EPSDT: Medicaid’s Critical But Controversial Benefits Program for Children

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Overview — The Early and Periodic Screening, Diagnosis, and Treatment (EPSDT) program under Medicaid provides the most comprehensive set of health benefits for children and adolescents in the public or private sector. A cornerstone of early childhood preventive and treatment services in the nation’s health care “safety net,” the EPSDT program serves nearly 30 million low-income children, including children with disabilities and special needs. Over the years, states have expressed frustration with the administrative burdens of EPSDT requirements. Rising Medicaid costs have put all Medicaid benefits, including the EPSDT program, in the budgetary crosshairs. This issue brief reviews the fundamental characteristics of the EPSDT program and highlights some of the challenges it has faced over the years. This paper also describes some of the changes proposed to preserve access to comprehensive care while controlling costs and encouraging administrative simplification and flexibility.
EPSDT: Medicaid’s Critical But Controversial Benefits Program for Children

Medicaid is the largest program in the federal “safety net” of public assistance programs, providing essential medical and medically related services to more than 55 million low-income children and families, elderly, and individuals with disabilities. The program plays a critical role in the health of these groups, particularly children. Medicaid covers one-quarter of all children in the nation, over 60 percent of poor children, and 39 percent of near-poor children. Over 28 million children were served by Medicaid in 2003.

The Medicaid program is a federal-state partnership in which states administer individual programs, within federal guidelines, and the federal government matches state funds spent (the matching rate ranges from 50 to 77 percent, depending on the state). The federal Medicaid statute includes a set of mandatory benefits that must be provided to all Medicaid beneficiaries, as well as a set of optional benefits that states may elect to cover. The Early and Periodic Screening, Diagnosis, and Treatment (EPSDT) program is the cornerstone of Medicaid’s mandatory benefit package for children.

A “program within a program,” EPSDT is Medicaid’s “comprehensive and preventive child health program for individuals under the age of 21.” Designed to promote child health and development as well as treat diagnosed illness, EPSDT has a striking scope of coverage. Under EPSDT, Medicaid children are entitled to health care screenings and access to all Medicaid-covered services they are found to need, regardless of any Medicaid benefit restrictions imposed on adult beneficiaries by their state. The range and depth of services provided under EPSDT, coupled with a unique medical necessity standard, has resulted in an unparalleled and comprehensive health benefit package for children.

However, the breadth and depth of EPSDT services, the challenges states face in fully meeting its requirements, and its perceived impact on overall Medicaid costs have long been points of criticism by states and policymakers. In recent years, EPSDT has been targeted for change as part of broader efforts to provide greater state flexibility and constrain Medicaid costs. Asserting that EPSDT is too costly and complex to fully implement in its current form, some policymakers have sought to redefine, restrict, and even eliminate the EPSDT program.

Despite these efforts, the need for EPSDT in its current form continues to be supported at the national level. The Deficit Reduction Act (DRA) of 2005 made fundamental changes to the Medicaid program but left the current
EPSDT requirements intact. Many child health advocates, however, are wary of new Medicaid state flexibility under the DRA and its potential effect on preventive, diagnostic, and treatment services for low-income children.

As discussions over the future direction of the Medicaid program move forward, it is important to understand the unique aspects of EPSDT and the effect the program has on the various medical needs of Medicaid children. It is equally important to be aware of the challenges states and families face in administering and receiving EPSDT benefits.

THE DEFICIT REDUCTION ACT OF 2005

State and federal struggles to constrain Medicaid costs and provide state flexibility in recent years culminated in the passage of the Medicaid provisions of the DRA. The act incorporates Medicaid reform recommendations from the National Governors Association (NGA), including a provision to allow states the option to use “benchmarks” or standards of coverage similar to those used under the State Children’s Health Insurance Program (SCHIP) for certain Medicaid beneficiaries. Benchmark coverage, such as state employee health benefits plans, can be less comprehensive than the traditional Medicaid federal benefit requirements, which include EPSDT.

The benchmark option gives states latitude to alter or tailor benefit packages for different Medicaid populations as a means to control costs. With this new ability to tailor benefit packages comes a fundamental shift in Medicaid policy. Prior to the DRA, every Medicaid beneficiary within a given state was guaranteed the same benefits. This is no longer the case. States also are now allowed to increase cost sharing and premiums for certain beneficiaries, another major shift in Medicaid policy. Together these changes are expected to save $43 billion in the next 10 years.

In the context of these new provisions, the outcome for EPSDT is an interesting wrinkle in the politics surrounding this often-debated program. Despite the new state discretion for Medicaid benefits, current EPSDT requirements are to remain intact for children who are enrolled in Medicaid. States opting to use the DRA “benchmark” coverage for children must make available an additional “wrap-around” benefit that includes EPSDT services as defined in current law.

Although EPSDT was not modified in the statutory language of the DRA, questions about the new benchmark coverage and the implications for EPSDT were raised immediately. The administrator of the Centers for Medicaid and Medicare Services (CMS) was prompted to issue a statement declaring children will “…still be entitled to receive EPSDT benefits in addition to the benefits provided by the benchmark coverage…." The statement further asserted that CMS would not approve any state Medicaid plan that does not include the provision of EPSDT benefits. Even the bill’s sponsors, Sen. Charles Grassley (R-IA), chairman of the
Senator Committee on Finance, and Rep. Joe Barton (R-TX), chairman of the House Committee on Energy and Commerce, felt it necessary to clarify the position of EPSDT, stating in a letter to Health and Human Services Secretary Michael Leavitt that EPSDT benefits are “not an option” and that “Congress intended to make no changes to EPSDT coverage.” EPSDT remains a “required benefit to all individuals under the age of 19 who have been determined eligible for Medicaid and, if the state elects to provide coverage up to the age of 21.”

