Q & A
CMS Guidance on EPSDT Services for Children with ASD in Medicaid[1]

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Q. Our office represents many families of children with Autism Spectrum Disorder (ASD) who are on Medicaid. Their doctors often recommend intensive behavioral therapies, such as Applied Behavioral Analysis (ABA) therapy, to treat some of the behaviors associated with ASD. Our state has a limited Medicaid Waiver program that will cover these services, but many children are not eligible for the program because they do not require an institutional level of care. I heard that the Centers for Medicare & Medicaid Services (CMS) recently instructed states to cover services for children with ASD in their regular Medicaid programs under EPSDT. When I asked my state when it would offer therapy pursuant to this new guidance, our Medicaid Director told me that the state is not required to cover ABA. What services is my state obligated to provide to children with ASD under EPSDT?

A. As explained below, under longstanding Medicaid law, the state Medicaid agency must cover particular treatments—including intensive behavioral services—if they are coverable Medicaid services, necessary to correct or ameliorate a child's ASD, and no alternative, equally effective treatment is appropriate for the child. A recent CMS guidance letter and FAQ discuss coverage of services for children with ASD. They do not require states to cover ABA therapy per se; however, they suggest that, if the state does not cover ABA therapy under EPSDT, it must cover comparable services that are expected to achieve comparable outcomes.

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Discussion

Background on EPSDT

EPSDT is a mandatory Medicaid service for children and youth under age 21. Congress clarified and strengthened the EPSDT provisions in 1989, adding, among other things, an explicit "correct or ameliorate" treatment requirement. *See* 42 U.S.C. §§ 1396a(a)(10)(A), 1396a(a)(43), 1396d(a)(4)(B), 1396d(r). States must effectively inform all Medicaid-eligible persons under age 21 about the availability of EPSDT. *Id.* at § 1396a(a)(43)(A). The Medicaid Act requires states to arrange for corrective treatment when a licensed provider detects an illness or condition during a screening visit. *Id*. at § 1396a(a)(43)(C). It also establishes the scope of covered benefits and the medical necessity standard for assessing each child's needs. The scope of benefits includes all mandatory and optional services listed in the Act at 42 U.S.C. § 1396d(a) (listing 29 service categories), whether or not such services are covered for adults. These categories include other licensed practitioner (OLP) services, preventive services, rehabilitative services, and therapy services, along with physician services, hospital services, private duty nursing, personal care services, and others. The Act requires coverage of "necessary health care, diagnostic services, treatment, and other measures [described in § 1396d(a)] … to correct or ameliorate defects and physical and mental illnesses and conditions[.]" *Id.* at § 1396d(r)(5). The state Medicaid agency must "make available a variety of individual and group providers qualified and willing to provide EPSDT services," 42 C.F.R. § 441.61, and ensure the timely provision of screening and treatment services, *id.* at § 441.56.

In sum, the EPSDT provisions are designed to ensure "that poor children receive comprehensive health care at an early age ... [and] provide health education, preventive care, and effective follow-up care for conditions identified during check-ups." *Salazar v. District of Columbia*, 954 F. Supp. 278, 303 (D.D.C.1996); *Antrican v. Buell*, 158 F. Supp. 2d 663, 672 (E.D.N.C. 2001) (same). Courts have interpreted the EPSDT provisions to require states to cover particular treatments when they are necessary to treat a child's condition, and other treatments will not be effective. *See, e.g., S.D. ex rel. Dickson v. Hood,* 391 F.3d 581 (5th Cir. 2004) (regarding incontinence supplies); *Pittman ex rel. Pope v. Sec'y Fla. Dep't of Health & Rehab. Servs*., 998 F.2d 887 (11th Cir. 1993) (regarding transplants and incidental service needs).

