

Autism Screening, Diagnosis & Treatment in Kentucky

Expanding access to behavioral health
care for children with disabilities



ABA Advocates is a 501(c)(6) nonprofit organization dedicated to advocating for children with autism throughout Kentucky. As a trade association, ABA Advocates focuses on supporting Applied Behavior Analysis (ABA) providers across the state, working together to address and overcome challenges that limit access to ABA therapy and essential resources.





Introduction

Today, thousands of children with autism across the Commonwealth of Kentucky are unable to access behavioral healthcare services to diagnose and treat their conditions. Undiagnosed and untreated conditions can lead to significant impacts on their quality of life both now and throughout their entire lifespan.

1:36

Children
diagnosed with
autism

18,000

Kentucky
children with
ASD

48%

Children on
Medicaid



Research shows that early intervention requires access to care when the neuroplasticity of the brain is highest. Missing this window of care causes children to lose progress they can never recover across their entire lifespan.

Facts about Autism

Warning Signs

Parents or other caregivers notice things like reduced eye contact, delayed speech, limited response to name, or repetitive actions as compared to peers.

Starting the Journey

Parents meet with their pediatrician to share observations and discuss next steps. The pediatrician often uses a screening tool to evaluate the likelihood of an autism diagnosis.

Referral for Diagnosis

If screening shows clinical concerns, the pediatrician will refer the child to a specialist, often a licensed clinical psychologist, for a comprehensive evaluation.

Getting Diagnosed

Wait times for a diagnostic appointment frequently last months and often years. Many families have to travel out of their community, or even out of state for a diagnosis.

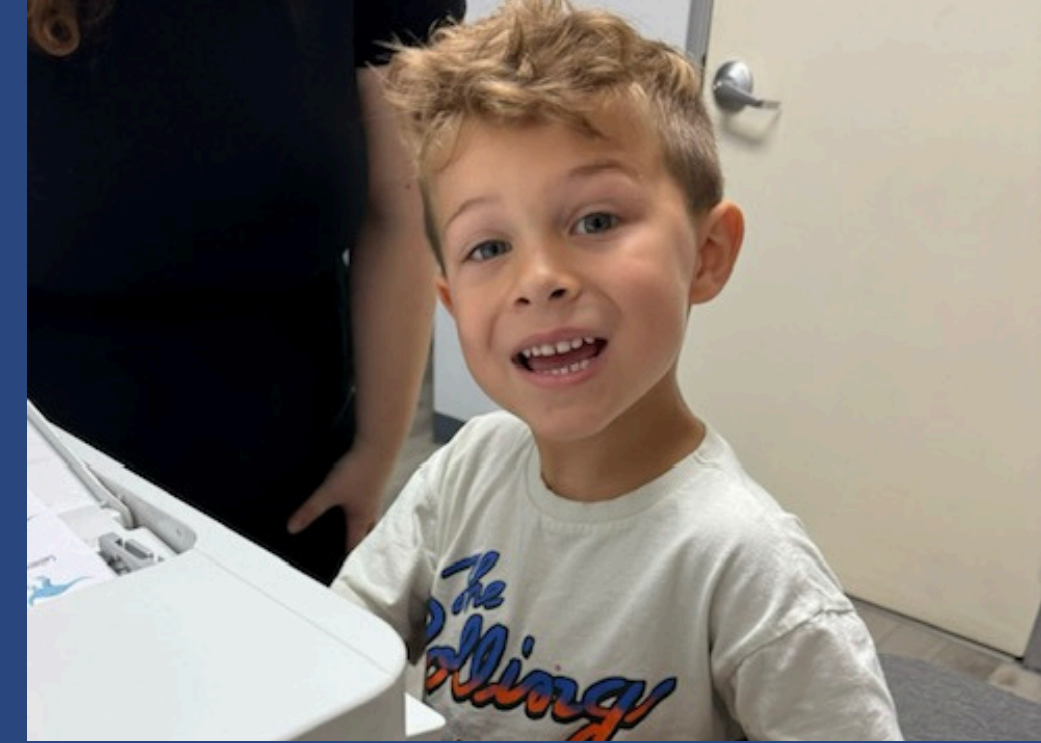
Treatment

ABA is widely recognized as the leading evidence-based and validated treatment for ASD. ABA is effective across the lifespan, but early intervention is critical.

