

In the order in which they should be presented.

Introduction

This is a toolkit to help parents decide if Applied Behavior Analysis (ABA) treatment is appropriate for their child. It is not meant to convince anyone that ABA is the best or a perfect treatment. The goal of this toolkit is to educate, so parents can make an informed choice and decide what is best for their child and family. The toolkit is made up of four sections: Stigma/Myths, How to Find a Good Provider, What is ABA, and How to Get Started. This toolkit was put together by a LEND (Leadership Education in Neurodevelopmental Disabilities) social work trainee at Children's Hospital Colorado.

What is ABA and who provides services?

- ABA
 - From Autism Speaks: “‘ABA’ stands for Applied Behavior Analysis. ABA is a set of principles that form the basis for many behavioral treatments. ABA is based on the science of learning and behavior. This science includes general “laws” about how behavior works and how learning takes place. ABA therapy applies these laws to behavior treatments in a way that helps to increase useful or desired behaviors. ABA also applies these laws to help reduce behaviors that may interfere with learning or behaviors that may [be] harmful. ABA therapy is used to increase language and communication skills. It is also used to improve attention, focus, social skills, memory, and academics. ABA can be used to help decrease problem behaviors.”
<https://www.autismspeaks.org/sites/default/files/2018-08/Applied%20Behavior%20Analysis%20Guide.pdf> for more information
- BCBA (Board Certified Behavioral Analyst)
 - A specifically trained individual with a Master's degree (BCBA-D means they have a doctoral degree) who has completed the necessary hours and training to be qualified to supervise other therapists and lead a treatment team.
<https://www.bacb.com/> for more information
- RBT (Registered Behavior Technician/Therapist)
 - A trained individual who will be working with your child directly. There are no higher education requirements beyond high school for this certification; to become an RBT someone needs to do 40 hours of training and pass an exam.
<https://www.bacb.com/> for more information

What will a session look like?

- Depending on your child's unique needs and the goals you have for them, ABA treatment can happen in your home, in a clinic, or in the community. The BCBA will provide you with a recommendation for the level of services; a typical ABA treatment plan will have

your child in therapy anywhere from 10 to 40 hours a week. It sounds like a lot, but consider this: if your child's behaviors are very intense, dangerous, or difficult to manage, those are 40 hours where you have a professional supporting you and you're not on your own. This might be difficult to manage if your child is in school; talk to your BCBA about the possibility of reducing the hours so it doesn't affect academics, or if their RBTs can work in the school with your child.

- There are many different interventions used with ABA therapy, but the theory behind all of them is the same. ABA is about the *antecedent*, or what comes before or what triggers the behavior. After the *behavior* there is a *consequence*, either the behavior is rewarded or reinforced.
 - There are many types of interventions and Autism Speaks has a booklet to explain some of them (and many other types of therapies not related to ABA).
- Example schedule:
 - 1:00-1:15: Pairing (Free play), Preference assessment
 - 1:15-1:45: DTT (desk time with breaks)
 - 1:45-2:15: Snack time, Clean Up, Pairing (Free time)
 - 2:15-2:30: Brushing teeth
 - 2:30-3:00: Functional communication training (FCT)
 - 3:00-3:30: Social skills group
 - 3:30-4:00: Gross motor activities
 - 4:00-4:15: Life skills
 - 4:15-4:45: NET (activities change based on day and child preference)
 - 4:45-5:00: Clean up, Pairing (free play)
- What does ABA work on?
 - Effective communication skills, like conversation and self-advocacy
 - Emotional regulation, i.e. reducing outbursts
 - School difficulties such as focus and impulse control
 - Self care tasks
 - Transitions
 - Reducing instances of self-injury and aggression towards self and others
 - Pro-social skills, i.e. sharing, turn taking

Stigma

The goal of this section is not to dispel every myth and stigma stated on the internet. Rather, this section is meant to serve as an educational tool to help parents and caregivers think about ABA as one of many evidence-based interventions meant to support the healthy functioning of children and individuals with ASD and I/DD.

