

Fact Sheet
Medicaid EPSDT Litigation—Case Trends¹

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The Early and Periodic Screening, Diagnostic and Treatment 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). Promising both clinical care and coordination with education, nutrition and public health, EPSDT is critical for children with limited family incomes. Over the years, however, states have not been steadfast to their responsibilities, and litigation has resulted. This Fact Sheet summarizes the federal requirements for EPSDT and discusses legal and policy trends.

Overview of EPSDT

Early and Periodic Screening, Diagnostic and Treatment (EPSDT) is a mandatory Medicaid service for children and youth under age 21. Screening forms the foundation of EPSDT. Four separate screens are required: vision (including eyeglasses), hearing (including hearing aids), dental (including restoration of teeth), and medical. The medical screen has five required components: a comprehensive health and developmental history, unclothed physical exam, immunizations, laboratory testing, and health education and 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 to determine whether a child has a condition that needs further care. *Id.* at § 1396d(r)(1)-(4). 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).

The Medicaid Act requires the state Medicaid agency to “arrange for (directly or through referral to appropriate agencies, organizations, or individuals) corrective treatment.” *Id.* at § 1396a(a)(43)(C). The Act prescribes a comprehensive scope of

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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, *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 needed, it should be covered to the extent needed and allowed as determined using the EPSDT coverage standards. 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 recently 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.

CMS, *EPSDT-A Guide for States: Coverage in the Medicaid Benefit for Children and Youth 1* (June 2014), https://www.medicaid.gov/Medicaid-CHIP-Program-Information/By-Topics/Benefits/Downloads/EPSDT_Coverage_Guide.pdf (last visited March 9, 2016).²

Case Trends

EPSDT litigation is focusing on treatments, particularly those needed to ameliorate developmental and/or intellectual disabilities.

In previous years, EPSDT litigation focused broadly on states' failures to implement the requirements for screening and informing. *E.g.*, *John B. v. Menke*, 176 F. Supp. 2d 786 (M.D. Tenn. 2001) (holding managed care program failed to meeting EPSDT mandates); *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); *Stanton v. Bond*, 504 F.2d 1246 (7th Cir. 1974) (rejecting state's “somewhat casual 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

² CMS produced this EPSDT Guide in collaboration with the National Health Law Program.

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);³ 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).

Other cases focus on ensuring coverage of particular treatment services that reflect the prevailing standard of care. Services for children with autism spectrum disorders (ASDs) have been a particular focus of litigation. Two federal circuit courts of appeals have affirmed lower court injunctions requiring coverage of Applied Behavioral Analysis (ABA) therapy services 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); see also *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); see generally *J.E. v. Wong*, No. 14-00399, 2015 WL 5116774 (D. Haw. Aug. 27, 2015) (holding EPSDT provisions conferred rights that are privately enforceable under § 1983 in case seeking Medicaid coverage of ABA therapy treatment).

³ 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.* For more information, contact Kim Lewis, Managing Attorney, NHeLP-LA.

The *Garrido* case merits some additional discussion. As noted above, the court rejected the State’s argument that ABA is “experimental” under Florida law. The state Medicaid director had relied upon various analyses of the efficacy of ABA, including a report from the federal Agency for Healthcare Research and Quality (AHRQ), to conclude that there was an insufficient evidentiary basis to support the efficacy of ABA. However, the court discounted these reports because, among other things, they were not peer-reviewed and had not, as required by Florida law, been published in the authoritative and scientific literature. Rather, the court found that ABA has been the “consensus in the medical community” for treatment for autism and ASDs since the 1990s. 981 F. Supp. 2d 1275, 1287 (S.D. Fla. 2013) (permanent injunction) (citing testimony of autism specialists, treating physicians, and former editor of the *Journal of Applied Behavioral Analysis*). The court was also persuaded by numerous analyses finding ABA effective and the fact that private insurers and other Medicaid programs cover ABA. *Id.*