Background on the Recent CMS Guidance

In July 2014, the Centers for Medicare & Medicaid Services (CMS) issued guidance clarifying that evidence-based treatments for children with autism spectrum

disorders (ASD), including behavioral and communication approaches to treatment, are eligible for federal financial participation under at least three services coverable through the State Medicaid Plan: (1) other licensed practitioner (OLP) services, (2) preventive services, and (3) therapy services. *See* CINDY MANN, DIRECTOR, CENTERS FOR MEDICAID & CHIP SERVICES, CLARIFICATION OF MEDICAID COVERAGE OF SERVICES TO CHILDREN WITH AUTISM 2-3 (2014) [hereafter CMS GUIDANCE], http://www.medicaid.gov/Federal-Policy-Guidance/Downloads/CIB-07-07-14.pdf. CMS explained that states are obligated to cover these services for children under age 21, even if they are not covered for adults under the State Plan, when they are medically necessary. *Id.* at 5. In September 2014, CMS issued an FAQ, further explaining states' obligation to cover services for children with ASD. *See* CENTERS FOR MEDICAID & MEDICARE SERVICES, MEDICAID AND CHIP FAQS: SERVICES TO ADDRESS AUTISM (2014) [hereafter CMS FAQ], http://www.medicaid.gov/Federal-Policy-Guidance/Downloads/FAQ-09-24-2014.pdf.

Pre-2014 Limitations on Medicaid Services for Children with ASD

ASD is a developmental disability that can cause significant delays in social, communication, and other behavioral skills, and many services that treat ASD are aimed at building skills and reducing maladaptive behaviors. *See* CMS GUIDANCE, *supra* at 1. Until recently, many states limited services to children with ASD because they considered those services to be "habilitative" services aimed at acquiring new skills.

In addition to the services states must provide under EPSDT, the Medicaid Act also allows states to offer home and community-based services to people who are at risk of institutionalization through programs known as "waivers." *Id.* § 1396n(c). These programs enable states to cover a range of services, including services that are regularly covered under State Medicaid Plans as well as certain services that would not otherwise be covered, including housekeeping, respite and "habilitative" services. *Id.* § 1396n(c)(4)(B). The home and community-based waiver provisions of the Medicaid Act define habilitative services as those services "designed to assist individuals in acquiring, retaining, and improving the self-help, socialization and adaptive skills necessary to reside successfully" in community settings. 42 U.S.C. § 1396n(c)(5)(A). CMS has taken the position that habilitative services do not fit into the categories of state plan services listed in § 1396d(a) and, as a result, can be covered only through a home and community-based waiver option, not EPSDT. *Id.*

Because they considered certain behavioral health treatments, such as ABA therapy to be habilitative services, many states only provided those services through home and community-based waiver programs, which may limit the number of children enrolled. Therefore, not all children with ASD in Medicaid have been able to access

treatments they need. Moreover, other services that are routinely covered under EPSDT in state Medicaid programs, including speech and occupational therapy, have sometimes not been available to children with ASD. Some states claimed that such services were habilitative services for children with ASD, because for those children, the treatment goal was aimed at building new skills. *See* SARAH SOMERS, NAT'L HEALTH LAW PROG., Q & A: MEDICAID COVERAGE OF THERAPEUTIC TREATMENT FOR CHILDREN WITH AUTISM 2-4 (2009), *available at* http://www.healthlaw.org/issues/ disability-rights/medicaid-coverage-of-behavioral-therapy-for-children-with-autism. The CMS guidance and FAQ should now make clear to states that any such limitations are not permissible and that all EPSDT services must be provided to children with ASD when they are necessary to correct or ameliorate the ASD.

