

Contents

Section 1: Introduction

Section 2: ABA in the Autism Community

Listening to the Autism Community

Negative Comments

Positive Comments

Mixed Reviews

Difficulty with Body Control

Advice From a Non-Speaker

Section 3: What Professionals Say About ABA

About ABA

Goals of ABA

About ABA Providers

Unique Support

ABA and Age Groups

Importance of Working Together

Section 4: Conclusion

Making Informed Decisions

Quality Indicators

Section 1: Introduction

The Autism Society of America helps people with Autism by giving them the resources they need to live their lives to the fullest.

Everyone with Autism is different and has different needs and goals. It's important for everyone to have information they can understand when deciding what kinds of services and supports they want to help them meet their needs and reach their goals.

One type of therapy called Applied Behavior Analysis (ABA) is sometimes recommended for people with Autism. There are different opinions about whether ABA is good or bad.

The Autism Society wanted to help people learn about different perspectives and make informed decisions.

The Autism Society worked with experts, Autistic people, families, and caregivers in the Autism community to develop this resource.

This resource has information about:

- ABA
- The history of ABA
- The purpose of ABA
- ABA practices
- People's good and bad experiences with ABA
- Things to look for if you're choosing ABA
- Questions to ask ABA providers

The Autism Society believes that people with Autism and their families should be able to make their own decisions about which supports and services to use. No matter what services a person chooses, they should promote independence, inclusion, and a better quality of life.

There have been concerns about ABA in the past, such as the use of electric shock for punishment. The Autism Society is strongly against electric shock for punishment. We work to promote laws and policies that protect the human rights and civil rights of people with Autism.

Section 2: ABA In the Autism Community

Listening to the Community:

The Autism Society of America hosted "Town Halls" to listen to the Autism community. We listened to Autistic people, parents, and specialists talk about ABA. Hundreds of people wrote to the us to share their ideas and experiences about ABA.

The "Town Hall" meetings showed that people have different opinions about ABA. Some people said good things and some people said bad things. The most important thing was why people were doing ABA. If they were trying to make Autistic people seem less Autistic, it was bad. But if they were trying to help people stay safe and have a better life, it was good.

Negative Comments:

What were the most common negative things that people shared about their ABA experience?

1. A Focus on "Normal" Behavior

Some people worry that ABA therapy tries to make Autistic people seem "less Autistic." They worry that ABA only focuses on making people act like people who don't have Autism. They think that is wrong and harmful because it could hurt people's mental, emotional, or behavioral health.

- ABA was a really bad experience for me. As an adult, I'm still working on feeling better after being forced to change who I am.
- ABA teaches you to do what others want, even if it's not safe. That's a really bad thing for people with Autism who are already at risk for getting hurt.
- The idea behind ABA is that Autism is a bad thing that needs to be fixed. That's not true! We're just different and that's okay.
- Trying to hide my Autism has made me very tired and caused me a lot of problems with my mental health.

2. Quality of ABA Services

Some people worry about the quality of ABA services. Sometimes, insurance only pays for ABA therapy, but not all ABA therapy is the same. Different places and people who do ABA do different things. They have different rules, ways of teaching, and how they make sure things are good. This can be a problem because not all ABA is high-quality and everyone deserves the best quality of care.

Ideas and experiences people shared about this:

- Some people who help kids with Autism are only in it for the money.
- It is important for kids to get help early. But if the people helping aren't well-trained, it causes more problems.
- ABA can be really helpful if it's done right by people who know what they're doing.
- We need better rules to make sure only qualified people work with our kids.

3. Not Enough Teamwork

Some people worry that therapists and other providers aren't working together. Sometimes people get help from different doctors and therapists, but they don't always work together. This can be a problem because everyone is different and needs different things.

Some people with Autism only get ABA therapy, but this is not always the best way to help. People have different cultures and beliefs that need to be respected. If doctors and therapists work together, they can help make sure everyone gets the help they need.

- My child did better once they started seeing doctors and therapists who understood their anxiety and worked together.
- Speech therapists can help with different kinds of talking and communication for people with Autism. These specialists should be included in ABA therapy, too.

Positive Comments:

What were the most common positive things that people shared about their ABA experience?

