MEDICAID

Stronger Efforts Needed to Ensure Children’s Access to Health Screening Services
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Abbreviations

AAP American Academy of Pediatrics
BBA Balanced Budget Act of 1997
CMS Centers for Medicare and Medicaid Services
EPSDT Early and Periodic Screening, Diagnostic, and Treatment
HCFA Health Care Financing Administration
HHS Department of Health and Human Services
OBRA 89 Omnibus Budget Reconciliation Act of 1989
SCHIP State Children’s Health Insurance Program
July 13, 2001

The Honorable Henry A. Waxman
Ranking Minority Member
Committee on Government Reform
House of Representatives

The Honorable John D. Dingell
Ranking Minority Member
Committee on Energy and Commerce
House of Representatives

Medicaid, a joint federal and state program, finances health coverage for 21 million, or more than one in four, of the nation’s children. For many years, one of its central services has been to screen children for various conditions so that health problems can be found early and treated before they worsen. This service, called Early and Periodic Screening, Diagnostic, and Treatment (EPSDT), calls for states to provide children and adolescents under age 21 with access to comprehensive, periodic evaluations of health, developmental, and nutritional status, as well as vision, hearing, and dental services. Despite the importance of these services, there is concern that families are not sufficiently informed of benefits and that enrolled children are not receiving them. In addition, the adequacy of state efforts to ensure children’s access to these services has been challenged in court cases throughout the country. These lawsuits have alleged that state Medicaid programs are not doing an adequate job of screening children for medical conditions or providing treatment for the children who need it.

An additional area of concern has been how these services are faring under managed care plans. Increasingly, state Medicaid programs are contracting with such plans to provide Medicaid-covered services, including EPSDT. In many cases, states pay these plans a prepaid fee per Medicaid enrollee (a “capitated” fee) to provide most medical services. Managed care plans have traditionally placed an emphasis on preventive care as a way to provide appropriate care in the most efficient setting, to avoid or correct health problems before they become more acute or costly. However, Medicaid beneficiaries in some arrangements are “locked in” to a particular plan for a period of time—and therefore are restricted to receiving care solely from providers in that plan. This restriction in
choice—together with concerns that the prepayment of capitated fees may create incentives for health care providers to under-provide services to maximize profit—has raised awareness of the need for assurance that managed care plans provide required EPSDT services.

To better understand federal and state efforts to ensure that children in Medicaid receive EPSDT services, you asked that we examine:

1. the extent to which children in Medicaid are receiving EPSDT services;
2. efforts that selected states are taking to improve delivery of EPSDT services, particularly within managed care; and
3. federal government efforts to ensure that state Medicaid programs provide covered EPSDT services.

To assess the extent to which EPSDT services were being provided, we reviewed state reports submitted to the Health Care Financing Administration (HCFA), the agency that administers Medicaid at the federal level. We also reviewed major reports and studies on the provision of EPSDT services. To assess actions or innovative practices that states had in place or were implementing to provide EPSDT services, we contacted selected states and visited five—California, Connecticut, Florida, New York, and Wisconsin. We selected these states to represent different regions of the country and because they had either relatively high numbers of children in managed care or a reputation for having an innovative EPSDT program, or both (see app. I for details on the states we visited). We also reviewed several major legal settlement agreements and court orders to identify examples of practices being put in place to respond to concerns about access to EPSDT services. Finally, to determine what federal efforts were under way, we reviewed documents and discussed EPSDT monitoring with HCFA central and regional office representatives, and we obtained related reports from reviews conducted since 1995. We conducted our work from September 2000 through June 2001 in accordance with generally accepted government auditing standards.

1In June 2001, HCFA’s name was changed to the Centers for Medicare and Medicaid Services (CMS). Since our fieldwork was conducted while the agency was known as HCFA, we are referring to the agency in our report findings by its former name.
The extent to which children in Medicaid across the country are receiving EPSDT services is not fully known, but the available evidence indicates that many are not receiving these services. A comprehensive view is not possible because annual state reports to HCFA on the delivery of EPSDT services are unreliable and incomplete, particularly for children in managed care. The most reliable evidence comes from studies of specific EPSDT services, such as lead screening or dental services, and reviews conducted in a handful of states or covering the medical records of a relatively small number of patients. For example, prior studies we have conducted of lead screening and dental care nationwide found that most children in Medicaid do not receive services, although they are at significantly higher risk than other children. A Department of Health and Human Services (HHS) Office of Inspector General study specific to managed care similarly found that less than one-half of enrolled children in their sample received any EPSDT screens. These and other studies have found that several factors contribute to the lack of services. Some involve program issues, such as inadequate systems for ensuring that services are provided. Others involve beneficiary issues, such as parents’ being unaware of the need for or availability of covered services.

The five states we visited were taking actions to improve the compiling and reporting of data to better monitor whether children were receiving services. For example, Wisconsin is in the process of linking several state databases to provide a more complete picture of the care being given to individual children in multiple settings. As an incentive for managed care plans to report all health screenings, New York publishes statistics that compare the performance of these plans on child health-access measures such as lead screening and well-child visits. The states were also acting to better ensure that providers and managed care plans delivered required services and to improve outreach and education to Medicaid children and families in need of services. California, for example, requires health plans to contract with local health departments to coordinate care for children, and Florida mails reminder letters to parents when their children are due for EPSDT screens.

Federal efforts to ensure that children are receiving services have focused largely on changing the format and specificity of state reports so that they can collect reliable information about the extent to which children are being screened. While these efforts take a positive step, they do not adequately address the difficulties that states face in obtaining information about EPSDT service delivery, particularly in capitated managed care settings in which payments are not directly tied to services provided. Obtaining accurate data will require additional time and effort by states,
plans, and providers. To identify areas for improvement, some HCFA regional offices have worked with states to assess EPSDT activities. For example, HCFA’s San Francisco Regional Office conducted a collaborative review with California that helped identify such issues as gaps in informing beneficiaries about EPSDT benefits. HCFA has in recent years conducted eight studies in other regions or states that included any review of EPSDT, only four of which focused exclusively on EPSDT. Although many of the actions taken by one state to improve the delivery of services may apply to other states, HCFA does not have mechanisms in place for identifying and highlighting such actions. HCFA has recently signaled a renewed focus on EPSDT, proposing that it expand its role in overseeing and promoting state EPSDT activities. A specific plan for how HCFA—now called CMS—will implement these efforts has not yet emerged.

We are recommending that CMS work with states to develop criteria and a timetable for assessing and improving the reporting and provision of EPSDT services. We are also recommending that CMS develop mechanisms for identifying and highlighting practices that could be used as models for other states. In commenting on a draft of this report, CMS generally concurred with our recommendations that the agency work with states on these criteria and time frames and develop mechanisms for sharing information among states, but said improvement plans may not be needed for all states. We clarified our recommendation to indicate that CMS should determine the need for state improvement plans based on the outcome of a consistent assessment of all states.

Background

For more than 30 years, federal law has provided comprehensive health coverage for low-income children through Medicaid. The children eligible for such care have made up a significant and growing portion of the nation’s population, as eligibility for Medicaid benefits has expanded to cover increasing numbers of previously uninsured children. In 1998, Medicaid covered more than one-third of young children ages 0 through 5, and more than one-fourth of children under age 21 (see figure 1). The 21

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2Specifically, the Social Security Amendments of 1967 (P.L. 90-248) enacted the EPSDT benefit.

3The Omnibus Budget Reconciliation Act of 1989 (P.L. 101-239) required states to cover pregnant women and children under age 6 in families with incomes at or below 133 percent of the federal poverty level. The Omnibus Budget Reconciliation Act of 1990 (P.L. 101-508) required states to phase in coverage (to 2002) of children ages 6 through 18 in families with incomes at or below 100 percent of the federal poverty level.
million children covered by Medicaid that year composed slightly more than half of the 41 million people in the program while the $32 billion spent for their care was about 23 percent of the $142 billion spent on the program by the federal government and states.