These declarations underscore the significance of Congress’s decision to retain the EPSDT program in its current form in the midst of major Medicaid benefit changes. They also are an indication of federal support of a mandatory program states have sought to alter throughout its 40-year history.

EPSDT BASICS

When the Medicaid program was created in 1965, the focus of the joint federal and state program was to finance health care treatment for diagnosed, episodic illness in low-income individuals. Each state was allowed to establish its own eligibility standards, benefits package, payment rates, and program administration under broad federal guidelines. The original statute, Title XIX of the Social Security Act, did not include specific standards related to the coverage of children, and no minimum preventive and developmental benefit package was specified.

Two years after passage, however, amendments to Title XIX were made as part of an effort to improve the availability and quality of pediatric health care in the United States. Interest in this effort stemmed from the findings of a government study analyzing the 50 percent rejection rate among military draftees in 1962. This study, One Third of a Nation: A Report on Young Men Found Unqualified for Military Service, found that the majority of young men rejected for military service in the early 1960s failed as a result of physical and mental health conditions, many of which could have been diagnosed and treated in childhood and adolescence. At the same time, concerns were being raised regarding widespread disability among low-income preschool children enrolled in the Head Start program.

The EPSDT provisions of the Social Security Amendments of 1967 expanded Medicaid’s role beyond treatment of illness to include promoting childhood growth and development. Under EPSDT, Medicaid provides early and periodic screening and diagnosis of children to identify physical and mental conditions and provide treatment to “correct or ameliorate defects and chronic conditions” discovered. The goal of the EPSDT program is the early identification and treatment of health conditions that can impede children’s natural growth and development and thereby avoid long-term disability and its accompanying health and financial costs.

EPSDT benefits for Medicaid children are more generous than most private health insurance benefit packages. Commercial insurance plans are typically designed to meet the needs of adults and tend to limit what is
covered to treatments or services that diagnose or treat illnesses or injuries to restore normal functioning. As a result, certain types of treatments can be excluded. EPSDT, on the other hand, was designed to promote the health and development of children. EPSDT ties medical need to children’s individual conditions and requires coverage consistent with the goal of ensuring healthy child development. When comparing EPSDT to commercial plans that are considered generous, such as the Federal Employees Health Benefits (FEHB) Program Blue Cross Blue Shield Standard Option, there are numerous differences (Table 1).

Over the years, Congress has taken steps to strengthen EPSDT. In 1972 and 1981, specific outreach and family support requirements to promote

### TABLE 1
Comparison of Certain Benefits for Children: EPSDT and FEHB Program
(Standard Option Blue Cross/BlueShield Plan)

<table>
<thead>
<tr>
<th>Benefit</th>
<th>EPSDT</th>
<th>FEHB</th>
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<tbody>
<tr>
<td>Physical, Speech &amp; Related Therapies</td>
<td>Covered without limitations other than medical necessity; no “recovery” requirements; therapy covered for conditions identified through early intervention and child care programs.</td>
<td>Limited to inpatient coverage. “Maintenance therapy” expressly excluded. Also excluded are “recreational and educational” therapy and “any related diagnostic testing except as provided by a hospital as part of a covered inpatient basis.” All services billed by schools or a member of school staff are excluded.</td>
</tr>
<tr>
<td>Hearing Services</td>
<td>Covered without limitations, including test, treatment, hearing aids, and speech therapy related to hearing loss and speech development.</td>
<td>Testing covered only when “related to illness or injury.” Routine hearing tests excluded other than as standard part of “routine” screening for children; hearing aids excluded along with testing and examinations for the prescribing or fitting of hearing aids.</td>
</tr>
<tr>
<td>Eye Examination &amp; Eyeglasses</td>
<td>Covered without limitations, as medically necessary</td>
<td>One pair of eyeglass replacement lenses or contact lenses to “correct an impairment directly caused by a single instance of accidental ocular injury or intraocular injury”; eye examinations for specific medical conditions; nonsurgical treatment for amblyopia and strabismus from birth through age 12. Eyeglasses and routine eye examinations specifically excluded, as are eye exercises, visual training, and orthoptics except in connection with the specific diagnosis of amblyopia or strabismus.</td>
</tr>
<tr>
<td>Durable Medical Equipment (DME)</td>
<td>Covered without limitations, as medically necessary</td>
<td>Certain DME covered but only if prescribed for the treatment of “illness or injury.”</td>
</tr>
<tr>
<td>Home Nursing</td>
<td>Covered without limitations, as medically necessary, home visits can cover health educators, therapists, health aides, and others.</td>
<td>Covered for two hours per day, 25 visits per year, when furnished by a nurse or licensed practical nurse and under a physician’s orders.</td>
</tr>
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health care access were added. In 1989, the treatment component of the EPSDT program was broadened to ensure that all treatments allowed under the definition of “medical assistance” in 1905(r) of the Medicaid statute (that is, all mandatory and optional Medicaid services) are covered in all states. This mandates state provision of full Medicaid coverage for all physical, mental, and developmental conditions. The change was in response to evidence of limited access to care among children with mental and developmental disabilities.

