental assessments had never been done. The services necessary to carry out these tests were not available in the facilities to which the children had access.[9]

Dr. Robert Tidwell of the American Academy of Pediatrics' (AAP) Ad hoc Committee on EPSDT and the AAP Council on Pediatric Education, makes a similar observation:

> "Generally, medicine has seemed to look only at the presenting symptoms. . . The beauty of EPSDT is that it examines, searches, and finds problems, while other programs get at the visible tip of the problem."[10]

Dr. Effie Ellis, member of the American Medical Association's (AMA) Quality of Life Committee and Co-Director of the Quality of Life Center of Chicago, comments that many of the Committee's concerns could be eliminated if the health and medical care normally available to the poor really assessed their overall health status and responded to the conditions being found—as EPSDT does.[11]

Impact of Medicaid Eligibility

For many needy children getting care at all depends on their eligibility for Medicaid. Yet Medicaid is not universally available to the poor. Many States set their income eligibility for Medicaid well below the poverty line, and Medicaid coverage is not available for children whose families are not eligible for welfare. In some States, that automatically excludes the children with two parents who work but remain poor. In the South, where poverty is widespread and medical resources are particularly scarce, it has been estimated that only 24% of poor children receive Medicaid services.[12] Until EPSDT went into effect, even Medicaid-eligible children received only sickness care and in many States only the minimum of required services.

When a comprehensive study was made in Rochester, New York, of the impact of Medicaid on child health, it was found that even in the late sixties and early seventies poor families were still likely to get less care and have a higher proportion of illness-related, rather than preventive, medical contacts.[13]

FY 1975 Medicaid data suggest that many Medicaid-eligible children had only about two physician visits per year—and about two-thirds of those encounters occurred among children who were already hospitalized.[14] Since routine examinations of infants account for a substantial portion of physician-child encounters, this suggests that care for needy children over one year is likely to be inadequate.

The patchwork of other existing Federal programs is hardly the answer. The total capacity of all other Federal comprehensive care programs is 1.7 million children, about 40% of whom are Medicaid eligible.[15]

Some areas have medical resources, but they are not available to poor children. In some States as few as 30% of physicians participate in Medicaid, and nationally only about half of all physicians are participating as Medicaid providers.[16] In cities across the South (Raleigh, Jackson, Mobile, Jacksonville, and New Orleans) it is still common for physicians to refuse to take Medicaid patients.[17] Just 41% of dentists will see Medicaid patients. Even these figures may be overestimations, since a single Medicaid billing is often sufficient for a provider to be counted as "participating." For poor people, though, available doctors have never been the only issue. As the recent report of the Children's Defense Fund so ably demonstrates, "Doctors and Dollars are Not Enough."[18] To make the medical care system work, people need a range of health-related support services, which poor people usually are not able to provide for themselves.

Most middle-class people can provide their own transportation and their own "follow-up." They are more likely to understand how the health system works and have generally been able to use it. For the most part, this is not true about the poor; they often lack cars, do not understand how to make the system work for them, have had bad experiences in their attempts to get health care and need the support of others to try to use it once again. Without services that both support the health care system by making it more accessible, and support the individuals by making it easier for them to use the system, many poor people go without care until a crisis occurs.

For the poor enrolled in EPSDT, support services are proving to be critical. Two Texas counties which had been exceptionally low in enrolling eligible children became two of the most effective after a transportation service was put in place.[19] Personal contacts with outreach workers were responsible for 75% of the children screened during a three-year period in one Pennsylvania county.[20] South Carolina, which has enrolled 85% of its eligible children, sees its transportation contract with the local Community Action Program as a major factor in its high rate of participation.[21] In Maine, 1200 people were contacted over a three-month period. With personal contacts, only 1% refused EPSDT services; without outreach workers to explain the value of the program, service refusals jumped to 15%.[22] A review of the States that make up Region V concluded that "personal outreach and case management increase implementation levels."[23] For poor people particularly, good care means more than the availability of doctors or a way to pay the bills.

II. EPSDT May Be the Answer

Given the unmet needs of many poor children and the failure of the existing system to respond, clearly something different must be done to improve the health of this vulnerable group. No other Federal effort has been able to provide in a single program what needy children require to make the health care system work for them. What is required is a program that will take responsibility for reaching the children, for explaining to their parents why health care can make a difference before there is a crisis, for making no assumptions about care they might be getting elsewhere, and for causing the many parts of the system to work together to see that treatment is provided when needed.

