This Fact Sheet provides essential information to help advocates become EPSDT experts. After giving an overview to EPSDT, we focus on: (1) legislative milestones; (2) notable federal agency guidance; and (3) precedent-setting cases from the judiciary. Next, we provide a snapshot of states’ performance implementing EPSDT, using government reports from the last 20 years. We close by suggesting essential data sources that will allow you to track EPSDT nationally and in your state.

Introduction to EPSDT

To be eligible for Medicaid, a person must fit within a covered population group (e.g., children with family incomes below 133% of the poverty level, children with disabilities, children in foster care), have limited income, be a resident of the state in which they are applying, and be a U.S. citizen or meet requirements for eligibility for immigrants.

EPSDT is a mandatory service for Medicaid-eligible children under age 21. 42 U.S.C. §§ 1396a(a)(10)(A), 1396a(a)(43), 1396d(a)(4)(B), 1396d(r). EPSDT requires state Medicaid programs to cover four separate types of screens: vision (including eyeglasses), hearing (including hearing aids), dental, and medical. The medical screen has five components: comprehensive health and developmental history, unclothed physical examination, immunizations, laboratory testing (e.g., blood lead level assessment), and health education and anticipatory guidance.

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1 Produced with a grant from the Training Advocacy Support Center (TASC), which is sponsored by the Administration on Community Living (ACL), the Substance Abuse and Mental Health Services Administration (SAMHSA), the Rehabilitation Services Administration (RSA), and the Social Security Administration (SSA). TASC is a division of the National Disabilities Rights Network (NDRN).

2 Medicaid eligibility is explained in-depth elsewhere, see, e.g., Nat’l Health Law Prog., The Advocate’s Guide to the Medicaid Program Ch. III (Oct. 2012; update forthcoming Winter 2024). NHeLP has created a flip chart to help advocates navigate Medicaid eligibility and coverage for low-income youth with behavioral health needs.
Screens must be provided according to periodicity schedules set by the state in consultation with child health experts and at other times as needed to determine whether a child has a condition that needs care (known as “interperiodic screening”). Id. § 1396d(r)(1)-(4). Most states (N=37) ask providers to adhere to the American Academy of Pediatrics’ Bright Futures recommendations for medical screening content and periodicity.3

EPSDT treatment provisions require states to “arrang[e] for (directly or through referral to appropriate agencies, organizations, or individuals) corrective treatment” that a child needs. Id. § 1396a(a)(43)(C). The Medicaid Act establishes a nationwide EPSDT scope of benefits and standard for determining medical necessity:

- **Scope of benefits:** All mandatory and optional services that the state can cover under Medicaid, whether or not such services are covered for adults. Id. § 1396d(r)(5) (incorporating § 1396d(a) list of services).

- **Medical necessity standard:** All “necessary health care, diagnostic services, treatment, and other measures … to correct or ameliorate defects and physical and mental illnesses and conditions….“ Id. § 1396d(r)(5).

Finally, states must effectively inform all Medicaid-eligible persons who are under age 21 of the availability of EPSDT. Id. § 1369a(a)(43)(A). This includes appointment scheduling and transportation assistance. 42 C.F.R. § 441.56.

Designed for low-income children, EPSDT promises comprehensive screening services and a broad scope of treatment benefits. It also incorporates care coordination services to ensure that children and families know about EPSDT and that they are connected to other resources critical to overall health, e.g., nutrition, housing, and education.4 In short, “[t]he goal of EPSDT is to assure that individual children get the health care they need when they need it—the right care to the right child at the right time in the right setting.” CMS, EPSDT - A Guide for States: Coverage in the Medicaid Benefit for Children and Adolescents 1 (June 2014).

**Legal milestones**

In the early 1960s, a government study found that about one-third of 18-year-olds registering with the Selective Service failed to qualify for military service because of an untreated health condition. It was estimated that 62% of those conditions could be treated or prevented altogether if young people were receiving comprehensive and continuous health care. A

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4 42 C.F.R. § 441.61(c) (requiring EPSDT agencies to coordinate with other state agencies (e.g., vocational rehabilitation agencies) and other public health, mental health, education, and related programs (e.g., nutrition, education, housing programs)).
government research group suggested a program “to provide early case finding and treatment of congenital and other chronic disorders in children.”

In 1967, Congress responded to these concerns and amended the Medicaid Act to require states to provide:

[s]uch early and periodic screening and diagnosis of individuals who are eligible under the plan and are under the age of [21] to ascertain their physical or mental defects, and such health care, treatment, and other measures to correct or ameliorate defects and chronic conditions discovered thereby.

