



September 28, 2023

Department of Healthcare and Family Services  
Steffanie Garrett, General Counsel  
201 S. Grand Ave East, 3<sup>rd</sup> Floor, Springfield, IL 62763-0002

Re: DHFS Public Hearing on October 2, 2023. Proposed Amendments to Medical Payments 89 IAC 140; Section 140.457 and proposed new Section 140.465 for Adaptive Behavior Support (ABS) Services including the treatment modality applied behavior analysis (ABA) therapy.

Dear Ms. Garrett,

We appreciate the opportunity to provide public testimony on DHFS’ proposed amendments to Sections 140.457 and 140.465 Adaptive Behavior Support Services. The Illinois Autism Insurance Coalition’s provider network consists of over thirty autism service providers that offer ABA therapy, speech and occupational therapy, diagnostics, counseling, school consultation, and adult services.

Our Coalition has greatly appreciated the collaborative working relationship with DHFS and the Office of Medicaid Innovation over the past few years. We are very thankful for HFS’ engagement with advocates on the Medicaid Omnibus bill this past June which resulted in positive changes to open access to ABA therapy. The below chart depicts all the access barriers we provided public comments on back in February, along with barriers that were fixed in the Omnibus bill and continued existing barriers.

<b>Barriers Fixed before or within the Medicaid Omnibus Bill.</b>	<b>Existing Barriers Section 140.457 and proposed new Section 140.465</b>
ABA clinics and center-based programs are no longer required to be certified as a Behavior Health Clinic.	Comprehensive ABA Therapy is only available to children aged 6 and under.
Certified Behavior Analysts (BCBAs) no longer require supervision from a licensed professional to render and submit claims for ABA therapy within ABS services.	Focused ABA Therapy is only available to children aged 7 and older who exhibit severe behaviors.
Registered Behavior Technicians (RBTs) are no longer required to be at least 21 years of age.	The Behavior Assessment And Treatment Planning (BATP) service only focuses on behaviors and does not assess current skills.
Working collaborative agreements are no longer required between ABS Clinicians.	HFS will approve the evidenced-based practice guidelines.
Psychologists can now diagnose ASD and recommend ABA therapy.	Requiring Registered Behavior Technician (RBT) certification before rendering treatment services.
	Children are required to have a comprehensive diagnostic evaluation before starting ABA therapy.

After reviewing the proposed rules, our Coalition has the following remaining concerns and recommendations to address barriers to accessing ABA services within the ABS Services for Medicaid-eligible children which also includes obstacles in service delivery impeding providers:

- Restrictive Treatment Limitations in Determining Medical Necessity - Concern 1
- Assessment Tools and Location/Settings - Concerns 2 and 3
- Narrowing of an already Depleted Workforce - Concern 4

### Issues of Concern & Recommendations

#### **Concern 1: Restrictive Treatment Limitations within Medical Necessity Criteria utilizing Age, Severity, and only HFS-approved Guidelines in Section 140.465**

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

*(c)(2)(A)(i) Comprehensive Applied Behavior Analysis (ABA). Comprehensive ABA addresses development gains in individuals aged six years and under exhibiting adaptive living skill deficits, impairments in social skill or communication skill acquisition, or severe behaviors (harm to self, others, or property);*

*(c)(2)(A)(ii) Focused ABA. Focused ABA functions as an adjunct service supporting the delivery of a broad array of therapeutic support services for individuals aged seven through 20 years exhibiting severe behaviors (harm to self, others, or property);*

**Issue 1A:** HFS-approved evidence-based practice guidelines in 2(A) are vague and the state has already established guidelines by enacting PA 102-953<sup>1</sup> which created the Licensed Behavior Analyst Act and the reference to ASD within state's legislation<sup>2</sup>. Also, there are standards of care guidelines which are explained below. Utilizing the industry's developed generally accepted standards of care<sup>3</sup> (GASC) guidelines will offer a fair medical necessity process.

