Toward a Healthy Future:
Medicaid Early and Periodic Screening, Diagnostic and Treatment
Services For Poor Children and Youth

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About the National Health Law Program
The National Health Law Program (NHeLP) is a nonprofit public interest organization working to improve health care access for America’s working and unemployed poor, children, minorities, the elderly, and people with disabilities. Since 1969, NHeLP has served individuals, attorneys, community-based organizations, providers and policy makers who work to preserve and improve health care access.

**EPSDT Resources from the National Health Law Program**

*An Advocate’s Guide to the Medicaid Program* (June 2001)


*Early and Periodic Screening, Diagnosis and Treatment: Annotated Federal Documents* (Jan. 2000)

*EPSDT and Managed Care: Do Plans Know What They are Getting Into?, 28 CLEARINGHOUSE REV. 1248* (Mar. 1995)

*Fact Sheet: Early and Periodic Screening, Diagnosis and Treatment* (Mar. 1999)

*Fact Sheet: Medicaid Early and Periodic Screening, Diagnosis and Treatment As A Source of Funding Early Intervention Services* (June 2002)

*Fact Sheet: Medicaid Transportation Services* (June 2000)

*Medicaid Early and Periodic Screening, Diagnosis and Treatment As A Source of Funding Early Developmental Services* (Sept. 1999)

*Medicaid Managed Care and Children with Special Needs: An EPSDT Checklist* (Sept. 1997)

*State Initiatives to Improve Access to Dental Care* (June 2001)

*Using the Revised Reporting Form When Advocating for Improving EPSDT for Children and Youth* (Mar. 31, 2003)

*EPSDT Case Docket* (updated regularly)

*Toward a Healthy Future–Early and Periodic Screening, Diagnosis, and Treatment for Poor Children* (with Texas Rural Legal Aid) (Apr. 1995)

For more information about these resources and the National Health Law Program, visit http://www.healthlaw.org on the World Wide Web or call our Los Angeles office at (310)204-6010.
# Table of Contents

Introduction.......................................................................................................................... 1

Part I: The Need for Medicaid and EPSDT .............................................................................. 3  
  A. Many children are poor and uninsured................................................................. 3  
  B. Medicaid is a primary source of insurance for children........................................ 4  
  C. The importance of the Medicaid EPSDT service.................................................... 5  
  D. The effectiveness of EPSDT ..................................................................................... 6  
  E. An EPSDT report card ............................................................................................... 9

Part II: Medicaid Overview ..................................................................................................11  
  A. Medicaid background..............................................................................................11  
  B. Eligibility .................................................................................................................12  
    1. Fitting into a group...............................................................................................12  
    2. Limited income and resources .........................................................................15  
    3. Residency ............................................................................................................15  
    4. Citizenship/immigration Status ........................................................................16  
  C. Services ..................................................................................................................17  
  D. Administration .......................................................................................................17

Part III: Legal Requirements for EPSDT .............................................................................. 21  
  A. EPSDT background ...............................................................................................21  
  B. Requirements for outreach and informing .............................................................21  
  C. Requirements for screening services ................................................................. 22  
    1. Medical screens...................................................................................................22  
      a. Comprehensive health and developmental history .......................................23  
      b. Uncovered physical exam .........................................................................26  
      c. Laboratory tests ...........................................................................................27  
      d. Nutritional assessment .............................................................................28  
      e. Immunizations ...........................................................................................28  
      f. Health education .........................................................................................30  
    2. Hearing screens ..................................................................................................30  
    3. Vision screens ....................................................................................................31  
    4. Dental screens ..................................................................................................31  
  D. Requirements for periodicity of screens ................................................................32  
  E. Requirements for interperiodic screens ................................................................33  
  F. Requirements for diagnostic and treatment services ..............................................34  
    1. Scope of benefits .............................................................................................34  
    2. Timely treatment .............................................................................................35  
    3. Coverage standards .........................................................................................35  
    4. Other treatment topics ....................................................................................37  
  G. Provider participation ............................................................................................41  
  H. Cost-sharing ..........................................................................................................42  
  I. Reporting on child health .......................................................................................42
Part IV: Common Problems/Suggested Solutions .................................................................47
   A. Lack of outreach and informing .................................................................................47
   B. Lack of transportation ...............................................................................................52
   C. Provider shortages .................................................................................................54
   D. Denials of services by managed care organizations ..............................................57

Notes .....................................................................................................................................63

Appendix A: Legislative History to EPSDT

Appendix B: Age-appropriate Screening Forms

Appendix C: AAP Periodicity Recommendations v. States’ Periodicity Schedules, FY 1999

Appendix D: Scope of Medicaid Benefits
Introduction

Words to Remember:

We look toward the day when every child, no matter what his color or his family’s means, gets the medical care he needs, starts school on an equal footing with his classmates, seeks as much education as he can absorb – in short, goes as far as his talents will take him. . . .

13 Cong. Rec. 2883, 2885 (Feb. 8, 1967) (Statement of President Lyndon B. Johnson Introducing EPSDT)

Timely screening examinations and necessary medical treatment are needed to maintain and improve children’s health. Lower-income children are at particular risk for health problems. Thus, the Medicaid Act entitles them to comprehensive screening and treatment through a service called Early and Periodic Screening, Diagnostic and Treatment (EPSDT).

More than 20 percent of all children in the United States—one in five—are covered by Medicaid and thus entitled to EPSDT. Individuals who are working on behalf of children should be familiar with the EPSDT benefit.

This manual seeks to provide comprehensive information about EPSDT and offer practical suggestions for working with and improving the EPSDT program. It is organized as follows:

Part I provides background information on the needs of children and youth.
Part II gives a basic overview of the Medicaid program
Part III discusses the legal requirements for EPSDT
Part IV describes common barriers and offers examples of how these problems can be addressed.
**Part I
The Need for Medicaid and EPSDT**

**Abstract:** Part I sets forth facts and figures that illustrate the problem of child poverty in the United States today, to describe the critical role of the Medicaid program in meeting children’s health care needs, and to explain why Medicaid and EPSDT are effective programs for children and youth.

**A. Many children are poor and uninsured**

Nearly 12 million children under age 18 in the United States—16.6 percent of children—are poor.1 In America’s expensive pay-as-you-go health care system, almost no one can afford to pay for health care out-of-pocket. Either public or private health insurance is critical. During the prosperous 1990s, the number of uninsured Americans dropped as those provided employer-based coverage increased, along with the number of children enrolled in the newly-enacted State Children’s Health Insurance Programs (SCHIP) or Medicaid.2 By the end of the decade, however, the economy had cooled, and the number of uninsured Americans increased once again. By 2001:

- Over 9 million children in the United States (12.1 percent of children) were uninsured.3

- Three-quarters of these uninsured children were poor or nearly poor.4

- Children with special health care needs were about as likely as other children to be uninsured.

- In 12 states, 27 percent or more of children were uninsured (AK, AZ, CO, ID, LA, MT, NV, NM, OK, OR, TX, and VA).5

- Older children (ages 6 - 17) were more likely to be uninsured.

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Words to Remember:

The problem is to discover, as early as possible, the ills that handicap our children. There must be continuing follow-up treatment so that handicaps do not go untreated. . . . We must enlarge our efforts to give proper eye care to a needy child. We must provide health to strengthen a poor youngster’s limb before he becomes permanently disabled. We must stop tuberculosis in its first stages before it causes serious harm.

13 Cong. Rec. 2883, 2885 (Feb. 8, 1967)
(Statement of President Lyndon B. Johnson introducing EPSDT)
Hispanic children (at 32 percent) were more likely than children of other races or ethnicities to be uninsured.6

Uninsured children were:

- 6 times more likely than insured children to lack a usual source of care (24 percent v. 4 percent);7
- less likely to receive preventive care, with 1/3 not seeing a doctor in the past year (note: over 1/5 of children with special health care needs had no physician visit and lacked a usual source of care);
- at least 70 percent more likely not to receive medical care for common childhood conditions like sore throats;
- 2 times more likely to go without care for recurrent ear infections;
- 30 percent less likely to receive treatment when they are injured;
- over 5 times more likely to have an unmet medical care need;
- over 3 times more likely not to get a necessary prescription drug.8

B. Medicaid is a primary source of insurance for children

Medicaid is the single most important source of health insurance for children. The following facts and figures illustrate this:9
C. The importance of the Medicaid EPSDT service

Poverty is dangerous. Low socioeconomic status carries with it numerous by-products—poor nutrition, fewer educational opportunities, greater exposure to environmental hazards, and inadequate housing, to name just a few. All of these disadvantages increase the likelihood that a poor child will be in poor health. Indeed, children living in poverty—particularly children of color—are more likely than other children to suffer from ill health—including vision, hearing and speech problems, dental

Medicaid and Children: Facts and Figures:

- Over 21 million children in the United States – 1 in 5 – were enrolled in Medicaid in 2000.

- Over half of Medicaid enrollees are children.

- Children account for only 17 percent of Medicaid spending.

- Per-capita costs for children are the lowest among eligible groups ($1,225 in 1998, compared to $11,235 per elderly enrollee).

- Medicaid primarily covers children in working families, not children receiving cash assistance.

- Medicaid covers 78 percent of poor children under age 5 with disabilities and 70 percent of poor children aged 5-17 with disabilities. Medicaid covers 40 percent of near poor children under age 5 with disabilities and 25 percent of near poor children aged 5-17 with disabilities.

- Medicaid pays for 30 percent of all pediatrician visits, 38 percent of child hospitalizations, and 40 percent of all childbirths.

- More than 80 percent of the low-income uninsured children are eligible for coverage under Medicaid (60 percent) or SCHIP (24 percent).
health problems, skin lesions, elevated lead blood levels, sickle cell disease, behavioral health problems, anemia, asthma, and pneumonia.\textsuperscript{10}

Early detection and treatment can avoid or minimize the effects of many of these childhood conditions.\textsuperscript{11} For this to occur, however, the health insurance options offered to families with children must recognize that the health care needs of children and youth differ from those of adults and that poor children need assistance with obtaining health care services to a greater degree than adults do.\textsuperscript{12} Indeed, children pass numerous health and developmental milestones that must be assessed on time; if problems are not diagnosed promptly, the benefits of treatment can be lost forever.\textsuperscript{13} Moreover, children increasingly may experience health problems that cut across physical, mental, developmental, and psycho-social domains (e.g., family and neighborhood violence, drug and alcohol problems).\textsuperscript{14} Thus, they may require a range of services: comprehensive assessment, case management, mental health care, or rehabilitative therapies.

Early detection and treatment underlie the entire EPSDT program.\textsuperscript{15} Moreover, the EPSDT treatment package is comprehensive and broad precisely because, unlike private insurance, it is designed to cover poor children and children with special health care needs.

\begin{center}
\textbf{Words to Remember:}
\end{center}
\begin{quote}
The importance and cost-effectiveness of primary and preventive health care are well documented in the literature. Preventive care, early treatment of acute illness, and amelioration of chronic illnesses early in life may prevent more costly health problems later.
\end{quote}

National Governors Association, 1991
D. The effectiveness of EPSDT

Providing health coverage to children is effective and relatively inexpensive. Children comprise over half of the Medicaid population, but account for only 17 percent of Medicaid expenditures. Per-capita costs for children are the lowest among groups eligible for Medicaid ($1,225 in 1998, compared, e.g., to $11,235 per elderly enrollee). The EPSDT benefit itself has not resulted in a financial drain on purchasers. Researchers assessed the impact on the states of the EPSDT changes required by Congress in 1989 and found them to have been neither financially excessive nor administratively burdensome. An assessment of four states by the Research Triangle Institute, Emory University, and The MEDSTAT Group concluded that none of the study states had significantly changed the depth or breadth of coverage of diagnostic or treatment services for children in their Medicaid programs. Studies conducted by the American Public Welfare Association, an organization that works with state Medicaid directors, have also concluded that EPSDT spending has not had a significant impact on state budgets. According to the HHS Office of Inspector General, “Overall, the younger Medicaid patients require less care and less costly services than the aged and disabled, and very little long term care.”

By contrast, it is clear that the EPSDT program has a significant impact on children’s health. The four state study noted above looked at how the 1989 EPSDT changes have affected health status, service use, and expenditures for Medicaid children. It found that “although room exists for significant improvement . . . the net impact on children’s health service use of the Medicaid program changes during the 1989-92 period was unquestionably positive.” A study of Wisconsin children showed that children with access to EPSDT had fewer medical and dental health problems and more preventive dental care visits than children without access to an EPSDT program.

There are few studies of the cost effectiveness of the comprehensive EPSDT benefit; however, the existent studies show that EPSDT is a worthwhile benefit for poor children and children with disabilities. Moreover, many of the specific services included in the EPSDT package have been shown to be cost effective. For example:

- **EPSDT.** Early studies of the EPSDT programs in Michigan, North Dakota, Virginia, and Pennsylvania documented the effectiveness of the EPSDT program in improving children’s health status and lowering their medical costs. In Southeast Pennsylvania, researchers...
found their study of EPSDT to “attest to the beneficial effect of EPSDT on the health status of children served.” In particular, EPSDT was associated with a 30 percent decrease in the prevalence of abnormalities requiring care on rescreening.24

- **Prenatal care.** Early and comprehensive prenatal care saves about $3.00 for every dollar spent.\(^{25}\)

- **Prenatal AIDS care** (including HIV testing and counseling and AZT for infected mothers and newborns). Assuming a 25 percent rate of mother-to-infant transmission, the CDC found that the intervention would prevent 656 infections, with a net savings of $38.1 million.\(^{26}\)

- **Newborn screening.** (for hemoglobinopathies, PKU, and congenital hypothyroidism have been found to be among the 14 most cost-effective services.\(^{27}\)

- **Immunizations/vaccines.** Virtually all of the numerous studies on the topic conclude that immunizations/vaccines are beneficial and cost effective.\(^{28}\)

- **Chlamydia screening.** Among women under age 25, chlamydia screening has been found to be highly cost-effective.\(^{29}\)

- **Community-based care.** Community-based prenatal care programs specifically designed for adolescents have been shown to involve only 41 percent of the costs of traditional prenatal care, which is not adolescent focused.\(^{30}\)

- **Physician-based preventive care.** Assuming only five percent effectiveness with preventive health services, the delivery of those services would be cost-effective.\(^{31}\)

- **Eye care.** A 1992 study, which included children and adolescents, estimated that routine eye care would achieve annual savings exceeding $100 million.\(^{32}\)

- **Dental care.** Researchers have found that reducing severe caries through early interventions provides substantial cost savings.\(^{33}\) Dental sealant programs are cost saving when delivered to high risk populations like children in low-income households.\(^{34}\)

- **Family planning.** For every government dollar spent on family planning services, an average of $4.40 is saved as a result of averting
short-term expenditures on medical services, welfare, and nutritional services.35

- **Outreach by home visits.** Prenatal and infancy nurse home visitation programs can result in a net savings of money: one study indicated that the costs of such a program in New York were not only fully recovered, but actually produced a dividend when the corresponding reduction of expenditures on other government programs, such as Medicaid, were calculated.36

- **School-based care.** Of 75 students who received EPSDT screens in a school-based setting, 30 had abnormal laboratory tests while 14 children received 29 immunizations to counter immunization deficits.37 Vaccinating sixth grade students against Hepatitis B produced net savings of $75 per person.38

- **Substance abuse treatment.** In one study, for every $1 spent, $11 were saved in social costs.39

- **Health education.** Studies have found a variety of health education to be cost effective, including education about use of bicycle helmets among children,40 offering adolescents anti-tobacco counseling,41 and counseling adolescents to abstain from alcohol and drugs.42

E. An EPSDT report card

The discussion of EPSDT’s importance raises the question of how well EPSDT actually is meeting the needs of children and youth. As described more fully in part III, states report to CMS annually on their EPSDT performance.

Unfortunately, since it was enacted in 1967, EPSDT has not met the standards set by the federal government. There are many reasons for the failure. Policy makers did not aggressively engage in informing and education of beneficiaries and providers about EPSDT; federal authorities have never actively monitored or enforced EPSDT requirements; more recently, the authorities have focused more on enrolling children in health programs than actually serving them once enrolled.

In 1989, Congress amended the Medicaid Act to enhance the EPSDT requirements precisely because screening rates were low.45 And while screening rates have improved over the last decade, they appear to be doing so erratically. Using dental screening rates as an example, in 1996, only 21 percent of eligible children received a dental screen through
EPSDT; in 1998, 20 percent. Recent CMS-reported data show that, from the states reporting, only about 25 percent of eligible children received any dental services through EPSDT in 1999. The 1999 data also show:

- FY 1999 showed increases for most states in the numbers of older children enrolled in Medicaid and, thus, entitled to EPSDT. Some states attributed this to State Children’s Health Insurance Program outreach, which in many instances, was focused on aggressively enrolling older children and youth who were not previously covered by public or private health insurance.

- Screening percentages varied from state to state. Arkansas reported the lowest total screening ratio (25 percent), while Iowa, Nevada, and Rhode Island reported the highest (all at 100 percent).

- Children below age five were more likely to receive appropriate screening.

- Only 14.8 percent of children aged 1-2 received a lead blood test through EPSDT, while Medicaid requires all children to be tested twice, at 12 and 24 months.

EPSDT is a vital program for children, but it is misunderstood and underused. The remainder of this manual will provide child health advocates with information they need to improve children’s access to and use of the comprehensive range of EPSDT services.
Part II
Medicaid Overview

Abstract: This section provides background to the Medicaid program, of which EPSDT is a part. Federal rules governing eligibility, services and administration are outlined.