Today, many advocates regard EPSDT’s role in childhood growth and development as a critical component of the health care safety net, particularly as Medicaid eligibility is expanding to cover increasing numbers of previously uninsured children. States electing to expand Medicaid under SCHIP (rather than create a separate program), for example, are required to provide the same Medicaid benefit package, including EPSDT services, to SCHIP beneficiaries. In 2004, over 1.7 million children were enrolled in SCHIP Medicaid expansion programs and therefore eligible for EPSDT. This benefit requirement under SCHIP contributes to the increasing number of children eligible for EPSDT (Figure 1).11

The role of EPSDT with its generous benefit package, however, often collides with state concerns regarding administration and cost containment. The politics of EPSDT have been highly charged at various points since the program’s inception. Final regulations for EPSDT were not published until two years after enactment, leading to delays, controversies, and litigation over state implementation in the 1970s. The 1989 amendments were hotly criticized by some states, claiming the treatment requirements under EPSDT constituted an unfunded mandate. In the mid 1990s, a state-supported effort to block grant the Medicaid program would have repealed a child’s right to receive EPSDT services. After the veto of the Medicaid block grant

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**FIGURE 1**

Number of Children Eligible for EPSDT (in millions)

- 1991: 17.2
- 1992: 19.1
- 1993: 21.1
- 1994: 22.1
- 1995: 23.5
- 1996: 22.9
- 1997: 22.6
- 1998: 23.4
- 1999: 24.8
- 2000: 26.8
- 2001: 28.3
- 2002: 28.3
- 2003: 28.3

legislation in 1995, the NGA called for EPSDT rules to be relaxed and the treatment provisions repealed.12

The breadth and depth of EPSDT coverage, the administrative and regulatory requirements, and the inability of states to control access are key sources of tension between state and federal policymakers. A review of the specific requirements for the screening, diagnosis, and treatment services highlights the extensiveness of the benefits and mandates of this prevention-oriented program.

**Early and Periodic Screening**

EPSDT is designed to target health conditions and problems for which growing children are at risk, such as iron deficiency, lead poisoning, obesity, and dental disease. EPSDT services are also intended to detect and correct health conditions that can hinder a child’s development, such as vision and hearing problems.

Health screens, or well-child check-ups, are the foundation of the EPSDT program. Screenings allow providers to assess a child’s health needs and help ensure that problems are diagnosed and treated early, before they become more complex and their treatment more costly.

Under EPSDT, states are required to provide Medicaid children four types of health screens: medical, vision, hearing, and dental. Each of these health screens must be performed according to a periodicity schedule. States can determine the periodicity schedule for health screens; however, they must meet reasonable standards of pediatric and adolescent medical and dental practice. Federal regulations encourage states to follow the recommended periodicity schedules of the American Academy of Pediatrics, although states have discretion to follow other schedules. Each screen has its own distinct periodicity schedule established by the state. This discretion results in different screening schedules across the states, which complicates data collection efforts to track access and EPSDT-related expenditures.

EPSDT requires states to cover “interperiodic screens” or visits outside of the periodicity schedule if it is necessary to determine whether a child has a condition that needs further care. Individuals outside of the health care system including parents and teachers can determine the need for interperiodic screens.

The medical screening process has five components:

- Comprehensive health and developmental history, including assessment of both physical and mental health development
- A “head to toe” comprehensive, unclothed physical exam
- Appropriate immunizations13
- Laboratory tests, including lead toxicity screening14
- Health education
The vision and hearing screenings required under EPSDT must, at a minimum, include diagnosis and treatment for defects, including the provision of eyeglasses and hearing aids. The EPSDT dental screening, at a minimum, must include relief of pain and infections, restoration of teeth and maintenance of dental health. Dental services may not be limited to emergency services, and a direct dental referral is required for every child in accordance with the dental periodicity schedule.\textsuperscript{15}

Outreach and education regarding EPSDT are required elements as well. States must inform parents and guardians of Medicaid-eligible children of the availability of EPSDT services, the importance of immunizations, and the benefits of preventive care. In addition, prior to the due date of a child’s periodic examination, the state agency must offer and, if needed, provide assistance with transportation and appointment scheduling. These provisions are designed to help ensure all eligible children receive the services to which they are entitled.

**Diagnosis and Treatment**

If a need for further evaluation of a child’s health is determined during a periodic or interperiodic screening, states are required to provide a complete diagnostic evaluation. Diagnosis may be part of the screening and examination process. If a health condition is discovered, EPSDT requires states to ensure the provision of necessary treatment. All conditions—medical, mental, developmental, acute, and chronic—must be treated, including conditions not newly discovered during a screen.\textsuperscript{16}

EPSDT’s unique medical necessity standard is broad in scope to ensure access to care at a level consistent with each child’s medical needs. States are to provide all medically necessary services covered by Medicaid regardless of whether those services are part of the individual state’s Medicaid program. In other words, states must provide all federally defined Medicaid mandatory and optional benefits to children (see Appendix 1). While individual states may place limits on coverage for adults (for example, limits on mandatory benefits, no coverage for optional benefits) they do not have this discretion with respect to services for children. This federal treatment requirement and EPSDT’s definition of medical necessity results in uniform and comprehensive Medicaid coverage for children across the states, an aspect of Medicaid that is unique to coverage for children.

The treatment provisions of EPSDT are behind much of the controversy over the program, because they create unprecedented coverage for Medicaid children. Some view these provisions as a critical safety net for vulnerable populations. On the other hand, many others view them as the means to creating a level of care that exceeds necessity—often referred to as “Cadillac care.” While states have tried to control the costs of EPSDT benefits through medical necessity standards, it has been difficult and in some cases, litigation has resulted.
Delivery and payment for medical care in both the public and private sector hinges upon a finding of “medical necessity.” Medical necessity is generally considered as services or items that are reasonable, necessary, and/or appropriate according to evidence-based clinical standards. There are many definitions of medical necessity, and there are a variety of parties who interpret these definitions for different purposes, including providers, payers, and the courts. With respect to Medicaid and EPSDT, different interpretations of medical necessity can be a source of contention among child health advocates, families, federal and state officials, and Medicaid administrators.

