Medicaid EPSDT Litigation Trends

By Jane Perkins

Introduction

The Early and Periodic Screening, Diagnostic and Treatment (EPSDT) provisions are among the most specific in the Medicaid Act. *See* 42 U.S.C. §§ 1396a(a)(10)(A), 1396a(a)(43), 1396d(a)(4)(B), 1396d(r). EPSDT is critical for the millions of children with special health care needs and disabilities who depend on Medicaid for their health care and long terms services and supports.

This Issue Brief summarizes the federal requirements for EPSDT and discusses major legal and policy trends.

Overview of EPSDT

Early and Periodic Screening, Diagnostic and Treatment is a mandatory Medicaid service for children and youth under age 21. 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 required components: comprehensive health and developmental history, unclothed physical exam, immunizations, laboratory testing (including for lead poisoning), and health education (including anticipatory guidance). Screening services 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. 42 U.S.C. § 1396d(r)(1)-(4). Our 2017 review of state EPSDT policies finds most states referring to the periodicity schedules and screening content recommended by the American Academy of Pediatrics, *Bright Futures*.[1]

[1] Jane Perkins, National Health Law Program, Presentation at Prevent Blindness Conference: Medicaid: Vision Care for Children (June 28, 2017) (on file with author).

State Medicaid agencies must effectively inform all Medicaid-eligible persons in the state who are under age 21 of the availability of EPSDT. *Id*. at § 1396a(a)(43)(A). This includes effectively informing families and 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 the medical necessity standard that must 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). In sum, if a health care provider determines that a service is needed, it should be covered to the extent needed. For example, if a child needs personal care services to ameliorate a behavioral health problem, EPSDT must 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.

Case Trends

EPSDT litigation is focusing on necessary treatment, particularly home and community-based care.

In previous years, EPSDT litigation focused broadly on states' failures to implement the EPSDT benefit, often focusing on screening and informing. *See*, *e.g*., *Frew v. Gilbert*, 109 F. Supp. 2d 579 (E.D. Tex. 2000) (concerning screening, informing, and reporting); *Salazar v. D.C*., No. CA-93-452 (D.D.C. 1997) (remedial order concerning screening, informing and reporting) (on file with author); *Stanton v. Bond*, 504 F.2d 1246 (7th Cir. 1974) (rejecting state's approach to informing).

Recent cases have taken a more targeted approach, however, focusing, in particular, on treatments needed by children with developmental and/or intellectual disabilities. For example, a California case, *Katie A. ex rel. Ludin* v. *L.A. County*, 481 F.3d 1150 (9th Cir. 2007), produced a settlement whereby the state agreed to cover in-home support services needed by children in the foster care system, including therapeutic foster care and wraparound services. *See* No. 02-cv-05662 (C.D. Cal. Dec. 5, 2011) (Settlement Agreement, attached as Ex. 1 to Stipulated Judgment Pursuant to Class Action Settlement Agreement) (Docket Entry 779);[2] *see also*, *e.g.*, *Rosie D. v. Romney*, 410 F. Supp. 2d 18 (D. Mass. 2006) (ordering Massachusetts to cover home and community-based support services needed by children with serious emotional disturbances, including crisis intervention, in-home behavioral supports and therapy services, mentoring, and parent/caregiver support).

Services for children with autism spectrum disorders (ASDs) have also been a focus of litigation. Two federal circuit courts of appeals have affirmed lower court injunctions requiring coverage of Applied Behavioral Analysis (ABA) therapy for young children with autism. *See K.G. ex rel. Garrido v. Dudek*, 731 F.3d 1152 (11th Cir. 2013) (finding district court did not abuse its discretion in issuing a permanent injunction that overruled state's determination that ABA was experimental), *on remand*, 981 F. Supp. 2d 1275 (S.D. Fla. 2013) (permanent injunction requiring Florida to pay for ABA); *Parents' League for Effective Autism Servs. v. Jones-Kelley*, 339 F. App'x 542 (6th Cir. 2009) (enjoining state rules that restricted EPSDT coverage of ABA as a rehabilitative service), *aff'g,* 565 F. Supp. 2d 905 (S.D. Ohio 2008). District courts have also enforced the EPSDT provisions to require Medicaid coverage of ABA. *See*, *e.g.*, *Chisholm v. Kliebert,* No. 97-3274, 2013 WL 3807990 (E.D. La. July 18, 2013) (finding agency in contempt of remedial order and ordering agency to ensure direct enrollment of Board Certified Behavioral Analysts until the state has begun issuing licenses to providers who treat children with autism disorders).