Sources of information on Medicaid and EPSDT:

- Medicaid Act -- 42 U.S.C. §§ 1396-1396v
- Medicaid regulations – 42 C.F.R. §§ 430-456.725
- Medicaid EPSDT regulations -- 42 C.F.R. §§ 441.50-441.62 NOTE: These regulations predate the most recent amendments to the Act, in 1989 and 1993.
- Legislative history -- e.g. 1989 U.S.C.C.A.N. 1906, 2124-26
- CMS/HCFA transmittals and documents, see http://www.nhelp.org/publications.shtml
- Form-416 EPSDT reports (completed by each state)
- Federal and state court cases
- State statutes and regulations, policy letters
- State Medicaid managed care model contracts and policy letters
- State case worker and provider manuals
- State EPSDT periodicity tables

A. Medicaid background
Medicaid is the medical assistance program for low income people.\footnote{47} It was established in 1965 by Title XIX of the Social Security Act and is jointly funded by the federal government and the states.\footnote{48} States are not required to participate in the Medicaid program; however, all do.

The Medicaid Act specifies basic requirements that states must meet as well as options states may adopt. States must meet minimum standards regarding eligibility, scope of services, procedural protections, and due process. Once a state chooses to participate, these minimum standards are binding.\footnote{49}

The minimum requirements for Medicaid establish a set of eligibility doors through which each child must successfully pass before services will be paid for by the program.

<table>
<thead>
<tr>
<th>To qualify for Medicaid, a child must:</th>
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<tbody>
<tr>
<td>1. Fit into an eligibility group.</td>
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<tr>
<td>2. Have limited income (and in some cases resources).</td>
</tr>
<tr>
<td>3. Be a resident of the state.</td>
</tr>
<tr>
<td>4. Be a US citizen or have acceptable immigration status.</td>
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**B. Eligibility**

**1. Fitting into a group**

To qualify for Medicaid, a child must fall into one of the population groups that are specified in the federal statute: pregnant women, children, caretakers of children, individuals who are blind, or individuals who are disabled. The Medicaid Act lists specific categories of these individuals that states must cover if they participate in Medicaid.\footnote{50} In addition, the Act provides a number of optional coverage categories that states may choose to cover.\footnote{51} If a state chooses to provide Medicaid to an optional group, it must provide Medicaid to all eligible individuals in the group.\footnote{52} Finally, states may choose to cover individuals who fit into a category of eligibility, but whose income or resources exceed the categorically needy levels. Known as the “medically needy,” this group may qualify after “spending down” a certain amount of income.\footnote{53}
TANF/SSI. Historically, Medicaid eligibility was tied to eligibility for cash assistance programs—Aid to Families with Dependent Children (AFDC) or Supplemental Security Income (SSI). However, over the years, Medicaid eligibility has been de-linked from cash benefits. Many new categories unrelated to cash assistance eligibility have been created, while eligibility for public assistance may not automatically entitle a person to Medicaid. AFDC has been abolished and its successor program, Temporary Assistance to Needy Families (TANF), does not automatically entitle its recipients to Medicaid. However, those who would have qualified for AFDC as of the date it was abolished, June 16, 1996, do automatically qualify for Medicaid under a category of eligibility referred to as “Section 1931.”

It remains true that, in most states, eligibility for SSI entitles a person to Medicaid. To be eligible for SSI, an individual must meet certain income/resource standards and be disabled. Specifically, a child under the age of 18 is disabled for SSI purposes if the child has a medically determinable physical or mental disability which results in marked and severe functional limitation (precluding substantial gainful employment), and that disability can be expected to result in death or has lasted or is expected to last at least 12 months.

Federal poverty level categories. Many children eligible for Medicaid are eligible based solely upon their income. States must cover children and pregnant women under six with family incomes no greater than 133 percent of the federal poverty level. They must also cover children ages six to nineteen with family incomes no greater than 100 percent of poverty ($15,260 for a family of three in 2003). States may, but are not required to, cover pregnant women and infants with incomes between 133 percent and 185 percent of poverty.

Presumptive eligibility. States can also provide for an initial period of eligibility for children under 19 years of age who are determined presumptively eligible by a qualified entity. During this period, the child is eligible to receive any health care items and services that are covered under the state Medicaid plan, including EPSDT. The presumptive eligibility period ends on either the day that a decision is made as to whether the child is eligible for Medicaid or, if no application is made, the last day of the month following the month in which presumptive eligibility is determined.
## Coverage Categories for Children

### Mandatory Coverage Categories

**Poverty Level Categories:**

- Infants under age 1 with family incomes below 133 percent of federal poverty level
- Infants under age 1 born to Medicaid-eligible women
- Children ages 1-5 with family incomes below 133 percent of federal poverty level
- Children ages 6 to 19 with family incomes below 100 percent of federal poverty level

**Former AFDC-linked children (Section 1931):**

- Children who would have qualified for the Aid to Families with Dependent Children Program (AFDC)
- Children in welfare-to-work families (Transitional Medical Assistance)

**Other Title IV Program-linked children:**

- Title IV-E foster care children
- Title IV-E adoption assistance children

**Disability-related categories:**

- SSI recipients
- Children in “209(b)” States using more restrictive eligibility requirements than those in effect under SSI
- Children who were SSI recipients as of Aug. 22, 1996

### Optional Coverage Categories

**Poverty Level Categories**

- Infants under age 1 with family incomes less than 185% of federal poverty level
- Optional Targeted Low-Income Children
- Non-Title IV-E foster care children
- Non-Title IV-E adoption assistance children

**Disability Related Categories**

- Katie Beckett children - children who would be eligible for Medicaid if living in an institution (because their parent’s income is no longer deemed to them) and who are at risk for institutionalization without Medicaid home and community-based services.
- Children eligible under a home and community based waiver program
- Independent foster care adolescents
- Individuals receiving hospice care
- Individuals receiving optional state supplement payments
- Individuals with tuberculosis

**Medically Needy Children**
SCHIP coverage. Finally, states may cover “optional targeted low-income children.” This category of eligibility was created when the State Children’s Health Insurance Program (SCHIP) was enacted by Title XXI of the Social Security Act.62 States may offer eligibility to uninsured children with family incomes up to 200 percent of poverty.63 A state may offer this coverage by expanding its Medicaid program or by establishing a separate SCHIP program.64 Notably, states receive a higher federal matching rate for SCHIP than they do for Medicaid services, which gives them an incentive to participate.65

2. Limited income and resources
In addition to falling into a population group, applicants must meet financial requirements, which assess income and resources. Income consists of earnings, such as wages earned from employment, pension benefits, or tax refunds and of unearned income, such as interest on a savings account. Income also consists of “in-kind” income, such as the value of food and shelter received from another person living in the home.66 Resources consist of cash or other property that can be liquidated or converted into cash-in-hand, such as real property, automobiles, stocks, bonds, savings accounts or life insurance policies. “Disregards” are amounts that the state deducts from income and resources to determine the “countable” income and resources that will be used to determine Medicaid eligibility. “Exemptions” allow the applicant to exclude the value of certain income or resources, or the portion of the value, in order to calculate “countable” income and resources when determining financial eligibility.67

In general, the financial eligibility rules that apply to the Medicaid applicant are those used for the cash assistance category to which the person is most closely linked (AFDC-96 or SSI).68 However, states can choose to apply less restrictive methodologies when determining what income and resources are to be counted toward Medicaid eligibility.69

3. Residency
To be eligible for Medicaid in a state, a beneficiary must be a resident of that state. A state may not deny Medicaid because the individual has not resided in the state for a specified period.70 The following residency rules apply:

- For most children and youth under 21, the state of residence is that of the caretaker relative or legal guardian—where that adult is living with the intention to remain permanently or indefinitely.71
For institutionalized children and youth who are neither married nor emancipated and for institutionalized individuals who become incapable of indicating intent before age 21, the state of residence is the parent’s or guardian’s state of residence at the time of placement.

If the child has been abandoned, the state of residence is that of the individual who files the Medicaid application.72

When a state places an individual in an institution in another state, the state making the placement remains that individual’s state of residence.73

For individuals receiving a state supplementary payment (SSP), the state of residence is the state paying the SSP.74

For individuals receiving title IV-E foster care and adoption assistance, the state of residence is the state in which the child lives.75

For emancipated individuals under age 21 and individuals under 21 who are married and capable of indicating intent, the state of residence is the state where the person is living with the intention to remain permanently or indefinitely.76

4. Citizenship/immigration Status

All U.S. citizens who meet the eligibility requirements for Medicaid can qualify for the full range of Medicaid benefits.77 This includes children born in the United States, even if their parents are undocumented immigrants. So, the citizenship or immigration status of non-applicant parents (or other household members) is not relevant to the child’s eligibility, and states may not require that parents disclose this information.78

The Personal Responsibility and Work Opportunity Reconciliation Act of 1996 (PRWORA) bars most immigrant, non-citizen children from receiving full-scope Medicaid benefits for the first five years after they enter the country.79 There are some exceptions. “Qualified aliens” who entered the United States prior to August 22, 1996 are eligible for full-scope Medicaid, with certain time limitations.80 Qualified aliens include lawful permanent residents (“green card” holders) and certain refugees, asylees, and battered individuals and their children.81 Immigrants receiving SSI are also eligible for Medicaid.82

Moreover, as part of the immigration process, many immigrants need to have a sponsor. The PRWORA imposes greater responsibility on sponsors, including deeming requirements that attribute the income of an
immigrant’s sponsor and sponsor’s spouse to the immigrant for the purposes of determining eligibility for public benefits. Since a sponsor must have a minimum income of 125 percent of the federal poverty level, the attribution of this income (whether actually available to the immigrant or not) will raise many immigrants’ incomes above eligibility for Medicaid.83

Undocumented and not-qualified immigrants are not eligible for full-scope Medicaid. States must, however, cover treatment of “emergency medical conditions” for all immigrants otherwise eligible for medical assistance under the state plan, whether they are in the United States with or without documentation.84

C. Services

As with eligibility, there are certain services states must cover and others that the state may choose to cover. Mandatory services include hospital services,85 physician services,86 family planning services,87 and pediatric nurse-practitioner services.88 As discussed fully in part III, EPSDT is a mandatory Medicaid service. There are twenty-three optional services that services can choose whether to cover for adults, including prescription drugs,89 dental services,90 physical and related therapies,91 and transportation.92

Although Congress listed the mandatory and optional services, it did not explicitly define the minimum level of each service to be provided. Rather, the Medicaid Act requires states to establish reasonable standards for determining the extent of medical assistance. “Each service must be sufficient in amount, duration, and scope to reasonably achieve its purpose.”93 For example, while a state could limit inpatient hospitals days to, for example, twenty-one days per year, it should not be able to limit the service to one day per year.94 States also cannot arbitrarily deny or reduce services solely because of the diagnosis, illness or condition.95 For example, a state should not be able to exclude drugs needed by a Medicaid beneficiary because she is suffering from HIV/AIDS.96

D. Administration

As noted above, Medicaid is a cooperative federal-state program. The federal government administers Medicaid through the Centers for Medicare & Medicaid Services (CMS). CMS was previously known as the Health Care Financing Administration (HCFA).
CMS reimburses states for a substantial portion of their Medicaid costs. Federal Financial Participation (FFP) is available for services that are covered by the state’s Medicaid plan and for costs incurred by the state to administer and operate its Medicaid program. The federal matching rate for services varies from 50 percent to approximately 80 percent, with the actual percentage depending on the per capita income of each state. Poorer states have higher matching percentages.

To receive federal funding, each state is required to have in effect a comprehensive, written state plan for medical assistance that has been approved by the federal government. The plan must be amended to reflect changes in federal statute, regulation or court decisions and to reflect material changes in state law, policy, organization, or operation of the program. The plan must be administered by a single state agency.

**Managed care.** Over the past twenty years, Congress has given states increasing flexibility in deciding how they will administer their Medicaid programs. One of the most notable examples of this flexibility is the ability of states to contract with managed care entities to provide services to Medicaid beneficiaries. Managed care entities include managed care organizations that provide Medicaid beneficiaries with a specified package of Medicaid services in exchange for a fixed, prepaid payment per enrollee. Enrollment of children in managed care organizations has grown dramatically over the last fifteen years. As of 2002, 57 percent of Medicaid beneficiaries, many of them children, were enrolled in a managed care plan.

Since 1997, states have been able to require most children to enroll in managed care programs without obtaining special permission from the federal government. In other words, they must simply file a state plan amendment notifying the federal government of mandatory enrollment. However, states are still required to obtain federal permission, called a “waiver,” if they are going to require the following populations to enroll in managed care:

- children under age 19 with certain special needs children who are eligible for SSI, described in community-based coordinated care programs under title V, living at home under the Katie Becket option, receiving foster care or adoption assistance under title IV-E, or living in foster care or otherwise in out-of-home placement;

- individuals who are dually eligible for Medicaid and Medicaid (or Qualified Medicare Beneficiaries);

- certain Native Americans.
**Due process.** The fifth and fourteenth amendments of the U.S. Constitution prohibit the government from depriving citizens of life, liberty, or property without “due process.” Case law has determined that public assistance is property.108

The basic purpose of due process is to afford “an opportunity to be heard . . . ‘at a meaningful time and manner.’”109 The Medicaid Act and regulations also give applicants and beneficiaries the right to receive written notices that inform them of a proposed adverse action and to receive an impartial hearing to contest the action.110 If the beneficiary is currently receiving the benefit, then the notice must generally be provided in advance of the action, with aid continued pending the appeal.111
Part III
Legal Requirements for EPSDT

Abstract: This part provides in-depth discussion of the requirements for EPSDT programs. Outreach and informing are described, along with requirements for the provision of services: medical, vision, hearing and dental screening and diagnosis and treatment services. Laws designed to assure provider participation and reporting of EPSDT delivery are also discussed.

A. EPSDT background

The EPSDT service was added to the Medicaid program in 1967. Since its inception, the EPSDT law has been unique. Unlike other Medicaid services, which are geared to acute care needs, EPSDT emphasizes the early discovery of illness and the need for comprehensive care. In contrast to other Medicaid services, the state Medicaid agency must not only cover needed EPSDT services but actually engage in “arranging for . . . corrective treatment” that is needed. Thus, while the state generally is required only to pay for most services when medically necessary, the state must provide or arrange for EPSDT. This imposes an affirmative obligation on the states to ensure that children actually receive needed care. Finally, the state must cover a broad package of benefits for children, even if the benefits are not covered for adults.

By statute, all Medicaid-eligible children and youth under the age of 21 are entitled to receive EPSDT. Each state must offer an EPSDT program that includes: (1) outreach and informing; (2) screening, diagnosis and treatment services; (3) adequate provider participation; and (4) annual reporting on EPSDT performance.

B. Requirements for outreach and informing

If EPSDT is to work, states must engage in effective outreach and informing. Congress has said that states should take “aggressive action” to inform all Medicaid-eligible children and their families of the availability of EPSDT. Under federal law, states must use a combination of written and oral methods to effectively inform eligible individuals:

- about the benefits of preventive health care;
- about the services available through EPSDT;
that services are available without charge, except for premiums for certain families; and

that transportation and appointment scheduling assistance are available upon request. States should assure that transportation and appointment scheduling assistance are offered “prior to each due date of a child’s periodic examination.”

The ADA requires reasonable accommodations for any individual who may have difficulty receiving information about EPSDT because of a disability, such as a vision or hearing impairment or a learning disability. Federal laws also require meaningful access for families and children who do not speak English as their primary language.

C. Requirements for screening services

Screening examinations are a basic element of the EPSDT program. There are four separate screens: medical, vision, hearing, and dental.

1. Medical screens

To meet the federal EPSDT qualifications, the medical screen must include the following five components:

- a comprehensive health and developmental history which assesses both physical and mental health;
- a comprehensive, unclothed physical examination;
- appropriate immunizations;

The state’s somewhat casual approach to EPSDT hardly conforms to the aggressive search for early detection of child health problems envisaged by congress. . . . It is utterly beyond belief to expect that children of needy parents will volunteer themselves or that their parents will voluntarily deliver them to the providers of health services for early medical screening and diagnosis. . . . EPSDT programs must be brought to the recipients; the recipients will not ordinarily go to the programs until it is too late to accomplish the congressional purpose.

Stanton v. Bond, 504 F2d 1246, 1251 (7th Cir. 1974)
- laboratory tests (including lead blood testing at 12 and 24 months and otherwise according to age and risk factors); and

- health education, including anticipatory guidance to the child (or the child’s parent or guardian).  

Each of these elements is discussed below.

a. Comprehensive health and developmental history

The health and developmental assessment requires providers to determine whether the child’s physical and mental development are normal in relation to his age group and cultural background. Health and developmental assessments are part of the initial and every periodic examination.

Although “there is no universal list of the dimensions of development for the different age ranges of childhood and adolescence,” the CMS State Medicaid Manual (Manual) sets forth certain aspects that should be included in the assessment. In young children, providers must assess at least gross and fine motor development, communication skills or language development, self-help and self-care skills, social and emotional development, and cognitive skills. Evaluation of school-aged children requires assessment of visual-motor integration, visual-spatial organization, visual sequential memory, attention skills, auditory processing skills, and auditory sequential memory. Adolescents should receive special attention with regard to learning disabilities, peer relations, psychological and psychiatric problems and vocational skills.

The Manual does not specify standardized tests that must be used for the developmental assessment. However, several principles apply. To perform an effective developmental assessment, the providers must use information gathered during the screen and obtain information regarding an EPSDT-covered child through the observations of people familiar with the child, such as parents, teachers or health professionals. Assessments must be culturally appropriate and should not result in improper referrals for behaviors related to cultural heritage. Further, initial assessments should not prematurely label a child as having a problem. If necessary, the provider should refer the child for assessment by child development professionals.
Mental health assessment. To adequately screen for mental health problems, both a history and a screen are needed. The mental health history places the child’s current condition in context and should include assessment of cognitive and school function, family relationship history, peer relations history, emotional development history, stressful circumstances history, family mental health history, and substance abuse screening. As noted above, information about the child’s history should come from the child, parents, teachers, or others close to the child.