EPSDT screening may be the first thorough physical examination many needy children have had since birth, and EPSDT is the first program actually to take steps to see that they get the diagnosis and treatment that the findings of the examination warrant. Moreover, it links together for the first time a mandate to find all eligible poor children in need of care, the responsibility to make the medical care system respond to the needs of those children, and the Medicaid dollars to pay for the service. No other program is so far reaching.

The Status of EPSDT

In the four years since EPSDT got under way in 1972, some 5 million health screening examinations have been performed for Medicaid-eligible needy children. In the early years of the program when few States had begun to implement the law, the number of screenings annually was measured in the hundreds of thousands. By FY 1976, 1.95 million screening examinations were being performed across the country. And, with a program operating in every State but one, there will be an estimated 2.25 million screening examinations in FY 1977.

This level of program growth, however, reflects only a small part of EPSDT activity since screening is only the entry-point to the program. Getting children to the screening centers involves the mobilization of a wide range of outreach, transportation and other health support services, as well as the cooperation of medical care resources. Once children are screened there is all the activity that follows from referrals for diagnosis and, where needed, for treatment. Understood in those terms 7.25 million screening examinations in five years will represent no small accomplishment.

This is a mixed record, however, on two counts. The first involves the recognition by EPSDT program staff, as well as by its critics, that participation in the program could be much higher in many States, and that real program growth has been stalemated in some. The second cautionary note concerns the figures themselves. There is no straightforward way to measure program success against the number of children eligible for its services. However, because parents may not understand the value of the service, or may understand but choose not to take advantage of it as it operates in their State, it can never be assumed that all the children eligible for EPSDT at any point in time would be making their way through its system.

It should also be noted that not all of the 11.5 million EPSDT eligible children are to be screened each year. The program would be reaching the effective target population at a level of about 5.3 million screening examinations per year. This is based on an average of States' periodicity schedules and assumes that about 1.3 million eligible children are cared for by providers giving care equivalent to EPSDT services, and that roughly 20% will refuse service for their own reasons. In this context, then, EPSDT programs in FY 1976 were serving approximately 30% of the target population nationally.

The actual volume of EPSDT activity is largely a function of State interest in the program. This is reflected in the great variation between States in the participation of eligible children. States have not moved equally fast or equally well in getting their programs under way and in getting the program's benefits to eligible children. Some States claim to have reached 75% of their eligible children. On the other hand, New York has only reached 14% and California hovers near the bottom of the list with less than 3% of eligible children enrolled. Because these two States—New York and California—account for 28% of the eligible children in the nation, their relatively poor performance influences the national participation rate. The problem is apparently not a matter of size; Texas, Michigan, and Ohio all have large populations and large urban centers with concentrations of Medicaid-eligible children, yet their enrollment rates are much higher. If New York and California were to match the performance rate of Michigan, which has 25% of its eligible children coming through the program yearly, another 625,000 children would be added to the program each year.

EPSDT has been underway long enough now to be able to judge its performance in terms of more than numbers enrolled. Since more than half the children screened are found to be in need of diagnosis and treatment (7 States reported from 70% to 95%), referrals are also proving to be more significant than was originally expected. A recent study in 8 States and one jurisdiction revealed that 78% of the children found to have problem(s) reached treatment for at least one problem, and 72% for all problems found. These 9 jurisdictions surveyed between October and March 1977 included 44% of the program-eligible children in the United States.[24]

Even more significantly, the problems found are being corrected. For example, in Michigan the rate of referrals for treatment from rescreening dropped from 62% to 49%. According to the Michigan report, "Although more time is needed before conclusions can be drawn, at this point it appears that EPSDT is a wise investment financially and is an effective intervention in conditions that in many cases would otherwise result in irretrievable health impairment and suffering for many young people."[35]

Similarly, parents of needy children are becoming convinced of the program's value. In Maine, 85% are making appointments for the next screening examinations as they come through the system; and in Pennsylvania, 85% of the rescreening appointments are being kept. In the nine States studied, the show rate for treatment reflected a high degree of parental interest.[26]

With time and program growth, many of the States are changing their programs to reflect the realities of their experience. Minnesota has assigned EPSDT health district coordinators to cover the State; Texas, Washington, and Vermont, have hired additional outreach workers to explain the program to eligible families and to provide health education for them; Colorado is planning total program reorganization for increased effectiveness; and several States have begun to look at new arrangements for the involvement of a mix of public and private care providers. The next year or two is expected to see some important shifts in arrangements with medical care resources based on this experience. Increasingly, there is in the States an atmosphere of exploration, momentum, and growth.