Unlike Medicare, which defines medical necessity as services or items reasonable and necessary for the diagnosis or treatment of illness or injury or to improve the functioning of a malformed body member, the federal Medicaid statute does not define medical necessity. Whereas federal regulations establish requirements regarding amount, duration, and scope of Medicaid services,* there are no federal requirements regarding the definition of medical necessity. Each state is allowed to develop its own definition of medical necessity for operation of its Medicaid program. As a result, Medicaid coverage decisions vary across state programs; what a beneficiary may receive under one state Medicaid program may not be covered under another state Medicaid program.

The exception to this is services provided under EPSDT. Section 1905(r)(5) of the Social Security Act entitles children to “necessary…diagnostic services, treatment and other measures…to correct or ameliorate defects and physical and mental illnesses and conditions discovered by the screening services…” This statutory language establishes a broad medical necessity standard for EPSDT services that has been interpreted to require health care interventions at the earliest possible time.† States are legally bound to provide all needed services to Medicaid children, regardless of the state medical necessity definition used for adults. The intended result is for EPSDT to provide a uniform, comprehensive benefit for Medicaid children across all state programs.

However, interpretations of “necessary” are varied, and litigation has been brought against states for narrow interpretations of what is covered under 1905(r)(5). Courts have held that a broad interpretation of the EPSDT medical necessity standard is required to carry out the goals of the Medicaid program. Furthermore, they have held that in enacting the Medicaid program, Congress intended to invest broad discretion among physicians—but not other individuals or entities—to determine what treatment is medically necessary.‡ States may review the treating physician’s determination of medical necessity, but they must defer to his or her recommendation.§

* Code of Federal Regulations (CFR), 42 CFR, section 440.230 states that “each service must be sufficient in amount, duration, and scope to reasonably achieve its purpose. The Medicaid agency may not arbitrarily deny or reduce the amount, duration, or scope of a required service…to an otherwise eligible recipient solely because of the diagnosis, type of illness or condition….”
Low-Income Children and Special Health Care Needs

Since its inception, the EPSDT program has played an important role in the health and development of low-income children enrolled in Medicaid. Like children outside Medicaid, the health needs of Medicaid children range from modest to serious, and the unique treatment requirement under EPSDT is designed to ensure each child’s specific medical needs are met at the appropriate level.

Many argue that EPSDT paves the way to access to care for the country’s most vulnerable groups. Children enrolled in Medicaid are more likely than uninsured children, and as likely as children insured privately (usually through employer-sponsored insurance), to receive well-child care and to visit the doctor in a given year (Figure 2).

Studies suggest that access to such regular physician visits is important because low-income children with public insurance coverage are more likely to be in poor health. Children with public health insurance also are more likely to have special health care needs (for example, asthma, developmental delays, poor motor skills) and are at greater risk for long-term disability than children in families with higher incomes. Furthermore, children with special health care needs have, or are at increased risk for, chronic physical, developmental, behavioral, or emotional conditions and require services beyond those required by children in general.

The comprehensive benefits and broad medical necessity standard of EPSDT allow Medicaid to meet the extensive needs of children facing serious, often life-long disease and disability. The presence of EPSDT guarantees access to specialized services frequently needed by children with chronic and high-cost medical needs. These include rehabilitative services, extended inpatient care, physical and speech therapy, eyeglasses, hearing aids and other durable medical equipment, private duty nursing, medically necessary prescription drugs, and targeted case management services. EPSDT’s coverage of services does not distinguish between acute conditions that can be cured and lifelong and chronic conditions whose effects and severity can be ameliorated through health care. This extensive coverage protects children with disabilities and special health care needs from limits on services.

FIGURE 2
Low-Income Children Using Health Care Services, by Insurance Status, 2002

<table>
<thead>
<tr>
<th></th>
<th>One or More Well-Child Visits</th>
<th>One or More Doctor Visits</th>
<th>One or More Dental Visits</th>
</tr>
</thead>
<tbody>
<tr>
<td>Uninsured</td>
<td>44%</td>
<td>57%</td>
<td>47%</td>
</tr>
<tr>
<td>Employer</td>
<td>65%</td>
<td>84%</td>
<td>77%</td>
</tr>
<tr>
<td>Medicaid</td>
<td>75%</td>
<td>86%</td>
<td>76%</td>
</tr>
</tbody>
</table>

A recent study by the Maternal and Child Health Policy Research Center analyzed Medicaid benefit coverage for children without EPSDT. Assessing the amount, duration, and scope of coverage for 12 services needed by children with chronic or high-cost medical needs in 50 state Medicaid programs, the study found:

“...absent the EPSDT diagnostic and treatment service mandate, all states to varying degrees would omit or limit coverage for services that are frequently needed by children with serious physical and developmental conditions to achieve their optimal level of health functional status. The services for which adequate benefits are most likely to be unavailable are private duty nursing services, personal care services, home health care services, and also physical therapy, occupational therapy and speech-language pathology services...”

The study also notes that when benefits are provided, the states frequently impose “condition or treatment exclusions that ignore children’s unique needs for preventive and habilitative interventions.” Such exclusions would have the greatest effect on children with congenital anomalies and developmental conditions. Finally, the study highlights the variation in Medicaid coverage that might exist for children from one state to another without EPSDT.

In addition to extending a comprehensive health benefit package for children with disabilities or special health care needs, EPSDT plays a key supporting role in other childhood development programs. Medicaid, for example, will pay for care provided in settings that are not traditional medical settings, such as schools or early childhood development centers. While appropriate in most cases, this practice has elicited questions about the substitution of Medicaid payment for programs that might have previously funded health care through other means. Also through EPSDT, Medicaid finances the health care component of programs that provide educational and supportive services to children with disabilities and special health needs, namely programs under the Individuals with Disabilities Education Act and the Maternal and Child Health Services Block Grant (Title V).

