

Q & A

Medicaid Coverage of Therapeutic Treatment for Children with Autism¹

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- Q. My client is a Medicaid-eligible child with autism. Our state Medicaid agency has taken the position that therapy services for treatment of autism can only be covered through a home and community-based waiver. But, I have heard that a recent court decision held that Applied Behavior Analysis Therapy (ABA) must be covered for all Medicaid-eligible children. Is this true?
- A. Yes. The decision is *Parents League for Effective Autism Services, et. al. v. Jones-Kelly*, 565 F. Supp. 2d 905 (S.D. Ohio 2008) *stay den.* 2008 WL 2796744 (July 17, 2008). The court held that Medicaid's Early and Periodic Screening, Diagnostic, and Treatment (EPSDT) provisions require that ABA therapy be covered when necessary to correct or ameliorate a child's condition. The plaintiffs are represented by Ohio Legal Rights Services, Ohio's P & A. The decision has been appealed to the Sixth Circuit Court of Appeals, which will almost certainly address the scope of services that can be covered for children with behavioral health needs.

Discussion

Autism is a complex, neurodevelopmental disability that generally manifests during the first three years of life. It disrupts the normal development of the brain, causing impairments in social interaction, verbal and non-verbal

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communication, leisure and play activities, and learning.² The category Autism Spectrum Disorders (ASD) includes autism as well as Asberger's disorder and pervasive developmental disorder not otherwise specified, which manifest similar symptoms. Autism and the other ASDs are classified as mental disorders under the *Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition*. Autism is also, however, classified as a developmental disability³ and, under Medicaid regulations, considered a "related condition" to intellectual disability.⁴

Applied Behavior Analysis (ABA)

ABA therapy is an intensive behavioral intervention program for children with autism spectrum disorders. It is based on a one-on-one teaching approach relying on reinforced practice of various skills.⁵ The American Academy of Pediatrics defines it as:

[t]he process of applying interventions that are based on the principles of learning derived from experimental psychology research to systematically change behavior . . . ABA methods are used to increase and maintain desirable adaptive behaviors, reduce interfering maladaptive behaviors or narrow the conditions under which they occur, teach new skills, and generalize behaviors to new environments or situations.⁶

ABA programs are generally conducted under the supervision of a behavioral psychologist and have been shown to be most effective at intensive levels – at least 25 hours per week, up to 40 hours per week.⁷ ABA therapists are only certified after significant training.⁸ Thus, the therapy is costly. State Medicaid agencies are likely to balk when payment for the service is requested.

Medicaid Policy

Medicaid's Early and Periodic Screening, Diagnostic and Treatment EPSDT requires coverage of all Medicaid services that are necessary to "correct or ameliorate" a physical or mental condition of beneficiaries under age 21.⁹ This includes any service that falls into one of the categories listed in the federal statute at 42 U.S.C. § 1396d(a), regardless of whether the state chooses to cover

² *Parents' League for Effective Autism Services, Inc. v. Jones-Kelly*, 565 F. Supp. 2d 905, 907 (S. D. Ohio 2008).

³ See, e.g., Dep't Health & Human Servs., Centers for Disease Control and Prevention, "Autism Information Center," at <http://www.cdc.gov/ncbddd/autism/> (last visited Jan. 24, 2009).

⁴ 42 C.F.R. § 435.1010.

⁵ 565 F. Supp. 2d at 908.

⁶ Scott Myers et al., American Academy of Pediatrics, *Management of Children with Autism Spectrum Disorders*, 120 PEDIATRICS 1162, 1163 (Nov. 2007).

⁷ *Id.*, 565 F. Supp. 2d at 908.

⁸ See, e.g., Behavior Analysis Certification Board, Inc., at www.bacb.org (last visited Jan. 27, 2009).