Garrido adheres to the requirements of the Medicaid Act, finding that ABA does, in fact, reflect the standard of care and that it can be a rehabilitative service under EPSDT. Nevertheless, the position taken by the State is cause for concern. There is a growing interest in the development and application of evidence-based standards. While evidence-based standards are needed to avoid ineffective treatments and to establish performance measures for comparing health plans, a state- or health plan-imposed requirement that treatment for an individual child be premised on an evidentiary-basis can raise conflicts with federal EPSDT coverage requirements. Many treatments and clinical therapies—while quite effective for an individual child—will not have an evidentiary base. There are numerous reasons for this. Children have historically been excluded from clinical trials. Some conditions affect too few children to engage in a clinically valid study. In addition, as *Garrido* illustrates, even when clinical research exists, the state may base its coverage policy on reports and non-scientific summaries that do not completely or accurately reflect the scientific literature. Notably, the Social Security Act includes provisions to protect Medicaid-eligible children from the improper use of evidence-based measures. See 42 U.S.C. § 1320b-9a(h) (discussing development of state-specific child health quality measures for Medicaid and CHIP but stating that “no evidence based quality measure developed, published, or used as a basis of measurement or reporting under this section may be used to establish an irrebuttable presumption regarding either the medical necessity of care or the maximum permissible coverage for any individual child who is eligible for and receiving” Medicaid or CHIP); *Id.* § 1320b-9a(b)(7) (providing that development and use of pediatric quality measures shall not be construed as supporting restriction of coverage to only those services that are evidence-based).

States’ efforts to reduce Medicaid coverage of in-home nursing services for medically fragile children are being challenged as violating both EPSDT and the Americans with Disabilities Act.

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.⁴ 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.⁵ In *Olmstead v. L.C. ex rel. Zimring*, the Supreme Court held that “unjustified isolation ... is properly regarded as discrimination based on disability.”⁶ Section 504 of the Rehabilitation Act contains similar anti-discrimination provisions that apply to state programs and activities that receive federal funding.⁷ Because of the similarities between the two laws, courts apply them in a consistent manner.

The EPSDT/ADA interplay can arise when children with disabilities cannot promptly obtain the number of in-home nursing hours that the State has found the child needs or when the state and/or its contractors terminate or reduce in-home nursing hours absent any improvement in the child’s condition. When the facts are supportive, such children 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*.⁸ 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 it. One plaintiff was forced to live in an institution while others were being cared for at home by exhausted and sleepless parents who feared institutional placement would become necessary. The plaintiffs filed suit, bringing claims under the Medicaid Act, citing the EPSDT provision that requires the state Medicaid agency to arrange for the child to receive necessary treatment “(directly or through referral to appropriate agency, organization, or individuals)” and another Medicaid provision that requires the state to ensure that medical assistance is provided with “reasonable promptness.”⁹ The children also alleged violations of the ADA/504, arguing that the state agency is failing to provide nursing services in the most integrated setting appropriate to children’s needs and that the agency is treating them worse than other persons with disabilities for whom the State pays higher hourly rates for in-home

⁴ 42 U.S.C. § 12132.

⁵ 28 C.F.R. § 35.130(d).

⁶ *Olmstead v. L.C. ex rel. Zimring*, 527 U.S. 581, 607 (1999).

⁷ 29 U.S.C. § 794(a); 28 C.F.R. § 41.51(d) (integration mandate).

⁸ *O.B. v. Norwood*, ___ F. Supp. 2d ___, 2016 WL 1086535 (N.D. Ill. Mar. 21, 2016).

