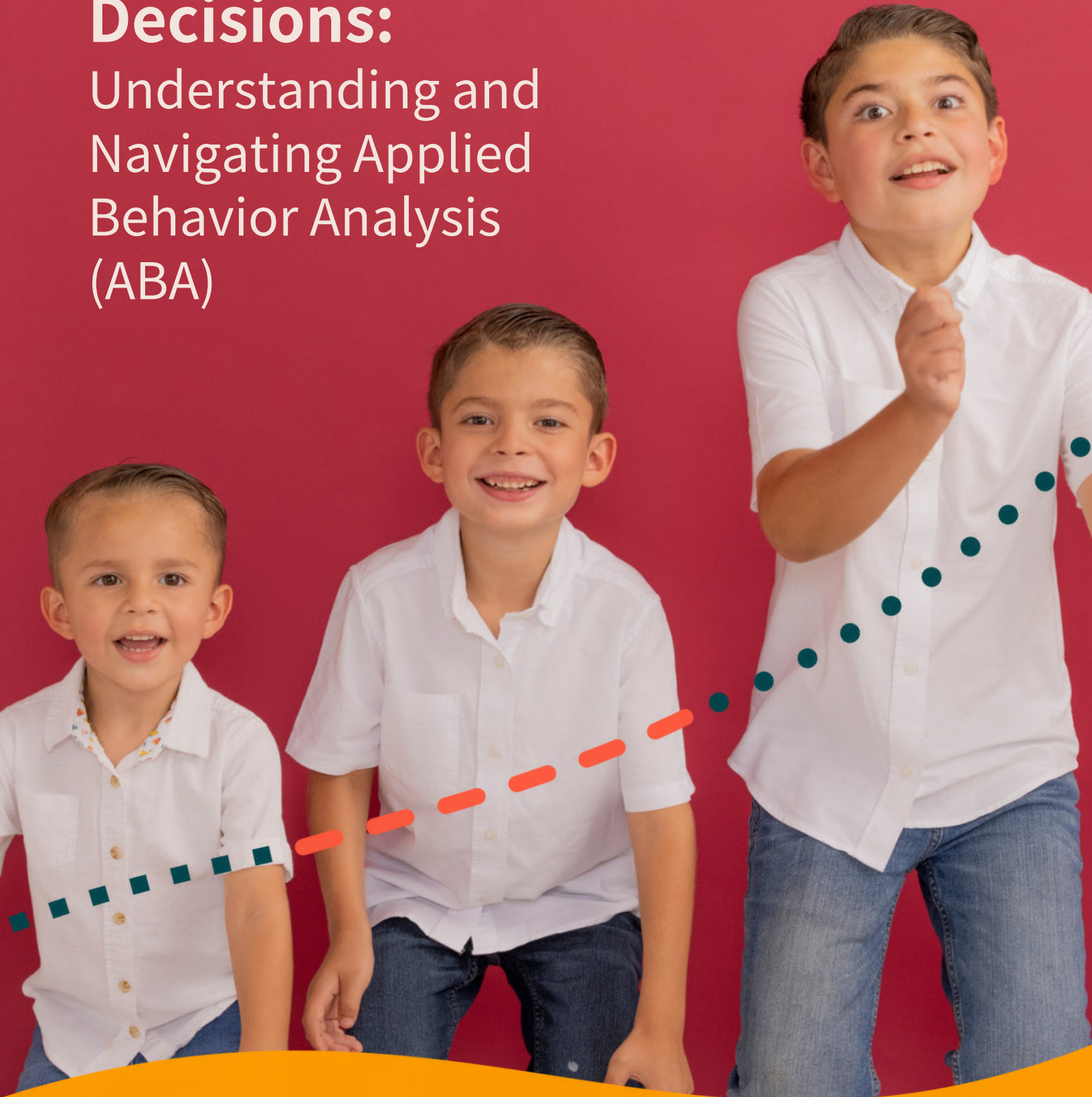


Making Informed Decisions:

Understanding and
Navigating Applied
Behavior Analysis
(ABA)



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Section 1: Introduction

The Autism Society of America’s mission is to create connections, empowering everyone in the Autism community with the resources needed to live fully. We know that everyone in the Autism community has a unique experience and different needs, hopes, and dreams. To make important decisions about services and supports, everyone deserves to access information that they can trust and understand.

Language Considerations

Just as there are different ways to experience Autism, people describe themselves and Autism in different ways. This includes person-first language such as “I am a person with Autism,” and identify-first language such as “I am Autistic,” along with other phrases. At the Autism Society of America, we honor individual preferences and use both person-first and identity-first language. We use a capital A when writing “Autism” to increase understanding of Autism as a culture and community with diverse identities.

What is ABA?

Applied Behavior Analysis (ABA) is a type of therapy that has been recommended for some people with Autism. There are different opinions about the practices of ABA with some people describing ABA as very good, and others describing ABA as very bad. The Autism Society works to provide information to help people make informed decisions about what services and supports are right for them.

Why did the Autism Society create an ABA Commission?

To help people make informed decisions about ABA, the Autism Society of America created an ABA commission. The ABA commission worked to learn about different perspectives and provide impartial guidance in this resource.



This resource includes:

- **Information about ABA, its history, purpose, and practice**
- **Information about different opinions and experiences** from people who have had good and bad experiences
- **Information that helps people to advocate for the best services** and supports for themselves and/or their loved ones.

