Update on EPSDT Litigation Trends

By Jane Perkins

Introduction

This Issue Brief provides an overview to the Medicaid Act's Early and Periodic Screening, Diagnostic and Treatment (EPSDT) benefit. It then gives a brief history of litigation filed to enforce the federal requirements for the benefit and concludes with a discussion of current litigation trends.

Overview of EPSDT

EPSDT is a mandatory Medicaid service for children and youth under age 21. *See* 42 U.S.C. §§ 1396a (a) (10) (A), 1396a (a) (43), 1396d (a) (4) (B), 1396d(r). Forming the foundation of EPSDT, four separate screens are required: vision (including eyeglasses), hearing (including hearing aids), dental, and medical. The medical screen has five components: a comprehensive health and developmental history, unclothed physical exam, immunizations, laboratory testing (including testing for lead poisoning), and health education and anticipatory guidance. Screens must be provided according to periodicity schedules set by the state Medicaid agency in

consultation with child health experts, and at other times as needed to determine whether a child has a condition that needs care. *Id.*at § 1396d(r)(1)-(4).[1]

State Medicaid agencies must inform all Medicaid-eligible persons in the state who are under age 21 of the availability of EPSDT and its benefits. *Id*. at § 1369a(a)(43)(A). This includes effectively informing children with disabilities and providing appointment scheduling and transportation assistance. *See* 42 C.F.R. § 441.56.

The Medicaid Act also requires the Medicaid agency to "arrange for (directly or through referral to appropriate agencies, organizations, or individuals) corrective treatment. . . ." 42 U.S.C. § 1396a(a)(43)(C). The Act prescribes a comprehensive scope of benefits and describes the medical necessity standard to be applied on an individual basis to determine a child's treatment needs:

> Scope of benefits: Covered services include all mandatory and optional services that the state can cover under Medicaid, whether or not such services are covered for adults, *see id*. at § 1396d(a) (listing services).
>
> Medical necessity: The Medicaid Act requires coverage of "necessary health care, diagnostic services, treatment, and other measures . . . to *correct or ameliorate* defects and physical and mental illnesses and conditions. . . ."

Id. at § 1396d(r)(5) (emphasis added). In sum, if a health care provider determines that a service is necessary, it must be covered to the extent needed. For example, if a child needs personal care services to ameliorate a behavioral health problem, EPSDT should cover these services to the extent the child needs them—even if the state places a quantitative limit on personal care services or does not cover them at all for adults. As stated by the U.S. Department of Health and Human Services Centers for Medicare & Medicaid Services (CMS),

> The 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.[2]

[1] The specific timing for the screenings is not mandated by the federal statute or agency but rather is set by the states and is supposed to be based on recommendations by appropriate experts. The National Health Law Program's 2017 review found most states referring to *Bright Futures*, which contains the periodicity schedules and screening content recommended by the American Academy of Pediatrics. For information, *see* https://brightfutures.aap.org/materials-and-tools/guidelines-and-pocket-guide/Pages/default.aspx.

[2] For in-depth explanation of the rules and policies for EPSDT coverage, *see* CMS, *EPSDT-A Guide for States: Coverage in the Medicaid Benefit for Children and Adolescents* 1 (June 2014), https://www.medicaid.gov/medicaid/benefits/downloads/epsdt_coverage_guide.pdf.

EPSDT Litigation History and Trends

Over the years, families and children have gone to court to enforce the EPSDT requirements. Early cases focused on getting the program in place. *E.g*., *Stanton v. Bond*, 504 F.2d 1246 (7th Cir. 1974) (rejecting state's "somewhat casual approach" and requiring state to establish effective informing). A second wave of cases involved broad, systemic challenges to states' failures to implement the benefit. *E.g.*, *Frew v. Gilbert*, 109 F. Supp. 2d 579 (E.D. Tex. 2000) (concerning screening, informing, and reporting) (later case history omitted); *Salazar v. D.C*., No. CA-93-452 (D.D.C. 1997) (remedial order concerning screening, informing and reporting) (later case history omitted).

In the 1990s, state attorneys began to challenge the right of families to enforce the Medicaid Act's EPSDT provisions in court. To date, these cases have been largely unsuccessful. Every federal circuit court of appeals to decide the question has concluded that the EPSDT provisions can be privately enforced by children who are being harmed by the state Medicaid agency's ongoing violations.[3]