[2] In *Katie A v. Douglas*, the U.S. Department of Justice (DOJ) stated, "A service must be covered by the EPSDT program if it can properly be described as one of the services listed in [section 1396d(a) of] the Medicaid Act." Comments of the United States in Support of Final Approval of the Proposed Settlement Agreement in the California EPSDT case at 13, *Katie A v. Douglas*, No. 02-cv-05662 (C.D. Cal. Comments filed Nov. 18, 2011) (on file with author). The DOJ also noted that states must provide required services "effectively" and, thus, "in a coordinated fashion" when necessary to meet the needs of children with serious emotional or behavioral disorders. *Id.* at 14 (citing *Katie A.*, 481 F.3d at 1161). The DOJ concluded:

> If such EPSDT services are medically necessary to correct or ameliorate a mental health condition … it is the State's obligation to provide the type of EPSDT required services that are included in therapies like ICC (Intensive Care Coordination), IHBS (Intensive Home Based Services), and TFC (Therapeutic Foster Care) services *effectively* to eligible children."

Id. at 18 (emphasis in original). The National Health Law Program co-counseled *Katie A*.

Advocates are pairing EPSDT with Americans with Disabilities Act/§ 504 claims to challenge states' efforts to reduce Medicaid coverage of in-home nursing services for medically fragile children.

Child advocates filing complaints on behalf of children with disabilities are teaming their EPSDT claims with causes of action to enforce the Americans with Disabilities Act and the Rehabilitation Act. Title II of the ADA provides that no individual with a disability shall, by reason of the disability, be excluded from participation in or be denied the benefits of services, programs, or activities of a public entity, or be subjected to discrimination by the public entity. 42 U.S.C. § 12132. An implementing regulation requires public entities to administer services, programs, and activities in the most integrated setting appropriate to meet the needs of individuals with disabilities. 28 C.F.R. § 35.130(d). In *Olmstead v. L.C. ex rel. Zimring*, the Supreme Court held that "unjustified isolation … is properly regarded as discrimination based on disability." 527 U.S. 581, 607 (1999). Section 504 of the Rehabilitation Act contains similar anti-discrimination provisions that apply to state programs and activities that receive federal funding. 29 U.S.C. § 794(a); 28 C.F.R. § 41.51(d) (integration mandate). Because of the similarities between the two laws, courts apply them in a consistent manner.

The EPSDT/ADA interplay may arise from various scenarios, for example when the state and/or its contractors terminate or reduce in-home nursing hours absent any improvement in the child's condition or when children cannot promptly obtain the in-home nursing that the State has found the child needs. When the facts are supportive, children and their caretakers are filing complaints that seek relief pursuant to both the Medicaid Act and the ADA/Rehabilitation Acts. Such a case may involve a Medicaid-enrolled, medically fragile child or child with intellectual disabilities or behavioral health diagnoses who is stuck in a hospital or institutional setting even though the treating providers have prescribed in-home services. Or, the child may be living at home but experiencing reductions or gaps in nursing shifts to the point where the child faces a serious risk of being institutionalized.

A recent case example comes from Illinois, *O.B. v. Norwood*, 838 F.3d 837 (7th Cir. 2016), *aff'g*, 170 F. Supp. 3d 1186 (N.D. Ill. 2016).[3] In *O.B.*, the Medicaid agency determined that each of the child plaintiffs qualified for Medicaid coverage of a certain amount of in-home shift nursing services; however, the children were not receiving them. One plaintiff, O.B., was forced to live in an institution while other plaintiffs were being cared for at home by exhausted parents toiling to avoid institutional placements. The plaintiffs filed suit, bringing claims under the EPSDT provision that requires the state to arrange for the child to receive necessary treatment "(directly or through referral to appropriate agency, organization, or individuals)," 42

[3] Counsel for the plaintiffs and class are Legal Council for Health Justice, Robert H. Farley, Jr., and the National Health Law Program.