The mental health screen reveals the child’s current condition. Previous research has shown that physicians who relied on their clinical judgment to screen failed to identify 83 percent of the children who actually had diagnosable emotional or behavioral problems. Therefore, use of a standardized screening form is highly recommended. Detailed, age-appropriate forms generally describe the necessary components of the EPSDT screen and can prompt providers on appropriate developmental milestones. Use of these forms has been associated with the provision of more comprehensive screens and increased EPSDT screening in general. Appendix B provides examples of age-appropriate forms. In addition, mental health screening tools can be used.
Dozens of screening and assessment tools have been developed, and this manual can only offer a few examples.

A number of state Medicaid programs use the Denver Developmental II to screen children under age six. This tool is useful for determining developmental delays and gross and fine motor skills, but it underreports conditions and, notably, it does not adequately screen for emotional and behavioral problems.\(^\text{130}\)

The Pediatric Symptom Checklist is a brief mental health questionnaire that has been validated for use in general pediatric office settings, as well as clinics, schools, outpatient, and low-income and minority settings.\(^\text{131}\)

The Child Behavior Checklist is a well-developed behavior rating scale for children from four to 18 years old; however, it has been criticized as taking too long for the parent to complete (15 to 20 minutes) and for the provider to score.\(^\text{132}\)

State Medicaid agencies have also developed mental health screens, among them Oregon, West Virginia, Florida, and Minnesota.\(^\text{133}\)

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**What to Look for in a Mental Health Screening Tool:**

- **sensitivity** – identifies as many problems as are present
- **specificity** – the individual actually has the identified disorder
- **reliability** – different raters will reach the same conclusion
- **validity** – screen actually identifies the problem in question
- **rapid administration** – easy to give and interpret
- **multiple sources of information** – obtain varying perceptions

b. Unclothed physical exam

Each medical screen must include a comprehensive unclothed physical examination.134 The unclothed physical exam includes a comparison of the child’s measurements (e.g. height, weight, head circumference with infants) with those considered normal for the child’s age.135 Providers are instructed to use a graph, commonly used by pediatricians, to chart the child’s height and weight over time.136 The general unclothed physical appearance of the child is also to be checked to determine overall status and appearance.137 All organ systems are to be checked.138 The unclothed physical exam is crucial to spotting physical defects, orthopedic disorders, skin diseases, genital abnormalities, and pulmonary, cardiac and gastrointestinal problems.139

c. Laboratory tests

Each state must provide “laboratory tests (including lead blood level assessment appropriate for age and risk factors).”140 The State Medicaid Manual requires that states identify as statewide screening requirements the

Suggestion for Investigation:

Assess the Adequacy of EPSDT Developmental Screening

It will be important to look at:

- **History.** Does the provider ask questions to obtain a comprehensive history of the child’s development?

- **Screening tools.** Does the EPSDT program use a screening tool that includes age-appropriate developmental prompts? Does the EPSDT program use a separate mental health screening tool?

- **Time allotment.** What is the usual length of an EPSDT screening visit? This can be determined through telephone interviews with EPSDT providers. The time allotment may differ depending on setting. One study found physician-supervised settings spending, on average, 20 minutes for the screen, with mental health assessment receiving less attention, while nurse-supervised settings allotted an hour and a half for an EPSDT screen, with mental health assessment receiving more attention. State of Minnesota, Office of the Ombudsman for Mental Health and Mental Retardation, Why do we wait: A Mental Health Report (Spr. 1999).
minimum laboratory tests of analyses to be performed for particular age or population groups.\textsuperscript{141} The Manual provides a list of examples of tests that states should consider providing, including hematocrit or hemoglobin screening, urinanalysis, TB skin testing, STD screening and cholesterol screening, and any tests that are mandatory under state law.\textsuperscript{142} In addition, the Manual suggests consulting with a variety of sources to develop minimum screening requirements, such as: state medical organizations, clinical practice guidelines such as the American Academy of Pediatrics Guidelines for Health Supervision, the AMA’s Guidelines for Adolescent Preventive Services, Bright Futures’ Guidelines for Health Supervision of Infants, Children and Adolescents; or Centers for Disease Control and Prevention (CDC) guidance.\textsuperscript{143} With the exception of lead toxicity screening, physicians are permitted to use their medical judgment to determine the applicability of laboratory tests.\textsuperscript{144}

**Lead screening.** Much attention has been focused on lead blood testing of Medicaid recipients. However, despite this attention childhood lead poisoning remains one of the primary preventable environmental health problem in the United States. Nearly one million children in the United States under the age of six have blood lead levels high enough to adversely affect their intelligence, behavior and development.\textsuperscript{145} Low-income and African American children are disproportionately affected.\textsuperscript{146} Lead poisoning can damage a child’s central nervous system, kidneys, and reproductive system and, at higher levels, can cause coma, convulsions, and death. Even low levels of lead are harmful and can interfere with intellectual development and function, growth and hearing.\textsuperscript{147}

Medicaid-enrolled children ages one to five are three times more likely than young children not on Medicaid to have elevated blood lead levels.\textsuperscript{148} Yet children on Medicaid are not likely to be screened for lead. A CDC study which was conducted from 1991 to 1994 indicated that 347,750 of the estimated 535,000 Medicaid-enrolled children aged 1-5 years, or 65 percent, had not been screened. Therefore, those unscreened children with lead poisoning had not received follow-up treatment.\textsuperscript{149} The CDC estimated in 2000 that approximately 81 percent of young children on Medicaid had not been screened with a lead blood test.\textsuperscript{150} Initial data from states FY 1999 EPSDT reporting confirm these low levels, revealing that, from those states reporting, only 14.8 percent of children aged 1-2 received a lead blood test through EPSDT.\textsuperscript{151}

Notably, CMS requires that all Medicaid-eligible children receive a screening blood lead test at 12 months \textit{and} at 24 months of age.\textsuperscript{152} Children between the ages of 36 months and 72 months of age must receive a blood screening test if they have not previously received one.\textsuperscript{153} In
addition, a lead blood level test must be used when screening Medicaid-
eligible children.\textsuperscript{154} CMS specifically requires states to adopt a state plan
that requires lead screening for all available children.\textsuperscript{155}

The \textit{State Medicaid Manual} is consistent with the recommendations of
the CDC.\textsuperscript{156} Acknowledging that high lead blood levels have remained
prevalent among children on Medicaid, the CDC in 2000 urged states to
take steps to combat this problem and, in particular, to adhere to existing
federal requirements.\textsuperscript{157} The CDC recommendations also reflected the
increasing role that managed care plays in the delivery of lead screening
services and asked state Medicaid agencies to review existing contracts to
ensure that blood lead screening and follow-up services are explicitly
included.\textsuperscript{158} Indeed, the role of managed care can be complex. In the
District of Columbia, a federal court recently found that children had
abysmally low rates of lead blood screening, despite a longstanding court
order that screening be conducted consistent with the federal Medicaid
requirements.\textsuperscript{159} The court ordered the District to issue a transmittal to all
managed care organizations and health care providers setting forth the
Medicaid EPSDT lead blood screening requirements to require corrective
action plans from each managed care organization.\textsuperscript{160}

d. Nutritional assessment

While the Medicaid statute does not specifically mention the
requirement for a nutritional assessment, legislative history, the EPSDT
regulations (current and proposed) and the \textit{State Medicaid Manual} do.\textsuperscript{161}
Nutritional assessment is now, and has long been considered, an essential
component of the initial and each periodic evaluation.\textsuperscript{162}

The \textit{Manual} indicates a set of screens to assess the child’s nutritional
status.\textsuperscript{163} The screens include: questions about dietary practices; a
complete physical examination, including an oral examination and attention
to features such as appearance, apathy and irritability; and accurate
measurement of height and weight. In addition, the \textit{Manual} specifically
requires a laboratory test for iron deficiency.\textsuperscript{164} Further, “if feasible,”
children over one year of age should have a serum cholesterol check,
especially if there is a family history of heart disease or hypertension.\textsuperscript{165}

e. Immunizations

Medical screens must include “appropriate immunizations according to
age and health history.”\textsuperscript{166} National periodicity and content schedules
control.\textsuperscript{167} Immunizations must be administered in accordance with the
schedule developed by the Advisory Committee on Immunization Practices
(ACIP).\textsuperscript{168} The \textit{State Medicaid Manual} incorporates the ACIP schedule.
It requires pediatric immunizations against diphtheria, pertussis, tetanus,
polio, measles, rubella, mumps, hepatitis B, varicella zoster (chicken pox), and haemophilus influenzae type b conjugate (Hib) vaccines.\textsuperscript{169}

Vaccines are administered by “program-registered providers” who are entitled to receive the vaccine without charge either for the vaccine or for its delivery. These providers can be any health care providers licensed or otherwise authorized to administer pediatric vaccines under state law, without regard to whether the provider otherwise participates in Medicaid.\textsuperscript{170} Providers: (1) question the child’s parent to determine whether the child is vaccine-eligible; (2) maintain records of the responses to the questions; (3) comply with the periodicity, dosage and contraindication schedule applicable to the particular vaccine; (4) provide vaccines in accordance with state law, including laws related to religious or other exceptions; (5) provide the vaccine at no cost, and (6) limit fees for the administration of the vaccine to those costs that the Secretary of HHS determines appropriate.\textsuperscript{171} Providers cannot deny administration of a pediatric vaccine to a vaccine-eligible child because the parent cannot pay an administration fee.\textsuperscript{172} However, providers are not required to administer a vaccine to every child who seeks one.\textsuperscript{173} Thus, as is generally the case with Medicaid, the extent of participation is left to the provider.

The statute requires states to take steps to assure adequate numbers of program-participating providers. Each state’s vaccine program must encourage participation by a wide range of providers, including private health care providers.\textsuperscript{174} The statute explicitly refers to the need for linguistic and cultural sensitivity in the delivery of immunization services. States must identify:

with respect to any population of vaccine-eligible children a substantial portion of whose parents have a limited ability to speak the English language, those program-registered providers who are able to communicate with the population involved in the language and cultural context and is most appropriate.\textsuperscript{175}

The Secretary of HHS must purchase and deliver sufficient quantities of vaccines without charge to each state or tribe.\textsuperscript{176} The federal government sets purchase prices through negotiation with vaccine manufacturers. States may obtain additional vaccines for state-eligible children by notifying the Secretary in advance of negotiations to allow her to include these additional needs in her negotiations. The state then purchases the vaccines from the manufacturers at the price negotiated by the Secretary.\textsuperscript{177}

f. Health education

The final mandatory element of the medical screen is “health education (including anticipatory guidance).”\textsuperscript{178} Legislative history stresses that
“anticipatory guidance to the child (or the child’s parent or guardian) is a mandatory element of any adequate EPSDT assessment.”

Health education rightfully has an important place in the panoply of EPSDT services. According to the State Medicaid Manual, health education includes counseling to both parents and children to “assist in understanding what to expect in terms of the child’s development and to provide information about the benefits of healthy lifestyles and practices as well as accident and disease prevention.”

The American Academy of Pediatrics produces Guidelines for Health Supervision, which recommend age-appropriate anticipatory guidance to include, for example, discussions of car safety restraints for a two to four week old, the need to encourage initiative and exploration in a one year old, avoidance of junk food and providing opportunities to interact with other children for an eight year old, avoidance of drugs and alcohol, and setting TV and video game limits for a ten year old. Discussion of tobacco use and discussion of smoking cessation programs should be included. The Bright Futures guidelines are also helpful.

2. Hearing screens
Hearing screens are an essential component of the EPSDT screen. “There is a clear need in the United States for improved methods and models for the early identification of hearing impairment in infants and young children.”

Even if hearing problems are less severe than deafness, they can cause significant impairment, such as interfering with normal language development. The first three years of life are crucial for language and speech development; accordingly, undetected hearing problems at that time mean that “much of the crucial period for language and speech learning is lost.” Further, hearing problems can also inhibit the development of the auditory nervous system as well as social, emotional, cognitive and academic development, including reading.

The Medicaid Act and rules require state EPSDT programs to assess hearing defects and establish a periodic schedule for hearing screens that is separate from the schedule for medical screens. Further, the Manual cautions states to require age-appropriate hearing assessments and suitable procedures, determined in consultation with audiologists or state health or education department personnel.

3. Vision screens
The importance of vision screening should not be underestimated. “Vision screening and eye examination are vital for the detection of conditions that distort or suppress the normal visual image, which may lead
Experts recommend that vision screening be performed at the earliest age practical. If not detected before age five, some vision problems are irreversible.

As is the case with hearing screens, the Medicaid Act and rules require screens for vision defects according to separate periodicity schedules. States must assure that the assessments are administered in an age-appropriate manner and using appropriate procedures, determined in consultation with ophthalmologists and optometrists.

4. Dental screens
Dental caries (tooth decay) is the single most common chronic childhood disease: five times more common than asthma and seven times more common than hay fever. Striking disparities in dental disease exist, based upon income. Poor children have five times more untreated dental caries than children in higher income families. Moreover, poor children suffer nearly 12 times more restricted-activity days than children from higher-income families. People of color, particularly Native Americans, experience significantly greater levels of untreated tooth decay. Not surprisingly, uninsured children are 2.5 times less likely than insured children to receive dental care. Unfortunately, Medicaid has not been able to fill in the gap in providing dental care to poor children. A report from the U.S. Office of Inspector General concluded that fewer than one in five Medicaid-covered children received preventive dental care each year. The National Health Law Program’s initial review of FY 1999 reporting finds that only about 25 percent of children in reporting states received any dental services through the EPSDT program.

The Medicaid Act EPSDT provisions, added in 1989, require states to provide dental services which at a minimum include: “relief of pain and infections, restoration of teeth, and maintenance of dental health.” Dental screens may take place in settings other than a dentist’s office, such as a school nurse’s office. However, screens should be performed by a dentist, or a professional dental hygienist under the supervision of a dentist. An oral screen by another health care provider, such as a physician, can be helpful; however as CMS has noted, it cannot substitute for a screen performed by a dental professional.

D. Requirements for periodicity of screens
EPSDT requires screening to occur at preset, state-established intervals. Each of the four types of screens — medical, vision, hearing, and dental — should be performed at distinct time intervals, as determined by
“periodicity schedules” that meet the standards of pediatric medical and dental practice.\textsuperscript{204}

With respect to medical screens, Congress and CMS have directed states (and, by extension, their contracting managed care organizations) to the standards of the American Academy of Pediatrics (AAP). Other expert-developed periodicity schedules include the AMA’s \textit{Guidelines for Adolescent Preventive Services} (GAPS) and the National Center for Education in Maternal and Child Health’s \textit{Bright Futures}.

The Medicaid Act requires that states provide dental screens “at intervals which meet reasonable standards of dental practice.”\textsuperscript{205} The state must establish the recommended age for initial screening through consultation with dental organizations involved in child health care.\textsuperscript{206}

\begin{tabular}{|l|}
\hline
\textbf{Websites for Periodicity Schedules:} \\
\hline
American Academy of Pediatrics: Recommendations for Preventive Pediatric Health Care, \textit{available at} \\
http://www.aap.org/policy/re9939.html \\
\hline
\hline
Bright Futures, \textit{available at} http://www.brightfutures.org \\
\hline
American Academy of Pediatric Dentistry, \textit{available at} \\
http://www.aapd.org \\
\hline
American Dental Association, \textit{available at} http://www.ada.org \\
\hline
\end{tabular}

CMS has cautioned that the periodicity schedule for dental examinations is not to be governed by the schedule for medical examinations, particularly for older children.\textsuperscript{207}

\textbf{Periodicity schedules for adolescents.} Many states do not routinely update their periodicity schedules, even though standards of pediatric medical and
dental practice are evolving. This has been particularly harmful to adolescents who may have undetected behavioral or psycho-social problems. The current recommendation of the AAP calls for screening adolescents once a year. Similarly, the AMA’s *Guidelines for Adolescent Preventive Services* recommend that teens receive annual screens that include a general health assessment, limited laboratory testing, and health education and anticipatory guidance concerning the stresses that adolescents commonly face. Yet the National Health Law Program’s review of states’ FY 1999 reporting shows that many states are using periodicity schedules that do not reflect the AAP recommendations. Appendix C compares states’ periodicity schedules against the AAP recommendations.

**Suggestion for Investigation:**

*Look at Your State’s Periodicity Schedules*

- When were your state’s EPSDT periodicity schedules last updated?
- Does the medical schedule include annual testing for adolescents, highlighting psycho-social concerns?
- Were medical, vision, hearing and dental pediatric and child health experts consulted, as appropriate?
- Does your state use the AAP, GAPS, or a state-developed medical periodicity screening schedule?

**E. Requirements for interperiodic screens**

In addition to covering scheduled, periodic screening examinations, EPSDT covers visits to a health care provider at “such other intervals, indicated as medically necessary, to determine the existence of an illness or condition.” These types of screens are called “interperiodic screens.”

Persons outside the health care system (e.g., a school teacher or parent) can determine the need for an interperiodic screen. Importantly, CMS has repeatedly said that “any encounter with a health care professional acting within the scope of practice is considered to be an interperiodic screen, whether or not the provider is participating in the Medicaid program at the
time those screening services are furnished.” This is important because these screening encounters, in turn, entitle the child to the broad range of treatment services included in EPSDT. These services are described below.

**NO Prior Authorization for Screens:**

To assure that the “preventive thrust” of the EPSDT program is maintained, a state cannot require prior authorization for either periodic or interperiodic screens.


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**F. Requirements for diagnostic and treatment services**

If an illness or condition is diagnosed during a periodic or interperiodic screen, EPSDT requires state Medicaid agencies to “arrange for (directly or through referral to appropriate agencies, organizations, or individuals) corrective treatment” for that illness or condition. In addition, the Medicaid Act defines a comprehensive package of possible EPSDT treatment benefits, and it sets forth the medical necessity standard that must be applied on an individual basis to each eligible child.

**1. Scope of benefits**

Covered services include all mandatory and optional services that the state can cover under Medicaid pursuant to § 1396d(a), whether or not such services are covered for adults. This includes a broad range of treatment services, such as prescription drugs, dental services, home health, medical equipment, physical therapy, and interestingly, preventive services. Appendix D lists the available Medicaid benefits.
Because EPSDT covers benefits that the state may not cover for adults and historically may not have covered, it is helpful to state administrators if requests for EPSDT services are clearly stated and supported. The chart below offers suggestions for making requests for treatment services through EPSDT.