The main goals of ABA, regardless of individual or specific goals, are to improve communication and emotional regulation/impulse control and grow your child's adaptive and social functioning skills. However it looks, strengthening these skills leads to improved

outcomes for children with autism. ABA should also be individualized to your family, and always working on the family's or individual's goals.

Emotional regulation

If a goal in ABA is to reduce occurrence of meltdowns, for example, what is really being targeted is emotional regulation (ER). The better a child is at implementing strategies to emotionally regulate, the more positive outcomes they will have in areas like psychological wellbeing and social functioning. Findings suggest that better emotional regulation leads to decreased symptomology related to social functioning (basically, better E.R. means better social functioning, which could mean more/better/healthier friendships, ability to navigate the world, work, and vocational functioning).

Communication

Another goal of ABA might be to work on communication skills, like asking before taking something or identifying thoughts and feelings. Good communication skills allow all of us to get what we need, express ourselves, and make friends.

Navigating information

Sifting through all the information available can be tricky and overwhelming. Here are some tips for when you're not sure if what you're seeing is legitimate

1. Be skeptical
 - a. Who wrote this? What is the position of the website? Do I trust them?
2. Slow down
 - a. Is this autistic individual like my child? Is this parent/family like me/mine? How is the emotion of this blog/article/etc impacting me?
3. Separate facts from opinion
 - a. What's coming from a place of emotion, and what is a statement of fact based on science, evidence, or real events? What gives this person authority to speak on this?
4. Resist confirmation bias
 - a. Am I seeking out opinions different from my own, or am I just reading things that I already agree with?

Important to note: these tips aren't just about ABA! Think about what you'd tell your child about information they find on the internet. This can be a very emotional topic for some, and it's good to consider and respect a variety of opinions. Remember to use these tips to keep your focus on the goal of determining whether or not ABA is right for you, your child, and your family.

How to Get Started

This information is to help you decide if ABA makes sense for you and your family. These sections will guide you through thinking about how ABA could help your child learn and grow, if ABA is the right option out of all the therapy options you have, and what to consider when it comes to insurance.

Step 1: Decide if ABA is an appropriate treatment for your child. Here are some things ABA can help with:

- communication and social interaction
- self-care tasks, such as how to get dressed or going to the bathroom independently
- Challenges in school and other community environments (i.e. behavioral outbursts, running away, following directions)
- transitions and deviations from the usual routine
- identifying and communicating basic emotional states
- challenging behaviors such as aggression or self-injury

Step 2: Other important things to consider:

- Considering the time requirements of ABA, will your child and family have time for much else outside of school and therapy? Are there other priorities you have, like the social and emotional benefit your child gets from extracurriculars?
- The younger you start with ABA, the quicker your child will pick up new skills
- There is no such thing as “too high-functioning” for ABA. A treatment program should be individualized to meet your child’s particular strengths.

Step 3: Consider possible goals for treatment.

- Goals for your child
 - Better focus at school/when doing homework
 - Communication skills like asking for what they want and communicating their wants and needs
 - Reducing or stopping self-harming behaviors
 - Increased independence in daily living skills
- Goals to improve your child’s and family’s quality of life:
 - Reducing tantrums or other outbursts
 - Pro-social skills like sharing
 - Reducing or stopping aggressive behaviors
 - Other goals for participating in things that are important to the family, like being safe during outings and sitting at the dinner table

ABA and Insurance

- *Health First Colorado* has a list of current providers who accept Medicaid here: <https://hcpf.colorado.gov/pediatric-behavioral-therapies-provider-list>. This list is broken up by in-home and clinic-based providers, and is maintained by the state. If it is easier for you to search providers by city, here is CHCO Developmental Pediatrics’ list of providers (updated March 2022).
- Most ABA agencies accept Medicaid. Colorado’s Medicaid program covers ABA treatment for individuals with a diagnosis of ASD or I/DD through age 21. **A letter of medical necessity from your child’s primary care provider is required for agencies**

to bill your insurance. If your child is not already on Medicaid, you can apply for coverage through the *buy-in program* (more information here: <https://hcpf.colorado.gov/medicaid-buy-program-children-disabilities>) or with your local community center board through the *CES waiver* (more information on CES here: <https://hcpf.colorado.gov/childrens-extensive-support-waiver-ces>; find your community center board here: <https://hcpf.colorado.gov/community-centered-boards>).