The Effectiveness of Screening

EPSDT is demonstrating the value of screening when incorporated into the total health care process. The use of screening for the prevention and detection of child health problems has long been an accepted part of medical practice, and over the past 50 years criteria for the uses of screening have been developed. Screening received official sanction as national policy in 1935 in the Title V section of the Social Security Act which established the Crippled Children's program to extend and improve programs:

> ". . . for locating. . . . children who are crippled or who are suffering from conditions which lead to crippling . . ."[27]

To identify such children, some type of screening was needed. Because the program was never funded sufficiently to permit States to carry out its broad goals, States limited themselves to developing registries of crippled children. Nonetheless, the overall goal of Title V, to "promote the health of mothers and children," was always understood to mean the promotion of well-child activities. Thus, screening for two purposes—well child care and the development of crippled children registries—became part of Federal child health policy through Title V.[28]

Over the years, however, the limited availability of Title V services, and the lack of a professional commitment to preventive health services generally, resulted in there being no broad agreement on the need for screening as a regular part of care.

In Canada, where a full health insurance system is in place, screening is included in routine care in the form of periodic health examinations: 3-6 such examinations in the first year of life; vision and hearing assessments at least in the second and fourth years of life; and every three to five years for otherwise asymptomatic individuals.[29]

In this country, where large numbers of children go without needed care, the uses of a screening program are quite different. Most recommendations for screening schedules, or in favor of particular screening procedures, assume that gross medical conditions are being dealt with elsewhere—that children who are sick or otherwise in need of care have it or will get it, and that screening procedures will be used only to further identify conditions that would otherwise go unnoticed. EPSDT is proving those assumptions to be unrealistic. EPSDT screening is not so much a matter of applying sophisticated techniques to the detection of subtle, unrecognized medical conditions, as it is the only way in which the overall health condition of many needy children will be assessed.

When EPSDT presented the need for a "screening package," there was little difficulty in reaching agreement among the pediatric community. Generally, child health experts can agree on the procedures that are most appropriate for preventive, ambulatory pediatric care. Three hundred and ninety "experts"—half of whom were clinicians and half of whom were academicians—were 85% in agreement on the major aspects of screening that need to be carried out.[30] When a sample of over 1800 practicing primary care physicians was asked to validate the criteria of the "experts," they, too, were found to be in substantial agreement.[31]

A significant level of dental, vision, and hearing problems could have been predicted from what is known about the present health care system.[32] The findings of the program in its operation to date also support the need for screening needy children for health problems, since almost half of the children screened are referred for diagnosis and treatment, many of them for serious and potentially disabling conditions.

For the present, it is still too early to assess the final impact of EPSDT on child health status and the reduction of disabling conditions. While the program is still being implemented, it has been necessary to rely on "process" measures, like the number of children screened, and tracked through to treatment. More sophisticated evaluation of EPSDT will only be possible as the program becomes more firmly established. Some States are already taking steps to do this. South Carolina, for example, is completing work on a set of management reports on all major aspects of EPSDT, Minnesota is evaluating its program, and Michigan has conducted its own review of how well the program is achieving its goals.

The Design of EPSDT

EPSDT is a State-administered program with considerable variation from State to State and latitude so broad that States can cover all optional Medicaid treatment services under EPSDT or only those otherwise covered for all Medicaid eligibles under their State plans. This has resulted in a program of uneven quality. Where State administrators support the concept and have been aggressive in enlisting the support of the medical community, the program is not only working, it is generating enthusiastic support among clients, providers, and the community at large. Where there is little support for the idea or a reluctance on the part of State administrators to take up the challenge posed by EPSDT, the program is floundering—links to treatment remain unsatisfactory; outreach and support services are poor; enrollment figures are low. These variations might be expected in any program in which Federal authority is limited by law to the setting of minimal standards while specific administrative and programmatic components are left largely to each State. However, the penalty statute and the monitoring it requires help assure that even weak programs will meet minimal standards.[33]

Under the circumstances, there is a surprising degree of uniformity in the program. For the most part, the EPSDT guidelines for what constitutes an acceptable screening procedure have been universally accepted so that virtually all States' screening packages include reviews of health history; immunization status; dental, hearing, vision, and developmental assessments; an unclothed physical examination; necessary laboratory procedures, and tests for sickle cell, lead levels, and parasite examination, where they may be relevant.