U.S.C. § 1396a(a)(43)(C), and the provision that requires the state to ensure that medical assistance is provided with "reasonable promptness," *id*. at § 1396a(a)(8). The children also alleged violations of the ADA and § 504, arguing that the State was failing to provide nursing services in the most integrated setting appropriate to children's needs and was treating the plaintiffs worse than other children with disabilities whose in-home nursing services were paid for at higher hourly rates. *O.B.*, No. 1:15-cv-10463 (N.D. Ill.) (Compl. at ¶¶ 13-15) (on file with author).

The district court first entered a preliminary injunction on the Medicaid claims and required the State to "take immediate and affirmative steps to arrange directly or through referral…, corrective treatment of in-home shift nursing services to the Plaintiffs and [similarly situated children]…." 170 F. Supp. 3d 1186, 1197-98 (N.D. Ill. 2016). The State appealed the injunction to the Seventh Circuit Court of Appeals. Writing for the court, Judge Posner rejected the State's argument against the injunction on grounds that it could not guarantee enough nurses:

But the plaintiffs aren't asking for a guarantee; they're asking for the nurses, and there is no indication HFS will (unless compelled by the courts) lift a finger to find nurses to provide nursing services for children in O.B.'s situation.[4]

*Following remand, the district court granted the Plaintiffs' motion for a preliminary injunction based on the disability claims, finding that the State's policies were inconsistent with the integration mandate.[5] The case is ongoing. There are other, similar cases. See, *e.g.*, *A.H.R. v. Wash. State Health Care Auth.*, No. C15-570, 2016 WL 98513, at *14-15 (W.D. Wash. Jan.7, 2016) (granting preliminary injunction on EPSDT claim, finding substantial evidence that state agency failed to arrange for provision of private duty nursing care at home and on ADA claim, finding children were threatened with placement in institutional settings); *Royal v. Cook*, No. 1:08-cv-2930-TWT, 2012 WL 2326115 (N.D. Ga. June 19, 2012) (on merits of EPSDT and ADA clams, granting permanent injunction prohibiting reduction in child's in-home skilled nursing hours); *accord M.A. v. Norwood*, 133 F.Supp.3d 1093 (N.D. Ill 2015) (finding allegations sufficient to state claims that EPSDT and ADA were violated by reduction in in-home shift nursing hours; eligibility standards were unreasonable, unwritten, and arbitrary in violation of due process; and notices of denial were inadequate).

[4] 838 F.3d at 841-42.
[5] *O.B.*, No. 1:15-cv-10463 (N.D. Ill. Feb. 2, 2017) (Order) (on file with author).

Courts are rejecting states' arguments that a recent Supreme Court case bars Medicaid beneficiaries from enforcing the EPSDT provisions.

Medicaid beneficiaries have traditionally enforced the EPSDT provisions through a civil rights statute, 42 U.S.C. § 1983. In *Gonzaga Univ. v*. *Doe*, 536 U.S. 273 (2002), the Supreme Court made it more difficult to enforce federal laws under § 1983. States have relied on *Gonzaga* to argue that the EPSDT provisions cannot be enforced. The circuit courts of appeal to have ruled on the question have held that the EPSDT provisions create enforceable rights. See *John B. v. Emkes*, 710 F.3d 394 (6th Cir. 2013) (agreeing that 42 U.S.C. §§ 1396a(a)(43)(B) and (C) are privately enforceable, but not an implementing regulation, 42 C.F.R. § 441.61(c), that requires the state to work with other entities to implement EPSDT); *Westside Mothers v. Olszewski,* 454 F.3d 532 (6th Cir. 2006); *S.D. ex rel. Dickson v. Hood,* 391 F.3d 581, 603-04 (5th Cir. 2004); *Ped. Specialty Care, Inc. v. Ark. Dept. of Human Servs.*, 293 F.3d 472 (8th Cir. 2002).[6]