UNFULFILLED POTENTIAL

Although EPSDT is designed to ensure access to essential preventive and developmental childhood health care services, the actual administration of EPSDT services is fraught with difficulty. Program complexity, a lack of accurate state data, limited family awareness, confusing managed care arrangements, and state administrative challenges are persistent problems. These problems are effectively barriers to services, and they keep most states from meeting the federal EPSDT mandate. In many cases, children do not receive the services to which they are entitled.

Data

One of the biggest challenges facing policymakers regarding EPSDT is the lack of reliable national and state data. Although states are required
to report annually to CMS on EPSDT (providing, among other information, participation rates, number of children receiving medical screens, dental services, and number referred for corrective treatment), state diligence in reporting has been variable, and the accuracy of the data is questionable. For example, some states and managed care organizations assert the data under-represent the number of children receiving EPSDT services. They are concerned that Medicaid providers do not consistently report when an EPSDT-covered service is provided. Also, because payments are under capitation arrangements, provider-beneficiary encounter data for specific services are not always submitted to states, making it difficult to track individual receipt of services in managed care.

Child health advocates, in contrast, suggest the data over-represent the number of children receiving EPSDT services because children are counted as having received a screening even if they did not receive all five required elements of the medical screen. State flexibility regarding periodicity schedules is another identified barrier to successfully tracking and monitoring EPSDT service delivery.

The lack of accuracy and completeness in state-reported EPSDT data prevents a comprehensive national view of the EPSDT program. In fact, the Government Accountability Office (GAO) noted that state-reported data to CMS on EPSDT are “unreliable and incomplete” and “inadequate for gauging the success of the program.” Studies of specific EPSDT services (for example, dental services, lead screening) found that most children in Medicaid do not receive these services.

Despite incomplete data, it is clear EPSDT’s success in screening and treating eligible children has not met expectations. Regardless of the accuracy of the data, the actual number of children states report as having received EPSDT screens is only a fraction of the children eligible (Figure 3). Furthermore, annual state-reported data indicate that most states fall well short of the long-standing federal participation goal that 80 percent of Medicaid children should receive timely EPSDT medical screens each year (see Appendix 2).
For example, in 2003 only 25 percent of children were reported as receiving a preventive dental screen, and just 15 percent of children under five years of age were reported as receiving a lead blood test. Medical screening rates, while high for infants (82 percent of Medicaid-enrolled children under the age of 1), declined with age (Figure 4).

**Barriers to Services**

Several factors contribute to the underutilization of EPSDT services. Three frequently cited barriers are low participation on the part of providers, lack of family awareness or understanding of EPSDT services, and vague managed care contract language.

**Low provider participation** in Medicaid hinders access to EPSDT services. GAO has found there is a shortage of dentists willing to serve Medicaid beneficiaries that directly contributes to the low use of dental services. Shortages of mental health and substance abuse professionals willing to treat Medicaid patients have been problematic as well. Under Medicaid managed care arrangements, state requirements regarding provider networks vary a great deal, from broad provisions stating plans must have “adequate” networks to very specific standards explicitly defining provider arrangements, such as the maximum number of patients per provider. As a result, access can vary dramatically under managed care. Access to participating providers is also limited when providers are unwilling to accept new Medicaid patients. No-show rates of beneficiaries are often cited as the main reason that private providers will not take Medicaid patients. Low payment rates and delays in payment also contribute to low provider participation.
Lack of parental awareness of Medicaid and EPSDT also affects utilization. Researchers have 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. Often parents are not aware of the breadth of health screening and treatment services their children are entitled to under Medicaid through EPSDT. States and managed care plans have been criticized for inadequate efforts to inform beneficiaries about EPSDT services. For states under pressure to lower Medicaid costs, however, EPSDT outreach and education may not be a priority.

Managed care responsibilities regarding EPSDT services are often not well defined. This is a significant issue given that 56 percent of Medicaid children are enrolled in managed care. Although states in general expect Medicaid managed care plans to honor the full EPSDT coverage obligation for enrolled children, state contracts often do not specify what this means. In addition, providers often are not informed of the availability of additional benefits for Medicaid children. This creates confusion over what is covered and can lead to inappropriate service denials. In addition, access to specialty care can be hindered by the need to obtain a referral if a provider is outside the managed care network.

Inherent financial incentives in capitated payment systems to control or limit utilization of services can also curb access to services. Many believe the incentive to cut costs may outweigh the incentive to promote preventive and primary care. States cannot delegate their responsibility to provide EPSDT services to managed care plans; they are expected to provide access to services not covered by managed care plans. Analysts have raised concerns that the combination of these factors calls into question states’ ability to ensure that EPSDT is provided. This could be especially problematic in some cases, such as under the new benefit options included in the DRA, where the state’s plan is to fulfill the EPSDT requirement by wrapping around the benefits offered in a less-comprehensive benchmark benefit plan.

Legal Action

State failures to adequately provide EPSDT services have resulted in litigation, usually focusing on specific aspects of the federal requirements. At least 28 states have been sued by beneficiaries or advocacy groups since the early 1990s for not providing required access to EPSDT services. Some cases specifically focused on the provision of screening services. Others involved obtaining coverage for treatment services. Early lawsuits sought to require state Medicaid programs to implement EPSDT; later ones have ranged from failure to cover selected services to alleged program-wide failures and deficiencies.
Examples of cases include:

- A 1998 case in Maine[^32] filed on behalf of Medicaid-eligible children who have severe mental impairments, including mental retardation, autism, or mental illness and who need home or community-based services. The complaint alleged the state was failing to provide needed EPSDT covered services, including case management, in-home aides, medication monitoring, and mental health counseling in a timely manner.

- A 1991 case in Maryland[^33] in which it was claimed that the state wasn’t providing timely screens for foster children.

- A 1993 case in Texas[^34] in which it was claimed that lead blood level assessments were not being provided under EPSDT.