An increasing number of children are also becoming eligible for EPSDT services, as federal policy designed to cover the growing number of uninsured children allows states to provide Medicaid services through the federally supported State Children’s Health Insurance Program (SCHIP). To implement SCHIP, states have the option of expanding their Medicaid programs, developing separate SCHIP programs, or doing some combination of both. If a state elects Medicaid expansion, it must offer the same comprehensive benefit package, including EPSDT services, to SCHIP beneficiaries as it does to Medicaid beneficiaries. In 2000, more than 1 million children were enrolled in SCHIP Medicaid expansion programs and were therefore also eligible for EPSDT services.
Although many coverage, eligibility, and administrative decisions are left to individual states, the federal government sets certain requirements for state Medicaid programs. Coverage of screening and necessary treatment for children is one of these requirements. EPSDT components are designed to target health conditions and problems for which growing children are at risk, including iron deficiency, obesity, lead poisoning, and dental disease. They are also intended to detect and correct conditions that can hinder a child’s learning and development, such as vision and hearing problems. For many children, especially those with special needs because of disabilities or chronic conditions, EPSDT is an important help in identifying the need for essential medical and supportive services, and in making these services available.4

The federally required EPSDT components that constitute an EPSDT “screen” include a comprehensive health and developmental history, a comprehensive unclothed physical exam, appropriate immunizations, laboratory tests (including a blood lead-level assessment), and health education.5 Other required EPSDT services include

- vision services, including diagnosis, treatment, and eyeglasses;
- dental services, including relief of pain and infections, restoration, and maintenance;
- hearing services, including diagnosis, treatment, and hearing aids; and
- services for other conditions discovered through screenings, regardless of whether these services are typically covered by the state’s Medicaid plan for other beneficiaries.6

While state Medicaid programs must cover EPSDT, they have some flexibility in determining the frequency and timing of screens. States develop, in consultation with recognized medical and dental organizations, their own “periodicity schedules,” which contain age-specific timetables that identify when physical examinations and certain laboratory tests and

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4See Children with Disabilities: Medicaid Can Offer Important Benefits and Services (GAO/T-HEHS-00-152, July 12, 2000).

5The required components of EPSDT are found in Section 1905(r) of the Social Security Act (SSA).

6Section 1905(r) of the Social Security Act requires that EPSDT include services, described in section 1905(a), that are necessary to correct or ameliorate defects and physical and mental illnesses and conditions discovered through screening, whether or not those services are covered by the state’s Medicaid plan.
immunizations should occur. These tables vary somewhat from state to state. For example, the number of recommended EPSDT screens ranged from 15 to 29 across the five states we visited (see table 1).

Table 1: Recommended Number of EPSDT Screens, by Age Group, for Selected States

<table>
<thead>
<tr>
<th>Age Group</th>
<th>American Academy of Pediatrics</th>
<th>California Fee-for-Service</th>
<th>California Managed Care</th>
<th>Connecticut</th>
<th>Florida</th>
<th>New York</th>
<th>Wisconsin</th>
</tr>
</thead>
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<td>6</td>
<td>8</td>
<td>8</td>
<td>8</td>
<td>6</td>
<td>6</td>
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<td>1-5</td>
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<td>6</td>
<td>6</td>
<td>6</td>
<td>6</td>
<td>7</td>
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<td>7</td>
<td>7</td>
<td>9</td>
<td>5</td>
<td>4</td>
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<td>15-20</td>
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<td>6</td>
<td>6</td>
<td>6</td>
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<td>3</td>
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<td>All ages</td>
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<td>15</td>
<td>27</td>
<td>27</td>
<td>29</td>
<td>20</td>
<td>20</td>
</tr>
</tbody>
</table>

Note: Table is based on periodicity schedules effective as of January 2001.

*The number of screens recommended by the American Academy of Pediatrics (AAP) is included for reference.

*California has separate periodicity schedules for fee-for-service and managed care programs.

*Florida exceeds AAP guidelines because it recommends check-ups at ages 7 and 9 for at-risk children.

Source: American Academy of Pediatrics and each state’s Medicaid agency.

The Growth of Medicaid Managed Care

States have increasingly turned to managed care as a way to deliver Medicaid services, including EPSDT. From 1991 to 1999, the proportion of all Medicaid beneficiaries enrolled in managed care—either capitated or in primary care case management models—rose from about 10 percent to about 56 percent. Only two states do not have at least some Medicaid beneficiaries in managed care plans.

Managed care, with its emphasis on preventive and primary care, is philosophically an ideal model for delivering EPSDT-type services. Under a capitated managed care model, states contract with managed care plans, such as health maintenance organizations, and pay a fixed monthly fee per

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This proportion represents the Medicaid population enrolled in capitated plans and programs known as primary care case management models (PCCM). The PCCM model is similar to a fee-for-service arrangement except that a primary care provider is paid a monthly, per-capita case management fee to coordinate care for beneficiaries. These programs are not included as part of our managed care review, but they are included here because specific calculations of Medicaid enrollees in capitated managed care over time were not available at the time of our review. Compared to PCCM enrollment, about five times as many beneficiaries are enrolled in capitated health plans.
Medicaid enrollee (a capitated fee) to provide most medical services.\textsuperscript{8} This model, with its fixed prospective payment for a package of services, creates an incentive for plans to provide preventive and primary care to reduce the chance that beneficiaries will require more expensive treatment services in the future. However, capitated managed care can also create a financial incentive to underserve or deny beneficiaries access to needed care. Moreover, Medicaid beneficiaries required to enroll in managed care may find it difficult to seek alternative care if their plan providers fail to meet their needs. Because of the potential to underserve, states must build in safeguards and accountability measures, such as grievance and appeals processes, to ensure that beneficiaries receive appropriate care.\textsuperscript{9}

The Congress has given states greater flexibility in moving Medicaid beneficiaries into mandatory managed care plans. Before the Balanced Budget Act (BBA) of 1997, a state could require Medicaid beneficiaries to enroll in managed care only if it first obtained approval from HCFA to waive certain statutory provisions, such as the freedom to choose providers. Under HCFA waivers, states have implemented a variety of mandatory managed care programs, ranging from programs serving limited populations in just a few counties to state-wide programs covering all Medicaid beneficiaries, including children with special needs.\textsuperscript{10} The BBA gave states new flexibility in implementing mandatory Medicaid managed care programs, allowing them to implement programs through an amendment to their state Medicaid plan without first obtaining a HCFA waiver.\textsuperscript{11}

\textsuperscript{8}States often “carve out” services, such as dental, mental health, or pharmacy, from their managed care benefit package. Providers of these services are generally paid on a fee-for-service basis.

\textsuperscript{9}See Medicaid Managed Care: Challenge of Holding Plans Accountable Requires Greater State Effort (GAO/HEHS-97-86, May 16, 1997).

\textsuperscript{10}See Medicaid Managed Care: Challenges in Implementing Safeguards for Children With Special Needs (GAO/HEHS-00-37, Mar. 3, 2000).

\textsuperscript{11}The BBA exempted certain groups from mandatory enrollment through state plan amendments. These include children with special health care needs, Indians who are members of federally recognized tribes, and beneficiaries eligible for both Medicare and Medicaid. States must still obtain HCFA waivers for mandatory managed care enrollment of these populations.
The Omnibus Budget Reconciliation Act of 1989 (OBRA 89) made significant changes to improve the provision of EPSDT services to children in Medicaid. It required that the Secretary of HHS set state-specific annual goals for children’s participation in EPSDT; mandated state-established periodicity schedules for screening in dental, vision, and hearing services; required blood lead assessments appropriate for age and risk factors; and imposed new reporting requirements.

To fulfill the state-specific goal requirement, in 1990 HCFA set a participation goal of 80 percent by 1995 for every state. To measure progress towards participation goals and in accordance with the OBRA 89 requirement that states report certain EPSDT statistics, HCFA required, starting in 1990, that states submit annual EPSDT reports (known as the form 416). The EPSDT report captures, by age group, the number of children who (1) received EPSDT health screens; (2) were referred for corrective treatment; (3) received dental treatment or preventive services; and (4) were enrolled in managed care plans. Since fiscal year 1999, states also are required to report the number of blood tests provided to screen children for lead poisoning.

Lawsuits have been filed in many states alleging shortcomings in the provision of EPSDT services. According to information from the National Health Law Program, at least 28 states have been sued by beneficiaries or advocates since 1995 for failing to provide required access to EPSDT services. These lawsuits range from single-issue suits—such as coverage of selected services including mental health services in Maine—to alleged programwide failures and deficiencies in Texas, Tennessee, and Washington, D.C. In several instances, the outcomes, including court orders and settlements agreed to by both parties to remedy known concerns, illustrate the difficulties states have encountered in providing services and also suggest strategies to remedy established EPSDT deficiencies.

Despite statutory reporting requirements, reliable national data are not available on the extent to which children in Medicaid are receiving EPSDT services. However, a number of studies of limited scope indicate that many children in Medicaid are not receiving EPSDT services. These studies also show that several factors are at work in limiting the successful delivery of EPSDT services. Some factors are program-related, such as a lack of providers or systems to ensure access to covered services. Others are related to beneficiaries themselves, such as the beneficiaries’ lack of
awareness about the importance of preventive health care and about services covered, or their difficulty in maintaining continuity of care with one provider.