**Issue 1B:** Age limits in the Comprehensive and Focused ABA are improper and violate federal law.

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<sup>1</sup> Illinois General Assembly, *Professions, Occupations, And Business Operations, (225 ILCS 6/) Behavior Analyst Licensing Act (2022)*. <https://www.ilga.gov/legislation/ilcs/ilcs3.asp?ActID=4308&ChapterID=24>

<sup>2</sup> Reference list of state laws and budgets signed by the Governor supporting Medicaid coverage of ABA for children ASD:

Public Act 102-0953- ABA Licensure Law: <https://www.ilga.gov/legislation/publicacts/102/PDF/102-0953.pdf>

Public Act 101-637- FY 2021 Budget: <https://www.ilga.gov/legislation/publicacts/101/PDF/101-0637.pdf>

Public Act 102-0017- FY 2022 Budget: <https://www.ilga.gov/legislation/publicacts/102/PDF/102-0017.pdf>

Public Act 102-0698-FY 2023 Budget: <https://www.ilga.gov/legislation/publicacts/102/PDF/102-0698.pdf>

<sup>3</sup> The Council of Autism Service Providers (CASP). Applied Behavior Analysis Treatment of Autism Spectrum Disorder: Practice Guidelines for Healthcare Funders and Managers. GASC, Second Edition. 2020, 12, <https://casproviders.org/asd-guidelines/>.

Pursuant to Medicaid’s EPSDT mandate<sup>4</sup>, the state Medicaid agency is responsible for ensuring that all medically necessary ABA therapy to correct or ameliorate a child’s ASD deficits and conditions is provided based on individualized determinations of medical necessity.<sup>5</sup> Managed care organizations administering Medicaid benefits are prohibited from using medical management criteria that are more restrictive than allowed by EPSDT or the federal Mental Health Parity and Addiction Equity Act<sup>6</sup>. Age limits are quantitative treatment limitations (QTLs) prohibited by the Parity Act, and managed care organizations are prohibited from imposing them.<sup>7</sup>

**Issue 1C:** Requiring an individual to exhibit “severe” symptoms before they can access Focused ABA intervention is ignoring the need for preventative treatments and allows non-severe symptoms to go untreated.

The established accepted standards (GASC) clearly define ABA therapy as being delivered through Comprehensive and Focused interventions and maintain Focused ABA should not be restricted by age, cognitive level, or co-occurring conditions.<sup>8</sup> Focused ABA targets treatment toward a limited number of key functional skills or challenging behaviors, and any definition should be inclusive of both.<sup>9</sup> The proposed language would prevent children seven through 20 years of age, who are not “exhibiting severe behaviors,” from receiving Focused ABA interventions.

**Family Impact:** Medicaid-eligible children with ASD most likely have never received behavioral intervention treatment services other than medication management and for those that could benefit, counseling. Living without access to care is very isolating and increases the chance of emergency room visits and out-of-home placements. This has been devastating for Medicaid families. In the proposed rules, adolescents who have waited to access services for years and need intensive treatment could only access the less intensive Focused treatment option because of their age. For some, the less intensive intervention would not result in a significant reduction in challenging behaviors.

**Recommendation 1:** Remove “HFS approved” from 2(A), the reference to age in Sections (c)(2)(A)(i) and (ii), and the reference to severe behaviors in (c)(2)(A)(ii).

2(A)BAI services must be delivered consistent with evidence-based and industry-accepted generally accepted standards of care practice guidelines using one of the following treatment modalities

(c)(2)(A)(i) Comprehensive Applied Behavior Analysis (ABA). Comprehensive ABA addresses development gains in individuals exhibiting adaptive living skill deficits, impairments in social skill or communication skill acquisition, and maladaptive and/or severe behaviors (harm to self, others, or property).

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<sup>4</sup> Center for Medicaid and CHIP Services. CMCS Informational Bulletin, *Clarification of Medicaid Coverage of Services to Children with Autism*. July 7th, 2014. [https://www.hhs.gov/guidance/sites/default/files/hhs-guidance-documents/CIB-07-07-14\\_104.pdf](https://www.hhs.gov/guidance/sites/default/files/hhs-guidance-documents/CIB-07-07-14_104.pdf)

<sup>5</sup> 42 U.S.C. §1396d(r)(5), [https://uscode.house.gov/view.xhtml?req=\(title:42%20section:1396d%20edition:prelim\)](https://uscode.house.gov/view.xhtml?req=(title:42%20section:1396d%20edition:prelim)).