States are urged to use the advice of relevant professional groups, but they are permitted to define their own periodicity schedules. Most have adopted some variant of the full schedule recommended by the American Academy of Pediatrics.[34] States are also urged to offer support and outreach services in addition to the minimal requirements for notifying eligible families of the service and helping them use it. The currently proposed EPSDT revised penalty regulations require specific actions of States in support of service delivery.

Although EPSDT is administratively linked to State welfare departments and most EPSDT eligibles are AFDC recipients, EPSDT health services are actually carried out by health, not welfare, professionals. Eight States rely entirely on private physicians for screening as well as treatment under EPSDT. Twenty-two States use a mix of health department facilities, special screening clinics, and private physicians to carry out their programs. Twenty-three States have arranged contracts with State and local health departments to carry out the screening portion of the program. Whether it relies on the private or the public health sector or a mix of the two to carry out its mandate, EPSDT has had to use existing medical care resources in new ways that make them more responsive to the problems of needy children.

States have always been urged to use comprehensive care providers whenever possible and programs are not permitted to consist just of screening. However, preventive screening procedures were a new element in many places and the screening requirement alone has made a critical difference. Where there were not enough physicians to carry out the screening, or where a scarcity of Medicaid physician resources made using them for screening seem inefficient, special services have been developed. In the process, EPSDT has broadened the use of specially trained physician extenders to carry out many of the screening procedures and has facilitated the cooperation of physicians and other kinds of health professionals.

In careful studies, physician extenders have been found to provide health care of comparable quality to that provided by physicians. In one comparison of the quality of care given to 100 low-income infants by a pediatric nurse practitioner with the care given to 100 middle-income infants by pediatricians, the nurse practioners performed as well as the pediatricians in carrying out the needed tests, and their patients were pleased with the care they received.[35] In another study, child health interns compared favorably with pediatricians in their diagnostic ability and competence,[36] and public health nurses have been found to achieve significant effectiveness in caring for patients in an acute care clinic.[37]

EPSDT is not only demonstrating the value of these new health professionals at a time when highly-trained physicians must be used more efficiently, it may also be showing that high quality care can be made available for needy children where health care resources have not existed before.

Inter-agency Relationships

The existence of EPSDT as a program which involves the use of new forms of delivering child health services but is technically part of the welfare programs administered by HEW, has resulted in changes in the ways that federal programs for children relate to one another. State Medicaid agencies are required by federal regulations to make maximum use of Title V programs operated by the Public Health Service (PHS)—for example, the Maternal and Infant Care and Children and Youth Projects, and the Crippled Children's Services Programs—in the delivery of services called for by EPSDT. As a result, in some States agreements have been made between these programs and the local Medicaid agency for the use of Title V-funded health care resources in delivering or arranging for EPSDT services. In many States, however, issues related to reimbursement policies and the scope of services that are provided have made substantial cooperation difficult. In one state, which relies on the 7,000 physicians participating in Medicaid for all of its EPSDT services, one-third of all the children seen in the Title-V well-child clinics are Medicaid eligible, but cannot have their care paid for by Medicaid because of a state regulation that forbids reimbursement for services performed in a free-standing clinic. By contrast, in another State the capacity of the Crippled Children's Services program has been overloaded by EPSDT referrals.

To promote better coordination between federally-sponsored child health programs, teams from the Office of Maternal and Child Health and EPSDT have been visiting States to promote agreements between the appropriate State agencies. A conference on Title V and EPSDT programs was held in January by the University of Michigan School of Public Health, and a joint issuance on appropriate and effective cooperative arrangements in the delivery of EPSDT services is being developed. In addition, proposed new penalty regulations, recommendations for "positive incentives" to the States to improve their programs, and State program improvement plans all emphasize the use of comprehensive care providers, particularly those under Title V and other agencies of the PHS. Still, with cooperative arrangements with all child health programs under the PHS, the full service capacity of these programs will be limited to less than 3 million children—and these are programs which are already heavily utilized by needy children including many who are not eligible for Medicaid.

In a similar fashion, agreements have been signed with the Head Start program under the Office of Child Development (OCD). Head Start programs serve many Medicaid-eligible children, and often have active outreach components. Although not usually thought of as health programs, Head Start programs are required to provide or arrange for health services for the children they serve, including follow-up and support services much like those required under EPSDT. To facilitate the coordination of efforts and avoid duplication, a demonstration project involving 200 Head Start projects and EPSDT services was funded and has recently been completed. The Office of Child Development subsequently made grant money directly available to support Head Start Coordinators who work in several State capitals and whose job it is to link their projects more effectively with EPSDT programs.