Reliable and Comprehensive National Data Do Not Exist

HCFA’s efforts to assemble reliable information about EPSDT participation in each state have so far been unsuccessful. State-reported data, upon which HCFA depends, are often not timely or accurate. For example, states were required to submit their fiscal year 1999 reports by April 1, 2000. As of January 2001, 15 states had not submitted their 1999 reports and another 15 states’ reports had been returned by HCFA because they were deficient. HCFA and state officials acknowledge long-standing difficulties that states face in their efforts to collect complete and reliable data, which are used as the basis for the EPSDT reports. These difficulties continue despite HCFA’s attempts to improve the reliability of state EPSDT reports by revising the report format and guidance.

One reason for the continued difficulty involves collecting data on EPSDT services provided under managed care. Under the more traditional fee-for-service approach, data on service delivery are often relatively easy to collect as part of the payment process because states pay providers for each service for which they bill the state. Under capitated managed care, however, states pay the managed care plan a prospective monthly per-enrollee fee that is not tied to the individual services provided. As a result, data on service utilization (often referred to as “encounter data”) are not necessarily captured. Instead, states have to rely on managed care plans to collect and report these data separately. Managed care plans, particularly those that also pay their participating providers on a capitated basis, often have difficulty collecting and reporting complete and accurate data.

States face continuing challenges in determining how to minimize the administrative burden on managed care plans and providers while still collecting information at the level needed to administer the program. For example, to facilitate the collection of EPSDT data, California uses a special EPSDT form for providers to use in documenting the components of EPSDT services provided. California’s managed care contracts also call for managed care plans to collect the EPSDT forms from their providers and submit detailed encounter data to the state. However, the state has had difficulty enforcing these requirements across the several layers of contractors involved in its managed care delivery system. For example, in the Los Angeles area, the state contracts with two large managed care organizations that subcontract with multiple commercial and nonprofit health plans, such as Blue Cross, that further subcontract with a network
of providers. Most of these contracts are on a capitated basis. State officials said that some of the health plans had difficulty collecting the required encounter data and that one plan had never submitted the required data. Also, they said that capitated providers of health plans had little incentive to fill out and submit the EPSDT form because their payments are not linked to it. The state’s Medicaid agency has not imposed sanctions against noncompliant plans or providers, restrained in part by its reluctance to lose any providers given the shortage of providers willing to serve children in Medicaid.

Although problems are more extensive with managed care data than with fee-for-service data, most of the states we visited had some difficulty obtaining complete and accurate data from fee-for-service providers as well. Florida illustrates the kinds of difficulties that can be encountered. Providers in Florida are required to use a specific EPSDT code and a claim form to document the components of EPSDT services they provide. However, according to state officials, providers often choose to use other codes instead. For example, providers may submit a claim under a comprehensive office-visit code for a new patient that pays a higher rate than an EPSDT screen or they may submit claims under other comprehensive office-visit codes that require less documentation.12

Compounding these difficulties are limitations in claims processing systems used by states for fee-for-service programs or by managed care plans. In Florida, for example, if a child receives laboratory work from one provider and the remaining components of a screening from another provider, some managed care plans’ data systems do not combine the services to correctly reflect that a full screening for the child has been provided. Similarly, some states have problems tracking referrals and follow-up treatment services. This tracking difficulty may explain why, in

12For example, under Florida's current Medicaid fee schedule for physicians, the payment rate for an EPSDT screen (code W9881) is $69.12. The payment rate for a comprehensive office visit of a new patient is $87.24 if it involves medical decision-making of high complexity (CPT code 99205) and $69.12 if it involves medical decision-making of moderate complexity (CPT code 99204).
HCFA’s 1998 compilation of state reports, seven states reported that no children had been referred for corrective treatments.13

Some Studies Show Screening Rates Are Low

While HCFA’s data cannot present a reliable and comprehensive picture of the extent to which children in Medicaid receive EPSDT services, other studies indicate that many of these children are not receiving such services. These other studies have been narrow in scope, allowing analysts to overcome the kinds of problems that so far have thwarted attempts to gather comprehensive data. They have focused on specific EPSDT services or reviews of a sample of patients’ medical records. For example, in recent years we have conducted reviews of screening rates for lead poisoning and dental care, basing our analysis primarily on data from national health surveys.14 Both studies found low screening rates for these specific services among low-income populations served by Medicaid. For lead poisoning, about 19 percent of children in Medicaid aged 1 through 5 were screened—a serious concern, because these children are almost five times more likely than others to have a harmful blood lead level. The screening rate for potential dental problems was similar, with about 21 percent of low-income children aged 2 to 5 having had a dental visit in the previous year. Older children fared somewhat better, with 36 percent of low-income children aged 6 to 18 having had a dental visit within the previous year.

Studies by others have shown similar results. A 1997 study by HHS’ Office of Inspector General, which examined a sample of 338 children’s medical records from 12 health plans in 10 states, estimated that only 28 percent of

13Determining whether children are receiving medically necessary treatment services is an even more difficult proposition, as providers determine appropriate medical treatment services based on the health condition of the individual child. The federally required EPSDT reports do not require information to track whether treatment services were provided or whether referrals for treatment resulted in any provided services. Most states we visited had no formal mechanisms for comprehensively tracking whether referrals for treatment resulted in provided services. Instead, they relied largely on small sample reviews of medical records to monitor whether children were receiving needed treatment services.

14Lead Poisoning: Federal Health Care Programs Are Not Effectively Reaching At-Risk Children (GAO/HEHS-99-18, Jan. 15, 1999), and Oral Health: Dental Disease Is a Chronic Problem Among Low-Income Populations (GAO/HEHS-00-72, Apr. 12, 2000). The first study used data from the National Health and Nutrition Examination Survey, which is conducted by the National Center for Health Statistics of the Centers for Disease Control and Prevention. The study also used data from HCFA’s State Medicaid Research Files. The second study used data from the Medical Expenditures Panel Survey, which is conducted by the Agency for Healthcare Research and Quality.
children enrolled in Medicaid managed care received all prescribed EPSDT screens and that 60 percent received no screens at all. In several states, organizations responsible for external quality review of the Medicaid program have conducted sample medical record reviews of children enrolled in fee-for-service programs as well as those in managed care, and they have found similar results. For example, a study by Minnesota’s external quality review organization found that nearly half of the children in managed care plans whose files were reviewed had not visited a clinic in the previous year, and only 6 percent of those due for an EPSDT screen had received a comprehensive screen. A study in Washington State found that for the sampled files of children in managed care, 32 percent of infants (birth to 15 months) and 20 percent of children age 3 to 6 years received screenings for all aspects of EPSDT. The screening rates for children in fee-for-service care were also low—7 percent for infants and 24 percent for children age 3 to 6 years.

Several Factors Contribute to Children Not Receiving Services

Studies such as those cited above have collectively identified a number of reasons why many children in Medicaid are not receiving EPSDT services. Some of these reasons involve program-related matters, such as limited provider participation in Medicaid. For example, low provider participation in Medicaid has been noted as a particular problem in dental and mental health. Our earlier study found that a shortage of dentists willing to treat Medicaid patients was the major factor contributing to the low use of dental services. Similarly, a study by the Economic and Social Research Institute for the Kaiser Commission on Medicaid and the


161999 External Quality Review Study Child and Teen Checkups Participation Rate Review Final Report, FMAS Corp. for the Minnesota Department of Human Services, August 2000.

172000 EPSDT Report—External Review for Washington Medical Assistance Administration, OMPRO. This study covered only those children who had 12 months or more continuous Medicaid eligibility—a longer period than the average eligibility of Medicaid children. Screening rates for such children are expected to be higher than rates for Medicaid children as a whole because children who have been eligible for a longer time are more likely to receive preventive care.

18Our study defined “substantial participation” in Medicaid as seeing 100 or more Medicaid patients a year—about 10 percent of a dentist’s normal caseload. Thirty-one states provided information to us on the extent to which their dentists participated in Medicaid. None of these states reported that more than half of its dentists saw 100 or more Medicaid patients a year; most states reported that fewer than one-fourth of their dentists did so.
Uninsured found shortages of mental health and substance abuse professionals willing to treat Medicaid patients.\textsuperscript{19}

Other program-related factors include inadequate methods for ensuring access to services. Our study of lead screening found problems with providers’ missing opportunities to perform follow-up tests when children returned for other care. Lawsuits brought in a number of states have also highlighted such problems as inadequate systems for informing beneficiaries about the availability of EPSDT services and poor coordination by managed care plans and state agencies. Several advocacy groups we interviewed echoed concerns that states and managed care plans do not adequately inform beneficiaries about the broad scope of EPSDT services or about beneficiary appeal rights. These groups also questioned the adequacy of the provider networks for serving children in Medicaid.