- A 1993 case in Virginia[^35] in which it was claimed that the state was not providing funds for medically necessary organ transplants to children under 21 who were otherwise qualified under the state’s Medicaid plan.

- A 1993 case in Florida[^36] in which it was claimed that the state was responsible to pay for liver-bowel transplant and incidental medical treatment for qualified Medicaid beneficiaries under the age of 21.

In all of these cases, the courts ruled in favor of the plaintiffs.

Between 2001 and 2003, the majority of EPSDT litigation focused on access to community-based mental and behavioral health services. Many of these cases have stemmed from state Medicaid agency contracts with private managed care entities to provide all or a subset of Medicaid services. Rulings in these cases repeatedly note that contracts with managed care entities or other “agents” do not allow the state to avoid responsibility for implementing EPSDT. The state remains legally responsible for ensuring the provision of services covered by the Medicaid program, including required EPSDT services. These cases included:

- A 2001 class action complaint in Tennessee[^37] alleging failure of the statewide managed care program to ensure that children get EPSDT services. Children and their families noted numerous problems in their complaint, including the lack of outreach and informing; failure to provide screening and diagnostic services; and failure to provide needed treatment, from wheelchairs to home-based mental health services.

- A 2003 case in Indiana[^38] that challenged the state’s refusal to cover long-term psychiatric residential treatment facility (PRTF) services for children under age 21. The state contended that other inpatient psychiatric offerings were sufficient to meet the children’s needs. The court rejected the state’s argument and found that PRTF services are included under covered EPSDT services.
Litigation has significantly influenced the EPSDT program. Lawsuits usually highlight state shortcomings to fully meet the federal EPSDT mandate. This creates a defensiveness on the part of states as well as a desire to limit the scope of the program. The lawsuits also provide opportunities to improve state EPSDT programs.

Many contend further administrative changes are needed to keep the EPSDT program current. Efforts are underway to “modernize” the administration of the EPSDT benefit. The operational and service delivery dimensions of the program have not changed despite changes in pediatric practice, the organization and delivery of health care, provider compensation arrangements, and quality performance measurement. An “operational prototype” for EPSDT services is currently under development by the Center for Health Care Strategies, Inc., and the George Washington University Center on Health Policy Research. The prototype will be a set of policy and procedural recommendations that seek to address key deficiencies in the current system and give agencies and managed care organizations that serve children some concrete tools to re-orient EPSDT toward integrated service provision, continuous quality improvement, and measuring key health outcomes.39

Misuse and Abuse

Fraud, waste, and abuse in the Medicaid program are not new, nor is the fact that providers are frequently the source. Although many common problems may be simple mistakes, there also are intentional abuses. Provider billing abuses have been found regarding the provision of EPSDT services. Such inappropriate practices include billing for health care screens that have never been performed, providing and billing for multiple visits for the same screening service within a given periodicity schedule, billing for screens performed on non-Medicaid children, and billing for services not medically justified. These abuses of the EPSDT benefits result in Medicaid overpayments for providers and tarnish the program’s reputation.

Efforts to eliminate improper Medicaid payments are not always a priority for states, most commonly because of limited resources. Another issue of concern is the effect on provider willingness to participate in Medicaid because they are generally paid much less than they would be under Medicare or private insurance. If states crack down too aggressively on provider overcharges, they could be faced with providers quitting the Medicaid program altogether. For example, Ohio’s Inspector General found that seven speech and hearing centers had exploited a loophole in the state Medicaid billing cycle and overcharged Medicaid by $3.4 million. The state chose to settle for $155,000 from two of the centers and decided to prosecute just one center. The state believed if it vigorously pursued the providers it would have essentially closed every speech and hearing center in the state.
Too Costly?

As the largest share of state expenditures, Medicaid has long been the center of state fiscal crises and the focus of state efforts to balance their budgets. As Tennessee Gov. Phil Bredesen stated, “Medicaid is a clear and present danger to the budgets and priorities of the states. It has become the gorilla that comes to the table and eats and drinks what it wants, and then education and public safety and state employees get to fight over what is left.”

Since 2001, states have employed several different strategies to reduce the growth in their Medicaid spending, from reducing provider payments to restricting eligibility and benefits and increasing beneficiary co-payments. The open-ended nature of the EPSDT program with its federal override of state benefit limitations has been alleged to contribute to higher Medicaid costs for states. The fact that it provides a richer benefit than most private insurance policies raises other concerns, particularly in light of increasing number of eligible working poor families. On the other hand, child health advocates contend EPSDT is not the “budget breaker” states portray it to be, arguing children remain inexpensive in comparison to other populations covered by Medicaid (Figure 5).

Lack of reliable data, however, makes it impossible to determine the additional cost implications, if any, of EPSDT. State Medicaid plans are broadly drafted and it is difficult to measure the extent to which federal EPSDT requirements override state limitations on benefits. In 2000, one study on EPSDT costs concluded that it is not possible to determine from a review of state Medicaid plans and managed care contracts the additional cost impact of EPSDT in relation to either conventional insurance or the level of coverage that would be available in the case of “standard” state Medicaid plan coverage for adults.

A broader examination of Medicaid costs shows lower costs for children enrolled in Medicaid than those with private insurance. A review of medical expenditure data including all the services covered by EPSDT, many of which are not typically covered by private insurance, for years 1996 through 1999 shows that Medicaid costs less per child on average ($924) than private insurance ($1,344). These lower costs can likely be explained by lower provider reimbursement rates and by the savings generated through widespread utilization of managed care in Medicaid.