1. Learning New Skills

People who had ABA therapy said it helped them learn new skills, like talking and making friends.

Ideas and experiences people shared about this:

- I used to have trouble with talking and asking questions at the doctor, but ABA helped me feel more confident.
- ABA helped my child stop running away and express themselves better.
- ABA helped my child make friends and behave better in school.

2. People Working Together

When different people work together to help someone with ABA, it can make a big difference. Families and providers need to communicate to make sure the person is doing well. When everyone is on the same page, it can make the therapy work better.

- My helpers were like my family. They knew me really well and helped me with my problems. They even knew when I wasn't feeling well. They taught my mom how to help me too.
- My therapists talk to each other to help me get better. When I felt scared or uncomfortable with something we were working on, they listened to me and changed it. I feel better now, and I'm doing well

3. Person-Centered-Planning

The person getting ABA therapy should be at the center of planning. Person-centered-planning means helping a person reach their own goals and do things they like, instead of trying to change them. It's like a team where the person getting help is the leader and they work with their family, helpers, and therapists. The team listens to the person's ideas and makes a plan together to help them do what they want to do.

Ideas and experiences people shared about this:

- The person who helps me is really great! They make sure we do things that I like and include my family.
- I get to choose what we work on with my helper. Sometimes I even get to come up with my own ideas. We work together to make a plan that works for me.

More ideas and experiences:

1. Mixed Feelings

Some people have mixed feelings about ABA because they noticed both good and bad things happening.

- I became less nervous in social situations at work...but it also made me feel more anxious in the long run.
- I think ABA can be helpful, but it needs to be done very carefully. People have to pay close attention to see if it's helping or hurting someone.
- It's important to understand how Autism affects communication and the senses.
- It's important to deeply understand Autism before addressing behaviors.

2. Difficulty with body control

Some Autistic people have trouble planning how to move their bodies or talk. This can make it hard to do things or say things they want. Doing the same thing over and over again can be stressful and uncomfortable for them. If someone with these difficulties gets ABA therapy, it's important for the ABA team to include communication and movement specialists.

3. Advice from a non-speaker

There are many people with Autism who are non-speakers, which means they cannot talk to communicate. Some non-speakers can't talk because they have trouble controlling their body movements. This can make ABA hard because they can't talk or move in the way they want to show they understand. Not all people who cannot talk to communicate has an intellectual disability. ABA providers need to believe in a person's ability whether or not they talk to communicate.

Section 3: What Professionals Say About ABA

About ABA therapy

ABA therapy is a way to help people learn new skills and improve behaviors that make their life hard. People who do ABA therapy use proven methods to help with things like playing, self-care, talking to others, and more. They can help with hard behaviors, like hurting themselves or being mean to others. ABA can be used in different places, like schools, clinics, and homes.

There are a lot of practices used by ABA therapists that have their own names and abbreviations. They include:

- DTT: Discrete Trial Training
- PRT: Pivotal Response Training
- VBT: Verbal Behavior Training
- NET: Natural Environmental Training
- FCT: Functional Communication Training
- PECS: Picture Exchange Communication System
- Visual Supported Instruction

There are therapy models that also include ABA practices that have their own names and abbreviations. They include:

- PBIS: Positive Behavior Interventions and Supports
- NDBI: Naturalistic Developmental Behavioral Interventions
- ESDM: Early Start Denver Model
- JASPER: Joint Attention Symbolic Play Engagement and Regulation
- RIT: Reciprocal Imitation Training

The Goal of ABA:

ABA therapy helps Autistic people learn important skills to live their lives on their own and make their lives better. It can help with physical and mental health, safety, independence, and relationships.

The goal is not to "cure" Autism.