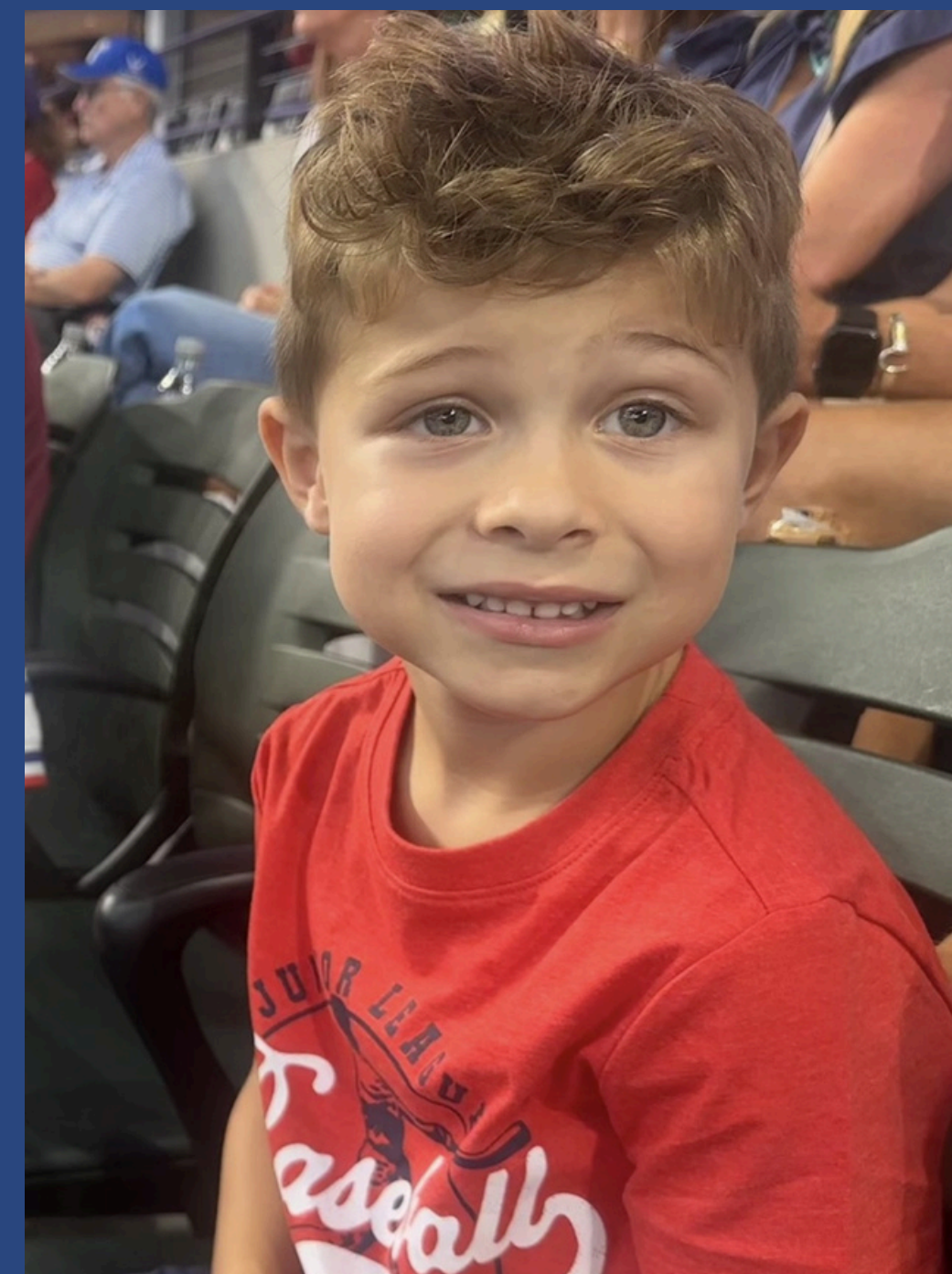
Outcomes

Early intervention can eliminate or reduce the need for ongoing treatment. However, when treatment is delayed, long-term or even indefinite intervention may be necessary.





Shaw Newman



Prevalence at Home



In 2023 Kentucky CHFS reported that, in western counties, Autism Spectrum Disorder is one of the top 5 most diagnosed conditions

CHFS Impacts by count legislative report for 2023;
<https://www.chfs.ky.gov/agencies/os/Pages/codat a.aspx>

Children	In McCracken County there are 9,920 children enrolled in Medicaid.
TOP 5 DIAGNOSES	<ul style="list-style-type: none"> Acute upper respiratory infection, unspecified Autism Spectrum Disorder Developmental disorder of scholastic skills, unspecified Developmental disorder of speech and language, unspecified Encounter for routine child health examination without abnormal findings
Children	In Marshall County there are 4,066 children enrolled in Medicaid.
TOP 5 DIAGNOSES	<ul style="list-style-type: none"> Attention-deficit hyperactivity disorder, combined type Autism Spectrum Disorder Contact with and (suspected) exposure to covid-19 Developmental disorder of scholastic skills, unspecified Encounter for routine child health examination without abnormal findings
Children	In Ballard County there are 1,007 children enrolled in Medicaid.
TOP 5 DIAGNOSES	<ul style="list-style-type: none"> Adjustment disorder with mixed anxiety and depressed mood Autism Spectrum Disorder Encounter for routine child health examination without abnormal findings Generalized anxiety disorder Other developmental disorders of speech and language
Children	In Carlisle County there are 777 children enrolled in Medicaid.
TOP 5 DIAGNOSES	<ul style="list-style-type: none"> Adjustment disorder with mixed anxiety and depressed mood Adjustment disorder with mixed disturbance of emotions and conduct Attention-deficit hyperactivity disorder, unspecified type Autism Spectrum Disorder Encounter for routine child health examination without abnormal findings