FIGURE 5
Per Capita Medicaid Spending, Children and All Medicaid Enrollees

<table>
<thead>
<tr>
<th>Children</th>
<th>$1,315</th>
</tr>
</thead>
<tbody>
<tr>
<td>All Medicaid Enrollees</td>
<td>$4,011</td>
</tr>
</tbody>
</table>

Source: Kaiser Family Foundation, August 26, 2005; available at statehealthfacts.org.
CHANGES ON THE HORIZON?

Individual state efforts to change EPSDT are not new. Through the Health Insurance Flexibility and Accountability (HIFA) “section 1115” demonstration initiative, some states are pursuing changes to EPSDT as part of a broader overhaul of state Medicaid benefits. Many of the changes involve state optional eligibility groups such as near-poor children. Some proposed changes, however, would affect all children, including federally defined mandatory eligibility groups of children.

■ Tennessee — Since 2002 the state with the landmark section 1115 demonstration that expanded Medicaid, called TennCare, has wanted to drop EPSDT services for its expansion population, which is an optional eligibility group. In addition, in its most recent waiver proposal, the state is seeking authority to apply a new, more restrictive medical necessity standard for all children. This new standard would approve services that are “the least costly alternative...adequate to address the medical condition.” Although the state indicated the new definition would be applied in a manner “consistent with EPSDT,” it is unclear what the effect on Medicaid children would be. Some are concerned the new standard would enable the state to determine whether EPSDT-covered services are “necessary” for a particular Medicaid child.

■ Washington — As part of its proposed effort to expand Medicaid eligibility, Washington wants to implement new cost-sharing requirements for optional services, as well as services accessed through EPSDT. The state has also specifically requested a waiver of the EPSDT service requirements for optional groups of children.

■ Michigan — In an effort to alter the state’s Medicaid benefits while expanding its SCHIP program, Michigan has proposed to replace EPSDT benefits with services that “meet the criteria” of the American Academy of Pediatrics for children in families with incomes up to 100 percent of the federal poverty level.

Early DRA Activity

The future of EPSDT will continue to come into question as states use new options under the DRA to transform Medicaid to look more like private insurance through benefit changes and increased cost sharing. The new EPSDT wrap-around benefit requirement created by the DRA is intended to preserve the program. However, as states start using the increased flexibility provided by DRA to reform their programs, changes in actual EPSDT coverage appear to be occurring.

West Virginia’s recently approved alternative Medicaid benefits package is alleged to restrict children’s access to screening and treatment services guaranteed by the Medicaid statute. The state has redefined EPSDT in its basic benefit package to include only screening exams and some dental,
vision, and hearing services that are part of the EPSDT benefit. Some analysts assert that the new state definition fails to include the follow-up diagnostic and treatment services that a health-care provider prescribes for a child on the basis of the child’s screening examination and, as a result, is contrary to federal law.

West Virginia’s decision to scale back or eliminate EPSDT services in its basic benefit package highlights the need for the wrap-around benefit requirement if the nature of the benefit as defined in federal law and regulations is to be maintained. Benchmark benefit packages allowed under the state plan amendment option of the DRA traditionally provide less comprehensive coverage than Medicaid. A recent review of the standard Blue Cross Blue Shield benefit plan offered under FEHB Program, an approved benchmark plan, found the plan to be generous with respect to coverage of basic medical services, including prescription drugs, but “insufficient to meet all of the needs of children with severe or complex physical or developmental conditions.” In addition, coverage of specialized services, “specifically therapies, home health care, durable medical equipment, and personal care, are typically limited in scope and amount and sometimes unavailable.”45

CONCLUSION

There is no doubt that EPSDT is a unique program with a critical role. Its unprecedented scope of health care coverage for Medicaid children of various medical needs is a critical component of the health care system for certain low-income families. The original premise of the program—that it is in the national interest to ensure preventive health care to poor, needy, and vulnerable children—is likely still a clear and valid justification for its continuation. However, questions about the administration, feasibility, and costs of EPSDT have persisted since its inception. The program is not reaching its potential, and, although much concern is expressed about costs and administrative complexity, poor data undermine efforts to understand the true cost implications of EPSDT. In theory, the EPSDT program can be viewed as ideal, but in reality children are not receiving all required screening and necessary treatment services.

As the Medicaid program continues to evolve in times of limited state and federal funds, increasing enrollment, and increasing health care costs, the role of EPSDT will be highly debated. As states model their Medicaid programs more like private insurance, it is important to recognize the elements of EPSDT that allow it to succeed where private insurance may fail, particularly with regard to providing specialty services for chronic and high-cost medical needs. Medicaid’s importance to children and adolescents is ongoing, and the role of EPSDT will undoubtedly be reconsidered and reconsidered.
ENDNOTES


14. All children are considered at risk for lead poisoning and must be screened. CMS requires that all children receive a screening blood lead test at 12 months and 24 months. Children between ages 36 months and 72 months must receive a screening blood test if they have not been previously screened for lead poisoning.


Endnotes / continued


18. NACHRI, “50-State Analysis.”


21. These 12 services are physician services, inpatient and outpatient hospital services, prescription drugs, physical therapy, occupational therapy, speech therapy, private duty nursing, home health care, personal care, durable medical equipment, and medical supplies.

22. Oregon was not included, but the District of Columbia was.


25. GAO, “Stronger Efforts.”


29. GAO, “Stronger Efforts.”


31. GAO, “Stronger Efforts.”


Endnotes / continued


42. Rosenbaum and Sonosky, “Federal EPSDT Coverage Policy.”


44. Cindy Mann, “The New TennCare Waiver Proposal: What is the Impact on Children?” Georgetown University, Health Policy Institute, March 7, 2005; available at http://hchp.georgetown.edu/pdfs/tenncareandchildren.pdf. Tennessee maintains that previous federal waiver approvals permit the state to refrain from providing the standard EPSDT services to the expansion group of children; currently these children are receiving EPSDT services.

