



Treatment for Children with Autism Spectrum Disorders and the EPSDT Benefit

Barbara Wirth and Vivian Gabor

Introduction

In July 2014, the Center for Medicare and Medicaid Services (CMS) issued an Informational Bulletin providing state guidance on coverage options available to provide services under Medicaid for individuals with autism spectrum disorder (ASD).¹ The document clarifies state obligations under existing Medicaid statute and regulations to provide coverage of all medically necessary services for children with ASD under the Early and Periodic Screening, Diagnosis and Treatment (EPSDT) benefit. Recognizing some states had not focused on this requirement, CMS has not provided a specific deadline for compliance and requested state Medicaid agencies review their current state plans and related waivers and expeditiously comply with the obligations.

The rising prevalence of ASD and the clarification that Medicaid-eligible children with ASD should have access to services through the EPSDT benefit may require states to review and amend their approach to providing ASD treatment. Multiple challenges may need to be addressed before a state can create a comprehensive state policy for the treatment of children with ASD, including ensuring a skilled network of accessible providers and addressing the potentially significant increase in costs for providing medically necessary services. State policymakers and other stakeholders supporting children with ASD will benefit from reviewing the CMS guidelines and also learning how other states are addressing the changes needed to ensure compliance with the EPSDT benefit and provide the individualized treatments for this growing population.

What is ASD?

ASD is the fastest growing developmental disability among children in the United States. In 2012, an estimated 1 in 68 children had a diagnosis of ASD, up from 1 in 150 in 2002.² ASD includes a set of diagnoses previously identified separately: autistic disorder, pervasive developmental disorder not otherwise specified (PDD-NOS) and Asperger syndrome. Symptoms and intensity vary widely for children with ASD and may include serious behavior problems, limitations in their cognitive and social development, as well as speech and language delays. Though no cure exists for autism, recent research shows that children with ASD who receive early and intensive behavioral treatment make significant advances in multiple areas including IQ, academic performance, language, and adaptive behaviors.³ The need for supports and services often continues through adolescence and into adulthood.⁴

This brief captures key themes that emerged during a November 2015 teleconference of state EPSDT benefit coordinators and CHIP directors convened by the National Academy for State Health Policy (NASHP) with the support of the U.S. Department of Health and Human Services (HHS) Health Resources and Services Administration (HRSA)'s Alliance for Innovation on Maternal and Child Health (AIM).

Treatments for ASD can be categorized into four types: 1) behavioral and communication approaches, 2) dietary approaches, 3) medications, and 4) complementary and alternative medicines. While more research is needed on the effectiveness of some treatments, many recognized evidence-based treatments for ASD exist and include behavioral health services, occupational therapy, sensory integration therapy, speech/language therapy, and services that teach other communication skills. Applied behavioral analysis (ABA) is one form of behavioral therapy focused on modifying specific behaviors and helping individuals develop various skills, including socially significant behaviors. Despite some recent public concerns over the goals and intensity of the treatment, ABA is currently the most widely accepted and commonly used evidence-based behavioral treatment for children with ASD.^{5, 6}

Medicaid Coverage for ASD Treatment

Prior to 2015, the majority of states provided services for children with ASD through their Medicaid Section 1915(c) Home and Community-based Services waiver programs. These waivers often differed across states in the age groups targeted, cost control methods employed (e.g. caps on enrollment and/or the amount and duration of services covered), and type of services offered.⁷ Dependent on the state and federal funds available, many states have had to maintain waiting lists for those eligible for services under the waiver. In 2014, for example, the average waiting time for the waivers for individuals with intellectual or developmental disabilities was 47 months.⁸

The CMS guidance specifies states are required to cover services to treat children with ASD as provided through the EPSDT benefit, section 1905(r) of the Social Security Act. The benefit is more comprehensive than the adult benefit and provides access to a broad range of services to meet the child's individual needs (see box). The benefit also requires coverage of any services determined to be medically necessary to prevent the onset of, correct, or ameliorate physical or behavioral conditions in children up to age 21.⁹ Those states using 1915(c) waivers to cover services will need to review, potentially contact CMS for technical assistance if needed, and revise the waivers at the next amendment or renewal and move the appropriate services to an approved Medicaid state plan.¹⁰ The guidance also recognizes that, for non-EPSDT covered services, states may choose to continue their 1915(c) waivers to cover services such as respite for family caregivers.

To support this shift, the CMS guidance provides information on how services for ASD could be reimbursed through different sections of 1905 including coverage under the benefit categories for other licensed practitioners, preventive services, and therapy services. When reviewing their Medicaid state plans, states are encouraged to make updates if necessary to ensure federal financial participation and the required state match is in place to support these expenditures.