In addition to these program-related factors, some beneficiary-related factors have also been found to limit screening services. For example, many Medicaid beneficiaries change eligibility status over short periods of time, and they may move frequently, making it more difficult to maintain continuity in their medical care.\textsuperscript{20} Researchers have also found that parents whose children are eligible to receive services under Medicaid tend to be less aware of the importance of preventive care than the general population. Those who try to obtain preventive care face other barriers. In our reports on oral health and screening for lead poisoning, we noted several other contributing factors, such as difficulty in getting time off from work, finding child care, arranging transportation to the provider, and overcoming language differences. These factors may contribute to a higher rate of broken appointments—a major concern among providers, particularly dentists. An American Dental Association survey reported that about one-third of Medicaid patients failed to keep appointments. A 1999 study conducted for the Florida Medicaid agency found that the top three reasons given by survey respondents for missing pediatric appointments were not having a ride to the appointment, the child no longer being sick, and forgetting an appointment.

\textsuperscript{19}Medicaid Managed Care for Persons with Disabilities: A Closer Look, Marsha Regenstein and others, The Economic and Social Research Institute for the Kaiser Commission on Medicaid and the Uninsured, April 2000.

\textsuperscript{20}For example, the average period of Medicaid eligibility reported by all states combined was less than 9 months in 1998.
States Have Taken Action to Improve Data Reporting and Delivery of EPSDT Services

The five states we visited have implemented a variety of initiatives intended to improve the provision of EPSDT services to children in Medicaid, including those in managed care. The state and health plan efforts we identified fall into three general categories: (1) improving data; (2) better ensuring that plans deliver services; and (3) improving beneficiary outreach and education. Although in most cases states and health plans could not provide information on their specific impact, these initiatives represented efforts that state and plan officials cited as helping to better ensure that children receive EPSDT services.

Improved Data Reporting

The five states we visited have taken a number of steps to improve the quality of the data they collect—especially from managed care programs—to monitor the utilization of services and to compile EPSDT reports to HCFA. These steps have not yet solved the states’ data and reporting problems; however, by moving toward more timely and reliable encounter data, states can better assess progress toward participation goals, identify specific plans or providers experiencing problems, and target corrective measures. As table 2 shows, these steps involve four main types of actions: requiring plans to submit detailed encounter data, validating those data, linking data with other sources, and reporting summary data in print or on the Internet. For example, to encourage health plans to report complete and accurate data, and to publicize comparative data, New York publishes summary statistics on individual plans on its health department Web site.

<table>
<thead>
<tr>
<th>Type of action</th>
<th>Description of initiatives</th>
</tr>
</thead>
<tbody>
<tr>
<td>Submitting encounter data</td>
<td>Some states have implemented systems and requirements for health plans to submit data from each encounter with patients. California, Connecticut, New York, and Wisconsin are states we visited that require health plans to submit detailed encounter data, including delivery of ESPDT services. Several officials told us that health plans that pay their providers on a fee-for-service basis, although they themselves are paid on a capitated basis, experience fewer problems with their encounter data because the data are based on claims information.</td>
</tr>
<tr>
<td>Validating data</td>
<td>A data validation process can provide information on the limitations of reported data. All five states we visited require annual external audits of health plan data. California, for example, contracts with an external quality review organization to develop baseline and annual assessments of health plans, including EPSDT services such as immunizations and well child visits. These external evaluations include a limited chart review, validating coding and data entry, and audits of computer systems.</td>
</tr>
<tr>
<td>Linking data from various sources</td>
<td>States can help close gaps in data on the provision of services by linking databases and information from numerous data sources. To ensure that the state has complete data on the care provided to children in Medicaid, Connecticut and Wisconsin are finding ways to link plan-reported encounter data with data from various data sources, such as local health departments or other state records. For example, as part of its new EPSDT encounter data system, Wisconsin is in the process of linking its EPSDT database to other health databases such as the statewide immunization registry and the lead screening database.</td>
</tr>
<tr>
<td>Type of action</td>
<td>Description of initiatives</td>
</tr>
<tr>
<td>----------------</td>
<td>---------------------------</td>
</tr>
<tr>
<td>Publishing data</td>
<td>How states use the data they collect can motivate health plans to pay more attention to the quality of the data they gather and submit to the state. New York, for example, publishes summary encounter statistics—including several EPSDT measures such as well child visits and lead screening—for each managed care plan on its health care Web site. This report, Quality Assurance Reporting Requirements, allows plan-to-plan comparisons. According to state and plan managers, such publicity is a strong incentive for health plans to report complete and accurate encounter data.</td>
</tr>
</tbody>
</table>

These states’ experiences demonstrate that gathering complete and reliable encounter data is a long-term effort. Wisconsin, for example, worked collaboratively with capitated managed care plans for 4 years to formulate a uniform encounter data set and reporting system that all plans are required to use. Wisconsin’s system did not become functional until May 2000 and has not yet produced its first report to HCFA. New York has required managed care plans to submit encounter data for the past 6 years, but state Medicaid officials said the first few years of data were unreliable. The data became more reliable around the fourth year, after state officials worked with health plans to improve their data collection and verification efforts.21

Ensuring Service Delivery

States have also put into action a number of initiatives to help ensure that managed care plans and health providers deliver screening and treatment services to children enrolled in Medicaid. The broad package of benefits offered under EPSDT can result in confusion and potential under-service if health plans and providers are not clearly informed of their responsibilities to provide EPSDT services. In California, for example, officials said some health plans were not performing screens according to the state’s managed care periodicity schedule. Plan providers were confused, they said, because the state’s Medicaid fee-for-service periodicity schedule called for fewer screens than its managed care periodicity schedule (15 compared to 27) and physicians often served both fee-for-service and managed care patients. In addition, a recent HCFA-sponsored study of Medicaid managed care contracts in more than three dozen states found that states often fail to spell out the full range of

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21While officials told us the encounter data are now reliable, through 1999 New York did not report actual encounters in their annual report to HCFA because health plans were categorized as “continuing care providers” that were assumed to provide full EPSDT screens. Their data were therefore overstated. Officials expect to report actual managed care encounters in their 2000 data submission.
EPSDT services that plans are responsible for providing.\textsuperscript{22} The study concluded, among other things, that while states routinely expect managed care plans to provide the full range of EPSDT service obligations, they do not always explain in contracts what this means and may not require contractors to educate beneficiaries about the benefit package offered under EPSDT.

To better ensure EPSDT service delivery, the states we visited have taken action in several areas (see table 3). Some of these actions have involved states’ laying out expectations for managed care plans or providers through extensive specification of responsibilities in contracts or provider education. Other actions have involved the monitoring of health plans, the use of incentives and sanctions for provision of services, and requirements for plans to coordinate care with public health departments. States have also increased reimbursement rates for EPSDT services. For example, in 1995, to encourage fee-for-service providers to screen more children, Florida more than doubled its reimbursement rate for a comprehensive EPSDT screen. The examples in table 3 represent a few of the promising actions these states and health plans have implemented.

<table>
<thead>
<tr>
<th>Type of action</th>
<th>Description of initiatives</th>
</tr>
</thead>
<tbody>
<tr>
<td>Detailed contract requirements</td>
<td>Specific and comprehensive contract language helps ensure that health plans know their responsibilities and can be held accountable for delivering EPSDT services. Connecticut's contract, for example, contains three pages of specific EPSDT requirements, including requirements for (1) EPSDT screens, (2) services such as scheduling appointments, arranging transportation, and providing interpreters for enrollees with limited English proficiency, and (3) coordinating with other assistance programs, such as Head Start. The contract also contained a 27-page appendix of EPSDT periodicity schedules and guidance.</td>
</tr>
<tr>
<td>Provider education</td>
<td>Policies and procedures governing EPSDT, as well as the EPSDT benefit package itself, can vary substantially from the typical commercial policy. As a result, provider education is an essential health plan activity. Florida conducts provider training and outreach, including coverage of EPSDT services and promotional materials, through 11 area EPSDT coordinators. Wisconsin holds annual conferences for providers and others to discuss topics such as EPSDT policies, processes, and barriers to providing services.</td>
</tr>
<tr>
<td>Increased state monitoring</td>
<td>Monitoring of individual plan performance allows states to identify the need for specific corrective actions. New York uses encounter data to compare each health plan to statewide averages and the plan's own prior year performance. Plans performing below statewide averages or showing decreased performance are required to implement corrective actions that are monitored by the state to ensure improvement. Connecticut established an independent Children’s Health Council to, among other things, help</td>
</tr>
</tbody>
</table>

monitor delivery of EPSDT services. The Council’s responsibilities include operating a complaint hotline, analyzing health plan encounter data, and publishing newsletters and reports on the delivery of EPSDT services.