A more effective relationship between EPSDT programs and public schools has been actively pursued because of the obvious advantages of reaching eligible children, especially older children. There are outstanding examples, most notably in New Orleans and Philadelphia, of how case-finding, screening, referral and follow-up can be effectively coordinated in and through school settings. Also, linkages with services available under Title I of the Elementary and Secondary Education Act are being explored in some States. These relationships must be specifically explored in each locality, however, because administrative problems and confidentiality and reimbursement arrangements can be very complex. The health service capacity and interest of local school systems in EPSDT varies widely. Further, increasing emphasis on the provision of comprehensive services in EPSDT programs may limit the likelihood of involvement with most school health programs as they now exist.

Related Program Benefits

The existence of EPSDT has meant that new services are being provided in many States. Far from delivering second class care—as some have charged—in some States EPSDT has meant that a full range of comprehensive health care services is being made available for the first time. Among the many new services attributable to EPSDT:[38]

- Georgia, Pennsylvania and Kentucky now have audiometric testing equipment
- Texas has purchased seven dental vans staffed by teams headed by dentists and working full time in underserved areas
- Vermont, Minnesota, and Wisconsin are now offering EPSDT screening services to the general public on a fee-schedule basis. In Minnesota, 60% of those screened are paying for the service privately
- Ohio refers all Medicaid children over three years old to dentists
- West Virginia has introduced preventive dentistry for Medicaid children
- California introduced counselling to adolescents and families for obesity and high blood pressure
- the number of AAP State chapters with EPSDT committees is up from 16 to 49; 22 State Medical Societies have EPSDT committees
- In Mississippi, phonocardio scans and audiometers are now available at all screening sites
- Oregon—100 children received previously unavailable orthodontia through EPSDT
- Pennsylvania and Kentucky have elements of quality control, and can "decertify" screening providers
- Kansas and Missouri are developing quality control systems
- Texas lab turnaround time reduced from months to one week

III. Making the Program Work

Implementing a program as demanding as EPSDT is a major undertaking. Setting up a management structure for the program and creating a usable reporting system have been tasks yet to be completely mastered.

While EPSDT was never intended to be just a screening program, the statistics available from the program have sometimes given that impression, due largely to Medicaid's data and reporting problems. When EPSDT was beginning, the screening component was recognized as the new service and the element on which data collection could most easily be focused. That seemed a reasonable choice at the time, for the States were expected to be moving directly to establishing sophisticated Medicaid Management Information Systems (MMIS) that would collect and report all the EPSDT program data relating to diagnostic and treatment services. Since States have been slow to establish MMIS data capabilities, EPSDT has been left with only screening data and a need to answer charges that it was "just a screening program."

Medicaid programs had also never before been required to track recipients through a health care sequence and assure individual case management for a range of services to any population, least of all to one the size of the EPSDT population. Before EPSDT, Medicaid's primary function was to process claims. In fact, no public agency, whether Federal or State, health or welfare, has had a management and reporting task of this magnitude before. Title V projects are only expected to serve as many children as live in their project area or as many as they are capable of serving, and are not required to keep records in ways that would link a variety of services for each individual child. Thus, with or without MMIS, it was not surprising that States should have found the EPSDT management requirements difficult to meet.

Now, however, after a variety of false starts and several trying years, the worst of the difficulties are in the past. Twelve States already have information systems with the capability of assuring that the positive screening findings are referred for treatment, and they will soon be able to process the necessary records through the full delivery of treatment and through periodic screening as well. South Carolina has developed a billing system that shows EPSDT-related treatment separately by the simple device of a multi-part bill. As claims work their way through the Medicaid system, South Carolina now knows whether to attribute them to conditions discovered in the course of an EPSDT screening. Ohio has developed a system which relies on manual sorting of EPSDT-related treatment at the county level, where the numbers are manageable. Pennsylvania has developed its own version of multi-part billing, as has New Jersey. With the experience of a variety of models to choose from, the move to better reporting of EPSDT-related services is expected to occur much more rapidly in the remaining States. With some 20 States in various phases of establishing a management capability which will incorporate an EPSDT "module," full case management capability is no longer a distant possibility.

At a minimum, the requirements of EPSDT are forcing a healthy cooperation between State health and welfare agencies and between the public and private sectors involved in the delivery of care. The fact that 23 States implement their EPSDT programs with nearly exclusive involvement of the States' public health systems, and another 22 rely on public health departments to a significant degree, has made an important impact on those programs. While eight States rely solely on private practitioners for EPSDT, physicians are integrally involved in all States, especially for the essential diagnosis and treatment services.