State of the Commonwealth

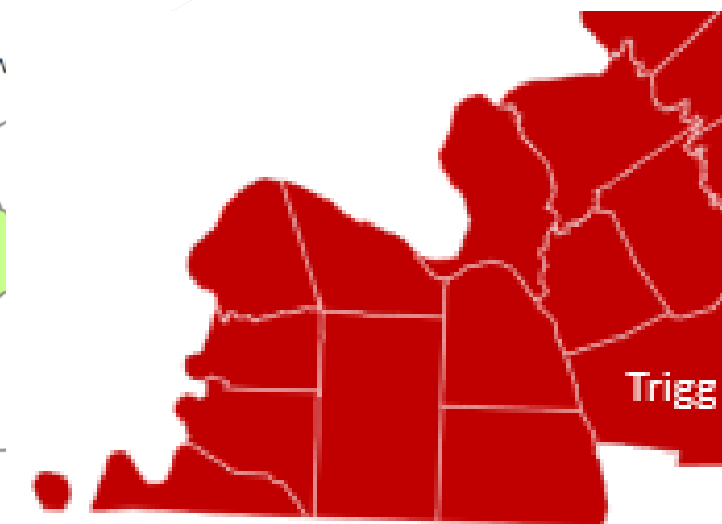


The methods used by payers today to calculate network adequacy are incomplete and provide an overly optimistic representation of what is happening in our communities. Frequently the methods of calculating adequacy are not aligned with the generally accepted standards of care and do not take into account multiple other factors.

2023 MCO Data



Reported Adequacy



Actual Adequacy

Actual adequacy is calculated by using the generally accepted standards of care published by the Council for Autism Service Providers.

Inaccurate Network Reporting

➤ KY Medicaid
Reported BCBA's

3253

➤ Actual Licensed
Behavior Analysts*

521

Commercial payers and Medicaid are reporting inflated provider networks for Behavior Analysts. This is leading to refusals to negotiate higher rates and unavailable services to children

*Q1 2023 DMS FOIA request



Factors Affecting Access to Care

ABA providers struggle to provide services to patients due to the evolving job market. Licensed Behavior Analysts are able to secure substantially higher salaries by adding a few minutes to their commute and providing services in our border states. Behavior Technicians who perform the actual therapy can earn more money working at fast food restaurants and gas stations where they are not subjected to the physically and mentally challenging environments that working with children and adults with severe behaviors often create.

➤ Long Waitlists for Diagnosis and Treatment

Why?

➤ Insufficient Participation in provider Networks

Why?

➤ Low motivation to treat Medicaid clients

Why?

➤ Rates not commensurate with rising employment costs



Efforts currently Underway

Understand

Bluegrass Alliance for Behavior Health "Autism Across Kentucky" survey released to understand barriers in the communities across Kentucky

Expand

Work with our community partners to expand awareness of the need for more behavior health professionals and encourage students to seek those degrees

Retain

Work with providers and employers to prevent the high rate of burn-out in the behavior health profession.

Advocate

Present resources to caregivers, payers, policymakers, and providers to educate them on the issues and ways they can help.

Attract

Make Kentucky a place where both clinicians and paraprofessionals can work and earn a competitive wage

How you can help

Increase Medicaid Behavioral Health Fee Schedule rates by at least 25%

This funding increase would enable providers to recruit and retain the needed workforce, which is currently unattainable due to the limited compensation they can offer.

- Behavior Technicians, the people implementing ABA therapy, make the equivalent to cashiers at quick service food and retail businesses.
- All behavioral health positions must offer professional pay standards to attract and retain high-quality staff.
- The turnover rate for Behavior Technicians is high, with many leaving for non-healthcare jobs, resulting in excessive overhead costs for behavioral health clinics.

Work with DMS to ensure compliance with federal requirements and enforcement of MCO contracts

Legislative collaboration and oversight can help direct MCOs to maintain adequate provider networks across all Kentucky communities.

- Inadequate behavioral health networks have persisted among MCOs, leading to months to years-long waitlists for services.
- An independent analysis of MCO networks shows an over reporting of access within Kentucky's Medicaid ABA networks

How you can help

Evaluate Kentucky's network adequacy laws to ensure access to care in all communities

Empower the Department of Insurance to enforce penalties for inadequate networks and ensure that health plans have sufficient qualified providers available.

- Current statutes and regulations are more focused on medical/surgical benefits and do not capture the specific needs of behavioral health providers.
- Behavioral health services are utilized far more frequently than medical and surgical care, requiring more precise network adequacy standards to ensure equal access.

Invest in the development and expansion of programs training clinicians for diagnosis and treatment

Fueling initiatives for universities to train more clinicians will help build the capacity needed for behavioral health diagnostics and treatment to meet statewide demand.

- Early, timely diagnosis and treatment is essential for Autism therapy to be most effective and least intensive.
- Far too few providers can diagnose and treat autism across the state.
- Due to the lack of providers, many families face months and years-long waits for these essential services. These wait and travel times far exceed Federal requirements.
- Behavior health is a growing field, but universities need support building these programs.