As summarized below, since 1967, Congress has amended the EPSDT statutes many times. These amendments have always been designed to increase EPSDT’s role in ensuring that low-income children receive timely preventive care and treatment.

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Table 1: EPSDT Legislative Timeline

<table>
<thead>
<tr>
<th>Year</th>
<th>Event</th>
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<tr>
<td>1965</td>
<td>Medicaid is established as a federal-state program to provide “medical assistance”—health insurance coverage—to designated low-income populations, including families with dependent children and children with disabilities.</td>
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<tr>
<td>1967</td>
<td>EPSDT is established as a mandatory service for Medicaid-eligible children and youth under age 21.</td>
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<td>1981</td>
<td>Congress requires states to inform all Medicaid beneficiaries under age 21 of EPSDT and to arrange for screening and treatment services.</td>
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<td>1989</td>
<td>Congress strengthens states’ obligations to ensure that children receive early screening and necessary treatment, e.g. screening now explicitly includes lead blood level assessment, and treatment includes a nationally designated scope of benefits and the “correct or ameliorate” medical necessity standard.</td>
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<tr>
<td>1990</td>
<td>Congress requires state Medicaid agencies to collect and report information about EPSDT services to CMS.</td>
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<tr>
<td>1994</td>
<td>Vaccines for Children program is established, providing federally purchased vaccines at no cost to Medicaid-eligible individuals age 18 or younger.</td>
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<tr>
<td>2018</td>
<td>Annual reporting of child health quality measures—the Child Core Set—becomes mandatory effective 2024.</td>
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Significant federal agency guidance

The U.S. Department of Health and Human Services Centers for Medicare & Medicaid Services (CMS) is the federal Medicaid agency. CMS has promulgated regulations and sub-regulatory documents to guide implementation of the Medicaid EPSDT provisions.

The EPSDT regulations can be found at 42 C.F.R. §§ 441.50–441.62. These regulations have not been amended since the significant statutory changes in 1989. As a result, some of these regulations are inaccurate. Advocates should carefully cite them. Do not cite the regulation using et seq. or the regulatory span (as we have done above). Rather, cite specific regulations. The following rules continue to be consistent with the statute: 42 C.F.R. §§ 441.56(a) (regarding informing), 441.56(e) (requiring timeliness standards set in cooperation with child health experts and, generally, an outer limit of 6 months after the request for a screen), 441.61(b) (requiring states to make a variety of providers available), 441.61(c) (requiring states to work with other child serving agencies, e.g. public and mental health, nutrition, education), 441.62 (requiring transportation and appointment scheduling assistance).
CMS has also issued extensive, mandatory guidance to states in Part 5 of the *State Medicaid Manual*. See CMS, *State Medicaid Manual* §§ 5010–5360. Unlike the regulations, the *State Medicaid Manual* has been updated since 1989. In particular, the *Manual* details EPSDT requirements for screening (e.g. developmental, nutritional, lead blood), coordination with other programs (nutritional, housing, educational), and monitoring and reporting (including instructions for annual EPSDT performance reporting on the Form CMS-416, which is discussed below).

In June 2014, CMS published *EPSDT – A Guide for States: Coverage in the Medicaid Benefit for Children and Adolescents* to help states, health care providers, and others understand EPSDT. While it does not establish new EPSDT policy, this guide serves the important purpose of compiling federal EPSDT policy guidance over the years into one place. The Guide reminds states that EPSDT is “designed to ensure that children receive early detection and care, so that health problems are averted or diagnosed and treated as early as possible.” Id. at 1. An updated version of this Guide is forthcoming.

Additional sub-regulatory documents come in the form of informational bulletins and Dear State Medicaid Director letters posted on the [CMS website](https://www.cms.gov). Over the years, CMS has issued a number of guidance documents that examine EPSDT requirements for screening and treatment services and changes to these requirements resulting from recent public health developments, legislation, and court decisions. A few examples are provided below:


**Subject Matter:** Highlighting existing guidance and providing examples of ways EPSDT can be used to provide behavioral health services in response to a CDC report showing that “from the beginning of the pandemic in March 2020 until October 2020, mental health-related emergency department visits increased 24 percent for children ages 5 to 11, and 31 percent for those ages 12 to 17 compared with pre-COVID-19 levels.”