<sup>6</sup> CMS. *The Mental Health Parity and Addiction Equity Act (MHPAEA)*. 2023. [https://www.cms.gov/CCIIO/Programs-and-Initiatives/Other-Insurance-Protections/mhpaea\\_factsheet](https://www.cms.gov/CCIIO/Programs-and-Initiatives/Other-Insurance-Protections/mhpaea_factsheet)

<sup>7</sup> 42 CFR 438.910(d)(1), <https://www.law.cornell.edu/cfr/text/42/438.910>.

<sup>8</sup> The Council of Autism Service Providers (CASP). *Applied Behavior Analysis Treatment of Autism Spectrum Disorder: Practice Guidelines for Healthcare Funders and Managers*. GASC, Second Edition. 2020, 12, <https://casproviders.org/asd-guidelines/>.

<sup>9</sup> The Council of Autism Service Providers (CASP). *Applied Behavior Analysis Treatment of Autism Spectrum Disorder: Practice Guidelines for Healthcare Funders and Managers*. GASC, Second Edition. 2020, 12, <https://casproviders.org/asd-guidelines/>.

(c)(2)(A)(ii) Focused Applied Behavior Analysis (ABA). Focused ABA functions as an adjunct service supporting the delivery of a broad array of therapeutic support services that target a limited number of key functional skills or maladaptive and/or severe behaviors.

## **Concern 2: Proper Assessment Tools in Section 140.465**

*(c)(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...*

**Issue:** The language above needs to include assessments of current functional skills and skill deficits. This includes skill acquisition, maintenance of skills, and/or the prevention of the condition worsening.

The Medicaid Act prohibits discrimination of benefits based on diagnosis<sup>10</sup> therefore, “treatment of ASD cannot be limited to maladaptive and disruptive behaviors.” Pursuant to Medicaid’s EPSDT mandate, all deficits and conditions arising from a child’s diagnosis of ASD must be treated.<sup>11</sup> Other states have considered and rejected nearly identical language. We urge our state to reject language that limits access to autism treatment.

Children with ASD often present skill deficits that must be addressed to improve their developmental trajectory. Additionally, treatment may be medically necessary to maintain skills and functioning and prevent regression, and this care must also be covered under EPSDT. Such treatment goals are covered under the industry’s standards of care and EPSDTs broad “correct or ameliorate” standard.

**Family Impact:** Families need to have an understanding of their child’s current level of functioning before treatment starts. The BATP service needs to ensure skills and behaviors are assessed and are included in the developed treatment plan. As treatment progresses and future evaluations or assessments are completed, families will be able to see the treatment progress by comparing testing results throughout the child’s treatment.

**Recommendation 2:** Amend this section to add skills assessment as part of the BATP Service.

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

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<sup>10</sup> 42 C.F.R. §440.230 (c) The Medicaid agency may not arbitrarily deny or reduce the amount, duration, or scope of a required service under §§ [440.210](#) and [440.220](#) to an otherwise eligible beneficiary solely because of the diagnosis, type of illness, or condition.

<sup>11</sup> 42 USC §1396(r)(5), [https://uscode.house.gov/view.xhtml?req=\(title:42%20section:1396d%20edition:prelim](https://uscode.house.gov/view.xhtml?req=(title:42%20section:1396d%20edition:prelim).

### Concern 3: Location/Settings to include in Section 140.465

(a)(3)(C) *Delivered in a home or community setting, or at the office of a BHC enrolled to deliver ABS services.*

**Issue 3A:** The DHFS-certified Behavioral Health Clinics (BHC) requirement was deleted in the Medicaid Omnibus bill.

**Issue 3B:** Limiting service delivery locations and not including natural environments where we find children such as in schools, pre-schools, and daycares, limits access to these vital services. The behaviors and deficits commonly associated with ASD may occur across all of a child's natural environments and must be addressed in the environments in which they occur as noted in the industry's generally accepted standards<sup>12</sup> of care guidelines relied upon for ethical service delivery and medical necessity criteria for ABA therapy in the treatment of ASD.