⁹ 42 U.S.C. § 1396d(r)(5).

the service for adults. These categories include physician services, hospital services, private duty nursing, personal care services, physical therapy, and others. One of the categories of services covered, sometimes referred to as the “rehabilitation” option, is:

Other diagnostic, screening, preventative and rehabilitative services, including any medical or remedial services (provided in a facility, 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.¹⁰

Medicaid also allows states to offer home and community-based services to people who are at risk of institutionalization through programs known as “waivers.”¹¹ These programs enable states to cover a range of services including services that can otherwise be covered under Medicaid as well as certain special services, including housekeeping and respite.¹² Waivers may also cover “habilitation” services “designed to assist individuals in acquiring, retaining, and improving the self-help, socialization and adaptive skills necessary to reside successfully” in community settings.¹³ CMS has stated that habilitation services are not regular state plan services and cannot be covered under EPSDT.¹⁴

Parents League for Effective Autism Services v. Jones-Kelly

Plaintiffs, an association of parents and families with children diagnosed with autism sued to enjoin Ohio’s Medicaid agency, the Ohio Department of Jobs and Family Services (ODJFS), from implementing rules that would have excluded coverage for ABA therapy services. Plaintiffs are represented by Ohio Legal Rights Services (OLRS). They argued that this exclusion would violate EPSDT requirements. The Court agreed, denying Defendant’s motion to dismiss¹⁵ and issuing an order preventing the state rules from going into effect.¹⁶ The Court also brought in the federal Centers for Medicare and Medicaid Services (CMS), which oversees the Medicaid program, as a defendant.

For a number of years, Ohio had covered ABA therapy services through EPSDT. In 2005, CMS sent a letter to the state Medicaid director informing her that some of the services the state was proposing to cover under the rehabilitation option were actually habilitative and could not be covered outside of a waiver program. In 2007, CMS proposed regulations that would narrow the

¹⁰ *Id.* § 1396d(a)(13).

¹¹ 42 U.S.C. § 1396n(c).

¹² 42 U.S.C. § 1396n(c)(4)(B).

¹³ 42 U.S.C. § 1396n(c)(5)(A). *See also* Sarah Somers, NHeLP, “Q & A: Habilitation Coverage and Medicaid Services,” October 2006, available from NDRN and NHeLP.

¹⁴ *Id.*

¹⁵ 565 F. Supp. 2d 895 (S.D. Ohio 2008).

¹⁶ 565 F. Supp. 2d 905 (S.D. Ohio 2008).

scope of services that could be covered under the rehabilitation option.¹⁷ Congress has placed a moratorium on these regulations.

Shortly after CMS issued the rehabilitation regulations, ODJFS proposed rules that would narrow the definition of community mental health services: They could only be covered if they provided for “the maximum reduction of mental illness and are intended to restore an individual to the best possible functional level.”¹⁸ CMS later wrote to ODJFS stating that it “generally views treatment for autism as habilitative rather than rehabilitative” and stated that it might not reimburse some of the payments that ODJFS had made to ABA providers.¹⁹

The Court granted the injunctive relief. It held that the Plaintiffs were likely to succeed on the merits because they had “provided sufficient evidence that ABA therapy, when recommended by a licensed practitioner of the healing arts, is a medically necessary service . . . [thus] the proposed [state] rules will effectively cut off funding for medically necessary services,” violating the Medicaid Act.²⁰

First, the Court discussed “the extremely broad EPSDT obligation,” emphasizing that

while a state has discretion in determining which medical services, beyond the mandatory [ones], it will cover for adults, states are bound, when it is medically necessary, to make available to Medicaid-eligible children all of the twenty-eight types of care and services included as part of the definition of medical assistance in the Act.²¹

In addition, “the fact that a state plan does not mention a particular service does not mean it is not a covered EPSDT service.”²²

ABA therapy services are covered within the scope of the rehabilitation option, the Court held, rejecting the argument that the services were habilitative.²³ The Court reasoned that

Unlike the definition of “rehabilitative” services, the definition of “habilitative” services does not contain the requirement that the services be “medical or remedial” and “recommended by a physician or other licensed practitioner of the healing arts.” Moreover, habilitation services are not . . . recommended for the “maximum reduction of physical or

¹⁷ See Sarah Somers, NHeLP, “Fact Sheet: Proposed Medicaid Rules: Rehabilitation Services,” (Sept. 2007), available from NHeLP or NDRN.

¹⁸ 565 F. Supp. 2d at 910.

¹⁹ *Id.*, citing Letter, CMS to Helen Jones-Kelly (March 21, 2008).