However, as federal court access has come under increased scrutiny, more recent EPSDT cases have sought targeted relief as opposed to broad, system-wide change. E*.g*., *Parents' League for Effective Autism Servs. v. Jones-Kelley*, 339 F. App'x 542 (6th Cir. 2009) (enjoining state's refusal to cover Applied Behavioral Analysis); *S.D. ex rel. Dickson v. Hood*, 391 F.3d 581 (5th Cir. 2004) (same, regarding incontinence supplies). This targeted approach includes cases to obtain coverage of evidence-based home and community services for children with intensive behavioral health needs. *E.g., Katie A. v. Douglas*, 481 F.3d 1150 (9th Cir. 2007) (holding that wraparound services and therapeutic foster care are within state's EPSDT obligations under federal law, but that if all EPSDT-mandated components of these services are provided through existing state programs, then state need not repackage them as plaintiffs request), *rev'g & remanding*, 433 F. Supp. 2d 1065 (C.D. Cal. 2006); *Rosie D. v. Romney*, 410 F. Supp. 2d 18 (D. Mass. 2006) (requiring state to establish system for coverage of screening, service coordination, and crisis and home-based services for children with serious emotional disturbances). Additional trends include:

- Most litigation is focusing on the treatment component of the EPSDT benefit, as opposed to informing and screening. In particular, families are seeking to obtain home and community-based care, including long-term services and supports. In these cases, advocates are bringing claims under the EPSDT provisions, the Medicaid reasonable promptness provision (42 U.S.C. § 1396a(a)(8)), and the American's with Disabilities Act (ADA)/section 504 requirements for providing services in the least restrictive setting and/or through unbiased methods of administration. *See*, *e.g*. *O.B. v. Norwood*, 838 F. 3d 837 (7th Cir. 2016) (requiring state to affirmatively arrange for in-home shift nursing

[3] *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. 207, 227 (2016).

services needed by children with medically complex conditions), *aff'g*, 170 F. Supp. 3d 1186 (N.D. Ill. 2016) (enforcing Medicaid EPSDT "arrange for" and reasonable promptness requirements and later extending injunction to ADA/§ 504 claims).

- While courts are recognizing the broad scope of EPSDT treatment benefits established in the Medicaid Act, there is some confusion with application of the Act's "correct or ameliorate" standard when deciding how much of a covered service is necessary. The problem stems from *Moore v. Reese*, 637 F.3d 1220 (11th Cir. 2011), a case holding that both treating providers and the state have roles to play when deciding the amount of covered Medicaid services. While acknowledging that the EPSDT statute requires coverage of services necessary to correct or ameliorate a child's condition, the court's discussion is not clear, and at the time, there were concerns that *Moore* would be misapplied by subsequent courts.[4] This happened in *D.U. v. Rhoades*, when a Wisconsin district court cited *Moore* to deny a preliminary injunction to a child seeking coverage of 70 hours of private duty nursing services. *See* 2015 WL 224932 (E.D. Wis. Jan. 15, 2015). On appeal, the Seventh Circuit affirmed, finding that the child would not suffer irreparable harm. *See* 825 F.3d 331 (7th Cir. 2016). Unlike the district court, the appellate court found the plaintiff was likely to succeed on the merits. However, in so doing, it did not apply the correct or ameliorate standard. *Id*. at 337-38. Rather, the court said, "Although EPSDT broadened the categories of care that participating states are required to provide to Medicaid-eligible children, it did not change the medical necessity limitation." *Id*. at 335. Finding that "[m]edical necessity is not expressly defined in the Medicaid Act," the court referred to the definitions that the State uses for adults. *Id*. In a subsequent ruling in the same case, the lower court—citing both the Seventh Circuit and *Moore*—rejected D.U.'s argument that Wisconsin's definition of "medically necessary" was narrower than the EPSDT program's "correct or ameliorate" definition. 2018 WL 1010486 (E.D. Wis. Feb. 20, 2018).

Conclusion

The Medicaid EPSDT provisions are designed to furnish children and youth with comprehensive care—from well-child check-ups to the care and services needed to correct or ameliorate episodic illnesses and injuries and long-term chronic and disabling conditions. Over the years, states and their contractors have fallen short of the federal requirements for EPSDT. Litigation has only infrequently been filed to address these problems, but when filed and successful, it has often produced long-lasting improvements. And while courts have repeated affirmed children's rights to enforce the EPSDT laws in court, there are cases pending at the Supreme Court that could affect private enforcement of many provisions of the Medicaid Act, including those governing EPSDT. *See Planned Parenthood of Kan. v. Anderson*, 882 F.3d 1205 (10th Cir. 2018), *pet for cert. filed*, No. 17-1310 (Mar. 23, 2018) (allowing private enforcement of Medicaid freedom of choice provision, 42 U.S.C. § 1396a(a)(23)(A)); *Planned*

[4] See Jane Perkins, National Health Law Program, *EPSDT, Deference to Providers, and Moore v. Reese* (June 2011) (on file with author and NDRN).

Parenthood of Gulf Coast v. Gee, 862 F.3d 445 (5th Cir. 2017), *pet. for cert. filed*, No. 17-1492 (May 1, 2018) (same). *But see Does v. Gillespie*, 867 F.3d 1034 (8th Cir. 2017) (holding (a)(23) is not privately enforceable). These cases will need to be monitored closely.