- Some agencies accept other insurances as well, although you will need to check with your insurance provider to find out how much they cover and for up-to-date provider information. Thanks to *HIMAT (Health Insurance Mandated Autism Treatment)*, insurance companies have to cover ABA treatment as a “medically necessary” intervention for autism. There are different rates of coverage based on age, hours, and insurance, and ABA companies should run your insurance and give you a cost estimate before you start services with them.

If ABA still doesn’t feel like the right fit for you and your child, don’t worry! There are other treatment options that can work on many of the same things as ABA.

- Occupational Therapy
 - Tasks of daily living like hygiene, toileting, social skills, eating
 - Fine and gross motor skills
- Physical Therapy
 - Fine and gross motor skills
 - Walking, running, jumping, and all skills involved in playing and athletics
- Speech Therapy
 - Social skills
 - How to start and carry on a conversation
 - Forming words and sounds
 - Eating/feeding therapy

How to Find a Good Provider

Just as important as the type of therapy is the person providing it. When looking for a provider, it’s helpful to know what to ask and what to look out for. You’re hiring this person, or team of people, for a job, and you want to make sure they’re a good fit to work with your family and child. We suggest interviewing at least two to three providers to start. You know your child best and are the expert on your family, so follow your instincts to pick the provider who’s right for you.

Important questions to ask a provider:

- Where are the specific services they provide? Can you tour the center (if doing in-center).
- Who will be working with your child? Ask if the team is led by a BCBA.
- How are goals created and progress measured?

- Do they provide services outside of ABA therapy (like advocating at IEP meetings or having speech or occupational therapists on staff).
 - How will they address specific behaviors (i.e. aggression and self-harming).
 - What is your role in treatment going to be as the parent?
 - What are your family's values, and how will ABA support you living out those values?
- See our complete list of questions if you want to get into more detail with your interview.

Red Flags ▶ Be concerned if you come across any of the following:

- **It's not an evidence-based practice**
 - Be wary of programs that haven't been proven to be effective through research. ABA is evidence-based, but if they're calling it something else, be sure to double-check that studies have been done on the method's efficacy.
- **There isn't any data collection**
 - ABA relies heavily on data collection. If you're not being shown data on a regular basis to be able to see improvement in numbers, something's not right.
- **Therapists aren't receiving supervision**
 - Supervision doesn't necessarily mean somebody watching them work with your child every day. Therapists, or RBTs, should be meeting regularly with the BCBA to discuss interventions, problem solve difficulties, and create goals for professional training and growth.
- **Your child has a "one size fits all" treatment plan**
 - Your BCBA or treatment team might specialize in working with children under six or who have aggressive behaviors, but that doesn't mean that they should be using the same plan with every client. You should have an individualized treatment plan that focuses on your goals and your child's needs and interests.
- **There is a lack of positive reinforcement techniques and/or punishment is used.**
 - Learning should happen through positive reinforcement, such as praise and reward systems. Punishment is NOT considered a normal or acceptable practice within ABA. Policies on restraints to maintain safety will vary from agency to agency, but they should only be used if someone is in immediate danger and other attempts at de-escalation have failed.
- **Your treatment team is more focused on getting rid of "bad" behaviors, and less focused on building new skills and strengthening existing ones.**
 - Not all "autistic behaviors" (i.e. stimming behaviors such as hand flapping) are bad, so be concerned if a therapist is pushing to "fix" or get rid of these behaviors.
 - ABA sessions should not be about changing your child and taking away the things that make them who they are.
 - There's a lot of focus on getting rid of behaviors considered problematic, and little on development of new skills and behaviors.