**Subject Matter:** Providing guidance on the applicable federal regulations and policies related to Medicaid-coverable services provided to children in a school setting. Noting the Bipartisan Safer Communities Act, Pub. L. No. 117-159 (June 25, 2022), requires the Secretary of HHS, in consultation with Secretary of Education, to issue additional guidance to states in the near future.
CMS, CMCS Informational Bulletin, Requirements of Section 12005 of the 21st Century Cures Act, Institution for Mental Diseases (IMD) Exclusion and Inpatient Psychiatric Hospital Services for Individuals Under Age 21 Exception (June 20, 2018).

Subject Matter: Providing background on Medicaid coverage of services furnished to children under age 21 in inpatient psychiatric hospitals and facilities and outlining the amended requirements for these services in the 21st Century Cures Act: “Section 12005 of the Cures Act requires that individuals under 21 in qualified inpatient psychiatric hospitals and facilities are guaranteed access to the full range of EPSDT services.”

CMS, CMCS Informational Bulletin, The Early and Periodic Screening, Diagnostic and Treatment (EPSDT) Benefit for Children and Youth in Managed Care (Jan. 5, 2017).

Subject Matter: Discussing how states that contract with managed care organizations to deliver some or all of the services covered by EPSDT can ensure that eligible children have access to the full EPSDT benefit.


Subject Matter: Noting that the water crisis in Flint, Michigan serves as a reminder that children can be exposed to lead through different pathways (e.g., paint, air, food, water, dust, soil). Reviewing EPSDT blood lead screening requirements and identifying steps that states can take to improve lead screening rates and reporting.

CMS and SAMHSA, Joint CMCS and SAMHSA Informational Bulletin, Coverage of Behavioral Health Services for Youth with Substance Use Disorders (Jan. 26, 2015).

Subject Matter: Explaining that children and youth should be screened for both substance use and mental health disorders wherever they present and recommending screening tools. Identifying resources for states to help design and implement services to treat and care for youth with behavioral health disorders.


Subject Matter: Describing approaches for providing services, including Applied Behavioral Analysis (ABA), to children with autism spectrum diagnoses.

Major rulings from the judiciary

Here, we describe the four major waves of EPSDT litigation over time, with case citations to illustrate. As noted in the NHelP EPSDT Litigation Docket, there are other, excellent examples
of courts enforcing the Medicaid EPSDT provisions, many of these cases the result of advocacy by Disability Rights/Protection & Advocacy attorneys.

Early cases focused on getting EPSDT in place. This is illustrated by *Stanton v. Bond*, 504 F.2d 1246 (7th Cir.), aff'd, 372 F. Supp. 872 (N.D. Ind. 1974), a class action case that challenged Indiana’s failure to effectively inform families about EPSDT. Rejecting the State’s “somewhat casual approach” to informing, the Seventh Circuit noted:

> 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. By the time an Indiana child is brought for treatment it may too often be on a stretcher. This is hardly the goal of “early and periodic screening and diagnosis.”

*Id.* at 1251.

A second wave of cases involved broad, systemic challenges to the Medicaid agency’s failures to implement the benefit, often focusing on the lack of periodic screening. An example is *Salazar v. District of Columbia*, 954 F. Supp. 278 (D.D.C. 1996). Ruling for the plaintiffs, Judge Kessler began:

> 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 governmental 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’ found herein is a human face and the reality of being poor in the richest nation on earth.

*Id.* at 281; see also, e.g., *Frew v. Gilbert*, 109 F. Supp. 2d 579 (E.D. Tex. 2000) (later case history omitted).

In the 1990s, a third wave of litigation was initiated by state attorneys challenging the right of families to enforce EPSDT provisions in court. To date, these arguments have been largely unsuccessful. See Jane Perkins, *Pin the Tail on the Donkey: Beneficiary Enforcement of the Medicaid Act Over Time*, 9 ST. LOUIS U. J. HEALTH L. & POL’Y 207 (2016), as updated NHelP, *Fact Sheet: Private Enforcement of the Medicaid Act Under 42 U.S.C. § 1983* (Feb. 25, 2022). Most recently, the Supreme Court refused to block enforcement of Medicaid Nursing Home Reform Act provisions in a case that maintained individuals’ rights to enforce a limited number of Medicaid Act provisions. *Health & Hosp. Corp. of Marion Cnty. v. Talevski*, 599 U.S. 166 (2023), aff’d, 6 F.4th 713 (7th Cir. 2021); see Jane Perkins, NHelP, *Case Explainer: Health & Hosp. Corp. of Marion Co., v. Talevski* (Aug. 1, 2023).
The final, current wave of litigation focuses on the treatment component of EPSDT, in particular home and community services for children with special health needs. When such children are living in restrictive settings or the state is administering programs in a biased way, the case may include claims under the Americans with Disabilities Act and section 504 of the Rehabilitation Act. For example:

- **O.B. v. Norwood**: In this class action involving children with medically complex conditions, the court enforced the requirement that the state “arrange for” EPSDT services, noting that “[a]s far as we can glean. . ., [the Medicaid agency] has given up on searching (if it ever did) for nurses for children whom the agency deems entitled to home nursing. It's left the search to parents many or even most of whom may not be competent to conduct a timely and effective search for multiple nurses. . . .” 838 F. 3d 837, 841 (7th Cir. 2016), aff’g, 170 F. Supp. 3d 1186 (N.D. Ill. 2016) (also enforcing Medicaid reasonable promptness requirement and later extending injunction to ADA/§ 504 claims).

- **Katie A. v. Douglas**: This case for children in foster care found that “[s]tates have an obligation to cover every type of health care or service necessary for EPSDT corrective or ameliorative purposes that is allowable under § 1396d(a). The states also have an obligation to see that the services are provided when screening reveals that they are medically necessary for a child.…States also must ensure that the EPSDT services provided are reasonably effective.” 481 F.3d 1150, 1158-59 (9th Cir. 2007). But, if all EPSDT-mandated components of these services are provided through existing programs, the State need not repackage them as wraparound or therapeutic foster care. *Id.* at 1162-63.

- **Rosie D. v. Romney**: In this class action on behalf of children with serious emotional disturbances, the court concluded that the state’s failure to provide for service coordination, crisis services, and home based services violated EPSDT and reasonable promptness provisions of Medicaid Act. 410 F. Supp. 2d 18 (D. Mass. 2006).

**Implementation track record**

Over the last 20 years, both the U.S. Government Accountability Office (GAO) and the HHS Office of Inspector General (OIG) have assessed implementation of EPSDT by the states. Unfortunately, these agencies consistently find there is work to be done and are repeatedly calling on CMS to improve oversight and monitoring of state Medicaid programs. Major reports are annotated below:
From the U.S. Government Accountability Office, five notable reports: 8


Major findings: In FY 2017, about 59% of all beneficiaries who should have received at least one well-child screening received one (meaning 41% did not). About 48% of beneficiaries received a preventive dental service (meaning 52% did not). Older beneficiaries tended to have lower rates of screening.

Medicaid Preventative Services: Concerted Efforts Needed to Ensure Beneficiaries Receive Services (August 2009) (full and accessible reports).

Major findings: Data from 1999-2006 suggested that nearly 1 in 5 Medicaid children aged 2-20 (an estimated 18%) were obese, but about half of these children had not been diagnosed as overweight. Four percent of children aged 8-20 had high blood pressure, and 10 percent of children aged 6-20 had high cholesterol. Additional data suggested that from 2003-2006, approximately 41% of children in Medicaid did not receive a well-child check-up during a 2-year period.


Major findings: The extent to which children in Medicaid across the country are receiving EPSDT services is not fully known, but the available evidence indicates that many are not receiving these services. A comprehensive view is not possible because annual state reports to the federal Medicaid agency on the delivery of EPSDT services are unreliable and incomplete, particularly for children in managed care.


Major findings: 21% of children aged 2-5 had had a dental visit in the previous year; 36% of children aged 6-18 had a dental visit within the previous year.


Major finding: Only about 19% of children in Medicaid aged 1-5 were screened. This is a serious concern, because these children are almost five times more likely than others to have a harmful blood lead level.

8 The GAO’s mission is to provide Congress with fact-based, nonpartisan information that can help improve federal government performance and ensure government accountability.
From the Department of Health and Human Services Office of Inspector General, nine notable reports:

**High Rates of Prior Authorization Denials by Some Plans and Limited State Oversight Raise Concerns About Access to Care in Medicaid Managed Care** (July 2023)

- **Major finding:** Overall, MCOs in the review denied one out of every eight requests for the prior authorization of services in 2019, and states were not engaging in robust oversight. The review found inappropriate denials for, among other things, health screening services for children.


- **Major findings:** 38% of Medicaid-enrolled children in 5 states (CA, NY, OH, PA, TX) did not receive a required blood lead screening test on schedule. 50% of children did not receive a blood lead screening test at 12 months of age. 65% of children did not receive blood lead screening test at 24 months of age.