⁹ See 42 U.S.C. § 1396a(a)(43)(C) (regarding EPSDT); *Id.* at § 1396a(a)(8) (regarding reasonable promptness).

nursing services.¹⁰ The district court recently entered a class-wide preliminary injunction in the case, pending class certification, finding it undisputed that the defendant has found all the named plaintiffs and putative class members eligible for Medicaid-covered in-home shift nursing services based on medical necessity and that she has failed to provide adequate services for months, if not years, after the services were approved. On this evidence, the court concluded that plaintiffs' likelihood of success on the Medicaid claims is "firmly established."¹¹ See also *A.H.R. v. Washington State Health Care Authority*, 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 Medicaid agency had failed to arrange for the provision of private duty nursing care at home and on the ADA claim, finding the children were threatened with placement in institutional or group home 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 claims, granting permanent injunction prohibiting reduction in child's in-home skilled nursing hours); *accord M.A. v. Norwood*, No. 15-C-3116, 2015 WL 5612597 (N.D. Ill. Sept. 23, 2015) (in case challenging reduction of children's in-home shift nursing hours, finding allegations sufficient to state claims that EPSDT and ADA were violated, that eligibility standards were unreasonable, unwritten, and arbitrary in violation of due process, and that written notices of denial were inadequate).

State attorneys are citing a recent Supreme Court decision to argue that Medicaid beneficiaries do not have a cause of action under 42 U.S.C. § 1983, the traditional pathway to enforcing the EPSDT provisions in court.

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 clarified the requirements for private enforcement and made it more difficult to enforce federal laws pursuant to § 1983. State attorneys frequently cite *Gonzaga* as the basis for dismissing Medicaid cases, including cases seeking to enforce the federal EPSDT requirements.

The federal circuit courts of appeal to have ruled either before or after *Gonzaga* have held that the EPSDT provisions create rights that are enforceable under § 1983. In *S.D. ex rel. Dickson v. Hood*, for example, the Fifth Circuit held that the EPSDT provisions require that "health care and services must be provided to all eligible recipients under the age of twenty-one" and have "precisely the sort of 'rights-creating' language identified in *Gonzaga*." *S.D.*, 391 F.3d 581, 603-04 (5th Cir. 2004). See also *John B v. Goetz*, 626 F.3d 356 (6th Cir. 2010); *Westside Mothers v. Olszewski*, 454 F.3d 532 (6th Cir. 2006); see generally *Ped. Specialty Care, Inc. v. Ark. Dept. of Human Servs.*, 293 F.3d 472 (8th Cir. 2002); cf. *John B. v. Emkes*, 710 F.3d 394 (6th Cir. 2013) (affirming lower court holding that 42 U.S.C. §§ 1396a(a)(43)(B) and (C) are privately

¹⁰ See Compl. at ¶¶ 13-15. This case is co-counseled by Legal Council for Health Justice; Robert H. Farley, Jr.; and the National Health Law Program.

¹¹ *O.B.*, 2016 WL 1086535, at *6.

enforceable, but not an implementing regulation, 42 C.F.R. § 441.61(c), requiring the state to work with other entities to implement EPSDT fully).¹²

A recent Supreme Court case, *Armstrong v. Exceptional Child Center*, is causing some state attorneys to attack this enforcement track record.¹³ Writing for a 5-4 majority in *Armstrong*, Justice Scalia finds that health care providers cannot enforce the Supremacy Clause to make a state comply with the Medicaid Act's "equal access" payment provision.¹⁴ *Armstrong* also holds that health care providers cannot rely on courts, sitting in equity, to enjoin state laws that are inconsistent with the equal access provision.¹⁵ The Court looked to see whether Congress intended to allow providers to bring an equitable action and concluded that it did not for two reasons. First, the "sole remedy" Congress provided in the Medicaid Act authorizes the Secretary of Health and Human Services (HHS) to terminate federal funding to all or parts of the state Medicaid program until the state stops violating the federal law.¹⁶ The majority found that the "express provision of one method of enforcing a statute suggests that Congress intended to preclude others."¹⁷ Second, while acknowledging that the termination of funding provision might not, by itself, preclude the providers' lawsuit, the majority concluded that the Medicaid equal access provision does because it is so broad and non-specific as to be "judicially unadministrable."¹⁸

Notably, *Armstrong* does not concern § 1983.¹⁹ Nevertheless, state attorneys have sought to extend *Armstrong* to bar EPSDT claims pursuant to § 1983. So far, courts have rejected these efforts in cases brought by Medicaid beneficiaries. In *O. B. v. Norwood*, discussed above, the district court soundly rejected the State's argument that *Armstrong* foreclosed any private right of action seeking to enforce the Medicaid Act provisions or the ADA/§ 504.²⁰ The opinion points 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

¹² Dozens of district courts have found the EPSDT provisions enforceable under § 1983. For in depth discussion, see Jane Perkins, National Health Law Program, *Fact Sheet—Update on Private Enforcement of the Medicaid Act: The Supremacy Clause and 42 U.S.C. § 1983* (Sept. 29, 2015) (available from NHeLP).

