



AUTISM SPEAKS™
It's time to listen.

February 5, 2019

Senate Finance Committee Chair Liz Krueger
Assembly Ways and Means Committee Chair Helene E. Weinstein
State Capitol
Albany, New York 12224

Re: 2019-2020 Executive Budget Proposal
Medicaid Coverage for Applied Behavior Analysis Treatment for Children with Autism

Dear Mesdames Chairwomen,

I submit testimony today on behalf of Autism Speaks regarding Medicaid coverage for applied behavior analysis treatment for New York children diagnosed with autism spectrum disorder (ASD). We are profoundly grateful that this coverage was proposed in Governor Cuomo's 2019/2020 Executive Budget. Timely access to medically necessary treatment is critical for children with (ASD).

Autism Speaks is the world's leading autism science and advocacy organization and over the past decade has been at the forefront of increasing coverage of healthcare treatments for ASD. The State of New York recognized this and took an important step in 2011, when Governor Cuomo signed legislation requiring state-regulated health plans to cover medically necessary care for ASD. Since then, individuals diagnosed with ASD have had access to meaningful interventions, often reducing their need for special education services and improving their quality of life, opening the door for further education and employment.

In addition to our work in the private health insurance market, we have been working with state Medicaid agencies and stakeholders around the country to ensure access to medically necessary care pursuant to Medicaid's Early Periodic Screening Diagnostic and Treatment (EPSDT) mandate and CMS' 2014 Informational Bulletin on Clarification of Medicaid Coverage of Services to Children with Autism.¹

The proposal included in Governor Cuomo's 2019-2020 Proposed Executive Budget coverage will make great progress towards meeting this requirement and for this we are deeply appreciative. In its original form, it states:

¹ Center for Medicaid and CHIP Services. Informational Bulletin, Clarification of Medicaid Coverage of Services to Children with Autism, July 7, 2014 (hereinafter "CMS Informational Bulletin"), available at <http://www.medicaid.gov/Federal-Policy-Guidance/Downloads/CIB-07-07-14.pdf>.

The Budget supports expanding Medicaid to cover Applied Behavioral Analysis treatment for over 4,000 children with autism, including those who have aged out of the Early Intervention program, to ensure they are able to continue receiving necessary services

It is important to note that the previously referenced CMS Bulletin points to medically necessary care for children diagnosed with autism spectrum disorder (ASD) under EPSDT. EPSDT applies to *all* children Medicaid-enrolled children under the age of 21.

In order for the proposed coverage to be in compliance with the aforementioned CMS requirement, the related budget item should include coverage for Medicaid-enrolled children under the age of 4 as well as for Medicaid enrolled children who are being served by early intervention. (We have clarified this in conversations with the Department of Health and our understanding is that the language has been adjusted.)

As budget negotiations continue, it is imperative that coverage of *all* Medicaid-enrolled children diagnosed with ASD under the age of 21 remain intact.

Over 40 states having implemented meaningful coverage of treatment for ASD under EPSDT, including applied behavior analysis for those under the age of 21. Just this past week, Administrative Law Judge, Joseph H. Young, issued a decision compelling the Oklahoma Health Care Authority to cover applied behavior analysis for children covered by the state's Medicaid program, SoonerCare. It is our hope that New York State will move forward expeditiously in the provision of this coverage for the entirety of this vulnerable population.

Thank you for your time and consideration. Should you need additional information, please do not hesitate to contact me at judith.ursitti@autismspeaks.org.

Sincerely,



Judith Ursitti
Director, State Government Affairs

Attachments



A TIMELINE OF ACTIONS RELATED TO COVERAGE FOR APPLIED BEHAVIOR ANALYSIS (ABA) FOR AUTISM UNDER MEDICAID/EPSDT

Federal Actions		
Medicaid enacted	1965	
EPSDT benefit added to Medicaid	1967	
EPSDT expanded to ensure that all treatments allowed under the definition of "medical assistance" are covered in all states in response to evidence of limited coverage for children with mental and developmental disabilities	1999	
		Litigation and Court Findings
	2009	Parents League for Effective Autism Services (PLEAS) v. Jones-Kelley et al (8th Circuit). ABA is coverable as medical assistance under Medicaid and must be covered under EPSDT
	2012	Washington Autism Alliance and Advocacy (WAAA) v. Porter (E.D. Wash) Settlement to cover ABA under EPSDT and submit a State Plan Amendment
	2013	Chisolm v. Klebert (E.D. La.) ABA must be provided under EPSDT. ABA must be provided by Board Certified Behavior Analysts (BCBAs) if there are an insufficient number of licensed providers.
		K.G. v. Dudek (11th Circuit) ABA is not experimental and must be made available as a covered Medicaid service under EPSDT
CMS informational Bulletin, "Clarification of Medicaid Coverage of Services to Children with Autism"	2014	
	2015	K.D. v. Winterer (Neb) Exclusion of certain medically necessary treatments, including ABA, for children with autism violates EPSDT
	2016	Sonny O v. Dallas (M.D. Pa.) Pennsylvania Medicaid was not providing the full scope of ABA, used inappropriate medical necessity guidelines, failed to offer providers who had training in ABA, and failed to allow many qualified ABA providers to enroll in the MA program, leaving children without access to this critical evidenced based service.