<table>
<thead>
<tr>
<th>The request for treatment services should include:</th>
</tr>
</thead>
<tbody>
<tr>
<td>· the physician’s orders (e.g. on a prescription pad)</td>
</tr>
<tr>
<td>· written justification from the physician and other providers of medical need, which includes:</td>
</tr>
<tr>
<td>· patient history</td>
</tr>
<tr>
<td>· diagnosis/prognosis</td>
</tr>
<tr>
<td>· medical justification</td>
</tr>
<tr>
<td>· description of the benefits</td>
</tr>
<tr>
<td>· length of time the service/treatment is needed</td>
</tr>
<tr>
<td>· when appropriate, include product information on:</td>
</tr>
<tr>
<td>· how an item will meet the child’s need</td>
</tr>
<tr>
<td>· photographs illustrating use (preferably by the child)</td>
</tr>
<tr>
<td>· comparable prices</td>
</tr>
<tr>
<td>· a statement that the service is being requested under EPSDT to correct or ameliorate the child’s condition and how the service fits within the Medicaid scope of benefits.</td>
</tr>
</tbody>
</table>

2. Timely treatment
   The Medicaid Act generally requires medical assistance to be provided with “reasonable promptness.” In addition, there are specific EPSDT requirements. The state Medicaid agency must set standards for the timely provision of EPSDT services that meet reasonable standards of medical and dental practice. The agency must also employ processes to ensure timely initiation of treatment as the child’s medical condition requires and generally within an outer limit of six months after the request for screening services.

3. Coverage standards
   The Medicaid Act provides the standard that must be applied to the individual child to decide if that child needs a covered benefit: A service must be covered for a child if it is among the package of benefits and is “necessary . . . to correct or ameliorate defects and physical and mental
illnesses and conditions[.]” For example, if a child needs physical therapy services to ameliorate his condition, then EPSDT should cover those services to the extent the child needs them, even if the state places a quantitative limit on physical therapy services (e.g., 60 visits per year) or does not cover them at all for adults.218

The determination that a service is necessary lies primarily with the child’s treating physician or other health care provider. The state may review this determination; however, absent the circumstances described below, it should defer to the recommendation of the treating physician.219

**Words to Remember:**

*The physician is to be the key figure in determining the utilization of health services . . . it is the physician who is to decide upon admission to a hospital, order tests, drugs and treatments[.]*


EPSDT’s coverage, while broad, is not unlimited. CMS has told states to exclude services or items that are not medical in nature.220 The agency also has said that states can place utilization controls on services, including:

- requiring **prior authorization** for treatment services, so long as it does not delay delivery of care and is consistent with the “preventive thrust” of the EPSDT;221

- placing **tentative limits** on services so long as there is a process to allow the child to go beyond the limit;222

- providing the service in the **most economic mode**, so long as it is “similarly efficacious” to alternative services, does not delay services, and does not violate other federal laws such as the Americans with Disabilities Act;223

- excluding services that are considered **unsafe or experimental**.224 Note, however, that simply because a treatment is rarely performed (for example, because the medical condition is rare) does not mean that the treatment is experimental.225
Other treatment topics

Children with disabilities/mental health needs. EPSDT treatment services are particularly important to children with chronic needs, disabilities, and/or mental health problems. In addition to acute-oriented services, such as hospital and nursing care, Medicaid EPSDT can cover a number of home and community-based services. As listed in Appendix D, these benefits include home health services, medical equipment and supplies, personal care, skilled nursing, private duty nursing, physical and related therapies, and rehabilitative services. If a child is entitled to EPSDT services, even if the sole reason for qualification for Medicaid is the waiver.

It is important to remember that children receiving Medicaid services through a home and community-based waiver (HCBW) are also entitled to EPSDT services. CMS has unequivocally stated that children who receive services under HCBWs are also entitled to all needed EPSDT services, even if the sole reason for qualification for Medicaid is the waiver. Moreover, according to CMS, while states may refuse to offer HCBW services to a child if those services would be too expensive, they may not limit services that can be covered through EPSDT based on cost. Issues may arise, however, if a state imposes individual cost caps upon HCBW recipients. Though a child may be entitled to EPSDT services without regard to cost, a state may refuse to cover the services that exceed the waiver cost cap. In these cases, it will be important to consider whether the child would be eligible to receive Medicaid services even if she is not on a waiver and whether EPSDT, as opposed to waiver services, will best meet the needs of the child.

Rehabilitative services. EPSDT coverage of rehabilitative services has been a particular issue. Rehabilitative services are optional for adults.
However, as a result of EPSDT, these services are mandatory for children when they are necessary to “correct or ameliorate defects and physical and mental illnesses and conditions.” The Medicaid Act defines rehabilitative services as including:

any medical or remedial services (provided in a facility, a home, or other setting) recommended by a physician or other licensed practitioner of the healing arts within the scope of their practice under State law, for the maximum reduction of physical or mental disability and restoration of an individual to the best possible functional level.

Consistent with these requirements, the need for rehabilitative services should not be preconditioned or limited to, for example, children with short-term mental or physical rehabilitative needs or children receiving special education services. Moreover, rehabilitative services can include a range of services, for example:

- **basic living skills** to restore independent function in the community, including food preparation, maintenance of living environment, and mobility skills;

- **social skills** to develop skills needed to enable and maintain community living, including communication and socialization skills and techniques;

- **counseling and therapy** to eliminate psychological barriers that impede development of community living skills; and

- **rehabilitative equipment**, including daily living aids.

Some states and managed care plans have taken the position that, for services to be covered under this option, it must be possible for the condition to improve or to be prevented from worsening. This interpretation is incorrect. “Maintenance” services, which correct or compensate for a deficiency, can be covered to the extent that the services prevent conditions from worsening or prevent development of additional health problems.

Note, as well, that the recommendation for rehabilitative services can be made not only by a physician but by other licensed practitioners. Depending on state law, this can include psychologists, clinical social workers, registered nurses, nurse practitioners, physical therapists, speech pathologists, and audiologists. Similarly, delivery sites are not limited to facility settings but include the home and “other settings.” This could include clinics, rural and community health centers, day treatment providers, day care facilities, small residential treatment centers, group
homes, schools, and shelters. Finally, the statute and regulations are silent regarding the types of providers who can render rehabilitative services. However, under EPSDT, children have the right to receive medical care from “licensed practitioners within the scope of their practice as defined by State law.” CMS allows states to develop criteria for setting “reasonable standards” relating to qualifications of providers. But, the criteria should not limit children to inappropriate care givers or cause harmful delays in care, and absent a waiver, must assure recipients’ free choice of provider.

**Case Management.** Case management case be classified as either an administrative activity or a covered medical service, depending on what specific activities it includes. States have the option to cover case management as a service for adults; however, when needed by a child, the service is mandatory.

Case management services are those services which will assist the individual in gaining “access to needed medical, social, educational, and other services.” The federal agency has noted that EPSDT case management should be defined “in the broadest context” and used when needed to enable an individual “to function at the highest attainable level or to benefit from programs for which he or she might be eligible.” The agency has also said:

[Case management] may be used to reach out beyond the bounds of the Medicaid program to coordinate access to a broad range of services, regardless of the source of funding for the services to which access is gained. The services to which access is gained must be found by the Medicaid agency to be medically necessary for the child. However, the medically necessary services do not have to be medical in nature or reimbursable under the Medicaid State Plan.

Finally, CMS has made it clear that contacts with parents or other non-eligible individuals can be considered a Medicaid-covered case management activity when the purpose of the contact is directly related to the management of the eligible child’s care.
Unusual medical needs. Some children will have a medical need for a service that may not ordinarily be considered medical in nature. The following are some examples of services that may be covered if medically necessary for a child with a disabling condition:

- car restraint seat,\textsuperscript{243}

- computer system and bedside communication device for a child with cerebral palsy,\textsuperscript{244}

- exercise equipment, including exercise bikes, therapeutic toys, swing sets, and tricycles,\textsuperscript{245}

- health club memberships and swimming fees,\textsuperscript{246}

\textbf{Practice Tip: Fit The Service into a Medicaid Box}

Providers may not prescribe services using Medicaid terms. The provider is making a medical decision, not a legal one. If the state/managed care plan denies coverage saying the service is not among the list of Medicaid benefits, then you will need to fit the service within the list of services at § 1396d(a).

Examples:

- A provider determines that a 15-year-old patient with behavioral problems needs “basic living skills assistance from a behavioral aide,” “daily living aids, including special eating utensils,” and “family therapy.” The Medicaid Act lists none of these services by name, but each can be fit into a service category, such as home health or rehabilitative services. Family therapy must be for the exclusive benefit of the Medicaid-eligible child.

- A provider determines that a child needs “maintenance services” because she is not able to regulate a bodily function without continual medical assistance. The Medicaid Act list does not name this service, but it can be covered as private duty nursing on a continuous basis.

- A provider determines that a profoundly deafened child needs a “cochlear implant.” The Medicaid Act does not list this device by name, but it can be covered as a prosthetic device.
- TouchTalker, DynaVox, computer with printers and adapted software;\textsuperscript{247}
- air conditioner to lessen seizures for child with seizure disorder;\textsuperscript{248}
- beeper to promote communication with child with brain damage;\textsuperscript{249}
- swimming lessons for a child with cystic fibrosis;\textsuperscript{250}
- incontinence supplies;\textsuperscript{251}
- early intervention day treatment;\textsuperscript{252}
- hyperbaric oxygen therapy for a child with cystic fibrosis\textsuperscript{253}

### Practice Tip: Make Clear YOUR Use of EPSDT Terms

<table>
<thead>
<tr>
<th>Term:</th>
<th>You mean:</th>
<th>Others may assume you mean:</th>
</tr>
</thead>
<tbody>
<tr>
<td>Check up or well-child exam</td>
<td>An EPSDT medical screen that includes all five components required by the Medicaid Act. You say, “EPSDT Medical Screen.”</td>
<td>The screen provided to children who are not insured through Medicaid, which may not include all five EPSDT components.</td>
</tr>
<tr>
<td>Case management</td>
<td>Medicaid-covered service, which assists individuals in gaining access to needed medical, social, educational, and other services.</td>
<td>Utilization review process of deciding whether requested services are or continue to be needed.</td>
</tr>
<tr>
<td>Rehabilitative services</td>
<td>Medicaid-covered medical or remedial services (provided in a facility, home or other setting) recommended by a licensed practitioner for the maximum reduction of physical or mental disability and restoration of an individual to the best possible functional level.</td>
<td>The pre-set or average amount of rehabilitative services covered by private insurers or under the state Medicaid plan for adults.</td>
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### G. Provider participation

The Medicaid Act includes a number of general and EPSDT-specific provisions designed to assure an adequate number and range of child-
serving providers. States must assure that payments to providers are consistent with quality of care and are sufficient to enlist enough providers “so that care and services are available . . . at least to the extent that such care and services are available to the general population in the geographic area.” CMS has recognized that the rates that are paid to providers is important to the success of EPSDT. Medicaid-participating managed care organizations must also have an appropriate range of services and access to preventive and primary care services and a sufficient number, mix, and geographic distribution of providers of services.

Federal provisions enacted in 1989 prohibit the states from limiting participation to only those providers who are able to deliver all components of the EPSDT screen. Federal regulations call on the state Medicaid agency to “make available a variety of individual and group providers qualified and willing to provide EPSDT services.” Moreover, the agency is supposed to “assur[e] the availability and accessibility of required resources” and “take advantage of all resources available” to provide a “broad base” of EPSDT providers.

In addition, Congress has relaxed requirements for collecting payments from third parties where EPSDT services are involved. Regarding preventive services, including EPSDT, where there is potential third party liability, the state must first pay the provider and then chase after the third party resource (a process known as “pay and chase”). By contrast, in other instances, the state generally makes the provider exhaust third party resources before it will pay (a process known as “cost avoidance”).

H. Cost-sharing

States can impose cost-sharing on some Medicaid beneficiaries. However, states are prohibited from imposing premiums, deductibles, copayments, cost-sharing, or similar charges on services furnished to individuals under age 18 (and at state option, individuals under age 21, 20, or 19).

I. Reporting on child health

Data on child health are essential if policy makers and advocates are to target areas for improvement, identify effective interventions, and hold programs accountable. There are a number of resources in the federal statistical system for tracking the well-being of children and youth. CDC Wonder offers online access to many of the databases supported by the Centers for Disease Control and Prevention. A number of health surveys also provide helpful information, including the Youth Risk Behavioral Survey, Youth Tobacco Survey, National Immunization Survey, State and
Local Area Integrated Telephone Survey (SLAITS) of Children with Special Health Care Needs, and the National Health Interview Survey. In addition, the federal Medicaid agency has encouraged state Medicaid managed care programs to report using performance measures contained in the Health Plan Employer Data and Information Set (HEDIS), which is published by the National Committee for Quality Assurance.

<table>
<thead>
<tr>
<th>HEDIS child and adolescent health measures:</th>
</tr>
</thead>
<tbody>
<tr>
<td>· Low birth weight babies</td>
</tr>
<tr>
<td>· Well child and adolescent visits</td>
</tr>
<tr>
<td>· Treating children’s ear infections</td>
</tr>
<tr>
<td>· Child and adolescent immunization rates</td>
</tr>
<tr>
<td>· Use of appropriate asthma medications</td>
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<tr>
<td>· Children’s access to primary care providers</td>
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<tr>
<td>· Substance counseling for adolescents</td>
</tr>
<tr>
<td>· Family visits for children undergoing mental health treatment</td>
</tr>
</tbody>
</table>

There are also reliable sources of information from non-government sources. For example, the Annie E. Casey Foundation produces the Kids Count Data Book, which offers state-by-state profiles for numerous indicators of child well-being. The Children’s Defense Fund produces Children in the States and The State of Children in America’s Union, which assesses such factors as child poverty, hunger, health, and education. The National Health Law Program publishes Children’s Health Under Medicaid: A National Review of Early and Periodic Screening, Diagnosis and Treatment, using state EPSDT reporting forms to analyze national and state-by-state EPSDT performance.

**Federal Requirements for EPSDT Reporting.** The Medicaid Act requires states to report annually, by age group and basis of eligibility:

- the number of children provided screening services;
- the number of children referred for corrective treatment;
- the number of children receiving dental services, and
- the state’s results in obtaining participation goals set by the HHS Secretary.

The Act also provides that the HHS Secretary shall, not later than July 1, 1990, and every 12 months thereafter, develop and set annual participation goals for each state for participation of children in EPSDT. In 1990, the
HHS Secretary established that, by fiscal year 1995, each state should be providing at least 80 percent of EPSDT recipients with timely medical screens.\textsuperscript{271} The Secretary has not subsequently complied with the mandate to set annual participation goals.

States are to report EPSDT compliance on the Form 416 and to submit the completed form to CMS by April 1st of each year. According to CMS, the information on this form serves dual purposes:

1) to demonstrate the state’s attainment of participant and screening goals; and

2) to show trend patterns and projections “from which decisions and recommendations can be made to ensure that eligible children are given the best possible health care.”\textsuperscript{272}

EPSDT reporting is not without controversy. Few states report that they meet the Secretary’s (now outdated) 80 percent participation goal.\textsuperscript{273} Some states and managed care organizations claim that forms are under-representing the actual numbers of children receiving EPSDT services, that children receive screens from providers who do not report their activity and/or that the use of capitation payments means that claim forms (and, thus, information) for specific services are not submitted to the state. Some child advocates complain that the form over-represents the number of children receiving EPSDT services and that children are counted as having received a complete medical screen when they did not receive all required elements of the screen. There are also problems when managed care organizations cease operations or participation in Medicaid and do not report the required data or leave unverified data with the state.\textsuperscript{274}

In fact, there have been few efforts to verify the accuracy of the numbers or to enforce accurate reporting. When studies have occurred, however, they have confirmed the low compliance rates reflected on most of the states’ Form 416s.\textsuperscript{275} Data from some states have shown that screening rates have gone down under managed care.\textsuperscript{276} A recent report from the General Accounting Office found that plan-submitted data that states use to monitor children’s use of services through Medicaid and SCHIP was “compromised by continuing problems in most states with encounter data’s completeness and reliability” and that information derived from beneficiary satisfaction surveys was “not representative of all Medicaid managed care beneficiaries.”\textsuperscript{277}

At any rate, the Form 416—like all other uniform reporting forms completed by the states and submitted to CMS—represents the state’s own presentation of its activities, and its importance should not be discounted.
**Words to Remember:**

The EPSDT participation and screening data are vital to decision makers in their assessment of the services provided to eligible children.


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**The revised reporting form.** In 1999, the Health Care Financing Administration revised the Form 416 significantly. These changes included a number of improvements but also introduced a number of problems. On the positive side, the revised form contains some new elements. For example, the form requires states to report using additional age groupings. Prior to 1999, states reported on the following four age groupings: <1 year, 1-5 years, 6-14 years, and 15-20 years. The new form requires states to use seven age groupings:

- <1
- 1-2
- 3-5
- 6-9
- 10-14
- 15-18
- 19-20

Such reporting can assist states with better targeting age-appropriate outreach activities to improve screening rates. The revised Form also requires states to report information about the number of children who are receiving preventive dental care and treatment and blood lead tests. These new reporting cells could serve as an important reminder that children’s access to dental care and lead tests are mandatory under EPSDT and that states’ performance in this area will be subject to more precise scrutiny.
On the other hand, CMS also made some changes to the reporting requirements that are less helpful. For example, the previous Form 416 used the screening schedule recommended by the American Academy of Pediatrics for measuring screening rates. On the revised form, states can report according to their own state-developed periodicity schedules. This could have negative consequences. First, the form does not acknowledge that, for immunizations, the state must use the schedule established by the Advisory Committee on Immunization Practices. Also, the change frustrates the very purpose of the form, which is to uniformly track patterns and projections for the nation, individual states, and geographic regions. Because each state can use a different periodicity schedule, comparison among states obviously is made more difficult.