²⁰ 565 F. Supp. 2d at 917.

²¹ 565 F. Supp. 2d at 911-912 (internal quotations omitted).

²² 565 F. Supp. 2d at 912.

²³ 565 F. Supp. 2d at 915.

mental disability and restoration of a recipient to his best possible functional level.” *What truly differentiates “habilitative” and “rehabilitative” services is the “medical necessity of those services.”*²⁴

In particular, the Court took issue with ODJFS’ claim that in order to be rehabilitative, a service would have to restore skills that a child previously had. “Taken to its logical conclusion, such a restrictive interpretation . . . would mean that no child who is born with a disability, could ever receive rehabilitative services. This does not comport with the broad coverage afforded under the EPSDT mandate.”²⁵ The Court also noted that section 1396a(a)(13) provided for coverage of “preventive” services as well as rehabilitative services and opined that the ABA services at issue “may well be ‘preventative’ as well as ‘rehabilitative.’”²⁶ The Court also found that the other requirements necessary to issue an injunction were satisfied.

In addition, the Court held that it was not required to refrain from deciding the case under the *Burford* abstention doctrine.²⁷ Under *Burford*, federal courts should decline from exercising jurisdiction over actions challenging the validity of a state administrative order.²⁸ The doctrine applies only when there are difficult questions of state law related to important policy problems, or where federal review would disrupt state efforts to establish policy related to an important public concern. And, in a separate opinion, the Court also held that the EPSDT requirements were enforceable through Section 1983 and that the association had standing to bring an action on behalf of its members.²⁹

ODJFS appealed the decision to grant the injunction to the Court of Appeals for the Sixth Circuit.³⁰ It did not appeal the denial of the motion to dismiss or the rejection of the *Burford* doctrine. It also requested a stay of the injunction, which the Court rejected in another written opinion.³¹ In addition to reiterating its earlier holding that ABA services are not habilitative, the Court also pointed out that the state had impermissibly attempted to limit coverage of rehabilitative services only for those with mental illness.³²

In asking for a stay, Defendants argued that the Court should defer to CMS’ determination habilitative services could not be covered by Medicaid. The Court rejected this argument on the basis that Plaintiffs had shown that ABA therapy services were not habilitative.³³ The Court did not discuss the letter from

²⁴ 565 F. Supp. 2d at 916.

²⁵ 565 F. Supp. 2d at 916.

²⁶ *Id.*

²⁷ 565 F. Supp. at 913-914.

²⁸ *Id.* at 914, *see also* [abstention Q & A]

²⁹ 565 F. Supp. 2d 895.

³⁰ No. 08-3931(6th Cir.)

³¹ No. 2:08-cv-421, 2008 WL 2796744 (S.D. Ohio July 17, 2008).

³² *Id.* at *2.

³³ *Id.*

CMS that stated that treatment for autism was generally habilitative. However, a representative from CMS appeared at the hearing. The judge pressed him to state whether ABA therapy services were habilitative, but he refused, stating that “all coverage and eligibility and reimbursement issues are in play” with regard to whether ABA services would be covered.³⁴ It is likely that the Court gave the CMS letter no weight in light of this conflicting statement of position.

Next Steps

The appeal has been fully briefed. An *amicus* brief was filed on behalf of Plaintiffs by a group of health care providers, public interest law firms, and protection and advocacy programs, including NDRN, the Disability Law & Advocacy Center of Tennessee, Michigan Protection & Advocacy Service, Inc., and Kentucky Protection and Advocacy. Oral argument has not yet been scheduled.

CMS has, thus far, taken a very passive approach to this litigation. It remains to be seen whether this will change with a new administration.

The rehabilitation regulations are still subject to a moratorium. It is hoped that the Obama administration will withdraw them entirely. Advocates are also hopeful that there will be more clarification about coverage of services for children with developmental disabilities and ASDs.

Advocates should monitor NDRN and NHeLP’s website for further developments in connection with the lawsuit and with the rehabilitation regulations. For more information about the case, advocates may want to contact Michelle Atkinson or Susan G. Tobin at OLRs, <http://olrs.ohio.gov/ASP/HomePage.asp>.

³⁴ Record, Tr. Trans. At 239-241 (available from NHeLP).