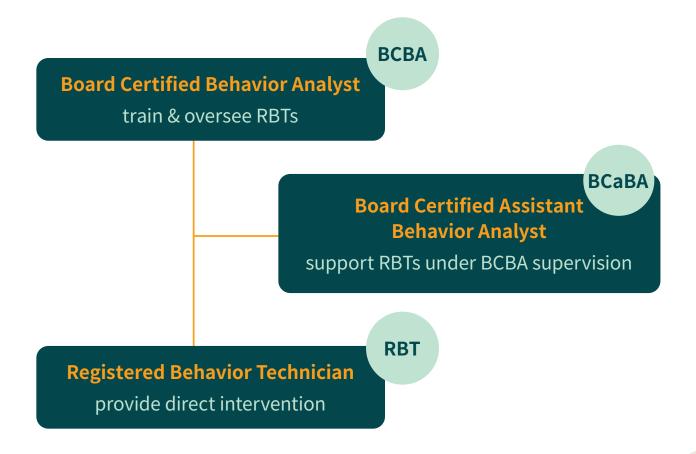
About ABA Providers:

To be an ABA provider, a person needs special training. They have to pass a test to become a Board Certified Behavior Analyst (BCBA). A BCBA might work alone or with other ABA providers in a center.

The BCBA is in charge of training and supervising Registered Behavior Technicians (RBTs). RBTs can help provide ABA therapy. The RBTs must be supervised by the BCBA for at least 5% of the ABA service hours they provide.

Some BCBAs work with an assistant (BCaBA), who has more training than an RBT but less training than a BCBA.

Whether you work directly with a BCBA, or get help from a team of specialists, the goal is always the same. The goal is always to improve a person's health, independence, and quality of life. The specialists working with the person will do many things. They will keep track of data and communicate with the person, their family, and the team.



BCBA Code of Ethics

BCBAs have rules they follow to make sure they do what's best for their clients. They make their client the most important, even if that means they need to change their plan. BCBAs work with other specialists who know different things to make sure they do the best job. This means they only work on things they are good at, and ask for help from other specialists if they need it. It's important for BCBAs to work with people from different jobs like teachers, doctors, and therapists. This helps them to set the best goals for their clients.

Unique Needs

Each person with Autism is unique, so the amount of ABA therapy they need is also unique. Some studies found that the amount of ABA a child gets each week can affect how much they learn. But, other studies found that the exact number of hours doesn't matter. That's why it's important to make sure that each person has unique supports that meet their unique needs, goals, and values.

ABA and Age Groups

ABA therapy can help kids, teens, and adults with Autism learn important skills that improve their lives.

Young kids can learn skills in different areas like talking, playing, and moving around. It's important to teach these skills where they will use them, like at home, school, and in the community.

Older kids and teens can learn skills for things like making friends and getting around their community.

Ideas and experiences people shared about this:

 Adults with Autism can also benefit from ABA therapy, but it can be hard to find and pay for. But no matter how old someone is, they can always learn and make progress with ABA therapy.

Working together is important

It's important for different kinds of doctors and therapists to work together to help people with Autism. They should each do what they're best at and talk to each other a lot to make sure they're all helping in the best way.

Different doctors and therapists can help with things like talking, moving, and understanding things. If someone who isn't trained in a certain area tries to help with therapy, it could be bad for people with Autism.

Providers have different strengths:

A provider is a person like a doctor, speech therapist, occupational therapist, or ABA therapist. It's important for providers to only work on things they know a lot about. If they don't know something, they should ask someone who does.

Some doctors and therapists have more than one type of training, which makes them extra knowledgeable. But when lots of people are helping one person, they should all talk to each other and work together. When different providers work together, it's important that they each do what they are best at.

Working together looks like:

- All the providers work together and help each other in all places where the person needs care.
- Providers communicate a lot with each other and with the person and family.
- If a provider doesn't know how to help with something, they should ask another helper who knows more about it.
- All providers should talk to each other often and talk about what is going well and what could be better.
- The providers should make sure to talk to each other and not make it the person or their family's job.

Section 4: Conclusion

There are many therapies and teaching methods. There isn't one therapy or method that is best for everyone with Autism. Everyone is unique. It's important to look at different choices and think about what's best for you or your child. Some people don't use any therapy at all. ABA is one type of therapy, and it's being studied and made better, but it's not the only therapy.

When looking at your choices, be careful of people who promise big results or say they can cure Autism. Ask for scientific proof that their therapy works. Talk to people you trust who know you or your loved one well and ask for their advice. It's okay to ask for help from people who aren't involved. Ask others who have used the same therapy, or contact the Autism Society in your area.

Learn more about our "Making Informed Decisions" and "Guiding Principles For Selecting Interventions and Therapies."