The revised form also adds a provision allowing states to use certain listed Current Procedural Terminology (CPT) codes or state-specific EPSDT codes as a proxy for the EPSDT medical screen. The listed codes are CPT-4 codes for preventive medical services; thus, sick visits or episodic visits are not to be reported unless an initial or periodic exam also was performed during the visit. However, nothing in the CPT codes reveals whether all five of the mandatory components of the EPSDT medical screen have been provided (that is, a developmental assessment, unclothed physical examination, immunizations, laboratory tests, and health education). The federal agency did include the following instruction when it introduced this change: "Use of these proxy codes is for reporting purposes only. States must continue to ensure that all five age-appropriate elements of an EPSDT screen, as defined by law, are provided to EPSDT recipients."281

In yet another change, the revised screening form eliminates reporting for vision and hearing assessments. The only mention of these mandatory screens is a reminder to states to include vision and hearing referrals when reporting on total eligibles referred for corrective treatment. It is not clear why these reporting cells were eliminated from the form. At any rate, CMS has written off monitoring the provision of these two mandatory elements of the EPSDT screen, and in so doing has made it more difficult to monitor EPSDT performance and possibly less likely that children will receive these screens.

Part IV
Common Problems/Suggested Solutions

*Abstract:* The following issues are addressed in this section: (1) lack of outreach and informing; (2) lack of transportation; (3)
provider shortages; and (4) denials of services by managed care organizations.

This part of the manual describes some of the common problems with the delivery of EPSDT services. After the problem is identified, potential solutions are discussed. Both administrative and legal responses are included.

A word about private enforcement of the Medicaid Act:

Some state attorneys are challenging the ability of private individuals to bring lawsuits against states for violating the Medicaid Act, including EPSDT. These attorneys argue that only the federal government can enforce the Medicaid Act (or specified provisions of the Act). These evolving, politically charged arguments raise complex issues of federalism, states’ rights, and individual rights, and the ultimate resolution of these arguments could affect the methods for addressing common problems that are discussed in this section. For updates, see National Health Law Program’s CourtWatch webpage: http://www.healthlaw.org/courtwatch.shtml.

A. Lack of outreach and informing

States must engage in outreach and informing regarding EPSDT services. If beneficiaries are not aware of EPSDT and the benefits of preventive care, they will not seek out the EPSDT program. This is critical because the Medicaid Act provides that screening services are to be provided “in all cases where they are requested.” Some states have argued that their low screening rates are justified because the beneficiary has not formally asked the state for the screening service. However, low screening rates should not be excused for this reason: if effective outreach and informing have not occurred, parents cannot be expected to ask for EPSDT screens.
Common problems. In most states, information about EPSDT is provided during the eligibility interview and through a brochure that is sent to new Medicaid enrollees and, in some states, annually to all beneficiaries. These basic measures are necessary; however, states need to do more. Families have cited information overload during the eligibility determination process and the lack of knowledge of the EPSDT program as common problems.284

Problems are also created when participating providers do not know the EPSDT rules. Physicians and other licensed practitioners may not realize the mandatory components of the EPSDT screen, or they may not know about the broad package of benefits that is available through EPSDT. Case managers are also a vital component and must be educated about the program. Particular problems can arise when case managers from other state agencies, such as the developmental disabilities unit, are providing services to an EPSDT-eligible child. In these situations, it is critical that the case manager know about EPSDT and understand the approval process for services. Finally, when Medicaid is provided through managed care entities, problems may arise due to lack of understanding or structural barriers.285

Administrative solutions. Some states have engaged in innovative and unusual strategies to reach children; for example:

- Covering Kids in North Carolina partnered with a discount store in Buncombe County to increase awareness of Health Check (EPSDT) and SCHIP. Information and applications were provided at tables in the front and back of the store. To encourage people to visit the tables, a bike and helmet were raffled. Permanent information racks were

Practice Tip: Find examples from SCHIP outreach

States receive a higher federal matching percentage for SCHIP services than they do for Medicaid services. States may therefore conduct more aggressive outreach for their SCHIP programs. Advocates may want to investigate states’ methods of SCHIP outreach to see if they could be useful in EPSDT programs.

mounted in the layaway and pharmacy departments. The program has also partnered with a local fast food restaurant to provide information about Health Check and SCHIP on food tray liners.286

- The Neighborhood Health Plan, a Rhode Island managed care organization, has offered ten dollar gift certificates to video and music stores to teenagers who receive screening services. Delaware has approved a similar program.

- Ohio has offered a coupon book to pregnant women and parents of children under age two which can be redeemed only after validation by a medical provider.287

- Connecticut has included extensive requirements in its contracts with health plans that cover EPSDT, including outreach, appointment scheduling and transportation assistance, interpreter services, and coordination with other programs.288

- Individual health plans have developed EPSDT member handbooks (Wisconsin), special calendars (New York), reminder letters and follow up phone calls (Florida).

- Home visiting with first-time mothers has been shown to enhance self-care and improve birth outcomes, including reduction in reports of child abuse/neglect.289 Managed care plans in Connecticut have engaged in home visiting to inform new mothers and families about EPSDT and have obtained neighborhood assistance in connecting with families.

- Connecticut Medicaid notifies health plans of children who are due for EPSDT screens, so that plans can take steps to schedule screening for children.290

- Tennessee has offered managed care organizations financial incentives to engage in outreach to improve screening rates.

- The Nevada EPSDT program has previously partnered with the AARP to sponsor retired persons to assist in EPSDT outreach.291

- Alabama, the District of Columbia, and West Virginia provide “medical passports” (made of heavy-duty passport-like materials) to Medicaid families that provide information to families about EPSDT screening components and developmental milestones and allow the family to chart the child’s development and use of services.
In a pilot program in Washington, dentists received special training and were certified to receive enhanced payments for dental services under Medicaid. The program used heightened outreach efforts and provided enhanced benefits for children under age five. In the first year, screening rates increased.\textsuperscript{292}

Tennessee is providing continuing education credit to physicians who receive training on EPSDT; the District of Columbia is considering this.

The Arizona Medicaid agency has worked with the University of Arizona to produce an EPSDT training video for providers.\textsuperscript{293}

Washington has established a program called Kidscreen which requires screening of children in out of home placements within thirty days of placement, to help increase EPSDT participation among this population.

The District of Columbia has developed a script for case workers to use to inform beneficiaries about EPSDT. The script includes information

\begin{center}
\textbf{Examples of Outreach and Enrollment Strategies in Los Angeles County, CA}
\end{center}

\textbf{Traditional Methods:}
- Publishing informational guides to programs in multiple languages
- Increasing numbers of outstationed workers at non-traditional sites such as clinics, churches and schools
- Establishing a toll-free information line to initiate Medicaid applications
- Advertising health programs through community media
- Providing additional training for eligibility workers
- Participating in enrollment fairs

\textbf{Expanded Methods:}
- Monitoring and supporting school-based programs
- Reaching out to small businesses that did not provide health insurance
- Integrating financial screening at medical facilities
- Expanding training for eligibility workers, providers and other staff
- Focusing attention on retention of benefits over time

as well as a list of answers to frequently asked questions (e.g. where to get check ups and transportation assistance and the distinction between services needed at home and at school). Properly worded, such a script can help assure that vital information is uniformly communicated.

Legal efforts. Litigation has also been used to force states to comply with the Medicaid Act’s informing provisions. Typically, the cases arise in situations where the state has no special training for case workers and providers, where there is little or no oral informing regarding the program, and where the written materials describing EPSDT are not uniformly available or are not up-to-date. Informing cases have also occurred when the Medicaid program has given “erroneous information” as to eligibility requirements for EPSDT. Relief in these cases has included:

- In a case to improve screening for children in out of home placement, West Virginia agreed and was ordered to take a number of steps, including oral and written informing of foster and birth families about EPSDT, development of a provider desk guide to explain EPSDT, production of a video for foster care workers and providers that explains EPSDT and how/where to get it, use of a toll-free telephone number for information or assistance, and a pullout “medical passport” that parents/guardians can use to chart the child’s immunizations and medical visits.

- A California case, Emily Q v. Bonta, focused on outreach and informing to beneficiaries with mental health needs and resulted, in part, in revised and updated EPSDT brochures and specialized outreach materials that discuss mental health treatment services and how to get them. Plaintiffs’ counsel participated in development of these materials.

- French v. Concannon was filed on behalf of children in Maine who have severe mental impairments, including mental retardation, autism, or mental illness, and who need home or community-based services to treat their impairments. The settlement of this case included a number of outreach strategies: (a) a series of regional EPSDT training sessions for providers and case managers; (b) a “regional resource directory” to include information about available providers and resources; (c) revision of the EPSDT brochure to add information about the range of behavioral services that are available to children; (d) development of EPSDT provider screening forms that reflect age-specific information about mental health needs and anticipatory guidance. The forms are reproduced in Appendix B. When the state failed to meet the timeliness requirements of the French agreement, a follow up action was filed, Risinger v. Concannon. That case settled when the state agreed, among other things, to: (1) develop and comply
with time frames for providing in-home behavioral health and case management services, and determining eligibility; (2) require that treatment plans be prepared for children who need behavioral health services within set time frames; and (3) develop a system for identifying and tracking children who have requested services.

B. Lack of transportation

The Medicaid Act provides two avenues for covering transportation services for children. First, states must address transportation in the administration of their programs and “specify that the Medicaid agency will ensure necessary transportation for recipients to and from providers and describe methods that the agency will use to meet this requirement.” Second, because transportation services are included as an optional Medicaid service in § 1396d(a), states must cover transportation, including “related travel expenses,” under EPSDT when necessary for a child. This includes the costs of transportation by ambulance, taxicab, common carrier or other means; meals and lodging to and from care; attendant’s transportation, meals, and lodging; and, if the attendant is not a family member, salary. The EPSDT guidelines also require transportation to be offered prior to each due date of a child’s periodic examination. The family or recipient also must be offered necessary appointment scheduling assistance.

Common problems. Families complain of difficulty reaching EPSDT providers. Transportation problems that cause broken appointments can also affect providers. In a government survey, dentists cited appointment “no shows” as a major reason for not participating in Medicaid.

Administrative solutions. A number of states have begun using transportation brokerages, administrative managers, and capitated transport services for non-emergency transportation.

Transportation brokerages. Transportation brokerages are entities created to coordinate transportation services for Medicaid recipients, including screening of recipients, determination of eligibility and arrangement and payment of actual transportation. The State of Washington uses transportation brokerages, having established 13 medical transportation service districts and contracted with a network of regional transportation brokers to cover the entire state. Brokers receive an administrative fee to coordinate the program as well as reimbursement for direct costs. When a patient needs a ride to a medical provider, she calls the broker, who verifies Medicaid eligibility, determines the necessity of each trip, and assigns the appropriate
provider. Depending on the patient’s needs, the broker can use a variety of resources, such as volunteers, transit buses, mileage reimbursement, and shared-ride taxis. Providers are reimbursed based upon a pre-arranged fee.  

- **Administrative managers.** Administrative managers are state Medicaid agency personnel who are gatekeepers in arranging transportation services. Idaho has established a statewide administrative managers system, contracted through Integrated Transport Management (ITM). ITM handles requests for transportation through toll-free telephone lines. ITM employees verify eligibility, obtain authorization, and refer recipients to approved transportation providers. Providers are reimbursed by the state Medicaid agency.  

- **Capitated services.** Under a capitated transportation services model, non-emergency transportation is included in the Medicaid managed care contract. The capitated rate adjusts for projected transportation costs to and from medical providers, and the health plan assumes responsibility for providing necessary transportation. Health plans participating in the Arizona Health Care Cost Containment System (AHCCCS) are responsible for the medical transportation needs of their members and receive funding in their capitated rates. The plans award competitive contracts to transportation providers to provide ambulatory taxi and van service and stretcher and wheelchair vans.  

**Legal efforts.** Over the years, a handful of Medicaid transportation cases have been filed, with varying results. While courts have generally held that states are mandated by federal Medicaid laws to assure necessary transportation for Medicaid recipients to and from providers, they have applied varying standards in determining exactly what is required. In *Daniels v. Tennessee Department of Health and Environment*, the court found that states have an obligation to assure that transportation will be available for recipients; however, it found the state could satisfy this requirement by establishing a network of paid volunteers and that persons owning cars could be assumed to be able to pay for gas. Other courts have been more demanding in their interpretation of the federal requirements. West Virginia and Texas, for example, have been required to include reimbursement of travel costs for Medicaid beneficiaries and necessary attendants. Finally, the District of Columbia has been ordered to offer transportation and appointment scheduling assistance prior to each due date of a child’s EPSDT screening examination. In contracts with managed care organizations, the District has required plans to provide letter reminders and follow-up telephone calls to offer this assistance.
C. Provider shortages

As noted in Part II, above, the Medicaid Act includes specific provisions aimed at assuring adequate participation by quality providers.

**Common problems.** Nevertheless, provider shortages often prevent EPSDT services from being predictably and uniformly available. A recent survey by the American Academy of Pediatrics found that many pediatricians (89.5 percent) report participating in the Medicaid program, but only about 61 percent of providers report accepting all Medicaid patients.\(^{316}\) Health care providers cite a number of reasons why they limit participation in or do not participate in the Medicaid program. Of the pediatricians surveyed by the AAP, 58.4 percent cited low reimbursement as an important reason why they limit Medicaid participation.\(^{317}\) In addition to low reimbursement rates from the state, primary care pediatricians also cited low capitated rates (fixed payment per child per month) from managed care organizations administering Medicaid and time-consuming and inefficient paperwork as reasons why they do not accept more Medicaid patients.\(^{318}\) Appointment “no shows,” lack of knowledge among beneficiaries of the importance of preventive care, and the on-again-off-again nature of Medicaid eligibility are also problems.\(^{319}\) Without doubt, lack of adequate reimbursement is the primary complaint, and indeed, increases in payment rates have been shown to increase provider participation in EPSDT.\(^{320}\) Unfortunately, provider participation could further deteriorate, as over half the states are reporting that their Medicaid provider payment rates are being cut or frozen.\(^{321}\)

Access to dental care has been particularly affected by shortages of dentists who will accept Medicaid.\(^{322}\) A recent report from the U.S. Surgeon General found that, while dental caries is the most common chronic childhood disease, dental provider participation for poor children has reached crisis-level lows.\(^{323}\) As illustrated below, administrative advocacy and litigation are being used to address the dental access problem.

**Administrative solutions.** Various entities, including state Medicaid agencies, dental provider associations, and consumer organizations, are sponsoring administrative advocacy to improve the availability of oral health care for children. Activities include:

- On January 18, 2001, CMS issued a “Dear State Medicaid Director” letter regarding children’s dental services, encouraging states to pay attention to improving children’s access to dental care and requiring each state to submit an dental care Action Plan.\(^{324}\)
- A number of states’ legislatures have commissioned studies to clarify the problems and potential solutions.  

- States have enacted legislation to allow dental hygienists to provide increased levels of preventive dental care.  

- Washington and North Carolina have reimbursed pediatricians for procedures that promote dental health, such as application of fluoride varnish during well child visits.  

- “Smile Alabama!” is a statewide initiative to increase dental provider participation and children’s utilization of dental services. The state increased payment rates for dentists in October 2000 to equal payments by Blue Cross/Blue Shield, the state’s largest insurer. The Medicaid agency uses site visits to dentists’ offices to educate providers about the program and to respond to issues and concerns. Regional meetings and workshops are being used to provide additional information. The Robert Wood Johnson Foundation provided partial funding for these meetings. The Medicaid agency also provides office-specific services to dentists, on request, using trained case managers to discuss the importance of preventive care with patients and to arrange and assist with appointment scheduling and transportation. The program has caused dentists’ participation in Medicaid to increase.  

- In 1997, the Indiana Office of Medicaid Policy and Planning formed a Dental Access Working Committee to develop recommendations to improve dental participation in Medicaid. Initially, the Committee focused on organizational buy-in from dental and pediatric associations, county health departments, and the Medicaid agency. Recommendations included: carving dental services out of managed care; increasing reimbursement rates; reducing turnaround time for dental claim data entry and receipt of payment; removing prior authorization requirements for dental procedures; continuing the role of the dental advisory panel; and improving communication with dental providers concerning coverage policies, eligibility verification, and common reasons for claims denials. Rates were increased by 119 percent, effective May 1, 1998. In 1999, about 20 percent more dentists participated in the program than in the previous year.  

- Health Care for All and Community Catalyst published a guide, *Addressing Oral Health Needs: A How to Guide*, that gives organizations and communities ideas for addressing oral health needs by profiling successes and challenges of various program that have been developed.
The Robert Wood Johnson Foundation has funded the Center for Health Care Strategies’ State Action for Oral Health Access Project. This program is designed to help states improve access to dental care by addressing policy barriers. States selected for grants through the project were Arizona, Oregon, Pennsylvania, Rhode Island, South Carolina, and Vermont.\textsuperscript{331}

**Legal efforts.** Litigation to improve children’s access to dental care is currently underway in at least seven states.\textsuperscript{332} These cases typically include claims based on the statutory requirements for equal access (§ 1396a(a)(30)(A)), reasonable promptness (§ 1396a(a)(8)), and EPSDT (§ 1396a(a)(43), 1396d(r)) requirements.

The California case *Clark v. Kizer* is the most well-known dental provider participation case.\textsuperscript{333} Granting summary judgement for the plaintiffs, the *Clark* court was persuaded by the fact that “the present rates are not even adequate to meet overhead, let alone allowing for some marginal profit.”\textsuperscript{334} The court ordered the state to implement compliance plans that:

- increased rates to 80 percent of the usual rate for 56 commonly performed procedure codes;
- provided annual cost of living adjustments;
- provided accurate information to beneficiaries on available dentists in their area, through a toll-free telephone service; and
- required the Medicaid agency to submit a plan for increasing utilization to at least 41.7 percent in 16 underserved counties.