Covered services under EPSDT for children with ASD:

Services covered under section 1905(a) of the Social Security Act include licensed practitioners' services; speech, occupational and physical therapies; physician services; private duty nursing; personal care services; home health, medical equipment and supplies; rehabilitative services; and vision, hearing, and dental services. *CMCS Information Bulletin*

State Strategies to Provide Coverage for ASD Treatments

"We are struggling with getting autistic children the services they need. They seem to be sitting in acute settings waiting on services needed with nowhere to go."

— State Official

As states shift their children with ASD into their Medicaid plans and ensure EPSDT benefits are accessible, the demands to create or modify state programs and policies may be significant. For example, as a result of the CMS guidelines, South Carolina anticipated an estimated 9,000 children in their state who had previously received little or no treatment for their symptoms would become eligible for treatment services potentially adding costs of \$30 million for autism services.¹¹ National parental surveys had also found that parents of children with ASD report a large gap between the needed services and the services actually received and are 1.4 times more likely to report an unmet need for any kind of therapy compared to other children with special health care needs.¹² Multiple factors have been cited as contributing to this imbalance between needed and available services including limited state funding, inability to access services that are available, and lack of providers with skills and experience necessary to treat children with ASD.¹³

Descriptions are provided below of several states who, soon after the release of the CMS guidance, pursued comprehensive changes to align with the guidelines. These brief descriptions provide examples of the significant work and resources state Medicaid agencies may need to undertake in order to put in place comprehensive programs for children with ASD.

- **California**, the first state to take action after the CMS guidance, directed its Medicaid health plans to define eligibility and provider participation criteria for ASD services, require utilization controls, define treatment options, outline the delivery system for behavioral health treatment services, require outreach to families, and include timely access standards for Medicaid-eligible children who had previously been receiving these services through the state's waiver or other funding sources.¹⁴
- In **Connecticut**, the state moved quickly to distribute a communication to Medicaid providers describing covered services, the prior authorization process, and requirements for caregiver participation in treatment. The state also established a fee structure for the new services, new state regulations, and detailed the qualifications and procedures for enrollment of ASD providers.¹⁵
- Soon after the guidance was issued and in anticipation of the expiration of their 1915(c) waiver, **Utah** established new ASD service policies to transition children to the EPSDT benefit. In July 2015, working with diverse stakeholders, public input, and their CMS regional office, Utah's Medicaid agency issued a detailed ASD-Related Services Policy and Procedures manual to providers serving children on Medicaid and educated parents on the new policy, ASD services and providers.¹⁶

Medicaid agencies will need to address any challenges to providing medically necessary services through the EPSDT benefit. Several issues raised during discussions with EPSDT Coordinators and Children's Health Insurance Plan (CHIP) Directors include:

- Determining which treatments for ASD adhere to the CMS guidelines among the array of behavioral treatment services available for children with ASD.
- Setting parameters for medically necessary treatment services for a child who receives an ASD diagnosis.
- Ensuring an adequate number of skilled and certified providers to meet the needs of treatment for children with ASD.

What Treatments for ASD Meet the CMS Guidelines?

Recognizing that ASD treatment is a rapidly evolving field, CMS has given each state Medicaid agency flexibility in determining which ASD treatment services to cover.¹⁷ The guidance recognizes the preponderance of national discussion specifically on ABA as an evidence-based ASD behavior treatment modality for children, but encourages states to consider going beyond providing ABA services, given that “there are other recognized and emerging treatment modalities for children with ASD, including those described in the recently commissioned CMS report: *Autism Spectrum Disorders (ASD): State of the State of Services and Support for People with ASD.*”¹⁸

States are using varying approaches to define what ASD treatment services will be covered, particularly behavioral health services. Some states have specifically focused resources on providing coverage for ABA services, while others include a broader range of intensive behavioral health services or define the covered services by their treatment purpose rather than service type.

- In **Michigan**, behavioral health interventions covered are those “identified as evidence-based by nationally recognized research reviews and/or other nationally recognized substantial scientific and clinical evidence... (and) any other intervention supported by credible scientific and/or clinical evidence, as appropriate to each individual.”¹⁹
- Under a new state plan amendment (SPA), **New Mexico** added coverage for a range of autism intervention services. The SPA listed behavioral methodologies that can be used for ASD treatment without limiting coverage to any specific types of treatment services. New rules also put in place detailed ABA billing instructions and extended the eligibility for ABA services for up to 21 years of age from an earlier limit of five years of age.²⁰
- **Washington** was one of the first states to design a delivery model for ABA with a comprehensive pathway for obtaining ABA services for children. The state also developed a guide for health plans and providers to help them operationalize the model and bill for covered services.²¹
- In **Minnesota**, the Medicaid state plan focuses on the purpose of covered ASD treatment services rather than the type of services provided. Specifically, the state plan provides coverage for “a range of individualized, medically necessary intensive developmental and behavioral interventions to address or treat, in a comprehensive manner, the functional skills and core deficits of autism spectrum disorder.”²²

How Can States Set Parameters for ASD Treatment Services?