Use of incentives and sanctions
States can build incentives and sanctions into contracts to help ensure that health plans deliver EPSDT services. New York rewards plans that do better in providing EPSDT services by assigning them a higher proportion of new enrollees who do not make a specific choice when they enroll. Each year, Wisconsin recoups payments for screens if health plans do not achieve an 80 percent screening rate. State officials expect to recoup $1 million to $2 million per year from plans that did not meet the 80 percent goal in 1998 and 1999.

Required contracts with local health departments
Close coordination between public health departments and Medicaid agencies can help ensure continuous, efficient care for those who receive services from different providers. To better coordinate care, California requires health plans to subcontract with the local health department in each county for public health services, including immunizations and other EPSDT services. Similarly, New York requires health plans to have agreements with local health departments and to coordinate public health related activities, such as outreach and reporting for immunizations.

Increased provider reimbursement
Higher Medicaid fees can attract new providers or motivate existing providers to see more patients. In Florida, reimbursement for an EPSDT screen in the fee-for-service program increased 116 percent in 1995 (from $30.00 to $64.82). After the fee increase and other concurrent initiatives, such as provider education, screening rates doubled—from 32 percent to 64 percent.

Improving Beneficiary Outreach and Education
The third area in which states have taken action is in educating and encouraging parents to better ensure that their children receive EPSDT services. Beneficiary outreach and education is typically a responsibility shared between the states and the health plans. At certain times in the process, the states may have primary responsibility for informing beneficiaries about covered services, such as when new beneficiaries are enrolled. Once a beneficiary is enrolled in a health plan, the state may require the plan to take measures to inform parents and families about covered services and how to access them. Officials from states and plans we visited reported a number of initiatives to better inform beneficiaries about EPSDT services (see table 4). These generally fell into four categories: designing clear and informative member handbooks, creating helpful and easy-to-understand materials to supplement member handbooks, developing programs to reach special populations such as children with disabilities, and conducting community outreach activities. For example, to encourage Medicaid beneficiaries, including those in managed care, to take advantage of preventive care, Florida mails reminder letters to families when their children are due for EPSDT screens.
### Table 4: Examples of Initiatives to Improve Beneficiary Outreach and Education

<table>
<thead>
<tr>
<th>Type of action</th>
<th>Description of initiatives</th>
</tr>
</thead>
<tbody>
<tr>
<td>Designing member handbooks</td>
<td>Member handbooks provide information on what services are covered, how to access care, and what to do in the event of questions or problems. One plan’s handbook in Wisconsin discussed the importance of preventive care under HealthCheck, the state’s EPSDT program, and listed the elements of an EPSDT screen that a beneficiary should expect to receive, such as a physical exam, hearing and vision tests, and complete immunizations.</td>
</tr>
<tr>
<td>Creating additional informational materials</td>
<td>States and health plans produce a variety of special publications to supplement member handbooks and promote health issues. For example, one plan in New York distributes special calendars for expectant and new mothers. The calendars provide useful information on what to expect during pregnancy, offer early-childhood tips, and have space for recordkeeping and doctor appointments. Florida sends reminder letters to all Medicaid enrollees, including those in managed care who are due for EPSDT screenings. Florida also created a “Child Health Checkup” card for families' use in tracking scheduled EPSDT screenings, similar to what a family might use to track a child’s immunizations.</td>
</tr>
<tr>
<td>Reaching special populations</td>
<td>Health plans use a variety of initiatives to reach special populations. For example, most plans we visited publish outreach material in foreign languages to reach non-English-speaking members. To attract adolescent members—another difficult group to reach—one plan in Wisconsin operates teen clinics that offer free pizza and gift certificates. New York awards grants to health plans to develop innovative delivery models. Grants for 2001 included initiatives to improve screening tools and treatment of children with disabilities.</td>
</tr>
<tr>
<td>Conducting community outreach activities</td>
<td>Health plans conduct a variety of activities to promote health issues, including EPSDT services, in their communities. For example, one managed care plan in California created community advisory committees that include health plan members, advocates, and providers in an effort to facilitate communications with members and strengthen ties within the community. In Connecticut, one health plan conducts home visits, obtaining neighborhood and community assistance in connecting with families.</td>
</tr>
</tbody>
</table>

In addition to these efforts in the five states we visited, children’s advocates also informed us that several states have implemented initiatives as part of settlement agreements arising from EPSDT-related lawsuits. Settlement documents and court orders from selected EPSDT lawsuits contain information on a number of state initiatives to improve delivery of EPSDT services. For example, Pennsylvania established a series of 18 performance standards and health outcome measures and incorporated them into managed care contracts. Standards and interim targets were established for the percentage of children to receive immunizations and EPSDT screens, and measures were established for treatment and prevention of asthma, anemia, and lead poisoning. Appendix II contains further information on the basis for selected lawsuits and actions taken by states in response.
HCFA Efforts to Ensure Children’s Access to EPSDT Have Been Limited

HCFA, now called CMS, is currently reevaluating how best to carry out its role in helping to ensure that children receive access to EPSDT services. In recent years, HCFA’s efforts have focused largely on trying to improve the guidance to states about reporting the extent to which children are being screened. Attempts to improve reporting have been time-consuming, and progress has been slow. Because HCFA’s focus has been mainly on improving the format and specificity of the state EPSDT reports, it has placed little emphasis on the extent to which states are improving the underlying data or meeting HCFA’s EPSDT participation goals. At the regional office level, where much of the responsibility for working with states resides, a few offices have begun to help states identify problems and promote state progress in increasing children’s use of services. However, because most regional offices have focused their resources on priorities other than EPSDT, these efforts have not been widespread. In January 2001, HCFA’s central office proposed to regional offices and other stakeholders that the agency work more closely with states to improve both reporting and children’s use of services, but a specific plan for how to do so has not yet been developed.

HCFA Is Acting to Improve State Reports, but Progress in Improving the Underlying Data Is Slow

Recognizing that progress in providing services is difficult to assess without good data as a starting point, HCFA has centered its monitoring efforts largely on revising the guidance and format in order to improve state EPSDT reports. These revisions were largely aimed at capturing more reliable and more consistent EPSDT information while minimizing the burden on states in completing the reports. For example, in 1999 HCFA changed the EPSDT report to, among other revisions, require new information on dental services and blood lead tests, and to add more precise definitions of certain required data elements. It also allowed states to use their own periodicity schedules to determine their participation and screening rates.

While these revisions have changed the reporting requirements, they have done little to address the continuing difficulties states face in their efforts to gather reliable and complete data. As our review of the five states showed, these problems require determined efforts at the state level, and because of the complexities associated with collecting managed care encounter data, such efforts take considerable time to accomplish. In the meantime, these EPSDT reports do not provide an accurate or complete picture of most state EPSDT programs, nor do they allow for reasonable national estimates of EPSDT screening and participation rates or for meaningful comparisons between states.
Although HCFA’s efforts to improve data collection are important, by themselves they do not represent a strategy for helping states meet EPSDT goals. In part because HCFA acknowledges the limitations of the state EPSDT reports, the agency has done little to address how well states are doing in meeting the goal of providing EPSDT services to 80 percent of children enrolled in Medicaid. The existing reports show that most states are considerably below this goal. However, even if issues regarding data and reporting are adequately addressed, improved EPSDT reports, taken alone, will not provide HCFA with sufficient program detail to perform other oversight duties, such as helping states identify and correct specific problems or share information on lessons learned from other states and model state practices.