Medicaid provisions have also sought to enforce Medicaid provisions, in particular, 42 U.S.C. § 1396a(a)(30)(A), a provision that requires states to ensure adequate payment rates. Following *Gonzaga*, numerous appellate courts held that health care providers could not enforce the provision under § 1983.[7] Providers turned to the Supremacy Clause in an effort to enjoin state payment laws. However, a 2015 U.S. Supreme Court, *Armstrong v. Exceptional Child Center*, decided that health care providers cannot enforce the Supremacy Clause to make a state comply with the provision. 135 S. Ct. 1378, 1383 (2015) (holding Supremacy Clause creates a "rule of decision" that merely "instructs courts what to do when state and federal law clash, but is silent regarding who may enforce federal laws in court, and in what circumstances they may do so."). *Armstrong* also refused to allow providers to rely on courts, sitting in equity, to enjoin state laws that are inconsistent with the payment provision. *Id.* at 1384.

Even though *Armstrong* does not concern § 1983, *id.* at 138 n. *,[8] states have argued that the case bars EPSDT claims pursuant to § 1983. To date, courts have consistently rejected the argument. In *O. B. v. Norwood*, discussed above, the district court pointed out that *Armstrong* addresses "a different statutory provision, asserted by different plaintiffs, under a different theory" while "every circuit court to have decided the question has concluded that Medicaid beneficiaries can enforce the EPSDT provisions and the reasonable promptness provision." 170 F. Supp. 3d at 1192 (distinguishing *Armstrong*, 135 S. Ct. 1378 (2015)). Similarly, in *Cruz*

[6] Dozens of district courts have found the EPSDT provisions enforceable under § 1983. For in depth discussion, *see* Jane Perkins, *Pin the Tail on the Donkey: Beneficiary Enforcement of the Medicaid Act Over Time*, 9 ST. LOUIS U. L. REV. 207 (2016).
[7] *Id.*
[8] * in original.

v. Zucker, the court allowed plaintiffs to pursue claims for transgender services under EPSDT, stating:

As numerous courts have held, the EPSDT Requirement (1) is unmistakably focused on the rights of Medicaid-eligible youth to receive the enumerated services, (2) provides detailed, objective, and manageable standards, including specific services that must be provided, and (3) is binding on states.[9]

Conclusion

As discussed in this Issue Brief, the subject matter of EPSDT litigation has shifted over time, with the current emphasis on protecting children's access to home and community-based treatment services. The National Health Law Program is often involved in the litigation that does occur and is available to provide assistance.

[9] *See*, *e.g.*, *H.E. v. Horton*, No. 1:15-cv-3792, 2016 WL 6582682 (N.D. Ga. Nov. 7, 2016); *Cruz v. Zucker*, 116 F. Supp. 3d 334, 340 (S.D. N.Y. 2015); *J.E. v. Wong*, 125 F. Supp. 3d 1099 (D. Haw. 2015); Order Dismissing Count II, Florida Pediatric Soc'y et al. v. Dudek, No. 05-23037, slip op. at 2 (S.D. Fla. May 11, 2015) (on file with author) (allowing EPSDT claim to proceed, noting that *Armstrong* "confirmed that *Gonzaga* set out the appropriate standard for determining whether a statute creates privately enforceable rights."). Careful pleading is called for to avoid misapplication of *Armstrong*. *See*, *e.g.*, *Providence Ped. Med. Daycare, Inc. v. Alaigh*, 112 F. Supp. 3d 234, 250-51 (D.N.J. 2015) (finding complaint cited "a litany of Medicaid statutory provisions and regulations [including EPSDT provisions] that were purportedly violated by Defendants" but did not address whether each of them passed the § 1983 enforcement test and, citing *Armstrong*, concluded that Providence could not enforce any of them).