In the footsteps of *Clark*, the recent settlement agreement of a North Carolina case included reimbursement increases targeted to frequently-used children’s dental codes, establishment of a dental advisory committee, effective staffing of a toll-free family assistance line, outreach to providers, and a requirement for the Medicaid agency to place information in the EPSDT brochure and member enrollee handbooks on EPSDT dental services and how/where to obtain them.\textsuperscript{335}

Before leaving this topic, it must be stressed that children also may experience problems locating specialists, case managers, and other providers. *Chisholm v. Hood* is an example of a Medicaid case which has resulted in activity to improve the availability of community-based providers for children with mental retardation/developmental disability, including:
· **Case managers.** The Medicaid agency will enter contracts with qualified case managers to provide services statewide, to include maximum caseload standards (35 patients per full time case manager), minimum qualifications, and training on EPSDT and Medicaid. Case managers will develop written comprehensive plans of care, with participation from the beneficiary, family, and providers.

- **Therapy providers.** Louisiana claimed that the services offered to class members as part of their special education services under the Individuals with Disabilities Education Act met their needs for treatment under Medicaid. The court disagreed and ordered Louisiana to permit home health agencies and rehabilitation service providers to enroll as Medicaid providers for children needing occupational therapy, speech therapy and audiological services and also enjoined the state from restricting the provision of these services to school-based providers or early intervention centers.

- **Providers for children with Pervasive Developmental Disorders (e.g. autism).** In another ruling, the court found the state was improperly limiting psychological and behavioral services, including the services of licensed psychologists, to children with pervasive developmental disorders. The state was ordered to take steps to open up Medicaid enrollment to these providers.336

**D. Denials of services by managed care organizations**

Medicaid managed care has introduced new opportunities and challenges for the delivery of EPSDT services.337 Approximately 57 percent of Medicaid beneficiaries were enrolled in Medicaid managed care as of 2002.338 Enrollment of children has grown exponentially as states targeted their initial efforts to children and families, and are increasingly including children with special health care needs. Thus, managed care is becoming the predominant method of delivering EPSDT services to poor children.

**Common problems.** Even as the move to Medicaid managed care has picked up speed, there is little empirical evidence to demonstrate that this is a superior delivery system.339 Consumer groups complain of the lack of pediatric care providers, particularly specialists, in these programs and of delays and denials of needed Medicaid-covered services. Studies, to date, suggest that managed care’s ability to save costs, at least among poor children, is limited.340 Medicaid managed care programs have shown mixed results in terms of improving access to preventive
services and treatment. A recent report from the Office of Inspector General found that fewer than one in three Medicaid children enrolled in managed care organizations received timely EPSDT services, and six of ten received none at all. For people with disabilities and chronic conditions, managed care presents special challenges in fashioning a system of care that accounts for individualized and complex care needs that go beyond traditional medical care and that recognize the need to provide care without a cure. Commercial insurance coverage standards, which may be the state-of-the-art for the health plan, may be too limited for the Medicaid beneficiary. From an assessment of early lessons learned, the United States Office of Inspector General has issued a number of recommendations for improving Medicaid managed care:

- Separate mental health services from other health services and phase-in conversion to managed care;
- Exclude the drug formulary from the managed care contract until reliable cost information can be generated;
- Use the existing public community mental health system and pay rural providers higher capitated rates, if necessary to develop rural services;
- Make contract language specific;
- Use liberal prior authorization policies to assure continuity of care and enhance provider participation;
- Provide community and beneficiary education early and often and include beneficiaries in the development process; and
- Involve beneficiaries and their families in treatment planning. Assign health care coordinators to work with beneficiaries to assure they obtain needed services.

Administrative solutions. Over the years, child health advocates have found themselves devoting significant time to press for consumer protections in managed care programs. This is time well-spent: well-designed and implemented programs can avoid service denials later on. Some of these efforts are described below:

- The Pennsylvania Health Law Project has sponsored Best Practices Seminars for state officials and advocates, featuring experts who discuss ways to improve the provision of EPSDT services in managed care settings.
The George Washington University Center for Health Services Research has reviewed and catalogued states managed care contractual provisions, including EPSDT. The Center also issues sample purchasing specifications, including for lead blood testing and pediatric care services.

The Tennessee Health Care Campaign publishes a graphic and informative newsletter for families, TennCare for Children. The Spring 2001 issue, for example, included information on recent changes in the program, a feature article on cost-sharing, and summaries of recently settled cases.

Consumer organizations in Kentucky and New Mexico have organized to monitor and comment on development of managed care. Consumers’ Voice, a project of Health Action New Mexico, has produced reports, including a report on how to maximize the consumers’ voice (1999). In Kentucky, the Office of Legal Services has worked with the state to draft a Medicaid Consumer Handbook (2001). In the past, consumer groups in both states have sponsored focus groups of managed care enrollees to find out what is working and what is not.

When the General Accounting Office analyzed four states’ experience with managed mental health care, the California Protection & Advocacy office analyzed the GAO’s report on California and offered recommendations to the state.

In cooperation with the Frank D. Lanterman Regional Center, and with funding from the state department of developmental disabilities, the National Health Law Program prepared a easy to read guide on enrolling in and using managed care: National Health Law Program, A Guide to Medi-Cal Managed Care for People with Developmental Disabilities Families and Professionals (1999).
Legal efforts. Two cases—from the District of Columbia and Tennessee—illustrate how problems are being addressed through the courts. In *Salazar v. District of Columbia*, the Court found a number of EPSDT violations, particularly regarding requirements for informing and screening. Under managed care, the screening rates had actually gone down. The District entered into a settlement that requires the following activities:

- Oral and written notice about the EPSDT program to families when they apply for Medicaid and at least once a year. Pocket-sized EPSDT schedules will be distributed at these times. The notices must include a strong recommendation that EPSDT services be used. Notably, the Court recently ordered the state to update its provider EPSDT training activities;\(^{347}\)

**Practice Tip**

**Review managed care contracts**

In addition to federal requirements, there is a contract that binds a managed care organization to provide EPSDT services when needed. Be sure to review any contracts your state has with managed care entities.

**Model EPSDT Managed Care Contract Provisions**

- Detailed program objectives which establish a clear, broad intent (Massachusetts)
- Explanation of requirements for outreach; transportation, appointment scheduling, and interpreter assistance, and coordination with other programs (Connecticut)
- Comprehensive description of what screening services must include (Missouri)
- More precise listing of vision and hearing services (Kentucky)
- Particular notice made of the “expanded services” requirements of EPSDT (Pennsylvania)

Detailed description of scope of benefits, with citations to Medicaid statute (North Carolina)
outreach to inform teenagers, persons who speak Spanish, persons who are blind or deaf, and persons who are illiterate. Recently, the Court ordered the state to focus on outreach to adolescents.\textsuperscript{348}

- contacting families to remind them when periodic screens are due and to offer assistance with appointment scheduling and keeping, including telephone calls, mailed reminders, and home visits. MCOs must provide case management services to assist children with obtaining needed social, educational, and other services; and

- developing a tracking system that shows whether each enrolled child has received EPSDT screening, referrals for corrective treatment, the date on which corrective treatment was received, and the date on which outreach activities were undertaken. (The Court recently ordered the state to begin using a uniform encounter form as the “basic building block” for the tracking system).\textsuperscript{349}

The settlement agreement also required the District to achieve participation rates at or exceeding 80 percent for each MCO. The agreement provided that if this percentage was not reached, the MCO would be required to develop corrective action plans and/or pay financial penalties. The District failed to meet these rates; accordingly, as part of the ongoing litigation, the MCOs have developed corrective action plans. Some of the corrective measures include:

- performing outreach to caregivers, consisting of phone calls, post cards and home visits, as well as health fairs, annual birthday cards and EPSDT wallet cards;

- providing ongoing education to providers;

- issuing a compliance report to provide clinics with a listing of EPSDT-eligible members who are due or overdue for screening and solicit feedback from providers on their status; and

- conducting incentive campaigns, including identifying age-appropriate rewards (e.g., diaper coupons for parents of babies and toddlers; movie coupons for teens).

The Tennessee case, \textit{John B. v. Menke}, represents a comprehensive challenge to a statewide managed care program’s failure to assure that children get EPSDT services.\textsuperscript{350} In their complaint, children and their families noted numerous problems, 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. The case settled when the state agreed to implement a plan that includes requirements for:

- improving outreach and informing of beneficiaries. Among other things, MCOs are required to target informing to “at risk” groups, including mothers with babies, adolescents, first time eligibles, and those not recently using the program;

- updating and implementing statewide periodic screening requirements to identify both medical and mental health problems. Developmental screening will include the use of culturally sensitive developmental assessments and avoidance of premature diagnosis labeling;

- improving access to needed treatments, with particular attention to children who are medically fragile. MCOs must provide services needed to correct, compensate for, improve, or prevent a condition from worsening — even if the condition cannot be prevented or cured;

- better integration of health care and custodial services for children in foster care.

- enhanced measurement of performance by collecting information called for by CMS Form 416 and the National Committee for Quality Assurance.

The case also has resulted in improved monitoring of service delivery. As part of the case, an external quality review organization assessed each health plan’s EPSDT performance. Among other things, it found the behavioral health organization had no system to identify members who are hearing or visually impaired and that eight of the nine managed care organizations had no systems at all. The most commonly denied services were durable medical equipment and therapy services.
Words to Remember:

This case is about people – children and adults who are sick, poor, and vulnerable – for whom life, in the memorable words of poet Langston Hughes, “ain’t been no crystal stair.” It is written in the dry and bloodless language of “the law” – statistics, acronyms of agencies and bureaucratic entities, Supreme Court case names and quotes, official government reports, periodicity tables, etc. But let there be no forgetting the real people to whom this dry and bloodless language gives voice: anxious, working parents who are too poor to obtain medications or heart catheter procedures or lead poisoning screens for their children, AIDS patients unable to get treatment, elderly persons suffering from chronic conditions like diabetes and heart disease who require constant monitoring and medical attention. Behind every “fact” is a human face and the reality of being poor in the richest nation on earth.

Judge Gladys Kessler, Salazar v. District of Columbia

Notes


8. See Kaiser Commission on Medicaid and the Uninsured, *Children’s Health – Why Health Insurance Matters* (May 2002), at http://www.kff.org. See also Eugene M. Lewit et al., The David and Lucile Packard Foundation, *Health Insurance for Children: Analysis and Recommendations*, 13 THE FUTURE OF CHILDREN 5, 6-7 (Spr. 2003, advance copy) (reporting on a number of studies concluding that insured children are more likely to have well-child care, dental and specialty visits, and recommended immunizations and less likely to have delayed needs for prescription drugs and medical, surgical, and dental care).


10. See Paul Newacheck et al., *Disparities in the prevalence of disabilities between black and white children*, 157 ARCHIVES OF PEDIATRICS & ADOLESCENT MED. 244 (Mar. 2003) (finding rate and prevalence of disabling chronic health conditions is higher in black children than in white and that poverty is a key indicator, with poor children to be twice as likely as children in families with higher incomes to have disabilities); Paul Newacheck et al., *The Effect on Children of Curtailing Medicaid Spending*, 274 JAMA 1468 (Nov. 8, 1995).


12. See generally Children’s Defense Fund, *Health Problems Among Children and Working-Age Adults* (Feb. 2, 1998) (finding that arthritis and high blood pressure, the most common chronic health problems for adults, are among the least common for children, and tonsil-adenoid disease and
speech impairment, among the most common chronic health problems for children, are least common among adults).


17. See Norma I. Gavin et al., *The Use of EPSDT and Other Health Care Services by Children Enrolled in Medicaid: The Impact of OBRA ‘89*, 76 *MILBANK Q.* 207, 236-37 (1998). The four states, California, Georgia, Michigan, and Tennessee, together account for about 25 percent of all Medicaid recipients and 17-18 percent of total expenditures. *Id.* at 212.


22. This is not surprising, given how few cost effectiveness studies have been reported for pediatric and adolescent medical services generally. Children have less opportunity to participate as research subjects, and funding for research on medical outcomes and cost effectiveness has been limited. See, e.g., Steven Berman, M.D., American Academy of Pediatrics, in A Pediatric Perspective of Medical Necessity, 151 ARCH. PEDIATR. ADOLESC. MED. 858 (Aug. 1997). For discussion of cost effectiveness, see Partnership for Prevention, What Policymakers Need to Know About Cost Effectiveness (Fall 2001), at www.prevnt.org.

23. See William J. Keller, PhD, Study of Selected Outcomes of the Early and Periodic Screening, Diagnosis and Treatment Program in Michigan, 98 PUB. HEALTH REPORTS 110 (Mar.-Apr. 1983) (summarizing study results).


25. See Greg R. Alexander and Carol C. Korenbrot, The David and Lucile Packard Foundation, The Role of Preventive Care in Preventing Low Birth Weight, 13 The Future of Children 6 (Spr. 2003, advance copy), see also William Drucker, M.D., Cost Effectiveness of Child Health Programs–To the Editor, 325 NEW ENG. J. OF MED. 210 (July 18, 1991) (citing 1990 report confirming that for every dollar spent, the savings in Medicaid hospital costs for mothers and infants in just the first 60 days of post partum care ranged $1.77 in Florida to $3.13 in North Carolina).


28. See U.S. Congress Office of Technology Assessment, Healthy
Children: Investing in the Future (Feb. 1988). See also, e.g., D.B. Huse et al., Childhood vaccination against chickenpox: an analysis of benefits and costs, 124 PEDIATRICS 869 (June 1994) (vaccination against varicella infection (chickenpox) yields net economic benefits of $66.47 per vaccine).

29. See Ashley B. Coffield et al., Priorities Among Recommended Clinical Preventive Services, 21 AM. J. PREVENTIVE MED. 21 (2001).

30. See Bonnie J. Kay et al., Process, Costs and Outcomes of Community-Based Prenatal Care for Adolescents, 29 MEDICAL CARE 531 (June 1991).


32. See Ackerman, Benefits of Preventive Programs in Eye Care are Visible on the Bottom Line, 15 DIABETES CARE 580 (Apr. 1992).


34. See Centers for Disease Control and Prevention, Preventing Dental Caries (Feb. 2003), at http://www.cdc.gov/nccphp/pe_factsheets/pe_oh.htm (assessing savings in school based programs).


38. See Murray Krahn et al., Costs and Cost-Effectiveness of a Universal, School-Based Hepatitis B Vaccination Program, 88 AM. J. OF PUBLIC HEALTH 1638 (Nov. 1998).

care costs over a two-year period).


42. Id.

43. Appendix A discusses the legislative history of EPSDT. See also, e.g., Liu, *Increasing the Proportion of Children Receiving EPSDT Benefits – A South Carolina Case Study*, C.D.F. REPORTS at 2 (July 1990) (reporting less than 33 percent of eligible children screened in 1988).


45. It is important to note that CMS has not reported data from six states, Idaho, Maine, New Hampshire, New York, Texas, and Washington, and that New York and Texas are particularly high population states. See National Health Law Program, *Using the Revised Reporting Form When Advocating for Improving EPSDT for Children and Youth* (Mar. 31, 2003), at www.healthlaw.org.

46. For additional discussion of FY 1999 reporting, see id.


51. See Id. at § 1396a(a)(10)(A)(ii).

52. See Id. at § 1396a(a)(10)(B)(i).

53. See Id. at § 1396a(a)(10)(C); 42 C.F.R. §§ 435.300-435.350. For additional discuss of medically needy spend down programs, see National Health Law Program, An Advocate’s Guide to the Medicaid Program 3.16 (June 2001).


56. The exception to this rule is the “209(b) option,” which allowed states to use their more restrictive, 1972 definitions of disability or financial eligibility rather than the current SSI standards. There are eleven of these states: Connecticut, Hawaii, Illinois, Indiana, Minnesota, Missouri, New Hampshire, North Dakota, Ohio, Oklahoma, and Virginia.


58. See 42 U.S.C. §§ 1396a(a)(10)(A)(i)(IV), (VI); 1396a(l)(1)(A), (B), (C).


60. See Id. at §§ 1396a(a)(10)(A)(ii)(IX); 1396a(l)(1)(A)-(B).

61. See Id. at § 1396r-1a. For additional discussion, see National Health Law Program, An Advocate’s Guide to the Medicaid Program at 3.13 (June 2001).

63. See 42 U.S.C. §§ 1396a(a)(10)(A)(ii)(XIV); 1397jj.

64. See 42 U.S.C. §§ 1397aa(a).

65. See 42 U.S.C. §§ 1397ee, 1396d(b).

66. See, e.g., 20 C.F.R. § 416.1102 (discussing in-kind income for SSI).


68. See 42 U.S.C. § 1396a(r)(2)(A); 42 C.F.R. § 435.201.

69. See 42 U.S.C. § 1396a(r)(2).


71. See 42 C.F.R. §§ 435.403(i)(1) and (i)(4); 435.403 (h)(3) (residency to be determined in accordance with the AFDC rules, 45 C.F.R. § 233.40). For additional discussion, see National Health Law Program, An Advocate’s Guide to the Medicaid Program 3.24 (June 2001).

72. See 42 C.F.R. §§ 435.403(h)(4), 435.403(i)(2). But see Bethesda Lutheran Homes and Servs. v. Leean, 122 F.3d 443 (7th Cir. 1997) (declaring § 435.403(i)(2)(ii) unconstitutional as violating the right to travel because it prevents out-of-state, mentally retarded residents from becoming state residents for Medicaid purposes), same case, 154 F.3d 716 (7th Cir. 1998), same case, 238 F.3d 853 (7th Cir. 2001).

73. See 42 C.F.R. § 435.403(e)(i). However, if the individual is capable of forming intent and leaves the out-of-state placement facility, the state in which the individual is present becomes the state of residence. Id. at § 435.403(e)(3).

