



THRIVING
with RETT

ABA THERAPY GUIDE

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My name is Bailey Simpson, and I am a Board-Certified Behavior Analyst (BCBA) with experience providing in-home Applied Behavior Analysis (ABA).

Applied Behavior Analysis (ABA) is a well-established, evidence-based practice grounded in the principles of behavior science (Cooper et al., 2020). ABA Therapy can be beneficial for individuals with Rett Syndrome by focusing on the following areas:

- / Promoting functional communication
- / Improving quality of life
- / Teaching meaningful adaptive skills

Applied Behavior Analysis (ABA) principles can be applied effectively and ethically to individuals with Rett Syndrome when therapy is thoughtfully adapted to fit their unique physical and communication needs. Because Rett Syndrome significantly affects movement and speech, therapy should never assume a child “won’t” do something when they physically may not be able to.

Individuals with Rett Syndrome frequently experience apraxia and motor planning challenges that affect their ability to initiate or execute movements (Dy et al., 2015). Therefore, instead of focusing on compliance, ABA can prioritize building meaningful, practical communication skills, often using eye gaze devices or other augmentative and alternative communication (AAC) devices, so children can express choices, needs, and feelings.

The primary goal of ABA therapy should be to improve quality of life, reduce frustration, and help the child participate more comfortably in everyday routines.



For example, improving quality of life might include teaching a child to use eye gaze to choose between two favorite activities, request a preferred song or activity, or indicate when they want a break. It may also involve helping an individual participate more comfortably in daily routines like mealtime (e.g., signaling “all done”), bath time (e.g., choosing a toy to bring in the bath), or family outings (e.g., requesting a favorite activity or location) by breaking tasks into small, manageable steps.



Reducing frustration often starts with giving a child a reliable and consistent way to communicate. All behavior serves a communicative function (Cooper et al., 2020), and challenging behaviors may emerge when an individual lacks the ability to express needs or preferences. If a child cries or becomes upset because they can’t express hunger, discomfort, or even boredom, ABA therapy can focus on teaching a clear way to signal those needs. Such as looking at a “help” icon, requesting “stop” on a communication device, or using a yes and no response system. When communication becomes easier, challenging behaviors frequently decrease because the child no longer relies on distress to be heard and understood.

ABA therapy typically requires a formal diagnosis of autism spectrum disorder from a licensed healthcare provider to establish medical necessity and obtain insurance coverage. However, in some cases, children with developmental delays, ADHD, OCD, or other behavioral concerns may also receive ABA services.



To get started, parents can look for ABA providers by seeking recommendations from doctors, checking with their insurance company for covered providers, or searching online for local, suitable options. Once a provider is selected, a Board-Certified Behavior Analyst will conduct an initial assessment to evaluate the child's needs, identify any target behaviors and skill areas, and determine the appropriate structure and intensity of therapy. During the initial assessment, the BCBA will indicate how many hours of ABA are medically necessary, allowing families the flexibility to fit therapy into their child's routine.

Based on the evaluation and observation, the BCBA will develop an individualized treatment plan that will be altered and monitored on-going as your child progresses.



Disclaimer:

ABA therapy is widely used to support communication and adaptive skills. As with any therapy, approaches and experiences may vary, and families are encouraged to do their own research and work with providers who understand the unique neurological and motor challenges of Rett syndrome.

References:

Cooper, J. O., Heron, T. E., & Heward, W. L. (2020). Applied behavior analysis (3rd ed.). Pearson.
Dy, M. E., Waugh, J. L., Sharma, N., O'Leary, H., Kapur, K., & Marschik, P. B. (2015). Defining the nature and extent of motor impairments in Rett syndrome. *Developmental Medicine & Child Neurology*, 57(6), 528-535.