

## Expansion of ASD treatment to a Medicaid EPSDT benefit

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### Introduction

The Centers for Medicare and Medicaid Services (CMS) recently issued guidance that treatment for autism is a required Medicaid state plan benefit under the Early and Periodic Screening, Diagnostic, and Treatment (EPSDT) program. The lack of historical coverage and other characteristics of Medicaid beneficiaries create significant analytical challenges that will necessitate risk mitigation strategies.

### Background

Autism spectrum disorder (ASD) is a neurodevelopmental disorder characterized by persistent deficits in communication, social interaction, and restricted repetitive patterns of behavior. Symptoms are generally recognized by age two and can cause lifelong impairments in social and occupational areas.<sup>1</sup>

The U.S. Centers for Disease Control and Prevention (CDC) estimates that approximately one in 68 children has been identified with an ASD. ASD is almost five times more common in males than females.

The term “spectrum” refers to the wide range of symptoms, skills, and levels of impairment or disability that children with ASD can have. From a claims coding perspective, ASD is generally coded using the following diagnosis codes:

- Autistic disorder (299.0): The most severe form, typically called “classic autism”
- Asperger’s (299.8): A milder form of ASD
- Pervasive developmental disorder not otherwise specified (299.9)
- Childhood disintegrative disorder (299.1)

Symptoms of ASD vary by type as well as age. Younger children up to age five may exhibit signs of irritability and hyperactivity. Children in the adolescent stage of life can become aggressive and demonstrate self-injurious behavior. Adolescents can exhibit symptoms consistent with depression, obsessive-compulsive disorder, and anxiety.<sup>2,3</sup>

In July 2014, CMS issued a letter to state Medicaid directors advising that treatment for ASD should be considered covered under the EPSDT benefit.<sup>4</sup> The EPSDT benefit is a comprehensive required benefit for all categorically needy children. CMS did not provide an effective date for this coverage but has encouraged states to complete benefit design work expeditiously and not delay or deny the provision of medically necessary services.<sup>5</sup> Historically, treatment of ASD has been confined to Medicaid waivers. CMS is in the process of meeting with states individually to determine how their existing waivers will change. Based upon the guidance from CMS, states will not be able to provide treatment for ASD under a waiver. Medicaid waivers typically request that certain Medicaid provisions be waived in order to meet one or more of the following conditions:

- Limit the operation of the waiver to specific geographic parts of the state
- Constrain services to specified target group(s) of Medicaid beneficiaries (waiver of comparability requirements)
- Set a ceiling on the total number of waiver participants
- Remove provider choice requirements

As an EPSDT service under the state plan, states will not be able to restrict ASD treatment by these measures. The main emphasis of the guidance encourages each individual state to submit a state plan amendment (SPA) detailing how it will provide ASD treatment services. The authority options under the state plan include Section 1905(a)(6) Other Licensed Practitioner, Section 1905(a)(13) Preventive Services, or Section 1905(a)(11) Therapy Services.

Some forms of treatment such as applied behavioral analysis (ABA) have been considered experimental and not covered by Medicaid for ASD treatment. In other cases, the services have been considered rehabilitative services focused on skill building and are also not covered by Medicaid. Recently, advocacy groups have waged legal fights at the state level to have ABA considered as an effective treatment for ASD and not deemed to be experimental.

1 National Institute of Mental Health. Autism Spectrum Disorder: What Is Autism Spectrum Disorder? Health & Education. Retrieved April 1, 2015, from <http://www.nimh.nih.gov/health/topics/autism-spectrum-disorders-asd/index.shtml>.

2 Sigman, M. & Capps, L. (1997). *Children with Autism: A Developmental Perspective*. Cambridge, MA: Harvard University Press.

3 Frith, U. (2003). *Autism: Explaining the Enigma*. United Kingdom: Blackwell Publishing; 2003

4 CMS (July 7, 2014). Clarification of Medicaid Coverage of Services to Children with Autism. CMCS Informational Bulletin. Retrieved May 13, 2015, from <http://www.medicaid.gov/Federal-Policy-Guidance/Downloads/CIB-07-07-14.pdf>.