States' Role in Implementation

This pattern of implementation serves to aid the integration of health and welfare services that is ultimately necessary if needy children are to get comprehensive care. In part, this has been possible because EPSDT has permitted the States wide latitude in the implementation of their programs. Federal regulations prescribed a set of actions that must be taken in relation to each child: informing the family, screening and giving treatment in a timely manner, providing for re-screening, and the provision of necessary related support services. EPSDT does not specify who will be responsible for these functions, or how they will be carried out. Those critical details have been left to the State to determine, and the States have chosen—each to suit their own conditions and needs—what the administrative structure of the program will be, how public and private health care providers will be involved, and what the data collection and reporting mechanisms for the program will be.

Ideally, there should have been extensive Federal planning and demonstration activity to precede the implementation of such a demanding new program. At the time the program was enacted, however, it was assumed that adequate provider and management capabilities were available and in place. Few anticipated that the significantly new requirements of EPSDT would be initially beyond the management capabilities of many States.

Given the flexibility permitted the States in their implementation of the program, and the management capabilities that have had to be developed in many places, each State has, in effect, become its own "demonstration" program. States like Michigan have developed their own internal management incentives to operate a successful and well-managed program—in part by negotiating screening targets between both the Medicaid agencies and the public health agencies at State and local levels. Both departments have been effectively involved in performing program work and each has positive incentives to monitor their own and the other department's activities with respect to EPSDT. In addition, Federal EPSDT staff is exploring ways to provide positive incentives to States.[39]

EPSDT's experience in managing and reporting on the outcomes of its processes is providing invaluable experience for the task that lies ahead if an even bigger undertaking like National Health Insurance is to be effectively managed.

The Cost and Quality of EPSDT Services

Evidence of the program's cost-effectiveness is already beginning to come in. In a recent study of the costs of the EPSDT program, it was found that in one State the children served by the EPSDT program used 55 percent fewer hospital days and 26 percent fewer physician visits (other than office visits) than those children not screened.[40]

In Portsmouth, Virginia, a package of EPSDT-type services produced dramatic results. Even with the added expense of transportation and other support services, those AFDC recipients who had received the comprehensive, EPSDT-like services were found to have Medicaid costs that were more than one-third lower than recipients who used Medicaid but not the EPSDT-style services. The screened group also spent one-third less time in the hospital than their unscreened counterparts, had about half as many physician visits, and drug costs of about one-half.[41]

Adults, who receive far more institutional care than children, have always been the more expensive recipients of Medicaid services—over $800 per Medicaid adult served v. under $200 per Medicaid child in FY 1975, due in large part to long-term care for the aged.[42] In FY 1976, States carrying out active screening programs spent less than one percent of their Medicaid funds on EPSDT screening and administration. Texas, which has a particularly active EPSDT program and high enrollment rates, has seen the number of children receiving care under Medicaid go up by 77% between 1972-76. Expenditures for that group rose 18%. During the same period, expenditures for adults rose 21%—though the number served went up by a mere 7%.[43] In all States less than 25% of their Medicaid funds was spent for all types of children's services; in some States this proportion is as low as 14%.[44]

Despite protestations by States that they cannot afford the additional costs of EPSDT, screening and treating the diagnosed conditions of children have potential dramatic long-term cost savings while adding little to immediate cost increases. The report of the Sub-Committee on Oversight and Investigations of the Committee on Interstate and Foreign Commerce, House of Representatives, in urging fullest implementation of the EPSDT program, estimates that a complete preventive child health care program through age 16 would only cost $1,000 per child—an amount comparable to just two weeks in a hospital at current prices.[45] In most States, a full EPSDT health assessment costs less than $30.[46]

By preventing acute illness and reducing the need for expensive institutional care, preventive programs like EPSDT represent the long-term advantages of removing from the State the fiscal burden of caring for severely handicapped people, as well as improving the quality of life for those individuals whose health future is protected.

Administering EPSDT

Given the direct health status implications of EPSDT for the children it serves, there is no question that it should be administered as a health care program and as part of overall DHEW health policy. That it is not is a necessary part of the program's history, but need not be part of its future. EPSDT began as the ultimate anomaly: a health delivery program attached to a reimbursement mechanism within the welfare system. Yet, despite the obvious difficulties that such an administrative arrangement suggests, and its health care implications, it is by no means clear that moving EPSDT to another agency would be advantageous.