<table>
<thead>
<tr>
<th>Mandatory Benefits</th>
<th>Optional Benefits</th>
</tr>
</thead>
<tbody>
<tr>
<td>Physician services</td>
<td>Prescription Drugs</td>
</tr>
<tr>
<td>Hospital services</td>
<td>Home health care</td>
</tr>
<tr>
<td>Rural and federally-qualified health center services</td>
<td>Physical, Occupational, Speech therapies</td>
</tr>
<tr>
<td>Family planning</td>
<td>Dental services and dentures</td>
</tr>
<tr>
<td>Certified pediatric and family nurse practitioners</td>
<td>Optometrist and eyeglasses</td>
</tr>
<tr>
<td>Nurse mid-wives</td>
<td>Mental health services</td>
</tr>
<tr>
<td>Laboratory and x-ray services</td>
<td>Intermediate care facility for mental retardation</td>
</tr>
<tr>
<td>Early and periodic screening, diagnostic, and treatment services for individuals under age 21</td>
<td>Nursing facility care for individuals under age 21</td>
</tr>
<tr>
<td>Pregnancy-related services</td>
<td>Private duty nursing</td>
</tr>
<tr>
<td>Medical and surgical services by a dentist</td>
<td>Personal care services</td>
</tr>
<tr>
<td>Nursing facility services for individuals age 21 and over</td>
<td>Case management, including targeted case management and primary care case management</td>
</tr>
<tr>
<td></td>
<td>Hospice care</td>
</tr>
<tr>
<td></td>
<td>Medical transportation</td>
</tr>
</tbody>
</table>

*Source: CMS, Medicaid at a Glance, 2005*
### Appendix 2: EPSDT Participant Screening Rates by State, 2003

<table>
<thead>
<tr>
<th>State</th>
<th>Participant Rate (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Alabama</td>
<td>48%</td>
</tr>
<tr>
<td>Alaska</td>
<td>50%</td>
</tr>
<tr>
<td>Arizona</td>
<td>56%</td>
</tr>
<tr>
<td>Arkansas</td>
<td>27%</td>
</tr>
<tr>
<td>California</td>
<td>41%</td>
</tr>
<tr>
<td>Colorado</td>
<td>50%</td>
</tr>
<tr>
<td>Connecticut</td>
<td>56%</td>
</tr>
<tr>
<td>Dist of Columbia</td>
<td>69%</td>
</tr>
<tr>
<td>Delaware</td>
<td>70%</td>
</tr>
<tr>
<td>Florida</td>
<td>55%</td>
</tr>
<tr>
<td>Georgia</td>
<td>100%</td>
</tr>
<tr>
<td>Hawaii</td>
<td>70%</td>
</tr>
<tr>
<td>Idaho</td>
<td>33%</td>
</tr>
<tr>
<td>Illinois</td>
<td>73%</td>
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<tr>
<td>Indiana</td>
<td>56%</td>
</tr>
<tr>
<td>Iowa</td>
<td>98%</td>
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<tr>
<td>Kansas</td>
<td>61%</td>
</tr>
<tr>
<td>Kentucky</td>
<td>48%</td>
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<tr>
<td>Louisiana</td>
<td>60%</td>
</tr>
<tr>
<td>Maine</td>
<td>59%*</td>
</tr>
<tr>
<td>Maryland</td>
<td>52%</td>
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<td>Massachusetts</td>
<td>92%</td>
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<td>Michigan</td>
<td>46%</td>
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<tr>
<td>Minnesota</td>
<td>81%</td>
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<tr>
<td>Mississippi</td>
<td>29%</td>
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<tr>
<td>Missouri</td>
<td>61%</td>
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<tr>
<td>Montana</td>
<td>55%</td>
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<tr>
<td>Nebraska</td>
<td>53%</td>
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<tr>
<td>Nevada</td>
<td>99%</td>
</tr>
<tr>
<td>New Hampshire</td>
<td>54%*</td>
</tr>
<tr>
<td>New Jersey</td>
<td>51%</td>
</tr>
<tr>
<td>New Mexico</td>
<td>49%*</td>
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<td>New York</td>
<td>89%</td>
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<tr>
<td>North Carolina</td>
<td>69%</td>
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<tr>
<td>North Dakota</td>
<td>49%</td>
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<tr>
<td>Ohio</td>
<td>45%</td>
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<tr>
<td>Oklahoma</td>
<td>45%*</td>
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<tr>
<td>Oregon</td>
<td>51%</td>
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<tr>
<td>Pennsylvania</td>
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<tr>
<td>Rhode Island</td>
<td>53%</td>
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<tr>
<td>South Carolina</td>
<td>31%</td>
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<tr>
<td>South Dakota</td>
<td>41%</td>
</tr>
<tr>
<td>Tennessee</td>
<td>39%</td>
</tr>
<tr>
<td>Texas</td>
<td>60%</td>
</tr>
<tr>
<td>Utah</td>
<td>47%</td>
</tr>
<tr>
<td>Vermont</td>
<td>88%</td>
</tr>
<tr>
<td>Virginia</td>
<td>56%</td>
</tr>
<tr>
<td>Washington</td>
<td>50%</td>
</tr>
<tr>
<td>West Virginia</td>
<td>50%</td>
</tr>
<tr>
<td>Wisconsin</td>
<td>55%</td>
</tr>
<tr>
<td>Wyoming</td>
<td>38%</td>
</tr>
</tbody>
</table>

**Participant Rate** — The unduplicated number of children who received one or more medical screen(s) through EPSDT compared to the number of eligible children expected to receive a medical screen, based on the annualized state periodicity schedule and the average period of eligibility.

**Federal Participation Goal** — 80%

*2003 data unavailable, percentage is for 2002