The CMS guidance notes all covered services necessary should be available and accessible to families to meet the needs of each individual child with ASD. In part due to concerns about the costs of ASD treatment services, ABA therapy in particular, states are examining how to best determine the frequency and duration of the services that are provided and are using varied approaches to make those decisions.

- In **Washington**, the State Health Care Authority authorizes ABA in three to six month increments with limits specific for each type of delivery sites (e.g. clinic, home or day treatment programs). Providers are allowed to request additional units of ABA services based on documented medical necessity.²³
- The state Medicaid program in **Connecticut** chose not to set limits on the number or duration of authorized ASD treatment services and, instead, established a rigorous prior authorization process based on a comprehensive diagnostic evaluation, behavior assessment, and a tailored mental health service plan. State officials emphasize that this process is designed to assure children obtain the services they need, while also providing oversight using required documentation for each child's individualized service needs.²⁴
- **Utah's** Medicaid ASD treatment policy places a limit on the number of hours of ABA treatment covered within each week, with separate caps for one-on-one and group treatments. More hours can be authorized following a case review when the provider submits documentation justifying its medical necessity.²⁵

How are States Building an Adequate and Trained Provider Network for Needed Treatments?

As states work to provide the medically necessary treatments for children with ASD, a common challenge seen within states is the shortage of available and qualified providers to serve the large number of children.²⁶ States are using various strategies to address this issue including expanding licensing of ASD treatment providers, particularly ABA providers, or covering non-licensed providers who meet a defined set of qualifications and work under the supervision of more highly trained licensed providers.²⁷

- **New York** created a new Board of Applied Behavior Analysis to provide licensing, continuing professional education and oversight of ABA professionals. State law defines licensure requirements and the services and activities that fall within and outside of the scope of practice for "licensed behavior analysts" as well as for "certified behavior analyst assistants" who can provide ASD treatment services under supervision.²⁸
- **Connecticut** is enrolling and engaging ASD providers in learning collaboratives to train them on the state's new ASD standards of care, documentation requirements for assessments, plans of care, and billing. The state is also reaching out to colleges and professional training organizations to inform them about the need for ASD treatment providers and encouraging them to address the shortage.²⁹
- Several states, including **New Mexico** and **Utah**, have amended their Medicaid state plans to expand the pool of providers able to serve children with ASD. Treatment services may be provided by licensed behavioral analysts or assistant behavioral analysts, and non-licensed behavioral technicians/therapy assistants who are supervised by licensed analysts.^{30, 31}

What Innovative Approaches are States Using to Provide ASD Treatment?

In addition to the more traditional mode of delivery treatment services, some states are exploring avenues outside of the provider office or clinic setting to offer needed treatments. Several states, including **Iowa, Hawaii, and Washington**, are either planning or currently using telehealth behavioral health services for children with ASD.^{32, 33, 34} Recent research has demonstrated families using telehealth and remote ABA video coaching may successfully treat behavior problems related to ASD and achieve similar outcomes at lower cost.³⁵ **Nebraska** is expanding access to ASD treatment services by covering the provision of these services in non-medical settings such as day treatment programs, schools, child care centers, and in the child's home, where the family/caregiver can also receive training or coaching.³⁶

Looking Ahead

In the past several decades, the rising prevalence of ASD has resulted in an increasing number of children and adults eligible for state services who often have significant behavioral, communication and social challenges. The 2014 CMS Informational Bulletin provides clarification to state Medicaid agencies on services to be provided to Medicaid-eligible children with ASD and, specifically, the expected adherence to the EPSDT benefit for providing medically necessary services to correct or ameliorate any physical or behavioral conditions. Providing coverage for potentially costly behavioral therapy, ABA in particular, has been and may continue to be a challenge for some states as they work to comply with CMS requirements.³⁷ As states move forward, Medicaid agencies and other policymakers will benefit from learning about effective and affordable approaches being used by other states and ensure their state develops its own long-term, comprehensive and quality health care benefit for individuals with ASD under age 21.

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