“Parent Bill of Rights”

You have the right to:

- **File a complaint**
 - You can file a report of alleged ethics violations here:
<https://www.bacb.com/ethics-information/reporting-to-ethics-department/>
- **Fire them and find a new provider**
 - This goes for any provider. If it’s not working, it’s totally fine to *find someone who might be a better fit*.
- **Give your child a break**
 - You know the difference between when your child is just unhappy and when they’re starting to really escalate. You’re allowed to put on the brakes when you feel the need.
- **Have goals that are based on your priorities for your child and that you willingly and enthusiastically agree to, and that you fully understand**
 - You don’t have to agree to a goal that wasn’t your idea and that you don’t see as necessary. *You can also change goals as you go*. Don’t feel pressured to sign off on goals that you’re unsure of, or that you don’t completely understand.
- **Demand change if things aren’t working**
 - If your team wants to keep trying something, ask why and work out a time frame for when progress needs to be made and, if it isn’t, when you’ll switch tactics.
- **Have a plan that is focused on “improving socially significant behavior”**
 - Your treatment plan should be centered around *building skills, not taking away aspects of your child’s personality* or eliminating behaviors that aren’t causing harm.
- **Ask for, and be given, progress reports**
 - ABA is based on *data*, and your team should be prepared to share that data with you. Feel free to *ask for the raw data, not just their interpretation of it*.

Tips for working with providers

- **Communication is key**
 - Be honest with your team and tell them what you want and what isn’t working, and keep telling them
- **ABA happens everywhere**
 - Be consistent with the skills your child is working on with their therapist, and practice them everywhere you can to increase their learning opportunities
- **Brace yourself for change (and probably some challenges)**

- A therapist may ask you to do some things a little differently, but the “why” and “how” of these changes should be clearly and respectfully communicated to you, and it should be done for the purpose of helping your child build their skills
- **Know about “Extinction Burst”**
 - Be prepared for behaviors that you might be trying to reduce to increase for a short time, either after initially starting therapy or after a short period of improvement. This is called an “extinction burst” and it’s a fairly common occurrence. If you want to know more about how and why this happens, this blog post has a good explanation with examples:
<https://evoketherapy.com/resources/blog/phil-bryan/extinction-bursts-its-going-to-get-worse-before-it-gets-better/>
- **Be a team player**
 - You’re an important part of the treatment team! This is your child, your family, and possibly your home where therapy is happening. If you need to assert yourself, don’t be afraid to do so. Your voice matters, whether you’re advocating for yourself or your child.
- **Remember that BCBAs make recommendations that are empirically validated**
 - There should be a reason why certain interventions are used, so ask your team if something doesn’t make sense
- **Even the best schedule will have its challenges**
 - ABA takes a lot of time, and some days it might feel hard to fit everything in or keep up a consistent routine. Communicate with your team if you’re feeling overwhelmed.
- **Help yourself**
 - Remember to take care of yourself, too! Easier said than done, but even doing the smallest things can make a big difference.
- **Practice everywhere**
 - The more you practice skills with your child, and the more places and situations where you practice them, the better you’ll both get at using the skills.
- **Listen to your child**
 - This is especially important for children who struggle with communication. Tell your treatment team what you’re seeing and hearing from your child, whether it’s during treatment times or not.
- **Ask for feedback**
 - Use your treatment team as a sounding board. What else can you be doing to practice skills? Is this toy useful, or would this one be better? Do they have advice for reading material to learn more about autism and ABA?
- **Don’t:**
 - Skip appointments

- This is inevitable sometimes, but it's important to try your best to make it to your ABA sessions and communicate in advance if something comes up (especially if someone is coming to your house for the appointment).
- Use Punishment
 - Punishment is not considered an effective way to teach skills. Reward is far more effective and less likely to cause harm.
- Backslide
 - Keep working on practicing those skills and reaching for your goals! You might feel like giving up when you're tired or not seeing progress. When this happens, it's best to take a break and ask for those data reports to see that progress really is happening, even if it's hard to see in the moment. Don't give up on the skills or goals just yet.
- Accelerate
 - At the same time, don't push too hard. Progress takes time, and your child will build skills and learn at their own pace.

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