

September 28, 2023

Steffanie Garrett
General Counsel

Illinois Department of Healthcare and Family Services 201 South Grand Avenue East,
3rd Floor

Springfield IL 62763-0002

HFS.Rules@illinois.gov

Re: Proposed Rulemaking which Amends 89 IAC 140.457 and Replaces 89 IAC 140.465, Pursuant to Public Act 101-0010, which Mandates Coverage of Treatment for Autism Spectrum Disorders

I write to you today on behalf of The Council of Autism Service Providers (CASP) regarding the proposed rulemaking as referenced in Illinois Register Volume 47, Issue 2 January 13, 2023:

Amends 89 IAC 140.457 and replaces 89 IAC 140.465, pursuant to Public Act 101-0010, which mandates coverage of treatment for autism spectrum disorders. The rulemaking introduces Adaptive Behavior Support (ABS) services into the service array, allowing for applied behavior analysis and developmental interventions to be rendered by qualified professionals. A State Plan Amendment (IL 21-0018) was approved on March 15, 2022.

CASP is a non-profit association of organizations committed to providing evidence-based care to individuals with autism. CASP represents the autism provider community to the nation at large, including government, payers, and the general public. We provide information and education and promote standards that enhance quality of care. We are also home to the clinical practice guidelines for applied behavior analysis, "[Applied Behavior Analysis Treatment of Autism Spectrum Disorder: Practice Guidelines for Healthcare Funders and Managers \(2nd ed.\)](https://casproviders.org/asd-guidelines/)"¹(Practice Guidelines).

¹ Council of Autism Service Providers. 2020. *Applied Behavior Analysis Treatment of Autism Spectrum Disorders: Practice Guidelines for Healthcare Funders and managers (2nd ed.)* <https://casproviders.org/asd-guidelines/>.

Of particular interest to our members is the coverage of evidence-based care in private health insurance plans and through Medicaid. Timely access to medically necessary treatment, including applied behavior analysis, is critical for children with autism spectrum disorder (ASD).²

The State of Illinois took a vital step more than a decade ago when it passed 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, reducing their need for special education services, improving their quality of life, and opening doors for further education and employment. In addition, the number of qualified providers has dramatically multiplied statewide, creating jobs in Illinois communities, and providing life-changing care.

Pursuant to Medicaid's Early Periodic, Screening, Diagnostic and Treatment (EPSDT) mandate and CMS' Informational Bulletin on Clarification of Medicaid Coverage of Services to Children with Autism³, medically necessary care for children under the age of 21 who have been diagnosed with autism, has also been implemented. We are grateful for this progress and for the opportunity to comment on the above referenced Illinois proposed rulemaking:

We respectfully ask for your consideration of our recommendations below:

Section 140.465 Adaptive Behavior Support Services

a) Payment for Adaptive Behavior Support (ABS) Services.

3) The services detailed in subsection (c) may be eligible for reimbursement pursuant to the Department's published fee schedule when the services are:

A) Recommended by a licensed physician operating within their scope of practice;

² The American Academy of Pediatrics has long recognized that immediate intervention is critical in the treatment of autism. Pediatrics, Vol. 120, No. 5, Management of Children with Autism Spectrum Disorders (2007), p. 1163. 46_dmhc_regs.pdf

³ 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>.

Limiting treatment recommendations “recommended by a licensed physician operating within their scope of practice” is in direct contradiction to EPSDT, which states:

*EPSDT also requires medically necessary diagnostic and treatment services. When a screening examination indicates the need for further evaluation of a child’s health, the child should be appropriately referred for diagnosis and treatment **without delay**. Ultimately, the goal of EPSDT is to assure that children get the health care they need, when they need it – the right care to the right child at the right time in the right setting.*

***The role of states is to make sure all covered services are available** as well as to assure that families of enrolled children, including children with ASD, are aware of and have access to a broad range of services to meet the individual child’s needs.*

According to the most recent guidance from the American Academy of Pediatrics⁴:

The primary care provider should discuss with the family the importance of both the assessment of developmental status and evaluation for an ASD diagnosis and assist the family in navigating through the process, including connecting them with community resources. Families with low income or language barriers may need additional attention to take the next steps.

*Although most children will need to see a specialist, such as a developmental-behavioral or neurodevelopmental pediatrician, psychologist, neurologist, or psychiatrist, **for a diagnostic evaluation, general pediatricians and child psychologists comfortable with application of the DSM-5 criteria can make an initial clinical diagnosis.***

Recommendation:

Revise the proposed language in Section 140.465 a)3)1 to state:

⁴ Hyman, S. L., Levy, S. E., & Myers, S. M., AAP Council on Children with Disabilities, Section on Developmental and Behavioral Pediatrics (2020). Identification, Evaluation, and Management of Children With Autism Spectrum Disorder. Pediatrics. 145(1):e20193447.

Recommended by a licensed physician or licensed psychologist operating within their scope of practice.

a) Payment for Adaptive Behavior Support (ABS) Services.

ABS Services. The following services are established as qualified ABS services when rendered by an ABS Clinician or ABS Technician:

1) Behavior Assessment and Treatment Planning (BATP). BATP is the formal process of assessing an individual's current maladaptive or disruptive behaviors and developing or updating individualized treatment goals, objectives and service recommendations based upon the assessment findings.

Additional BATP functions include:

administering, scoring, and interpreting the assessment(s); interviews with the individual's parent(s) or guardian(s); non-face-to-face analysis of treatment history; and discussing findings and recommendations with the individual and their parent or guardian, as appropriate.