Studies by Some Regional Offices Have Identified Areas for Improvement and Innovative Practices

A few HCFA regional offices have conducted reviews of state EPSDT programs. HCFA regional officials reported to us that eight such studies have been completed since 1995. Four included EPSDT as one element of a broader review of a state’s Medicaid managed care program; four focused exclusively on EPSDT. While these EPSDT and managed care assessments varied widely in their methodology and coverage of EPSDT issues, they have helped illuminate policy and process concerns and innovative practices of states. They have also identified needed actions to improve children’s access to EPSDT care. For example:

- In Oklahoma, an EPSDT-focused study conducted jointly by HCFA’s Dallas Regional Office and state Medicaid officials found several ways to increase screening and improve the quality of data submitted. The team found that providers relied on a review of a child’s medical chart to determine whether an EPSDT screen was due—a step they generally took only when an office visit occurred. As a result, children not visiting for other reasons were often not screened. The study recommended that the state establish a system to notify providers when children were due for screens. The study team also found that Medicaid provider knowledge of EPSDT services varied widely, and that many providers did not know about a monetary bonus the state offered to those providers who increased, to 60 percent or more, the proportion of eligible children who had EPSDT screens. To increase provider awareness, the study team recommended that the state annually include a discussion of EPSDT at provider education meetings.

- In California, an EPSDT-focused study conducted by HCFA’s San Francisco Regional Office with the cooperation of state Medicaid officials found that families of children in Medicaid were not being effectively informed about the availability of services or how to gain access to them.
State officials who responded to the report’s findings acknowledged the need for a more cohesive effort to provide information about EPSDT services, and they indicated that the state would work to ensure that systems are in place to provide adequate information to families of children in Medicaid. The same HCFA study also singled out commendable practices including state efforts to coordinate care between Medicaid managed care plans and community health providers such as county mental health centers.

- In Michigan, a review of the state’s Medicaid managed care program conducted by HCFA’s Chicago Regional Office and others included an assessment of certain EPSDT policies and processes. These included EPSDT-covered services; processes and responsibilities for outreach, informing, and providing transportation services to beneficiaries; provider access and coordination; data reporting; and the achievement of screening goals. The review contained observations such as problems the state was having in collecting reliable data for the state EPSDT reports and differences in the usefulness of health plan member handbooks for describing how beneficiaries can obtain transportation services covered under EPSDT. Stated goals of the review were to gather information that would be useful in improving access and quality in the managed care program and to identify areas of innovation and best practices that could be shared with other states.

While these assessments have helped those state programs that were reviewed and have identified best practices that might be applicable to other states, HCFA has reviewed only eight states since 1995 and has not established a mechanism for sharing lessons learned or innovative practices already in place among states. Since there is no HCFA requirement to periodically focus on and promote EPSDT on the state level, the decision to do so resides with management of each HCFA region. Most regions have not devoted resources to actively monitor or promote EPSDT. Some regional office staff cited other priority efforts, such as SCHIP, as diverting their resources. We found that regions typically have one staff person designated as EPSDT Coordinator, but with multiple responsibilities other than EPSDT.
Recent HCFA Proposal Aims to Improve EPSDT Performance, but Specific Plan Is Not Yet Developed

HCFA has recently begun to reevaluate the adequacy of its role in EPSDT. In a January 2001 letter to the agency’s regional offices, HCFA’s Director of the Center for Medicaid and State Operations introduced a proposal to broaden the agency’s role in promoting state EPSDT activities. In the letter, the Director sought input to a proposal designed to assure children’s access to services under the Medicaid program and to assist states in addressing problems in the collection and reporting of state EPSDT data.

HCFA officials told us that the goal of the letter was to obtain stakeholder comments on what HCFA’s focus and direction should be. As of April 2001, HCFA regional staff had reviewed and commented on the letter, as had representatives from the American Academy of Pediatrics, officials from HHS’s Health Resources and Services Administration, and the Maternal and Child Health Technical Advisory Group (an advisory group made up of 6 to 10 state Medicaid directors). HCFA officials informed us that stakeholder reaction to the proposed initiative had generally been positive. The current chair of the Maternal and Child Health Technical Advisory Group told us that the general tone of the letter represents a collaborative, partnership approach that would provide for needed technical assistance while affording the flexibility needed for states to address conditions and impediments unique to each state.

It is too early to determine whether this initiative will move forward, what form it will take, or what might result from it. The agency has not yet established a plan or devoted resources to develop and implement this proposal. HCFA officials said that they were continuing to solicit comments and input from stakeholders to develop a plan and that decisions about resources and implementation would depend on guidance and direction on agency priorities.

Conclusions

More than a decade ago, the Congress passed legislative changes to help ensure that millions of low-income children under Medicaid have access to important health screening and treatment services. In the years since then, the Congress has placed even more emphasis on providing a health care safety net by expanding coverage to more and more children who do not have health insurance. This safety net, however, cannot be considered fully in place unless there are assurances that the covered health care services are actually provided. Unfortunately, reported data are unreliable and incomplete. They are inadequate for gauging Medicaid’s success in providing screening, diagnostic, and treatment services to enrolled children. Particularly for children served by managed care plans—a
growing segment of the population—current information does not allow a thorough assessment of progress. However, the available information indicates that many children are still not receiving health screening services. Recognizing this concern, some states are taking a more active role in identifying ways to reach the at-risk population served by Medicaid.

HCFA, now called CMS, has recently indicated increased emphasis on EPSDT services and can build on these state efforts in several ways while still giving states the flexibility to administer the program. One way is to continue the important task of working with states to improve the reporting of information on service delivery. Many providers, plans, and states will need to improve their reporting in the long-term so that there will be a more accurate picture of how well they are doing in providing these services, especially in a capitated managed care environment. In the short-term, CMS can take action to obtain a better understanding of the many different state policies and practices so it can work collaboratively with states to improve data and reporting, monitor the provision of services, and better inform and reach beneficiaries. In its position of setting federal policy and assessing a broad array of state activities intended to help reach at-risk Medicaid children, CMS can help build on successful efforts by sharing successes among states and working with the many different agencies and parties to ensure a coordinated approach to this care. By signaling a broadening of its interest in state EPSDT efforts, the agency has taken a positive first step. An important next step is for CMS to develop a more specific plan and time frames for working with states to assess their efforts and results in providing services to children in Medicaid.

**Recommendations for Executive Action**

To strengthen the federal role in ensuring the delivery of EPSDT services and to bring greater visibility to ways that states can better serve children in Medicaid, we recommend that the Administrator of CMS:

- work with states to develop criteria and time frames for consistently assessing and improving EPSDT reporting and the provision of services, including requiring that states develop improvement plans as appropriate for achieving the EPSDT goal of providing health services to children in Medicaid; and
- develop a mechanism for sharing information among states on successful state, plan, and provider practices for reaching children in Medicaid.
We obtained comments on a draft of this report from CMS and the five states we visited. CMS commented that, as noted in the draft report, the problem is complex and not subject to an easy resolution (CMS’s comments are included in app. III). CMS agreed that more could be done to work with states to help ensure children’s access to services and compliance with federal requirements and stated that the agency’s regional offices are already starting to work with some states where problems exist. CMS partially agreed with our recommendation that it work with states to develop criteria and time frames for assessing and improving EPSDT reporting and the provision of services, including developing state-specific improvement plans for achieving EPSDT goals. While acknowledging the importance of working with states to improve the provision of services, CMS indicated that it was not certain that improvement plans for all states were necessary as part of this effort. Because of the unreliability of EPSDT reports, we believe that a more consistent assessment across all states is necessary to provide greater insight into states’ progress in achieving EPSDT goals. Depending on the assessment outcomes, improvement plans may not be needed for every state. We have clarified our recommendation accordingly. CMS agreed with our recommendation that the agency do more to foster information sharing and cooperation among states to improve EPSDT. The agency indicated that, as a first step, it is planning several activities with states, foundations, and others to promote the value of EPSDT services. The agency also provided technical comments that we incorporated where appropriate.

California and Connecticut reviewed our findings concerning their state programs and said they had no comments. Florida, New York, and Wisconsin provided technical comments, which we incorporated where appropriate. New York also commented that the draft did not acknowledge that compliance rates with screening requirements are uniformly low, even for children not in Medicaid, and stated that EPSDT expectations may not be realistic. While some available reports, such as our past work on lead and dental screening, do show low screening rates in the aggregate, these reports also show wide variations among states. Because available data are insufficient to gauge states’ progress in providing EPSDT services, assessing whether the agency’s 80 percent screening goal is realistic is difficult. We anticipate that once state EPSDT data are more reliable, CMS will be in a better position to reevaluate whether the annual screening goals that it set more than a decade ago are realistic and achievable. New York also commented that the shortfalls in the provision of recommended levels of preventive health services identified in the report apply to all children, not just those served by
Medicaid. Rather than perform a comparative analysis of the provision of services for children in Medicaid versus others, this report focused on the provision of EPSDT services to children in Medicaid, which our past work, as well as the work of others, has shown to be an at-risk population. New York’s comments are included in appendix IV.