  A follow up OIG report noted that 50% of children with a confirmed diagnosis of lead toxicity did not receive comprehensive follow-up testing and treatment services, as recommended for their identified blood lead level: *For Medicaid-Enrolled Children Diagnosed with Lead Toxicity in Five States, Documentation Reviewed for Diagnoses and Treatment Services Raises Concerns* (Dec. 2022).

**Most Medicaid Children in Nine States are not Receiving all Required Preventive Screening Services** (May 2010).

- **Major findings:** 76% of children in 9 states (AR, FL, ID, IL, MO, NC, TX, VT, WV) did not receive 1 or more of the required medical, vision, and hearing screenings. 41% of children did not receive any required medical screenings, and more than half of children did not receive any required vision or hearing screenings. Children were not receiving complete medical screenings. Nearly 60% of children who received medical screenings lacked at least one component of a complete medical screening.

  A follow up OIG report noted and assessed the steps CMS has taken to address problems: *Recommendation Followup Memorandum Report: CMS Needs To Do More To Improve Medicaid Children’s Utilization of Preventive Screening Services* (Nov. 2014).


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9 The OIG was established to protect the integrity of the HHS programs as well as the health and welfare of beneficiaries served by those programs. The OIG carries out its mission through audits, investigations, and inspections.
Major findings: 59% of Medicaid-enrolled children who were newly prescribed an ADHD medication did not receive follow-up care within 30 days; 21% did not receive 2 follow-up care visits within 300 days; 45% did not receive behavioral therapy as part of their ADHD treatment. And, 35% of Medicaid-enrolled children who were hospitalized for ADHD did not receive follow-up care within 30 days.

Medicaid Managed Care and EPSDT (May 1997) (full reports).

Major findings: In OIG’s sample, only 28% of children enrolled in managed care setting received all prescribed EPSDT screens; 60% of children in a managed care setting received no screens at all.


Major findings: Only 1 in 5 eligible children received preventive dental services in 1993, a slight decrease from the 22% who received services in 1992. Also in 1993, 3/4ths of the States provided preventive services to fewer than 30%, and no State provided them to more than 50%, of all eligible children. States vary in what data they collect and report to the federal government.


Major finding: The screening and participant ratios used to measure States’ performance in the EPSDT program are “essentially inadequate.”

Sources of EPSDT data

The Medicaid Act requires states to collect and report data on EPSDT enrollment and services to CMS. See 42 U.S.C. § 1396(a)(43)(D); CMS, State Medicaid Manual § 2700.4. State Medicaid agencies submit this data to CMS annually using Form CMS-416.¹⁰ The data collected are used to assess the effectiveness of state Medicaid programs in reaching EPSDT eligible children, by age and basis of Medicaid eligibility, who are provided child health screenings, referred for corrective treatment, and receiving dental and lead screening services.

States may also voluntarily report a set of health care quality measures, referred to as the Core Set of Children’s Health Care Quality Measures for Medicaid and CHIP (Child Core Set), 2010–2024 (showing year-to-year inclusion and exclusion of measures). The Child Core Set is updated annually. The data collected from the Child Core Set helps CMS to assess the quality of a state’s EPSDT services. Mandatory reporting of the Child Core Set will take effect in 2024. See Bipartisan Budget Act of 2018, Pub. L. No. 115-123, § 50102, 132 Stat. 64, 175 (amending

¹⁰ Section 2700.4 of the State Medicaid Manual contains instructions for completing Form CMS-416.

In addition to the Form CMS-416 and the Child Core Set, the American Academy of Pediatrics has posted individual state profiles, as well as state-by-state comparisons tracking states' EPSDT requirements in relation to the Bright Futures Recommendations and Periodicity Schedule, which can be found here and here. This data was originally prepared in 2016 and last updated in 2018.¹¹

Conclusion and Recommendations

As advocates, we can help ensure that children realize the promise of EPSDT. It takes time to become an EPSDT expert; however, that is time well spent. As this Fact Sheet suggests, advocates will build expertise by engaging in the following activities:

1. Read the statute and become familiar with its history.
2. Track regulatory developments, particularly sub-regulatory documents which CMS routinely issues through Informational Bulletins and Dear State Medicaid Director letters.
3. Be familiar with EPSDT litigation. NHeLP posts case updates regularly. If you have access to Westlaw, you can also set a case alert for “EPSDT.”
4. Monitor the GAO and OIG websites for reports on state implementation, and be alert for publication of other reports showing states’ EPSDT/child health performance.