5 Centers for Medicare and Medicaid Services (September 2014). Medicaid and CHIP FAQs: Services to Address Autism. Retrieved May 13, 2015, from <http://www.medicaid.gov/federal-policy-guidance/downloads/faq-09-24-2014.pdf>.

This is supported by the CDC, which has defined ABA as a therapy that encourages positive behaviors and discourages negative behaviors in order to improve a variety of skills. The CDC includes the following as examples of different types of ABA.

- **Discrete trial training (DTT):** DTT is a style of teaching that uses a series of trials to teach each step of a desired behavior or response. Lessons are broken down into their simplest parts, and positive reinforcement is used to reward correct answers and behaviors. Incorrect answers are ignored.
- **Early intensive behavioral intervention (EIBI):** This is a type of ABA for very young children with an ASD, usually younger than five, and often younger than three.
- **Pivotal response training (PRT):** Also known as pivotal response therapy or pivotal response treatment, PRT aims to increase a child’s motivation to learn, monitor his or her own behavior, and initiate communication with others. Positive changes in these behaviors should have widespread effects on other behaviors.

It is important to note that CMS has not opined on any particular form of treatment (including ABA), just that the treatment for ASD must be covered. In fact, the guidance letter referenced the CMS-commissioned paper “Autism Spectrum Disorders (ASD): State of the States of Services and Supports for People with ASD,” which describes a full inventory of ASD treatment approaches by individual states.<sup>6</sup>

**Analytical and rate-setting challenges**

From a fiscal analysis and rate-setting perspective, there are numerous challenges with the CMS guidance on ASD treatment. The utilization and costs of Medicaid ASD treatment are influenced by factors specific to the covered population, as well as the available supply of qualified providers and demand for services from individuals covered by other payer types. The following is a list of key considerations for state Medicaid programs developing an ASD treatment delivery system. For our discussion, we will assume that ABA and other treatment supports such as physical and speech therapy will be the mainstay of ASD therapy.

**Immature networks**

Until recently, ABA therapy has been considered experimental by many states and health insurance companies. This lack of coverage limited the network of providers qualified to deliver the service. With the expansion in coverage and length of training required for board-certified behavior analysts (BCBAs), it will likely take time for networks to develop and for supply and demand to approach equilibrium. In the near term, an approach to modeling ABA therapy and other supports is to consider utilization of services purely from a provider supply perspective, where the forecast for benefit expansion is built by assuming capacity of the network. For Medicaid, this can be problematic simply because it will need to compete with commercial carrier rates in geographies that have recently been subject to coverage lawsuits and/or passed commercial treatment laws for ASD.

Based on our observations, commercial rates for ABA therapy are approximately \$60 per hour for aide-level staff and \$120 per hour for supervision of the aide, which is generally performed by a BCBA.

**Therapy intensity and take-up**

ABA therapy is a time-intensive requirement. Some therapy estimates are as high as 20 to 40 hours a week for ABA therapy. Medicaid beneficiaries are time-restricted based on poverty, social, and occupational constraints. Families, many of which are headed by a single parent, may struggle to avail their child of the many hours that may be required for ABA therapy if it cannot be provided during school hours. The intensity assumed will not only impact cost-per-recipient estimates but it will also affect the number of unique children able to access services. Experience with ABA therapy is still immature, especially in Medicaid. As a result, it is currently very difficult to determine how many ASD children will access ABA services and the hours of service they will receive on a weekly basis. As with any new public health program, fiscal projections and rate calculations for ASD treatment are very sensitive to the take-up rates assumed in the analysis.

**Co-occurring conditions**

Medicaid also has a significant number of medically complex children with co-occurring conditions, including other intellectual and developmental disabilities. In some cases, providing additional services or therapies simply is not possible. The table in Figure 1 illustrates the co-occurring diagnosis activity sourced from claims data for one state Medicaid program. This data includes all eligibility groups and ages. We should note that the diagnostic activity does vary by age, eligibility group, and where the child falls on the ASD spectrum. Additionally, some of these diagnoses may be symptomatic of ASD. Cost modeling for ASD treatment programs should reflect the effect of co-occurring conditions in the development of treatment assumptions. In reviewing the percentage estimates in Figure 1, it should be noted that diagnosis of ASD could increase with the provision of additional services available.