¹³ *Armstrong v. Exceptional Child Center, Inc.*, 135 S. Ct. 1378 (2015) (concerning 42 U.S.C. § 1396a(a)(30)(A)).

¹⁴ *Id.* at 1383 (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.").

¹⁵ *Id.* at 1384.

¹⁶ *Id.* (citing 42 U.S.C. § 1396c).

¹⁷ *Id.* (quoting *Alexander v. Sandoval*, 532 U.S. 275, 290 (2001)).

¹⁸ 135 S. Ct. at 1385. For in depth discussion, see Jane Perkins, National Health Law Program, *Q&A: Armstrong v. Exceptional Child Center* (Apr. 2015) (available from NHeLP).

¹⁹ *Armstrong*, 135 S. Ct. at 138 n.* (asterisk in original).

²⁰ *O.B.*, 2016 WL 1086535, at *2-6 (distinguishing *Armstrong*, 135 S. Ct. 1378 (2015)).

provision.”²¹ The Illinois court cited a recent Hawaii case, *J.E. v. Wong*, which recognized the child plaintiffs’ rights to enforce the Medicaid availability (§ 1396a(a)(10)) and EPSDT (§ 1396a(a)(43)) provisions in their case seeking coverage of behavioral health therapy services.²² Similarly, in *Cruz v. Zucker*, a New York district 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.²³

There are no appellate opinions, to date. However, a recent case illustrates that careful pleading is called for. In *Providence Pediatric Medical Daycare, Inc. v. Alaigh*, a New Jersey court dismissed a case containing EPSDT claims. The court found that the complaint cited “a litany of Medicaid statutory provisions and regulations that were purportedly violated by Defendants” but did not “address whether each of the Medicaid statutes and regulations cited in the complaint individually pass” the § 1983 enforcement test.²⁴ Citing *Armstrong*, the court concluded that Providence, a health care provider, could not enforce any of the provisions, including the EPSDT provisions.²⁵

Conclusion

Courts are not often asked to enforce the federal EPSDT requirements. However, these cases do occur. As discussed in this Fact Sheet, the subject matter of EPSDT has shifted over time, with the current emphasis on protecting children’s access to treatment services, particularly home and community-based services for children with disabling and chronic conditions. Advocates can consult the attached annotated EPSDT docket for the specifics of EPSDT litigation that has occurred over the years. The National Health Law Program is often involved in litigation when it does occur and is available to provide assistance.

²¹ *Id.* at *2, *3.

²² See *J.E. v. Wong*, No. 14-00399, 2015 WL 5116774 (D. Haw. Aug. 27, 2015).

²³ *Cruz v. Zucker*, 116 F. Supp. 3d 334, 340 (S.D. N.Y. 2015). See also Order Dismissing Count II with Prejudice, Florida Pediatric Soc’y et al. v. Dudek, No. 05-23037, slip op. at 2 (S.D. Fla. May 11, 2015), ECF No. 1331 (allowing EPSDT claim to proceed, noting that “*Armstrong*, 135 S. Ct. at 138 n. *, confirmed that *Gonzaga* set out the appropriate standard for determining whether a statute creates privately enforceable rights.”).

²⁴ *Providence Ped. Med. Daycare, Inc. v. Alaigh*, 112 F. Supp. 3d 234, 250 (D. N.J. 2015) (finding health care providers could not enforce EPSDT provisions post *Armstrong* and finding evidence did not support children’s claim of that EPSDT services were denied).

²⁵ *Id.* at 251.