74. See Id. at § 435.403(f).

75. See Id. at § 435.403(g).
76. See 42 C.F.R. § 431.403(h).

77. See 42 U.S.C. § 1396a(b)(3).


79. See 8 U.S.C. § 1613(a); Personal Responsibility and Work Opportunity Reconciliation Act, Pub. L. No. 104-193, § 402, 110 Stat. 2105, 2262-64 (1996) (codified at 8 U.S.C. §§ 1601-1646), see also CMS, State Medicaid Manual §§ 3211.2-3211.3, 3211.6; CMS Immigrant Eligibility for Medicaid and SCHIP (undated), at http://www.cms/hhs/gov/immigrants/default.asp. After this five year period, states have the option to extend full-scope benefits to otherwise qualified immigrants or to continue to deny such coverage. See Id. at § 3211.7.B. See also 8 U.S.C. § 1613(a).


81. For a description of the categories of immigrants who may be eligible for Medicaid, see National Health Law Program, An Advocate’s Guide to the Medicaid Program at 3.25 (June 2001).

82. See 8 U.S.C. § 1612(b)(2)(F). See also 8 U.S.C. §§ 1612(a)(2)(D), (E), (F), (H) and (a)(3)(A); 1612(b)(F) (defining certain groups eligible for SSI).


84. See 8 U.S.C. § 1611(b)(A) (describing emergency medical conditions). See also Id. § 1611(b)(C) (immigrants eligible for public health assistance for immunizations and treatment of communicable diseases). See generally 42 U.S.C. § 1395dd; 42 C.F.R. § 489.24 (Emergency Medical Treatment and Active Labor Act requires Medicare-participating hospitals with emergency rooms to provide screening and emergency services without regard to whether the individual has the ability to pay).

85. See 42 U.S.C. § 1396d(a)(1)-(a)(2); see also 42 C.F.R. §§ 440.10, 440.20 (defining terms).

86. See 42 U.S.C. § 1396d(a)(5)(A); see also 42 C.F.R. § 440.50 (defining term).

88. See 42 U.S.C. § 1396d(a)(21); see also 42 C.F.R. § 440.166 (defining term).

89. See 42 U.S.C. § 1396d(a)(12); see also 42 C.F.R. § 440.120 (defining term).

90. See 42 U.S.C. § 1396d(a)(10); see also 42 C.F.R. § 440.100 (defining term).

91. See 42 U.S.C. § 1396d(a)(11); see also 42 C.F.R. § 440.110 (defining term).

92. See 42 U.S.C. § 1396d(a)(27); see also 42 C.F.R. § 440.170 (defining term).

93. 42 C.F.R. § 440.230(b).

94. See., e.g., Charleston Mem’l Hosp. v Conrad, 693 F.2d 324 (4th Cir. 1982) (upholding twelve day annual limit on inpatient hospital services because levels of care were sufficient to reasonably achieve their purpose).

95. See 42 C.F.R. § 440.230(c).

96. See, e.g., Weaver v. Reagan, 886 F.2d 194 (8th Cir. 1989) (holding that Missouri may not deny coverage of the drug AZT to AIDS patients who are eligible for Medicaid).

97. See 42 U.S.C. §§ 1396b(a), 1396d(b).

98. For example, the FY 2004 matching rate for California is 50 percent and for Mississippi, 77.09 percent. See 67 Fed. Reg. 69,223 (Nov. 14, 2002).

99. See 42 U.S.C. § 1301(a)(8). This is called the Federal Medical Assistance Percentage (FMAP) and must be published each year between October 1 and November 30. The FMAP is published in the Federal Register. See 67 Fed. Reg. 69,223 (Nov. 14, 2002).

100. See 42 U.S.C. §§ 1396b(a)(1), 1396d(b).


103. See 42 U.S.C. § 1396a(a)(5); 42 C.F.R. § 431.10.


107. Id.

108. See Goldberg v. Kelly, 397 U.S. 254 (1970) (holding that a hearing was required before welfare benefits could be terminated).

109. Id. at 267.


111. See 42 C.F.R. § 431.231.


113. Id. See also, George J. Annas et al., American Health Law 186-87 (1990).

114. See, e.g., Doe v. Pickett, 480 F. Supp. 1218, 1221 (S.D.W.Va. 1979) (holding that EPSDT “imposes on the states an affirmative obligation to see that minors actually receive necessary treatment and medical services”).

115. See 42 U.S.C. §§ 1396a(a)(10), 1396a(a)(43), 1396d(a)(4)(B), 1396d(r).


117. See 42 C.F.R. § 441.56; CMS, State Medicaid Manual § 5150.

118. See 42 U.S.C. § 12131 (Americans with Disabilities Act Title II provision requiring state and local entities to make reasonable accommodation).

119. See 42 U.S.C. §§ 2000d-2000d-7 (title VI of the Civil Rights Act);
see also, e.g., CMS, Dear State Medicaid Director (Aug. 31, 2001), at http://www.hcfa.gov/medicaid/smd83100.htm (enclosing Office for Civil Rights guidance on serving persons who are limited English proficient).


121. See CMS, STATE MEDICAID MANUAL § 5123.2.A(1).

122. Id. See also, e.g., National Center for Education in Maternal and Child Health, Bright Futures - Guidelines for Health Supervision of Infants, Children and Adolescents (1994, 2002).

123. Id., § 5123.2.A(1)(a).

124. Id.

125. Id. See also Michael C. Biehl et al., The Health of America’s Middle Childhood Population (2002).

126. See CMS, STATE MEDICAID MANUAL § 5123.2.A(1)(b).

127. Id.


130. See Cynthia Dailard and Michele Melden, Screening for Mental Health Problems in Children, 26 CLEARINGHOUSE REV 898. (Dec. 1992); Bazelon Center on Mental Health Law, An Evaluation of State EPSDT Screening Tools (June 1997).

132. *Id.*


136. *Id.*

137. CMS, *STATE MEDICAID MANUAL* § 5123.2.B(2).

138. *Id.*

139. *Id.*

140. 42 U.S.C. § 1396d(r)(1)(B)(iv); 42 C.F.R. § 441.56(b)(v).

141. *See* CMS, *STATE MEDICAID MANUAL* § 5123.2(D).

142. *Id.*

143. *Id. See also* Letter from Gary Wilks, Associate Regional Administrator, Director of Medicaid, Region VIII to Director, Medicaid Bureau (undated) (describing positive response of state Medicaid agencies to the *Bright Futures* materials and the steps states have taken to incorporate their guidelines into their programs).

144. *Id.*

145. For children aged under age six, the CDC has defined an elevated blood lead level as >10 micrograms per deciliter, but evidence exists for subtle effects at lower levels. Centers for Disease Control, *Blood Lead Levels in Young Children - United States and Selected States, 1996-1999*, 49 MORBIDITY AND MORTALITY WEEKLY REPORTS 1133 (Dec. 23, 2000), see Richard L. Canfield, Ph.D. et al., *Intellectual Impairment in Children with Blood Lead Concentrations below 10 Micrograms per Deciliter*, 348 NEW ENG. J. MED. 1517 (Apr. 17, 2003) (finding that blood lead concentrations below 10 micrograms per deciliter are inversely associated
with children’s IQ scores at ages three and five, and associated declines in IQ are greater at these concentration than at higher concentrations).


147. See Richard L. Canfield, Ph.D. et al., Intellectual Impairment in Children with Blood Lead Concentrations below 10 Micrograms per Deciliter, 348 NEW ENG. J. MED. 1517 (Apr. 17, 2003) (finding that blood lead concentrations below 10 micrograms per deciliter are inversely associated with children’s IQ scores at ages three and five, and associated declines in IQ are greater at these concentration than at higher concentrations); Sherry G. Selevan, Ph.D. et al., Blood Lead Concentration and Delayed Puberty in Girls, 348 New Eng. J. Med. 1527 (data suggest that environmental exposure to lead may delay growth and pubertal development in girls); Centers for Disease Control, Lead Poisoning Prevention Program Fact Sheet, at http://www.cdc.gov/nceh/lead/factsheets/leadfcts.htm.


149. ACCLPP, Centers for Disease Control and Prevention, Recommendations for Blood Lead Screening of Young Children Enrolled in Medicaid: Targeting a Group at High Risk, 49 MORBIDITY & MORTALITY WEEKLY REP. 3 ( Dec. 8, 2000), at http://www.cdc.gov/mmwr/mmwr.html.

150. Id.


152. See CMS, STATE MEDICAID MANUAL § 5123.2(D)(1).
153. Id.

154. Id.

155. Id. See also, CMS, Dear State Medicaid Director (April 13, 1998); CMS, Dear State Medicaid Director (October 22, 1999). See also Alliance to End Childhood Lead Poisoning, Track, Monitor and Respond: Three Keys to Better Lead Screening for Children in Medicaid, October 29, 2001, at http://www.healthlaw.org/pubs/200110.leadscreening.pdf.

156. See CMS, STATE MEDICAID MANUAL § 5123.2(D)(1). The lead screening requirements were actually changed in 1998.


158. See Id. at 6. See also Charles Duarte, Med-Quest Division Administrator, Hawaii Department of Human Services, to QUEST Health Plans, March 25, 1999 (clarifying roles and responsibilities of managed care plans in lead screening).


160. See Salazar v. District of Columbia, No. 930452 (GK) (D.D.C. Feb. 28, 2003) (order) See also Guerrero v. Idaho, CIV 00-578-S-MHW (D. Idaho Jan. 14, 2003) (Consent Decree and Judgment) (Idaho agreed to ensure that lead screening and treatment services are provided as needed, with particular emphasis on educating providers about the mandatory nature of lead testing and the reimbursement that is available for providing these services).


162. See HCFA Region VII, Medicaid State Bulletin - 225 (July 30,
1992) (nutritional assessment is a part of the comprehensive screen, not a “separate component”).


164. *Id.*

165. *Id.*


167. 42 U.S.C. §§ 1396s(e), 1396s(c)(2)(B)(i), 1396d(r)(1)(A)(i). In addition, federal financial participation will be denied with respect to any amount that the state expends for a single-antigen vaccine when a combined vaccine is medically appropriate (as determined by the Secretary).

168. 42 U.S.C. § 1396s(e).

169. CMS, *State Medicaid Manual* § 5123.2(C).


171. *See Id.* at § 1396s(c)(2).

172. *See Id.* at § 1396s(c)(2)(C)(iii).

173. *See Id.* at § 1396s(c)(2)(C)(i).

174. *See Id.* at §§ 1396s(c)(3); 1396a(a)(30)(A).

175. *See Id.* at § 1396s(c)(3)(B).

176. *See Id.* at § 1396s(a)(2)
177. See Id. at § 1396s(d).


180. CMS, STATE MEDICAID MANUAL § 5123.2.E.


185. Id.

186. Id. See also American Academy of Pediatrics, Newborn and Infant Hearing Loss: Detection and Intervention, 103 PEDIATRICS 527 (Feb. 1999).

187. See 42 U.S.C. § 1396d(r)(4); 42 C.F.R. § 441.56(b)(iv) (“appropriate hearing testing”); CMS, STATE MEDICAID MANUAL § 5123.2.F.

188. See CMS, STATE MEDICAID MANUAL § 5123.2.F(2).

189. Committee on Practice and Ambulatory Medicine, Section on Ophthalmology, American Academy of Pediatrics, Eye Examination and Vision Screening in Infants, Children and Young Adults, 98 PEDIATRICS
153 (July 1996).

190. Id.


192. See 42 U.S.C. § 1396d(r)(2); 42 C.F.R. § 441.56; CMS, STATE MEDICAID MANUAL § 5123.2.F(1).

193. CMS, STATE MEDICAID MANUAL § 5123.2.F(1).


196. Id. at 2.

197. Id. at 11-12, tbl. 3.

198. Id.


201. 42 U.S.C. § 1396d(r)(3).

202. Citing dental provider shortages, some states have begun to involve physicians more heavily in the provision of dental care. In North Carolina, for example, the Into the Mouth of Babes pilot program allows physicians to provide a package of preventive dental services, including oral screening, dietary and oral hygiene counseling to care givers, and the application of dental varnish to the teeth of young Medicaid-eligible children. See Press Release, North Carolina Dep’t of Health and Human Services, State Medicaid Program Wins Federal Grant to Attack Dental Decay in Infants & Toddlers (Jan. 17, 2001), at http://www.dhhs.state.nc.us/pressrel/1-17-01.htm.
203. See CMS, STATE MEDICAID MANUAL § 5123.2 (G). However, the Surgeon General has recommended that an oral examination be included as part of a general medical examination. See Department of Health and Human Services, U.S. Public Health Service, Oral Health in America: A Report of the Surgeon General, Executive Summary at 11 (2000).

204. See 42 U.S.C. § 1396d(r); 42 C.F.R. § 441.56(b).


206. See CMS, STATE MEDICAID MANUAL § 5123.2(G).

207. Id.

208. See National Health Law Program, Using the Revised Reporting Form When Advocating for Improving EPSDT for Children and Youth (Mar. 31, 2003), see also U.S. General Accounting Office, Medicaid: Stronger Efforts Needed to Ensure Children’s Access to Health Screening Services at 7 (July 2001) (showing variation in periodicity requirements in five states–CA (fee for service and managed care), CT, FL, NY, and WI).


210. E.g., Memorandum from Director, HCFA Medicaid Bureau, to Region III Administrator, Health Care Financing Administration (Apr. 12, 1991).


212. See part IV for discussion of common treatment problems, administrative advocacy, and legal efforts to address these problems.

213. See 42 U.S.C. §§ 1396d(r)(5), 1396d(a). See Collins v. Hamilton, 231 F. Supp. 2d 840 (S.D. Ind. 2002) (requiring coverage of residential psychiatric facilities for children under age 21 because § 1396d(a) includes this in its lists of coverable services); check organ transplant cases.

214. See 42 U.S.C. §§ 1396d(r)(5), 1396d(a). For the federal government’s discussion of preventive services, see CMS, STATE MEDICAID MANUAL § 4385 (describing preventive care as both an integral component of other covered services and a separate optional benefit).

216. 42 C.F.R. § 441.56(e). See Risinger v. Concannon, No. 00-CV-116B (D. Me. July 22, 2002) (order of dismissal and settlement agreement) (agreeing to provide medically necessary in-home behavioral health and case management services for children under 21 in a timely manner); French v. Concannon, No. 97-CV-24-B.C (D. Me. July 16, 1998) (order of dismissal and agreement) (agreeing that state will promulgate and implement a number of policy and regulatory changes to improve access to EPSDT and to reduce long waits for EPSDT services.; Chisholm v. Hood, 110 F. Supp. 2d 499, 504 (E.D. La. 2000) (describing portions of settlement agreement to increase availability and quality of case management services to eliminate waiting lists for services for children with mental retardation and developmental disabilities).

217. 42 U.S.C. § 1396d(r)(5). See Jackson v. Millstone, 369 Md. 575, 801 A.2d 1034 (2002) (holding state regulation requiring that services be both “necessary” and “appropriate” conflicted with EPSDT because the “appropriateness” is not required under EPSDT); Georgia Dep’t of Community Health v. Freels, 258 Ga. App. 446 (Ct. App. Ga. 2002) (holding that EPSDT status required only that a treatment be needed to correct or ameliorate a condition, not that a treatment be an acceptable standard of medical practice); see also Mitchell v. Johnston, 701 F.2d 337, 346-47 (5th Cir. 1983) (recognizing that states are required to provide all treatment necessary to correct or ameliorate mental and physical conditions).


219. See, e.g., Jackson v. Millstone, 369 Md. 575, 801 A.2d 1034 (2002) (holding that Maryland Medicaid regulation requiring that services be both “necessary” and “appropriate” conflicted with EPSDT because the
“appropriateness” is not required under EPSDT); see also, e.g., Weaver v. Reagen, 886 F.2d 194 (8th Cir. 1989) (holding that state must defer to treating physician); Hillburn by Hillburn v. Maher, 795 F.2d 252 (2d Cir. 1986)(same). See generally Lewis v. Callahan, 125 F.3d 1436 (11th Cir. 1997) (holding that, in social security and SSI disability determinations, the opinion of the treating physician must be given substantial weight unless “good cause” is shown).

220. See, e.g., Letter from Rozann Abato, HCFA Acting Director Medicaid Bureau, to State Medicaid Directors (May 26, 1993).


222. Compare Letter from Rozann Abato, Acting Director Medicaid Bureau, to State Medicaid Directors (May 26, 1993) (discussing state "flexibility" to use medical necessity or utilization controls, including "tentative" limits on services, which must not delay delivery of needed service or limit free choice of provider).


224. See, e.g., Letter from Rozann Abato, Acting Director Medicaid Bureau, to State Medicaid Directors (May 26, 1993) (services/items not covered include those that are unsafe or experimental, or not generally recognized as accepted treatment).

225. See Georgia Dept. of Community Health v. Freels, 258 Ga. App. 446 (Ct. App. Ga. 2002) (holding that the EPSDT statute requires only that a treatment be necessary to correct or ameliorate physical or mental conditions, not that a treatment be an acceptable standard of medical practice); Trusler v. Blouke, No. CV-95-106 (Mont. Jud. Dist. Sept. 25, 1995) (requiring coverage of a movable brace for child with scoliosis and rejected state’s argument that the service was experimental), see also CMS, STATE MEDICAID MANUAL § 4385 (stating that “the Medicaid statute does not preclude [states] from funding experimental types of care . . . “).

226. See 42 U.S.C. § 1396d(a), Letter from Division of Medicaid (Region V) to Patricia MacTaggart, Director, Minnesota Dept. Human Services (Sept. 20, 1995) (describing development of mental health “wraparound” services and how they can be covered under EPSDT). For additional
discussion, see Bazelon Center for Mental Health Law, Covering Intensive Community-Based Child Mental Health Services Under Medicaid: A Series of Issue Briefs (Apr. 2001); Bazelon Center for Mental Health Law, Making Medicaid Work to Fund Intensive Community Services for Children with Serious Emotional Disturbance (1994); Susan C dosReis et. al. Mental Health Services for Youths in Foster Care and Disabled Youths, 91 AM J. PUBLIC HEALTH 1094 (July 2001).