For additional resources or information, please visit the Autism Society of America's website at www.AutismSociety.org, or contact our National Helpline to speak to a trained Information and Referral Specialist at, 800-3-AUTISM (800-328-8476), or info@autism-society.org.

GREEN FLAGS:

If you're looking for a good ABA provider, here are some things to look for:

- A supervisor checks on the therapy often
- They make goals and plans that are just for you
- They focus on goals that help you in your daily life
- They know a lot about Autism
- They understand that different people with Autism have different needs
- They care about you and want to be your friend
- They work with other people like teachers and doctors
- They come to important meetings
- They write reports that are special for you
- They focus on goals that help you do things on your own
- They ask you what you like and try to include those things in the therapy
- They can recommend other experts if you need extra help
- They can work with your schedule and other services
- They let you pick some activities during therapy

YELLOW FLAGS:

If you see these things happening, you should talk to your ABA provider:

Workers leaving often. Sometimes it's normal for workers to leave, but if it happens a lot, you can ask:

- What will happen if my therapist leaves?
- How long do workers usually stay?
- Why do workers like to work here?

Too much of one type of teaching. This can happen if your therapist uses a lot of flashcards and drills. If you're worried, you can ask:

- How do you use different kinds of teaching?
- Can you teach me/my child in a different way?
- Can you show me how you teach in a natural setting?

Too many hours of therapy. If your therapist recommends 30 or more hours of therapy a week, you can ask:

- How do you decide how many hours of therapy I need?
- Can we reduce the hours later?
- Can we schedule ABA around other therapies?

If the ABA provider or agency is not owned by ABA clinicians, you can ask:

- Who is in charge of the agency?
- How much training and supervision do the workers get?
- What if I don't like my worker?

RED FLAGS:

These are signs that the service you are getting might not be the best. Remember that it doesn't always mean the provider is low-quality, but it's important to be aware of these things:

Be careful of providers who make big promises about outcomes or "cures" and ask them for proof.

- Goals are only to make the person act like everyone else instead of helping them be themselves and meet their goals
- They don't help non-speakers learn how to communicate
- They only use flashcards and drills to teach
- They don't keep track of how well the person is doing with their goals
- The people working with the person aren't trained well enough
- The therapy doesn't help the person use what they learn in different situations
- They only try to stop bad behavior without teaching new skills
- You can't observe or join in on sessions
- They don't have a plan for the person to interact with others
- The person with Autism gets upset or anxious during sessions
- The person with Autism has an increase in challenging behaviors
- They don't work with other specialists like speech pathologists or occupational therapists

(Red flag questions on next page.)

If you notice these red flags, these are questions you can ask your provider:

- Can I observe or invite someone to observe the next session?
- Who else are you working with?
- How are you using what other specialists have suggested in the program?
- Can we talk about how things are going with the goals we set?
- When is the next visit from the supervisor?

ABA Commission Members and Contributors:

This document reflects multiple viewpoints of the Autism community, the Autism Society of America, and our many contributors, and not the opinion of any specific contributor. Please note that hundreds of ABA Town Hall contributors are not listed directly due to privacy considerations. Additionally, the list below does not reflect the entirety of the ABA commission and contributors due to privacy preferences.

The "easy read" document has been adapted from our original ABA Resource document, which was developed by the contributors listed below. Additionally, please refer to the original document for a full list of references.

- Sam Brandsen
- Geraldine Dawson, PhD, Professor of Psychiatry and Behavioral
- Michael Gilberg, Esq.
- Andrew Glover
- Kris Guin
- Nicole Miller
- Kiya Olson, MA, MS, BCBA, LCPC

- Nanette Perrin, LBA, PhD, BCBA-D
- Dr. Cathy Pratt, BCBA-D
- Christine E. Reeve
- Chloe Rothschild
- Dr. Jack Scott, PhD, BCBA-D
- Régine Théodore
- Jennifer Twachtman-Bassett, M.S. CCC-SLP, CCRP
- Diane Twachtman-Cullen, Ph.D, CCC-SLP
- Jessica Winkler-Steinkamp, BCBA
- Patricia Wright, PhD, MPH

The connection is you. ™



Autism Society

ABA Resource © 2023 Autism Society of America