Two misconceptions accompany most discussions of moving EPSDT. The first is that moving EPSDT would be like moving a conduit to the money represented by Medicaid—almost as though Medicaid funds would automatically become available for the addition of skilled staff, organization of supportive services, and case management and other quality innovations in a way they are not available now. The second is that the existing health agencies are the best or only appropriate managers of health programs and that moving EPSDT would somehow eliminate its problems. That position suggests that EPSDT somehow faces problems of its own making, or at least directly related to where it is located. What that overlooks is that EPSDT faces major problems relating not to who is administering it, but to what it has been charged to do within the available resources and the existing health services structure.

EPSDT does face some special problems because it is related to the categorically-based welfare system. That welfare system has not been the most hospitable climate for a program which actively advocates its services and seeks to have them more widely used. Welfare programs have never been actively promoted, the eligible poor have never been urged to sign up for welfare, and generally welfare agencies do not judge program success by how many people are receiving benefits. It is also true that cooperation with other health care programs would no doubt be improved if EPSDT were recognized for what it is—a health care delivery program. In terms of personnel, EPSDT has been a health program; actual services have been provided by health care professionals using existing health resources—health departments, local clinics, hospitals, and private physicians. There is a need, however, for technical assistance teams from the PHS and the Medical Services Administration (MSA) as a regular part of the Federal resources available to assist States and programs serving the health needs of poor children.

Whether a transfer of EPSDT and Medicaid to another agency would solve any problems or result in a more effective program remains an open question for some. Nonetheless many existing gaps revealed by EPSDT programs occur in areas where other agencies already have responsibility, and some of the services needed to improve program quality such as quality assurance activities, health manpower development, and expanded dental services for children have always been "Health" activities, but remain inadequate. Further, the law governing Medicaid would not be changed by administrative maneuvering. State Medicaid agencies will be no more responsive to other agencies than to MSA in matters of resource allocation, interagency coordination, enrichment of service, improved fee schedules, simplification of bureaucratic requirements, more efficient reimbursement, and all those details, large and small, which affect the quality and availability of services. Many of those decisions lie, in any case, in State legislatures and governors' budget offices—certainly outside the control of State Medicaid or health personnel, and outside the control of the administering agency, wherever it is located.

IV. EPSDT and the People It Serves

Ultimately, a program must be judged by its ability to provide a needed service to those who are entitled to it. If the EPSDT recipients in Region V are any indication, then, as the report of that Region's programs concludes:

> ". . . the extremely positive feelings of clients toward the program are not to be discounted."[47]

The summary of that report notes:

> "Clients who have been through the program strongly advocate case management. Many of them even feel that EPSDT should be required as a condition of eligibility (for AFDC)."[48]

For the most part, clients like the program because they are receiving a service that was not available to them before. Even to the seasoned eyes of an AAP representative:

> "There has been less duplication of services than was expected; few screening exams are as comprehensive as the EPSDT exam."[49]

The Recipient Subcommittee of the Blue Ribbon Task Force for the Evaluation of Medicaid in Texas unanimously recommended that ". . . the EPSDT program should be expanded to cover all children from poor families. Preventive health measure (sic), like those provided by the EPSDT program , will improve the quality of health for children, and avoid the more expensive treatment when illness is neglected in its early stage."[50]

Eligibility

There are, however, problems that arise for the people using EPSDT. Eligibility for EPSDT depends in most States on eligibility for welfare benefits, and health care needs do not necessarily correspond to welfare status. Estimates of yearly turnover in welfare rolls vary. It has been found to be as low as six percent of the population in some places, but has been as much as 30% in some States at times. In Connecticut, 94% of the AFDC families who were eligible for Medicaid in January of 1973 had been on the rolls for more than two years.[51] A recent study by New York City authorities also indicated that a majority of AFDC families were on the rolls for an extended period of time.[52] The 1973 AFDC study indicated that only 23% of the families studied were discontinued during that year.[53]

Whatever the numbers, however, for those families whose welfare eligibility lapses before their health care needs are met, the problem is a serious one. Some children screened and diagnosed as having treatment needs may find their eligibility for Medicaid is gone before their treatment is completed. EPSDT reconfirms the need for a more continuous and comprehensive method of assuring the right to treatment for people whose incomes often vary widely from month to month.

Confidentiality

Other questions have been raised concerning clients' records and freedom of choice. Confidentiality requirements under AFDC and Medicaid are not a barrier to providing services. Medicaid agencies may release names and health data to other agencies providing services in EPSDT when the release of the information is directly connected with the administration of the program, e.g., to providing medical and health-related support services. Parental consent must be obtained, as in most matters concerning children.