Within the EPSDT (early, periodic, screening, diagnostic, and treatment) guidance to states, the Centers for Medicare & Medicaid Services (CMS) maintains that "Schools are particularly appropriate places to provide medical, vision, and hearing screenings; vaccinations; some dental care; and behavioral health services."<sup>13</sup> According to CMS, "The goal of EPSDT is to assure that individual 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."<sup>14</sup> Under the EPSDT mandate, state Medicaid agencies are responsible for ensuring that all medically necessary ABA and behavioral health treatments to correct or ameliorate a child's ASD deficits and conditions are provided based on individualized determinations of medical necessity. In additional guidance to states, CMS has said that regardless of any services provided by schools pursuant to IDEA or otherwise, the state Medicaid program retains primary responsibility for covering and ensuring delivery of all medically necessary healthcare services in school settings for Medicaid-eligible children.<sup>15</sup>

Excluding or limiting Medicaid coverage in school settings not only violates the federal EPSDT mandate and medical necessity, it also runs contrary to the Americans with Disabilities Act's (ADA) integration mandate. The ADA's integration mandate requires delivery of care "in the most integrated setting appropriate to the needs of qualified individuals with disabilities."<sup>16</sup>

**Family Impact:** Families need service options that work for their families. They want to have services delivered in their communities and in the right environments that will provide the best impact on their child's progress. They want treatment decisions to be made by their family and treatment team.

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<sup>12</sup> Standards (GASC): (1) Behavior Analyst Certification Board (BACB), *Clarifications Regarding Applied Behavior Analysis Treatment of Autism Spectrum Disorder: Practice Guidelines for Healthcare Funders and Managers 2<sup>nd</sup> Edition*, (2019). [https://www.bacb.com/wp-content/uploads/2020/05/Clarifications\\_ASD\\_Practice\\_Guidelines\\_2nd\\_ed.pdf](https://www.bacb.com/wp-content/uploads/2020/05/Clarifications_ASD_Practice_Guidelines_2nd_ed.pdf). (2) Council for Autism Service Providers (CASP), *Applied Behavior Analysis Treatment of Autism Spectrum Disorder: Practice Guidelines for Healthcare Funders and Manager*. (2020). <https://casproviders.org/asd-guidelines/>. (3) ABA Coding Coalition, *The Model Coverage Policy*. (2022). <https://abacodes.org/wp-content/uploads/2022/01/Model-Coverage-Policy-for-ABA-01.25.2022.pdf>

<sup>13</sup> Centers for Medicare & Medicaid Services (CMS). *EPSDT - A Guide for States: Coverage in the Medicaid Benefit for Children and Adolescents*. CMS, June 2014, 21, [https://www.medicaid.gov/sites/default/files/2019-12/epsdt\\_coverage\\_guide.pdf](https://www.medicaid.gov/sites/default/files/2019-12/epsdt_coverage_guide.pdf).

<sup>14</sup> Centers for Medicare & Medicaid Services. *EPSDT - A Guide for States: Coverage in the Medicaid Benefit for Children and Adolescents*. CMS, June 2014, 21, [https://www.medicaid.gov/sites/default/files/2019-12/epsdt\\_coverage\\_guide.pdf](https://www.medicaid.gov/sites/default/files/2019-12/epsdt_coverage_guide.pdf)

<sup>15</sup> U.S. HHS, Centers for Medicare and Medicaid Services, *State Medicaid Director Letter #14-006*, December 15, 2014, p. 3. <https://www.medicaid.gov/sites/default/files/federal-policy-guidance/downloads/smd-medicaid-payment-for-services-provided-without-charge-free-care.pdf>.

<sup>16</sup> 28 C.F.R. § 35.130(d) *Olmstead v. L.C.*, 527 U.S. 581. 1999 <https://www.ecfr.gov/current/title-28/chapter-I/part-35/subpart-B/section-35.130>

**Recommendation 3:** Amend the language to include schools, pre-schools, and daycares.

(a)(3)(C) Delivered in a home, community setting, school, pre-school, daycare, an office-based or center-based setting delivered by an ABS professional within their scope of practice, or at the office of a BHC enrolled to deliver ABS services.

**Concern 4: Narrowing of an already depleted workforce**

*(b)(2)(A) A Registered Behavior Technician (RBT), certified and in good standing with the Behavior Analyst Certification Board: or*

**Issue:** Adaptive Behavior Support services include the ABA therapy modality where the direct treatment is delivered by direct support professionals called Behavior Technicians (BT) or certified Registered Behavior Technicians (RBT). BTs who have completed the equivalent training of a registered behavior technician (RBT) certificate<sup>17</sup> and are deemed competent by their supervising certified Behavior Analyst (BCBA) should be able to deliver services and submit claims while waiting to take the RBT certification test and become an RBT. Some commercial plans allow BTs to deliver ABA therapy without the RBT certification.

