

AUTISM SPECTRUM DISORDER IN KENTUCKY

How Are Kentucky Families Affected by Autism?

Autism remains the fastest–growing developmental disorder in the United States, with one in 36 eight–year–old children identified with autism spectrum disorder (ASD)¹. In Kentucky today, tens of thousands of children have ASD diagnoses and far too many languish on waiting lists for medically necessary services, causing irreparable delays in their development, limiting their lifetime potential, and impacting their families' stability. Kentucky Medicaid's steep underfunding of ASD treatment–called Applied Behavior Analysis (ABA)–drives this severe restriction on access to care.

What Is Applied Behavior Analysis?

ABA is a highly structured and evidence–based therapy designed to improve specific behaviors in individuals with ASD and related intellectual and developmental disabilities. ABA has proven effective in enhancing communication abilities, social capabilities, and essential life skills and is the widely acknowledged standard of care for treating ASD, recognized by the American Academy of Pediatrics, the American Academy of Child and Adolescent Psychiatry, the National Institute of Mental health, and others.²

- ABA provides early intervention, allowing children to reach their full potential and reducing the need for more intensive, often more expensive, services later on.
- ABA teaches skills that allow individuals with ASD to lead more independent, self-sufficient lives.
- ABA services provide vital wellbeing lifelines that engage and strengthen families and ease the strain on the school system.

"[My child] was on the waitlist for about six to eight months. Since she's been receiving ABA services, she's been able to sit and complete a task. She tolerates having her hair brushed. She has gone from refusing to use the potty to being fully potty trained. She has progressed substantially."

 MOTHER OF 7-YEAR-OLD FROM INDEPENDENCE, KY Due to the underfunding of Kentucky Medicaid ABA reimbursement rates, families are waiting months—sometimes years—to access life-changing, medically necessary care.

What's Limiting Kentucky Access to ABA Services?

Kentucky is legally required to provide an adequate network of ABA providers—meaning children should not be placed on a waiting list for services. However, the demand for ABA services is skyrocketing while increasingly fewer ABA providers are able to accept Medicaid's low rates and others are at risk of closing due to operating with insufficient rates.

- Kentucky's most utilized ABA Medicaid rates are up to 26% lower than other states with similar demographic profiles, including our seven adjacent states, Illinois, Indiana, Missouri, Tennessee, Ohio, Virginia, and West Virginia.
- Additional states with recently updated ABA Medicaid rates include Arkansas, Colorado, Georgia, Iowa, Nebraska, and North Carolina.
- These disparities create a significant disadvantage when competing for employees with out-of-state providers offering higher wages and stifle our ability to offer the same network adequacy.



How can we help Kentucky children and families with ASD?

As the Kentucky General Assembly considers vital Medicaid rebasing measures, we urge legislative leaders to prioritize increasing the ABA rates within the behavioral health fee schedule by at least 25%, which will create closer parity with adjacent states, allow providers to compete with surrounding states for our critical workforce, and most importantly, create greater access to care for hundreds of Kentuckians struggling on waitlists today.

¹Center for Disease Control and Prevention's Morbidity and Mortality Weekly Report published on March 24, 2023

²Applied Behavior Analysis Practice Guidelines for the Treatment of Autism Spectrum Disorder published by the Council of Autism Service Providers (CASP), 2024

³50 State Applied Behavior Analysis Medicaid Benefit Comparison, Council of Autism Service Providers