The existence of a bank of health data has been a worry to some. This problem is an inherent part of a modern, complex society, and is certainly not confined to the EPSDT program. As with Medicaid data generally, most States seem to have adequate safeguards for confidential data at present. However, this issue will arise in the larger context of a universal program under National Health Insurance, and for adults as well as children.

Freedom of Choice

The size and scale of the EPSDT program has raised another question in those areas where States have elected to provide the screening services exclusively through public health departments. Some physicians and those concerned with the issues implicit in large-scale government health programs have worried that EPSDT recipients will not have sufficient freedom of choice in health care providers. For poor people whose only previous choice has been to have no care at all, the issue may be largely moot; they are pleased to participate in EPSDT because it does represent a choice—namely, health care. It is the case, however, that under Medicaid regulations recipients may seek EPSDT screening from their own physicians. Some States, in their efforts to organize services in manageable and economical ways, have not provided for this possibility. This is a program issue which needs closer attention through Medicaid compliance monitoring.

Questions are also often raised about recipient apathy. Most of the children are dependent children in their younger years, and relatively few are over 18. Thus, we need to recognize certain responsibilities for child health that might not be readily recognized nor attainable by the families of "EPSDT children," especially for those where the parents' education in the need for preventive health is integral to the program. The most binding part of the EPSDT regulations on States are those assuring supportive services; the need of the poor for these is demonstrated nationwide. As indicated above, parents are enthusiastic about EPSDT when the purpose of the program is explained to them and they understand it.

EPSDT, by helping improve child health, is one way to break the poverty cycle and reduce unnecessary dependency. It is not dependency-creating, since the focus is on improved access and better utilization of health care, not on "spoon-feeding" people with unneeded medical care.

V. The Bottom Line

EPSDT represents the first time a government agency—State or Federal—has undertaken a comprehensive health care program for a vast number of needy children, whatever their health needs, whatever the available resources, wherever they are. Many of the problems EPSDT faces reflect problems in the system: of access, of resources, of unwillingness to deal with the problems of treating Medicaid children, and sometimes of an inability to recognize the value of preventive care. EPSDT, whether managed out of "welfare" or "health," will still have to try to buy services from the system that failed poor children in the past, or try to improve the way it serves them.

Still, however important EPSDT is in the lives of individual needy children whose futures have been re-written by the program, an equally significant point may lie in the lessons it is providing. For many years the Congress and a wide variety of special health interest groups have been discussing first, whether, and more recently how, the United States should adopt a national health insurance program. Much of that discussion has been theoretical; we simply do not know how many of the lessons learned in other Western countries will prove applicable to the United States. But since 1965, when the Medicaid and Medicare programs were enacted, we have had the opportunity to learn what a limited form of national health care reimbursement would entail. With EPSDT in place, we are beginning to fill in some of the troublesome details about health service delivery as well. Whether EPSDT remains as a program or not, the issues it is grappling with and the services it is attempting to provide will have to be dealt with if National Health Insurance is going to serve any of us—but particularly the poorest among us—well.

Those lessons can be briefly summarized. EPSDT is confronting—in many instances for the first time in any extensive federal health care program:

—the role of public health departments in a system that relies largely on the private sector for the actual provision of care
—the value of preventive care, particularly for children
—the critical importance of health-related support services
—the role of health education in fostering appropriate use of health care resources
—the shortage and maldistribution of private health care providers
—the importance and difficulties of establishing a reporting and billing system that can follow a patient from problem identification through treatment
—the resistance that can develop when private providers are asked to give proof of the kind and quality of the services being given
—the inadequacies of "means-tested" medical care
—the difficulties of tying medical care eligibility to welfare eligibility standards
—what may be expected if critical decisions about services or reimbursement policies are left to the States for even part of the participating population.

Whatever may be said about its ambiguous beginnings, the planning failures, the gaps in service, and the unevenness of its implementation, EPSDT is making critical observations about the existing health care system, and particularly about its ability to serve the poor, and is doing something about it.

By having to confront what is in place, and trying to make it more responsive to the poor, EPSDT is coming to grips with fundamental problems in the ways in which our health care is provided. The managerial and programmatic gains of the program should be built upon and strengthened in the future, and not lost as we move toward new forms of health care delivery. The experience of the program, which indicates the need for development of preventive health services, health support services, and real management of health care delivery, should be carefully considered in National Health Insurance proposals.

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