Coverage of Intensive Behavioral Therapies in Medicaid

Intensive behavioral therapies are commonly used to treat children with ASD. Applied Behavioral Analysis (ABA) therapy is perhaps the best-known of these therapies, as it has received particular attention from providers, parents, researchers and courts. ABA therapy is based on a one-on-one teaching approach that relies on reinforced practice of various skills. SOMERS, *supra* at 2. According to the federal Agency for Healthcare Research and Quality (AHRQ), ABA therapy can include a variety of components including: antecedent package, behavioral package, joint-attention intervention, naturalistic teaching strategies, peer training, schedules, and story-based intervention package. AMY S. WEITLAUF, *ET AL.*, AGENCY FOR HEALTHCARE RESEARCH & QUALITY, THERAPIES FOR CHILDREN WITH AUTISM SPECTRUM DISORDER: BEHAVIORAL INTERVENTIONS UPDATE 6 (2014), *available at* http://effectivehealthcare.ahrq.gov/ehc/products/544/1945/autism-update-report-140929.pdf. ABA therapy is typically provided by certified therapists and a team of behavior technicians, pursuant to a referral from a licensed practitioner such as a neurologist or psychologist. *See* SOMERS, *supra* at 2. Although state laws are beginning to change, in most states, the therapists and paraprofessional staff who administer ABA therapy, though certified by a national board, are not licensed under state law. *Id.*

While ABA therapy is particularly well-known, many individuals with ASD receive other evidence-based behavioral health interventions. These interventions may be as effective, or even more effective, for some children with ASD, depending on their individual needs. They include communication supports, social skills training, cognitive therapies, and supported employment for young adults. *See* JULIE YOUNG *ET AL.,* IMPAQ INTERNATIONAL, AUTISM SPECTRUM DISORDERS (ASDS) SERVICES: FINAL REPORT ON ENVIRONMENTAL SCAN (2010) (cited in CMS GUIDANCE *supra* at 1), *available at* http://www.medicaid.gov/Medicaid-CHIP-Program-Information/By-Topics/Long-Term-

Services-and-Supports/Downloads/Autism-Spectrum-Disorders.pdf. For example, floortime therapy based on the Developmental Individual-difference Relationship-based model (DIR) is an approach that focuses on developing social communication and overcoming behavioral impairments by creating structured interactions and building relationships through child-led play activities. *See* WEITLAUF, *supra* at 2, 34-35. In contrast to ABA therapy, where the provider leads the therapeutic intervention, floortime follows the lead of the person with ASD in setting the pace and determining the content of therapy. *See id*.; *see also* YOUNG, *supra* at 17. In addition to non-ABA therapies like floortime, some people with ASD benefit from individual interventions that are sometimes components ABA therapy, like joint-attention interventions, peer training, or schedules. WEITLAUF, *supra* at 6.

To date, much of the advocacy to treat children with ASD in Medicaid under EPSDT has focused on ABA therapy. For several years advocates around the county have argued that, for children with ASD, ABA therapy could be considered a rehabilitative service or a preventive service. In states where ABA therapy providers are licensed by the state, advocates theorized that it could also be covered under the OLP authority. The longest running case, from Louisiana, has recently required coverage of ABA as an OLP service. See *Chisholm ex rel. CC v. Kliebert,* No. 97-3274, 2013 WL 3807990 (E.D. La. July 18, 2013) (modifying contempt order to require state plan coverage of ABA therapy and reimbursement of Board Certified Behavior Analysts to provide ABA therapy), *earlier opin.*, 133 F. Supp. 2d 894 (E.D. La. 2001) (community-based behavioral and psychological services for autism fall under § 1396d(a)(6) (OLP service) and d(a)(13) (preventive service)). Courts in a few other states, including Florida and Ohio, have held that the EPSDT requirement mandates states to cover ABA therapy. *See, e.g., Garrido v. Dudek,* 731 F.3d 1152 (11th Cir. 2013) (affirming district court holding that ABA is a rehabilitative service mandated under EPSDT for Florida Medicaid), *upon remand*, 981 F. Supp. 2d 1275 (S.D. Fla. 2013) (permanent injunction); *Parents League for Effective Autism Treatment v. Jones-Kelley*, 339 Fed. App'x 542 (6th Cir. 2009) (affirming preliminary injunction holding ABA was likely mandated in Ohio EPSDT as either a rehabilitative or preventive service).[2] Moreover, in the months before releasing its July 2014 Guidance, CMS approved state plan amendments from Louisiana and Washington to cover "services rendered by licensed behavior analysts," and "Applied Behavioral Analysis (ABA) Services provided by licensed practitioners," respectively, under the OLP authority. CENTERS FOR MEDICAID & MEDICARE SERVICES, STATE PLAN AMENDMENT # 14-06 at 3 (2014) (Louisiana), *available at* http://www.medicaid.gov/State-resource-center/Medicaid-State-Plan-Amendments/Downloads/LA/LA-14-06.pdf;