As arranged with your offices, unless you release its contents earlier, we plan no further distribution of this report until 30 days after its issuance date. At that time, we will send copies to the Secretary of Health and Human Services; the Administrator of CMS; appropriate congressional committees; and other interested parties.

If you or your staff have any questions about this report, please contact me at (202) 512-7118. Other contacts and major contributors are included in appendix V.

Kathryn G. Allen
Director, Health Care—Medicaid and Private Health Insurance Issues
Appendix I: Profiles of the Five States Visited

To obtain information about efforts states were taking to improve EPSDT services, particularly within managed care, we visited five states. These states—California, Connecticut, Florida, New York, and Wisconsin—were selected to represent different regions of the country and because they had relatively high numbers of children in managed care or a reputation for having an innovative EPSDT program or both. These states differed greatly in the size of their Medicaid populations and the number of participating health plans. Table 5 contains background information on the states we visited.

### Table 5: Background on State and Medicaid Populations and State Medicaid Managed Care Programs

<table>
<thead>
<tr>
<th></th>
<th>California</th>
<th>Connecticut</th>
<th>Florida</th>
<th>New York</th>
<th>Wisconsin</th>
</tr>
</thead>
<tbody>
<tr>
<td>State population, 2000</td>
<td>33,871,648</td>
<td>3,405,565</td>
<td>15,982,378</td>
<td>18,976,457</td>
<td>5,363,675</td>
</tr>
<tr>
<td>Total Medicaid enrollment, 2000</td>
<td>5,036,768</td>
<td>320,617</td>
<td>1,701,128</td>
<td>2,751,385</td>
<td>479,167</td>
</tr>
<tr>
<td>Proportion of Medicaid recipients under 21 years of age, fiscal year 1998</td>
<td>51%</td>
<td>53%</td>
<td>56%</td>
<td>49%</td>
<td>54%</td>
</tr>
<tr>
<td>Managed care enrollment, 2000</td>
<td>2,525,406</td>
<td>229,995</td>
<td>1,016,641</td>
<td>691,422</td>
<td>211,185</td>
</tr>
<tr>
<td>Proportion of Medicaid population in managed care, 2000</td>
<td>50%</td>
<td>72%</td>
<td>60%</td>
<td>25%</td>
<td>44%</td>
</tr>
<tr>
<td>Number of health plans participating in Medicaid managed care, 2000</td>
<td>33&lt;sup&gt;e&lt;/sup&gt;</td>
<td>4</td>
<td>14</td>
<td>29</td>
<td>14</td>
</tr>
<tr>
<td>Specific EPSDT screening goals established in managed care contracts</td>
<td>None</td>
<td>80 percent annual screening rate</td>
<td>60 percent screening rate for children 0-5 years of age and continuously enrolled for 8 months</td>
<td>None</td>
<td>80 percent screening rate per contract year</td>
</tr>
</tbody>
</table>

<sup>a</sup>As of June 30, 2000.

<sup>b</sup>Fiscal year 1998 is the most recent year for which these data are available.

<sup>c</sup>The percentage of the Medicaid population enrolled in managed care includes those enrolled in primary care case management arrangements, as well as capitated managed care plans.

<sup>d</sup>State officials reported contracting with 42 entities to deliver health, dental, and long-term care, and services to special populations. Thirty-three of these contracts were for health care services.

Sources: U.S. Census Bureau, HCFA, and state Medicaid agencies.
Lawsuits have been filed in at least 28 states alleging the states had failed to adequately provide EPSDT services. The seven cases summarized in table 6 were suggested by the National Health Law Program’s Director of Legal Affairs and other EPSDT advocates as examples of states that have adopted innovative or promising EPSDT practices as a result of lawsuits. The following information reflects our review of relevant court documents in each of these cases and, in some instances, follow-up contacts with state officials to obtain further information about the state’s efforts.

### Table 6: Description of Selected EPSDT-Related Lawsuits and Resulting State Actions to Improve the Provision of Services

<table>
<thead>
<tr>
<th>State</th>
<th>Basis for Selected EPSDT Lawsuits and Resulting State Actions</th>
</tr>
</thead>
<tbody>
<tr>
<td>California</td>
<td>Promulgating State Regulations on EPSDT services</td>
</tr>
<tr>
<td>(T. L. v. BELSHE, No. CV-S-93-1782 LKKPAN, E.D. Cal., 1995)</td>
<td>Plaintiffs alleged that the state had failed to provide prescribed EPSDT services. California promulgated EPSDT requirements in state regulations to clarify additional requirements for coverage for children beyond requirements for adult Medicaid coverage spelled out in its state Medicaid plan.</td>
</tr>
<tr>
<td>California</td>
<td>Expanded Availability of EPSDT Mental Health Services</td>
</tr>
<tr>
<td>(EMILY Q. v. BELSHE, CV-98-4181-WDK, C.D. Cal., May 5, 1999)</td>
<td>Plaintiffs filed a class action lawsuit alleging that the California Department of Health Services had failed to offer Medicaid-enrolled children the full scope of mental health services covered under EPSDT. Prior to the lawsuit, California had been institutionalizing children with severe mental health needs. The plaintiffs alleged that California had violated EPSDT notification and access requirements by failing to advise the children and their families about other noninstitutionalization options, such as Therapeutic Behavioral Services (TBS), which is a type of mental health service for children that involves having a trained, experienced staff person available on a one-on-one basis to work with the troubled child in his or her home and community throughout the child’s routine day. In their lawsuit, the plaintiffs argued that a less disruptive, noninstitutional approach—such as TBS—is a required EPSDT benefit. The Court ruled that TBS “could be considered as both preventive and rehabilitative as contemplated by the [EPSDT] statute, and therefore, when necessary should be a covered [state plan] benefit.” As a result of the lawsuit, California is now required to offer noninstitutionalization or “wraparound” services so that mentally ill children can receive treatment in the community instead of being institutionalized.</td>
</tr>
</tbody>
</table>
## Appendix II: Examples of State Actions Resulting From EPSDT Legal Settlement Agreements

#### State Basis for Selected EPSDT Lawsuits and Resulting State Actions

<table>
<thead>
<tr>
<th>State</th>
<th>Basis for Selected EPSDT Lawsuits and Resulting State Actions</th>
</tr>
</thead>
<tbody>
<tr>
<td>District of Columbia</td>
<td>Appointment of a Court Monitor to Oversee Corrective Action</td>
</tr>
<tr>
<td>(<strong>SALAZAR v. DISTRICT OF COLUMBIA</strong>, No. CA-93-452, Jan. 25, 1999)</td>
<td>Plaintiffs filed numerous challenges against the District of Columbia alleging that the District failed to provide Medicaid benefits, including access to EPSDT services, to its residents. The lawsuit alleged that the District of Columbia did not notify residents of EPSDT’s availability and that the District failed to provide EPSDT services when requested. In ordering relief, the court appointed a special monitor to oversee implementation of the corrective action required by the court’s consent decree. Other required actions include annual EPSDT training for all managed care plans and physicians; establishment of an EPSDT telephone referral and question hotline for providers and EPSDT recipients; interim participation goals; and a Spanish EPSDT Helpline.</td>
</tr>
<tr>
<td>Maine</td>
<td>Expanded Availability of EPSDT Mental and Behavioral Health Services</td>
</tr>
<tr>
<td>(<strong>FRENCH v. CONCANNON</strong>, No. 97-CV-24-B-C, D. Me, July 16, 1998)</td>
<td>Plaintiffs alleged that Maine was failing to comply with EPSDT requirements because the state was not apprising patients of the availability or providing access to mental health services under its EPSDT program. As a result of the lawsuit, Maine agreed to modify the EPSDT informational materials given to parents and providers to include specific information about screening and treatment services available to address behavioral health needs. The state also agreed to provide case management for behavioral and mental health needs, develop a resource directory, and conduct additional provider education.</td>
</tr>
<tr>
<td>Pennsylvania</td>
<td>Increased Outreach to New Mothers and Setting Performance Standards</td>
</tr>
<tr>
<td>(<strong>SCOTT v. SNIDER</strong>, No. 91-CV-7080, E.D. Pa., Dec. 2, 1994)</td>
<td>The plaintiffs alleged that Pennsylvania failed to properly implement the EPSDT program. The parties negotiated a consent order that required, among other things, that the state foster awareness of and access to EPSDT services, in part by requiring the state to have a mechanism to ensure that all new mothers meet with a primary care physician for their newborns. Pennsylvania established a series of 18 performance standards and health outcome measures and incorporated them into managed care contracts. Standards and interim targets were established for the percentage of children who received immunizations and EPSDT screens, and measures were established for treatment or prevention of asthma, anemia, and lead poisoning.</td>
</tr>
</tbody>
</table>
**Appendix II: Examples of State Actions Resulting From EPSDT Legal Settlement Agreements**