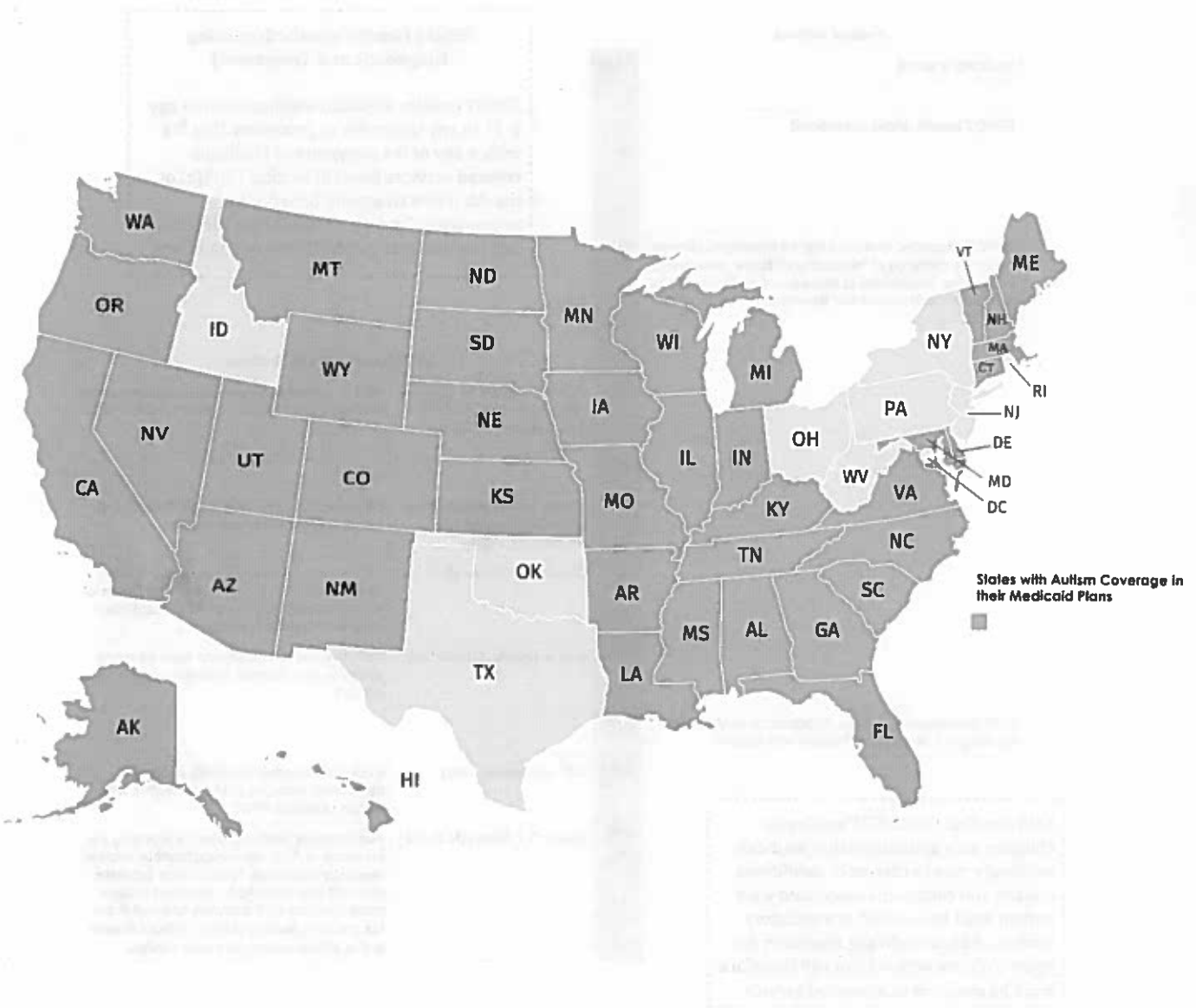
EPSDT (Early Periodic Screening Diagnostic and Treatment)

EPSDT entitles Medicaid-eligible children age 0-21 to any treatment or procedure that fits within any of the categories of Medicaid-covered services listed in Section 1905(a) of the Act if that treatment or service is necessary to "correct or ameliorate" defects and physical and mental illness or conditions.

CMS clarified that EPSDT applies to children with autism and that medically necessary care to correct or ameliorate deficits and conditions associated with autism must be covered as mandatory service. ABA is medically necessary for many children with autism and therefore must be available as a covered service.

Since the 2014 CMS Bulletin was published, 39 states have taken affirmative action to clarify that ABA is a covered service when deemed medically necessary for children with autism: Arkansas, California, Colorado, Connecticut, Delaware, Florida, Georgia, Hawaii, Indiana, Iowa, Kansas, Kentucky, Louisiana, Maine, Maryland, Massachusetts, Michigan, Minnesota, Mississippi, Missouri, Montana, Nebraska, Nevada, New Hampshire, New Mexico, North Carolina, North Dakota, Ohio, Oregon, Pennsylvania, South Carolina, South Dakota, Tennessee, Utah, Vermont, Virginia, Washington, Wisconsin and Wyoming. The remaining states, including New York, remain in violation of EPSDT as it relates to coverage for autism and are at risk of legal action.

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COVERAGE FOR APPLIED BEHAVIOR
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Autism Speaks is a national nonprofit organization dedicated to increasing awareness, understanding, and early diagnosis of autism spectrum disorders. The organization is committed to supporting research, providing resources, and advocating for the needs of individuals with autism and their families. This report highlights the progress made in securing Medicaid coverage for Applied Behavior Analysis (ABA) services, which are essential for many individuals with autism to receive necessary support and services.