[2] For discussion of factual investigation strategies for this kind of litigation, *see* Kathryn Rucker, Center for Public Representation, *Fact Investigation Strategies for the Development of EPDST and ADA Litigation on Behalf of Youth with Autism* (Sept. 2014) (available from TASC).

CENTER FOR MEDICAID & MEDICARE SERVICES, STATE PLAN AMENDMENT # 13-05 at 2 (2014) (Washington), *available at* http://www.medicaid.gov/State-resource-center/Medicaid-State-Plan-Amendments/Downloads/WA/WA-13-05.pdf.

Many advocates expected that, after approving the state plan amendments from Louisiana and Washington, CMS guidance would clarify, once and for all, that ABA therapy was not always a habilitative service and that states were required to cover it under EPSDT when it fit within a category of service listed in the Medicaid Act and was medically necessary for an individual child. But the July 2014 guidance never uses the word ABA. CMS's subsequent FAQ states explicitly that the guidance is not intended to mandate states to cover ABA per se. CMS will require states to meet their "long-standing EPSDT obligation . . . [by] providing medically necessary services for the treatment of ASD," but it "is not endorsing or requiring any particular treatment modality for ASD." CMS FAQ *supra* at 1. As CMS noted in its July 2014 guidance, current evidence supports a variety of different treatments for children with ASD. Thus, the CMS guidance requires each state to consider the full range of behavioral interventions available to treat ASD and design its EPSDT coverage according to the needs of affected children.

Next Steps

The EPSDT provisions of the Medicaid Act require states to cover particular treatments when those treatments are medically necessary to correct or ameliorate a particular child's illness or condition. While CMS's recent guidance did not mandate states to cover any particular therapies for ASD under EPSDT, it did make clear that a state that does not elect to cover ABA therapy must provide children with comparable services expected to achieve comparable outcomes. States could comply with this requirement for an individual child by covering individual components of ABA therapy in conjunction with other evidence-based therapies that the child needs. However, if ABA therapy is needed to treat a child's ASD, and no alternative treatment is appropriate for that child, state Medicaid agencies will most likely be required to cover that treatment.

Advocates should be aware that evidence-based treatments for children with ASD are often very intense, provided for multiple hours per day. *See* YOUNG, *supra* at 25-27. While there is strong evidence that services provided in home and community-based settings, such as in children's homes and schools, are more effective for most children, some children with ASD receive services in a disability-specific clinical environment. *Id.* at 23, 28.The Supreme Court's *Olmstead* decision prohibits public programs, like Medicaid programs, from unnecessarily segregating people with disabilities. *Olmstead v. L.C.*, 527 U.S. 581, 607 (1999). Thus, state Medicaid agencies

should provide services to children with ASD in a home or community-based setting whenever possible, considering the child's condition.

In the coming months, CMS will be working with states to update and expand the menu of services available to children with ASD. States that currently only offer certain EPSDT services for children with ASD through a Medicaid waiver must transition provision of those services to the state plan. CMS FAQ *supra* at 2. CMS has not set a particular deadline by which states must come into compliance with its guidance, but has indicated that states should "work expeditiously and should not delay or deny provision of medically necessary services." *Id.* at 1. Advocates should contact their state Medicaid agencies for more information about what the state is doing to comply with CMS's guidance. In particular, advocates should work with their state Medicaid agencies and CMS to ensure that services provided to children with ASD under EPSDT are delivered in home and community-based settings as appropriate for each child's condition.