**FIGURE 1: PERCENTAGE OF UNIQUE ASD RECIPIENTS WITH AN ADDITIONAL DIAGNOSIS**

DIAGNOSIS	PERCENTAGE
Developmental disorders	44%
Attention-deficit, conduct, and disruptive behavior disorders	34%
Mood disorders	18%
Anxiety disorders	14%
Adjustment disorders	14%
Disorders usually diagnosed in infancy, childhood, or adolescence	5%
Schizophrenia and other psychotic disorders	4%
Impulse control disorders, not elsewhere classified	3%
Delirium, dementia, and amnestic and other cognitive disorders	2%
Personality disorders	2%
Substance-related disorders	1%
Alcohol-related disorders	1%
Percentage of unique recipients with any additional diagnosis	72%

<sup>6</sup> L&M Policy Research (January 24, 2014). Autism Spectrum Disorders (ASD): State of the States of Services and Supports for People with ASD. Retrieved April 1, 2015, from [http://dlr.sd.gov/autism/documents/asd\\_state\\_of\\_the\\_states\\_report\\_2014.pdf](http://dlr.sd.gov/autism/documents/asd_state_of_the_states_report_2014.pdf).

**Average length of treatment episode**

The average length of an ABA treatment episode is another unknown assumption, which is currently due to the lack of ABA therapy experience. It is unknown if the average treatment episode will last six months, a year, or multiple years. Because ASD treatment services are now an EPSDT benefit, children up to age 21 are eligible for services. Some experience suggests that ABA therapy such as early intensive behavioral intervention (EIBI) is most effective in children under the age of six. To the extent that length of treatment assumptions vary, fiscal projections will be impacted.

**Medical necessity**

Medical necessity criteria is still immature. Given lawsuit and EPSDT requirements, many clinicians are hesitant to recommend detailed criteria that speaks to expected length, treatment, or age-appropriateness of ABA therapy. In the near term, this may not be a modeling issue simply because the demand for services will likely significantly outstrip the supply of providers.

**Reliability of diagnosis data**

Relying on diagnosis data to identify children with ASD is problematic when services have not generally been available to treat ASD. We have found it helpful to use multiple years of data rather than the diagnosis from testing or assessment claims, and to require more than one diagnosis in the spectrum. Even then, uncertainty should be associated with the observed diagnosis prevalence when performing financial modeling. We have seen material increases in diagnostic activity when states have recently implemented treatment programs. The table in Figure 2 illustrates the percentage change in prevalence sourced from claims data for a state Medicaid population before and after a court-mandated treatment option for ABA was implemented.

**FIGURE 2: PERCENTAGE CHANGE IN PREVALENCE OF ASD DIAGNOSES OVER FOUR YEARS**

DIAGNOSIS GROUP	AGE GROUP		
	18 MONTHS TO 5 YEARS	6 TO 12 YEARS	13 TO 18 YEARS
Autistic Disorder	24.5%	13.5%	23.8%
Asperger's Disorder	19.9%	19.5%	34.1%

**Increased supporting treatments**

As children enter into services for ASD treatment, they may encounter provider access issues in limited networks for services such as ABA. In lieu of readily available ABA services, children may be steered into services such as physical and speech therapy and

family training. These other supporting services may increase even when a child is receiving ABA concurrently with the supporting services. While most of these services are already offered in Medicaid programs, increases in utilization of certain non-ASD services should be anticipated with the implementation of an ASD treatment benefit.

**Risk mitigation**

For a number of reasons, listed above, a high degree of uncertainty should be associated with cost estimates for ABA treatment. These estimates are very sensitive to many assumptions used to develop them. As a result, methods to mitigate risk should be employed. Potential examples include:

- Initially keeping payment for ASD treatment in a fee-for-service delivery system until credible experience develops
- Cost settling on utilization with a standard unit cost (such as costs defined by a state fee schedule)
- Constructing narrow risk corridors

**Conclusion**

In summary, the actual costs for ASD treatment are dependent on a number of variables inherent in the potentially treated population and provider network. Similar to the introduction of other public health insurance programs or benefits, state Medicaid programs should recognize that long-term cost projections for ASD treatment may deviate significantly from actual experience. States, payers, and providers should approach service provision with proper risk protections to ensure that an ASD treatment delivery system develops that is sustainable from both a clinical and financial perspective.

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