228. Id. See also HCFA, Dear Ohio State Medicaid Director (July 6, 1992) (stating that a state must make EPSDT available for all Medicaid eligible individuals under age 21, regardless of whether the individual is eligible under the state’s HCBW) (available from National Health Law Program).

229. For in-depth discussion of this issue, see Sarah Somers, Cost-Related Community Integration Barriers in Medicaid: A Review of EPSDT and Home and Community-Based Waivers, 35 CLEARINGHOUSE REV. 719 (Mar.-Apr. 2002).

230. 42 U.S.C. § 1396d(r)(5). Note that coverage issues can arise if there is a dispute as to whether the services are for “habilitative” purposes of developing functional abilities of persons who never acquired them or for “rehabilitative” purposes of restoring certain functional losses. Some states have taken the position that habilitative services are not within the scope of benefits listed in § 1396d(a) and are covered only when provided by the ICF/MR benefit, a home and community-based waiver, or when provided under the community supported living arrangements benefit.

231. 42 U.S.C. § 1396d(a)(13); 42 C.F.R. § 440.130(d).


233. See Letter from A.W. Schnellbacher, Jr., Chief, Program Operations Branch, Division of Medicaid (Region VIII) to Richard Allen, Medicaid Director, Colorado Department of Health Care Policy and Financing (March 7, 1996) (stating that daily living aids such as specialized utensils “can be vital in allowing a beneficiary to achieve/reach/maintain his or her best visible functional level”).
234. See Letter from Andrew A. Frederickson, Chief, Medicaid Operations (Region VIII) to Garth L. Splinter, CEO, Oklahoma Health Care Authority (April 9, 1999); HCFA, Medicaid State Bulletin - 231 (Sept. 10, 1992); Letter from HCFA to Regional Administrator, Region VIII (Oct. 2, 1991).

235. However, CMS excludes room and board. See Texas v. United States Dep’t of Health and Human Services, 61 F.3d 438 (5th Cir. 1995) (upholding agency position to exclude room and board costs associated with the provision of EPSDT rehabilitative services in inpatient residential chemical dependency treatment facilities).

236. 42 U.S.C. § 1396d(a)(6).


238. See 42 U.S.C. §1396a(a)(23); 42 C.F.R. § 431.51.

239. 42 U.S.C. §§ 1396d(r)(5), 1396d(a)(19), 1396n(g). See, e.g., Chisholm v. Hood, 110 F. Supp. 2d 499, 504 (E.D. La. 2000) (describing portions of settlement agreement to increase availability and quality of case management services to eliminate waiting lists for services for children with mental retardation and developmental disabilities.)


243. See Letter from Rozann Abato, Acting Director, HCFA Medicaid Bureau, to Associate Regional Administrator, Dallas (June 14, 1993) (stating restraint seat may be prescribed as medically necessary as a prosthetic device or home health service for child with spastic motions).

244. See Letter from Rozann Abato, Acting Director Medicaid Bureau, to State Medicaid Directors (May 26, 1993) (finding state could determine that under certain circumstances computers are equipment that may be covered when used for a medical purpose).

245. See Letter from A.W. Schnellbacher, Jr, Chief, Program Operations Branch, Division of Medicaid (Region VIII) to Richard Allen, Medicaid
Director, Colorado (Mar. 7, 1996) (stating these benefits may be coverable rehabilitative and preventive services or therapy benefits and must be provided to EPSDT beneficiaries when medically necessary).

246. Id. (noting these services are covered for provision of medically necessary physical therapy but membership fees need not be covered if the services are available in other settings (e.g. hospitals, rehabilitation centers); noting that HCFA central office is reviewing coverage of hot tubs, jacuzzis, treadmills, and stair glides but this regional office is “inclined” to say that the state has the responsibility for determining medical necessity for these items on an individual basis).

247. See HCFA, Chicago Regional State Letter No. 82-92 (Dec. 1992) (policy change on assistive devices, allowing coverage as home health services).

248. See HCFA, Program Issuance Transmittal Notice Region IV (MCD-78-92) (Oct. 7, 1992) (service may be covered by state as “rehabilitative service” when medically necessary).

249. Id.

250. See Letter from Christine Nye, HCFA Medicaid Director, to Regional Administrator Region III (Oct. 8, 1991) (stating that swimming classes for child with cystic fibrosis may be medically necessary and coverable as physical therapy or rehabilitative services).

251. See S.D. v. Hood, No. 02-2164, 2002 U.S. Dist. LEXIS 23535 (E.D. La. Dec. 5, 2002) (on appeal) (holding incontinence supplies “are unquestionably within the scope of services fundable under § 1396d(a) for EPSDT recipients”); Letter from Reid Stacey, Attorney, Kansas Social And Rehab. Services, to Kirk Lowery, Topeka Independent Living Resource Center (Feb. 21, 2003) (announcing states’ reinstatement of coverage of incontinence supplies). Arkansas, Idaho, Michigan, Montana, and Virginia cover incontinence supplies as home health services in the state Medicaid plans; Missouri covers them as durable medical equipment; Maryland and Wisconsin also cover these services. See http://www.hhs.gov/medicaid/stateplans.

252. See Pediatric Speciality Care, Inc. v. Arkansas Dep’t of Human Services, 293 F.3d 472 (8th Cir. 2002) (affirming district court’s holding that a Medicaid eligible individual has a federal right to early intervention day treatment, to reinforce skills that children learn in individual therapies, when recommended by a physician).

254. Id. at § 1396a(a)(30)(A). See part IV for a discussion of common problems, administrative solutions and legal efforts regarding provider participation.


256. See Id. at § 1396u-2(b)(5).

257. See Id. at § 1396d(r). See also H.R. Rep. No. 101-247 at 400, reprinted in 1989 U.S.C.C.A.N. 1906, 2126. Some states, for example, had restricted EPSDT providers to public health departments.

258. 42 C.F.R. § 441.61.

259. CMS, STATE MEDICAID MANUAL § 5010.B.

260. Id. at § 5220.

261. Medicaid is the payer of last resort, so other sources of coverage must be identified and tapped.


263. See 42 U.S.C. § 1396o(a). The Bush Administration has allowed states to use a streamlined Medicaid waiver process to cut services (including EPSDT) to optional Medicaid populations. In addition, states can impose cost-sharing on families and children. See CMS, Health


265. For discussion of this and other data, see Brett V. Brown, Child Trends, Tracking the Well-Being of Children and Youth at the State and Local Levels Using the Federal Statistical System (Sept. 2001) (available from The Urban Institute, Washington, DC).

266. See National Committee for Quality Assurance, HEDIS 3.0 (July 1996). See Lee Partridge, The APHSA Medicaid HEDIS Database Project: Report for the Third Project Year at 2-3 (Data for 1999) (Dec. 2001) (finding health plans scored well on measures of access for children under age two, but “a pattern of weak scores” continued for adolescents and prenatal care and post-partum check ups were “consistently well below” the commercial population).

267. For more information, see http://www.aecf.org/kidscount.

268. For more information, see http://www.childrensdefense.org.

269. For more information, see http://www.healthlaw.org

270. See 42 U.S.C. §§ 1396a(a)(43)(D), 1396d(r)

271. CMS, STATE MEDICAID MANUAL § 5360.B.2 (Exhibit A, Expected Improvement in EPSDT Participation).

272. CMS, STATE MEDICAID MANUAL § 2700.4.A.


274. For example, in FY 2001, an independent audit could not verify the totality of the data reported on the District of Columbia Form 416, in part because Capital Community Health Plan had ceased operations and its data could not be verified.

275. See, e.g., U.S. General Accounting Office, Medicaid: Stronger
Efforts Needed to Ensure Children’s Access To Health Screening Services (July 2001); Office of Inspector General, U.S. Dep’t of Health and Human Services, Medicaid Managed Care and EPSDT (May 1997); Office of Inspector General, U.S. Dep’t of Health and Human Services, Children’s Dental Services Under Medicaid: Access and Utilization (Apr. 1, 1996). See generally Status Conference Agenda Proposal of Class Counsel in Salazar v. District of Columbia (Apr. 4, 2003) (reporting that four of the five participating health plans self-reported higher numbers of screens than the independent audit could verify through claims data) (available from National Health Law Program, Chapel Hill, NC); Connecticut Children’s Health Project, Quarterly Report to the Children’s Health Council on EPSDT On-Time Visit Rates (Dec. 8, 1997); State of Washington, Medicaid Assistance Administration, Health Options Quality Review (1996). But compare KM Schneider et al., Methods for evaluating the provision of well child care, 12 JT. COMM’N J. QUAL. IMPROV. 673 (Dec. 2001) (finding administrative data may underestimate the performance of EPSDT visits in comparison to medical record review but that having a claim for an EPSDT visit did not necessarily mean all required elements of the screen were performed).

276. For example, Michigan EPSDT Form 416s showed a decrease in medical screens after managed care was introduced, and in the District of Columbia, reporting of screens by managed care organizations as a result of a court order, also showed reductions. But compare J.S. Millar et al., Early and periodic screening, diagnosis, and treatment examination completion rates for Oklahoma Medicaid managed care: 1995-1998, 5 J. OKLA. STATE MED. ASS’N 151 (May 2001) (finding EPSDT screens improved under managed care).


278. See HCFA, Dear State Medicaid Director (July 19, 1999).


280. For example, as part of the ongoing Salazar case in the District of Columbia, plaintiffs’ counsel broke out reporting data on lead testing by managed care organization. This showed uneven performance among MCOs. See Lead Blood Screening Data from FY 2001 CMS Form 416 (printed July 23, 2002) (available from National Health Law Program, Chapel Hill, NC).
281. CMS, STATE MEDICAID MANUAL § 2700.4.E.


283. For example, New Mexico, North Carolina, and Texas have offered this justification in legal responses to cases challenging low screening and treatment rates.

284. See Roberta Riportella-Muller, et al., Barriers to the Use of Preventive Care Services for Children, 111 PUB. HEALTH RPT. 71, 74 (Jan./Feb. 1996).

285. See Philadelphia Citizens for Children and Youth, From Coverage to Care in Medicaid and CHIP: Getting out the Preventive Care Message to Pennsylvania’s Low-Income Families with Children (2001).


289. See, e.g., Home visits with first-time moms enhance self-care and improve birth outcomes, HEALTHCARE DEMAND & DISEASE MANAGEMENT 133 (Sept. 1998); Medi-Cal Community Assistance Project, Good Practices from Two-Plan County Medi-Cal Managed Care Plans at 6 (July 1999) (identifying home visits as an effective outreach strategy). But see Maija Selby-Harrington, Increasing Medicaid Child Health Screenings: The Effectiveness of Mailed Pamphlets, Phone Calls and Home Visits, 85 AM. J. OF PUB. HEALTH 1412 (October 1995) (finding that telephone reminders and home visits increased well-child screening, accordingly, alternative outreach methods are needed, especially for families without phones); Dorothy S. Oda et al., A Preventive Child Health Program: The Effect of Telephone and Home Visits by Public Health Nurses, 85 AM. J. OF PUB. HEALTH 854 (June 1995) (finding no statistically significant difference in the effectiveness of outreach by telephone vs. home visits).

290. See Connecticut’s Children’s Health Project, Quarterly Report to the


299. See Risinger v. Concannon, No. 00-116-B-C (D. Me. July 22, 2002) (order of dismissal and settlement agreement). In early 2003, the plaintiffs began to take steps to enforce this agreement.

300. The Americans with Disabilities Act and § 504 of the Rehabilitation Act also require states and transporters to assure physically accessible transportation services. For more discussion, see Manju Kulkarni, *Fact Sheet: Medicaid Transportation Services* (June 2000), at http://www.healthlaw.org.


303. Id.

304. See 42 C.F.R. § 441.62(a); CMS, *STATE MEDICAID MANUAL* § 5150.


307. Id.

308. Id.

309. Id.


311. Id. For example, Pima Health System, a Medicaid managed care plan, annually furnishes approximately 125,000 non-emergency medical trips to its members. On a per capita basis, PHS spends $2.37 per member per month.

312. Cases include Smith v. Vowell, 379 F. Supp. 139, 150-152 (W.D. Tex. 1974), aff’d, 504 F.2d 759 (5th Cir.1974) (providing only emergency transportation did not comply with federal requirements to assure the availability of transportation to necessary medical care); Bingham v. Obledo, 195 Cal. Rptr. 142 (1983) (state plan which limited transportation to beneficiaries who were too severely disabled to ride in automobiles or buses violated federal regulations); Fant v. Stumbo, 552 F. Supp. 617 (W.D. Ky. 1982) (state limitation of transportation reimbursement to four trips per month was invalid, arbitrary limit); Daniels v. Tennessee Department of Health and Environment, 1985 U.S. Dist. LEXIS 12145 (1985) (holding federal requirements met by forming a network of paid volunteer groups that provided transportation). But see Harris v. James, 127 F.3d 993 (11th Cir. 1997) (denying Medicaid recipients a federal right to transportation on the basis that the regulation did not define the content of any specific right conferred on recipients). Contra Boatman v. Hammons, 164 F.3d 286 (6th Cir. 1998) (because federal regulations have the force of law, Medicaid recipients were entitled to written notice of denials of transportation assistance and adequate information about transportation services and eligibility requirements for receiving those services).


314. See, e.g., Stump v. Miller, No. 2:91-0166 (S.D.W.Va., Dec. 29, 1991) (agreed order) (reimbursement for travel costs at the state employee


317. Id.  See also Adams, Factors Affecting Physician Provision of Preventive Care to Medicaid Children, 22 HEALTH CARE FINANCE REV 9 (Summer 2001).


319. E.g. Id.; Office of Inspector General, Dep’t of Health and Human Services, Medicaid Managed Care and EPSDT 8 (May 1997); Office of Inspector General, Dep’t of Health and Human Services, Dental Services Under Medicaid: Access and Utilization (Apr. 1, 1996).

320. E.g. Steve Berman, M.D., et al., Factors That Influence the Willingness of Private Primary Care Pediatricians to Accept More Medicaid Patients, 110 PEDIATRICS 239 (Aug. 2002).(finding that more pediatricians participate in Medicaid programs in states where Medicaid payments were higher and the prevalence of capitation and paperwork burden were lower); Norma I. Gavin et al., The Use of EPSDT and Other Health Care Services by Children Enrolled in Medicaid: The Impact of OBRA ’89, 76 MILBANK Q. 207, 209, 244-45 (1998). Alabama, Indiana, and South Carolina all reported increases in dental provider participation following increases in payment rates. See National Health Law Program, State Initiatives to Improve Access to Dental Care (June 2001), at http://www.healthlaw.org/pubs/200102dentalmemo.new.shtml.


325. Id.


332. Litigation has been filed in Connecticut, Massachusetts, Michigan, New Hampshire, North Carolina, Oklahoma, and Texas.

333. 758 F. Supp. 572 (E.D. Cal. 1990), aff’d in part & vacated in part sub nom. Clark v. Coye, 967 F.2d 585 (9th Cir. 1992), on remand, No. S-

334. 578 F. Supp. at 577. See also Scott v. Snyder, No. 91-CV-7080 (E.D. Pa. Dec. 2, 1994) (Order and stipulation of settlement), same case, (E.D.Pa. Aug. 11, 1993), reprinted in, Medicare & Medicaid Guide (CCH) ¶ 42,056 (stipulated settlement) (requires EPSDT informing of Medicaid-eligible mothers and infants at the time of the child’s birth and before the mother is discharged from care) (settlement requiring the state to meet, and to include in managed care organizations’ contracts, performance standards for a variety of EPSDT screening services, including for semiannual dental examinations and application of protective sealants on the chewing surfaces of their molar teeth).


336. For important rulings is Chisholm, see 110 F. Supp. 2d 499 (E.D. La. 2000) and 133 F. Supp. 2d 894 (E.D. La. 2001). In June 2002, the Court found the Medicaid agency in contempt of its previous order to cover licensed psychologists for children with PDD, see No. 97-3274 (E.D. La. June 17, 2002) (judgment) (ordering state to permit enrollment of licensed psychologists and to provide weekly updates on the implementation of the remedy).

337. See CMS, 2002 Medicaid Managed Care Enrollment Report, at http://www.cms.hhs.gov/medicaid/managedcare/mmcscss02.asp. See also Jane Perkins and Lourdes Rivera, EPSDT and Managed Care: Do Health Plans Know What They are Getting Into?, 28 CLEARINGHOUSE REV. 1248 (Mar. 1995) (noting that, while managed care offers opportunities for a medical home and coordinated care, managed care entities must understand the Medicaid population and Medicaid Act requirements).

338. See U.S. General Accounting Office, Medicaid: Stronger Efforts Needed to Ensure Children’s Access to Health Screening Services at 6-7
Interpretation of these enrollment figures can be difficult because enrollees include individuals in full and partial risk managed care organizations and primary care case management systems, which pay on a fee-for-service basis.


340. For citation to studies, see, e.g., The Kaiser Commission on the Future of Medicaid, Medicaid and Managed Care: Lessons from the Literature (Mar. 1995); Dana C. Hughes et al., Medicaid Managed Care: Can It Work for Children?, 95 Pediatrics 591 (Apr. 1995). For updates, visit http://www.kff.org.


343. See Families USA and National Health Law Program, A Guide to Meeting the Needs of People with Chronic and Disabling Conditions in Medicaid Managed Care at 4 (Jan. 1998).


346. See Melinda Bird, An Analysis of the GAO’s Recent Report on Medicaid Managed Care Mental Health “Carveout” Programs and the Implications for California (Nov. 3, 1999).


348. Id.

349. Id.

350. No. 3-98-0168 (M.D. Tenn. Aug. 28, 1998) (Order). Unfortunately, the state has not complied with the consent order, and the parties are in a dispute regarding enforcement of the settlement agreement.