**Family Impact:** Imposing these requirements would increase the likelihood that Medicaid beneficiaries will encounter limited access to ABS services compared to their commercially insured counterparts. Requiring direct care staff, who work under the supervision of a BCBA practitioner, to be RBT certified will dramatically decrease the workforce needed to meet the currently stretched workforce demands for delivering autism services. This leaves children with autism sitting on long waitlists to start ABA.

**Recommendation 4:** Allow both BTs and RBTs to deliver Behavior Analysis Intervention (BAI) under CPT code 97153.

(b)(2)(B) An individual who is 18 years of age or older, has a high school diploma or GED, and has received technical training equivalent to the training required for the Registered Behavior Technician certificate and shows competency to BAI services as determined by the supervision BCBA while waiting to take the RBT certificate exam or is a Registered Behavior Technician.

**Concern 5: Children are required to have a comprehensive diagnostic evaluation (CDE) before starting ABA therapy.**

a)3)B) in section 140.465, Provided to an individual under the age of 21 with a diagnosis of autism spectrum disorder, as indicated by a comprehensive diagnostic evaluation, to prevent disease, disability, and other health conditions. For their progression, to prolong life, and to promote physical and mental health and efficiencies in accordance with 42 CFR 440.130(c);

**Issue:** Medicaid members have struggled to get access to comprehensive diagnostic evaluations (CDE) for ASD. Our ABA providers have experienced many Medicaid members coming for ABA therapy who

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<sup>17</sup> Behavior Analyst Certification Board (BACB), *Registered Behavior Technician Certification*, 2023, <https://www.bacb.com/rbt/>



only have a pediatrician's prescription and a screening. Many Medicaid members are older and never had access to ABA. We don't want them waiting 18 to 24 months for a CDE.

Per the American Psychiatric Association, *“Although ASD can be diagnosed as early as 15 to 18 months of age, the average age of diagnosis is about 4.5 years, and some people are not diagnosed until adulthood. That's unfortunate, as prompt diagnosis is important for early intervention. Research has shown that intensive early intervention can make a big difference in the outcomes for people with ASD. If you suspect your child shows signs of the disorder, don't put off testing.”*<sup>18</sup>

Per the American Academy of Pediatrics, *“The M-CHAT-R/F is the most common screening tool used in pediatric offices. It is a 23-point questionnaire filled out by parents. Most families find it easy to fill out. Using this standardized screening tool, pediatricians will be prompted to start conversations about language delays, concerns about behavior, or possible next steps for a child at risk with additional genetic, neurologic, or developmental testing.”*<sup>19</sup>

**Recommendation 5:** Allow Medicaid-eligible children who have been screened for ASD and have a physician prescription of ASD or a provisional diagnosis of ASD to start treatment if ABA is prescribed and if the Medicaid member is on a waitlist for a CDE.

a)3)B) in section 140.465, Provided to an individual under the age of 21 with a diagnosis of autism spectrum disorder, as indicated by a comprehensive diagnostic evaluation or has a prescription or presumptive diagnosis of ASD and on a waitlist for a CDE, to prevent disease, disability, and other health conditions. For their progression, to prolong life, and to promote physical and mental health and efficiencies in accordance with 42 CFR 440. 130(c);

On behalf of our Coalition, thank you for the opportunity to provide public comment and recommendations on the proposed rules. As in the past, our Coalition is willing to support DHFS in the continued development of accessible ABS Services that align with generally accepted standards of care for treating ASD.

We continue to welcome any opportunity for further discussions and would invite DHFS to come and observe the ABA services our Coalition participants provide. The Coalition's network of providers greatly appreciates the collaborative working relationship with DHFS and we look forward to working collaboratively in the future.

Sincerely,

Marla Root  
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<sup>18</sup> American Psychiatric Association, 2023, <https://www.apa.org/topics/autism-spectrum-disorder/diagnosing>

<sup>19</sup> American Academy of Pediatrics <https://www.healthychildren.org/English/health-issues/conditions/Autism/Pages/How-Doctors-Screen-for-Autism.aspx>