<table>
<thead>
<tr>
<th>State</th>
<th>Basis for Selected EPSDT Lawsuits and Resulting State Actions</th>
</tr>
</thead>
<tbody>
<tr>
<td>Tennessee</td>
<td>Bonus Payment for Reporting Completed EPSDT Screens</td>
</tr>
<tr>
<td>(JOHN B. v. MENKE, No. 3-98-0168, M.D. Tenn., Feb. 25, 1998)</td>
<td>The plaintiffs filed a class action on behalf of all individuals under the age of 21 in Tennessee’s Medicaid managed care program. The lawsuit alleged that the state had failed to properly screen children in accordance with the required EPSDT periodicity schedules, properly diagnose children’s medical needs, or provide children with access to the full range of required EPSDT health care services. The parties negotiated a consent order, agreeing to take a series of steps to bring Tennessee’s Medicaid managed care program into compliance with EPSDT requirements as set forth in federal statute, regulations, and controlling HCFA guidelines. State officials told us that one of the results has been that Tennessee and its largest managed health care plan have developed a pilot project to document and encourage EPSDT screening by providers. The health plan has developed a simplified one-page EPSDT form that reduces the components into an 11-element checklist; for each completed EPSDT form—and thus EPSDT screen—a provider receives a monetary bonus.</td>
</tr>
<tr>
<td>West Virginia</td>
<td>Increased Outreach to Ensure Behavioral and Mental Health Services are Provided</td>
</tr>
<tr>
<td>(SANDERS v. LEWIS, No. 2:92-0353, S.D.W.Va., March 1, 1995)</td>
<td>Plaintiffs filed a class action lawsuit alleging that out-of-home-placement children were not being provided with access to mental health services under the state’s EPSDT program. Under the resulting consent order negotiated by the parties, West Virginia agreed to ensure that all appropriate state employees, foster care parents, and EPSDT providers received information and training on the disproportionate number of mental health problems experienced by these children. In addition, the state is required to ensure that EPSDT screens and treatment for this population include behavioral and mental health services.</td>
</tr>
</tbody>
</table>
Appendix III: Comments From the Centers for Medicare and Medicaid Services

DEPARTMENT OF HEALTH & HUMAN SERVICES

Health Care Financing Administration

DATE: JUN 22 2001

TO: Kathryn G. Allen
    Director, Health-Medicaid
    and Private Health Insurance Issues
    General Accounting Office

FROM: Michael McMullan
      Acting Deputy Director
      Centers for Medicare and Medicaid Services


Thank you for the opportunity to review and comment on the above-referenced report.

As noted in the draft report, this problem is complex and not subject to an easy resolution. Therefore, the Centers for Medicare and Medicaid Services (CMS) want to work collaboratively with States on issues regarding data collection, monitoring, provider networks, managed care contracting, etc. We appreciate GAO's acknowledgement of how managed care systems can work in a positive way to reach children and provide them needed services. Despite the fact that the lack of individual claims data can hinder traditional forms of data collection and oversight, it is absolutely true that a well run managed care environment can increase Early and Periodic Screening, Diagnostic, and Treatment (EPSDT) participation.

GAO Recommendation
CMS should work with states to develop criteria and time frames for assessing and improving EPSDT reporting and the provision of services, including developing state-specific improvement plans for achieving EPSDT goals of providing health services to the majority of children in Medicaid.

CMS Response
We partially agree with this recommendation. As the GAO noted, we issued a letter in early 2001 to our Associate Regional Administrators that outlined a proactive approach to working with states to help assure children's access to services under the Medicaid program and compliance with federal requirements. This memorandum contained four areas that we intend to focus on to determine if children are receiving appropriate, timely care. Those areas are informing and outreach, increasing provider participation, data quality and completeness, and
managed care. This letter was well received by the states and regions as a cooperative way to work together toward the important goal of improving children’s access to health services.

We believe that our regional offices, with central office oversight, are in the best position to work with states that are underachieving in this area. Most regional offices are undertaking work with some of their states where the largest problems seem to exist and one region is planning to review all eight of its state EPSDT service delivery and reporting systems by the end of fiscal year 2002.

Additionally, as mentioned in more detail below, CMS is planning several activities that will give states opportunities to share information and for CMS to respond to states concerns with training and guidance in numerous areas, including, among others, data reporting and managed care issues. We believe these approaches will foster a cooperative relationship with states as they work to improve their EPSDT reporting and provision of services. However, we do not know that improvement plans for all states is a necessary adjunct to these activities.

**GAO Recommendation**

CMS should develop a mechanism for sharing information among states on successful state, plan and provider practices for reaching children in Medicaid.

**CMS Comments**

We agree with this recommendation. CMS currently uses the Maternal and Child Health Technical Advisory Group as a conduit for some information sharing. However, we recognize that we should do a better job of fostering this type of cooperation. As a first step, CMS is planning several activities in conjunction with states, providers, foundations, and others, to promote the value of EPSDT services. This includes sharing information with states on understanding and addressing barriers to service delivery and promising approaches that states are taking to improve EPSDT participation. We believe that CMS, working with our regional offices, states, and other partners, is strengthening its efforts to ensure that children have access to critical screening services.

**Attachment**
Appendix IV: Comments From the State of New York Department of Health

June 25, 2001

Kathryn G. Allen
Director for Health-Medicaid
and Private Insurance Issues
United States General Accounting Office
441 G Street NW, RM 5A14
Washington, DC 20548

Dear Ms. Allen:

Thank you for the opportunity to review the draft report entitled Medicaid Stronger Efforts Needed to Ensure Children’s Access to Health Screening Services. The Office of Managed Care and the Office of Medicaid Management have reviewed the document and have the following general comments:

- The report fails to recognize that compliance rates are uniformly low across states, programs, and payment methodologies and misses the possibility that the expectations expressed in EPSDT are not realistic.

- While EPSDT is unique to Medicaid, the recommendations from American Academy of Pediatrics (AAP) apply to all populations, as does the notion of early screening, prevention, and treatment. The report ignores the fact that data from commercial populations show the same deficiencies. All kids are not immunized by age two. All kids are not lead screened. Most asthmatics do not receive treatment according to National Institute of Health (NIH) guidelines. These deficiencies do not appear to be a uniquely Medicaid problem. Again, maybe it has to do with the disparity between AAP (and other expert) recommendations and the reality of the delivery system (including what doctors do, how they document what they do, and parental values/behaviors). The report should consider this overall picture.

- We recommend that HCFA work with providers and health plans to develop outcome measures and benchmarks that can be used to improve providers and health plans performance.
• Consideration may be given to piloting some different approaches to identify effective measurement approaches and tools. In all cases, measures should be reasonably collected, defined, standardized, and audited.

• From the Medicaid fee-for-service program perspective, New York made a conscious decision many years ago not to set up a separate health care system for screening Medicaid children. The basic premise of New York's program, since 1973, has been that Medicaid children should be incorporated into the practices of community physicians and clinics where they would receive the same standard of care as provided to other children in the community. The State has tried from the providers’ perspective, to minimize differences between Medicaid and Non-Medicaid children, so that Medicaid would be considered another form of insurance and the children not be stigmatized. We have given up on elaborate EPSDT claim forms or special EPSDT tracking forms, and we, therefore, do not know at the time of payment that a provider has failed to provide all aspects of a screen and we therefore do not withhold payment. Also, as Medicaid income eligibility levels rise, we are reaching into the working poor population, many of whom have health insurance coverage which covers well child exams and other services. Since Medicaid data is based upon claims payment, we cannot report on the services received by Medicaid eligible children if Medicaid has not paid for the particular service.

If you have any questions concerning this reply, Dr. Foster Gesten, Medical Director, Office of Managed Care and Marcia Rao, Office of Medicaid Management would be happy to discuss the report with you. My telephone number is (518) 473-7467 and I would be happy to arrange a conference call.

Sincerely,

Barbara Meg Frankel
Assistant Director
Bureau of Program Planning
Office of Managed Care

cc: Kathryn Iritani
Appendix V: GAO Contacts and Staff Acknowledgments

| GAO Contacts | Katherine Iritani, (206) 287-4820  
|              | Terry Saiki, (206) 287-4819 |

| Staff Acknowledgments | Other major contributors to this report were Matthew Byer, Bruce Greenstein, Sophia Ku, Behn Miller, and Stan Stenersen. |
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