A) The BATP must:

i) Be completed once every 180 days;

Illinois [Public Act 102-0579](#); [215 ILCS 5/370c](#) amends the Illinois insurance code to require commercial insurers, health insurance marketplace plans and **Medicaid managed care organizations** to:

- Cover medically necessary treatment of mental health and substance use disorders (MH/SUD).
- Base any medical necessity determination or the utilization review criteria on current generally accepted standards for MH/SUD treatment.
- Conduct utilization review of covered healthcare services and benefits for the diagnosis, prevention, and treatment of MH/SUD conditions in children, adolescents, and adults, an insurer shall exclusively apply the criteria and guidelines set

forth in the most recent versions of the treatment criteria developed by **the nonprofit professional association for the relevant clinical specialty.**

Autism Spectrum Disorder is defined in the 5th Edition of the Diagnostic Statistical Manual of Mental Disorders and is protected under the previously referenced Illinois Mental Health Parity Law. This law requires that medical necessity determination or utilization review criteria to be based on current generally accepted standards of care, including those developed by the nonprofit professional association for the relevant clinical specialty.

As mentioned earlier, CASP is a non-profit association of organizations committed to providing evidence-based care to individuals with autism. We are also home to the clinical practice guidelines for applied behavior analysis, "[Applied Behavior Analysis Treatment of Autism Spectrum Disorder: Practice Guidelines for Healthcare Funders and Managers \(2nd ed.\)](#)"⁵(Practice Guidelines).

According to the Practice Guidelines:

The assessment process required for the initial development of Comprehensive treatment programs may take 20 hours or longer. Subsequent assessments and assessments for Focused treatments that involve a small number of uncomplicated goals often require fewer hours. The functional assessment process for severe problem behavior is often complex and may require considerably longer durations.

Assessment of overall progress toward comprehensive treatment goals should be summarized at regular intervals (for example, on a semiannual basis).

The Practice Guidelines go on to say:

Authorization periods should not typically be for less than six months.

⁵ Council of Autism Service Providers. 2020. *Applied Behavior Analysis Treatment of Autism Spectrum Disorders: Practice Guidelines for Healthcare Funders and managers (2nd ed.)* <https://casproviders.org/asd-guidelines/>.

Recommendation:

Revise the proposed language in *Section 140.465 a)1)A)i).* to state:

Be completed according to generally accepted standards of care, including those developed by the nonprofit professional association for the relevant clinical specialty.

c) Covered ABS Services. The following services are established as qualified ABS services when rendered by an ABS Clinician or ABS Technician:

2) Behavior Analysis Intervention (BAI). BAI services consist of evidence- based interventions identified on the individual's BATP that use behavioral stimuli and consequences to produce socially significant improvement in behavior. BAI services include: direct observation, measurement, and functional analysis of the relationships between environment and behavior; and, parent/caregiver coaching and training for the immediate and direct clinical benefit of the individual.

A) BAI services must be delivered consistent with HFS-approved evidence-based practice guidelines using one of the following treatment modalities:

Illinois [Public Act 102-0579](#); [215 ILCS 5/370c](#) amends the Illinois insurance code to require commercial insurers, health insurance marketplace plans and **Medicaid managed care organizations** to:

- Cover medically necessary medically necessary treatment of mental health and substance use disorders (MH/SUD).
- Base any medical necessity determination or the utilization review criteria on current generally accepted standards for MH/SUD treatment.
- Conduct utilization review of covered health care services and benefits for the diagnosis, prevention, and treatment of MH/SUD conditions in children, adolescents, and adults, an insurer shall exclusively apply the criteria and guidelines set forth in the most recent versions of the treatment criteria

developed by the nonprofit professional association for the relevant clinical specialty.

Autism Spectrum Disorder is defined in the 5th Edition of the Diagnostic Statistical Manual of Mental Disorders and is protected under the previously referenced Illinois Mental Health Parity Law. **This law requires that medical necessity determination or utilization review criteria to be based on current generally accepted standards of care, including those developed by the nonprofit professional association for the relevant clinical specialty.**

As mentioned earlier, CASP is a non-profit association of organizations committed to providing evidence-based care to individuals with autism. We are also home to the clinical practice guidelines for applied behavior analysis, "[Applied Behavior Analysis Treatment of Autism Spectrum Disorder: Practice Guidelines for Healthcare Funders and Managers \(2nd ed.\)](#)"⁶(Practice Guidelines).

Recommendation:

Revise the proposed language in *Section 140.465 c)2)A)*. to state:

BAI services must be delivered consistent with HFS-approved evidence-based practice guidelines according to generally accepted standards of care including those developed by the nonprofit professional association for the relevant clinical specialty.

According to the most recent estimates from the Centers for Disease Control, 1 in every 44 children is diagnosed with autism spectrum disorder. This means that 1.5% of Illinois children who are on Medicaid have an autism spectrum disorder and need access to appropriate care as mandated under EPSDT.

Thank you for your work in the past and moving forward to ensure that Illinois children with autism who are enrolled in Medicaid have access to life-changing, evidence-based care. Should you have any questions, please do not hesitate to contact me at jursitti@casproviders.org.

Respectfully,

⁶ Council of Autism Service Providers. 2020. *Applied Behavior Analysis Treatment of Autism Spectrum Disorders: Practice Guidelines for Healthcare Funders and managers (2nd ed.)* <https://casproviders.org/asd-guidelines/>.

Judith Ursitti

Judith Ursitti
Vice President of Government Affairs