The Autism Society has a **Making Informed Decisions** policy that suggests that it is up to each person and family to make decisions about interventions and services. This document is not an endorsement or opposition to ABA. No matter what services a person chooses, they should promote self-determination, inclusion, community engagement, and a better quality of life.

Historical Concerns

There have been concerns about ABA in the past, including that it was connected to conversion therapy with a focus on making people with Autism seem more like non-Autistic people. Other concerns include the use of aversive punishment procedures, like electric shock.

Position on Aversives

The Autism Society strongly opposes the use of aversive punishment procedures, like electric shock which was once used in ABA but is now banned in all but one institution and **described as unethical** by the Association of Professional Behavior Analysts. The Autism Society of America works to promote laws and policies that protect human rights and civil rights of people with Autism to live freely, without the risk of harm.

Section 2: ABA In the Autism Community, Outreach and Outcomes

Outreach

The Autism Society of America held virtual Town Hall events to listen to the experiences and perspectives of Autistic individuals, parents, and professionals regarding ABA. In addition to hearing the lived experiences of people during the Town Hall events, the Autism Society reviewed hundreds of personal stories that were shared with them.

Outcomes

The outcomes of these outreach efforts showed a wide range of perspectives, with key themes that include both positive and negative experiences of ABA. While some feedback identifies issues related to ABA practices, the biggest shared concern focused on the goal or purpose of ABA. When ABA was practiced with a goal to help people with Autism appear less Autistic – negative outcomes were identified. When ABA was practiced by a collaborative and person-centered team, with the goal of skill-building for safety and improved quality of life – positive outcomes were identified.



Common Concerns

The following concerns were frequently identified from the stories shared by Autistic individuals, parents/caregivers, and professionals about their experiences with ABA.

1. ABA therapy’s focus on neuronormativity

Neuronormativity is the idea that neurotypical brains are “right” and neurodivergent brains are “wrong.” If ABA focuses on trying to “normalize” an Autistic individual or behavior, there can be negative outcomes, such as trauma responses, masking, and other harmful mental, emotional, or behavioral consequences.

Below are examples of some of the views that were expressed by Autistic ABA recipients.

“My experience with ABA was traumatic. As an adult, I am still healing from the wounds inflicted on me by the ‘normalization’ process.”

“ABA corrodes trust, teaching harmful lessons that prioritize compliance. As Autistics, we are already at higher risk of sexual assault. Being taught to suppress your own feelings of safety for someone else’s approval is a very dangerous lesson.”

“As a society, we need to stop viewing Autism as a deficit or something that just needs to be fixed. We are just as human as anyone else—we just interact with the world in a different way.”

“The underlying lesson being taught is that Autistic people are ‘abnormal,’ and that we must change in order to fit into society, be accepted, or be respected. This contributes to feelings of inferiority, and masking that reinforces anxiety and depression.”

“Masking my Autistic traits has led to burnout, chronic fatigue, and severe mental health issues that continue to impact me as an adult.”

2. Lack of quality control, consistency, and oversight of ABA providers

Sometimes ABA is the only intervention that is covered by insurance, and this can become a problem because not all ABA services are the same. Different providers and centers have different values, models, training requirements, and quality-control measures.

(See quote on the next page.)

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“This field has become so money driven. Early intervention is key but not for children receiving services that claim to be ABA when it’s not. ABA can be very effective if it is implemented by trained professionals. There needs to be stricter guidelines as to who can work with our children.” — Parent

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3. Lack of collaboration between individuals, families, ABA providers, and other professionals

Many people described their experience with ABA as “one-size-fits-all,” pointing out a lack of respect for personalized values, cultures, and beliefs. Along with ABA, a person might get occupational, speech, and other therapies and educational, medical, and mental health services. Often, these providers don’t collaborate with each other which is recommended for many reasons, but especially because of the high rates of suicide for people with Autism.

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“I would have felt much more comfortable keeping him in ABA if it had more thoroughly addressed some of these underlying concerns (anxiety, sensory needs, etc.) My child started thriving once we switched him to neurodiversity-friendly clinicians (speech therapy, occupational therapy, and parent coaching) who were able to better address his anxiety and work with him more collaboratively.” — Parent

“Some ABA providers view echolalia and scripting as stimming and non-purposeful, or as ‘TV talk,’ targeted for extinction. Neither is true. Research points to 14 functions of delayed echolalia and the seven functions of immediate echolalia, all of which are important and serve useful purposes. SLPs have the training, knowledge and expertise needed to appropriately guide goal-setting and address the myriad of language & communication in Autism, and should be consulted.” — Professional

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Common Benefits

The following benefits were identified from the stories submitted by Autistic individuals, parents/caregivers, and professionals with direct ABA experience.

1. Improved Skill-Building

Many people with positive experiences with ABA noticed improved coping and adaptive skills, better communication and social skills, increased self-help and safety skills, and improved self-advocacy skills.



“When I started ABA, I was struggling to talk in most group settings. I had trouble filling out questionnaires. My medical care was being impacted, I didn’t really ask follow-up questions or initiate interactions. I had trouble making friends, and was often frustrated. My self-esteem and confidence were almost non-existent (low). I was very deficit-focused, I didn’t see the numerous strengths and gifts I have. ABA has helped me learn to embrace those strengths and gifts. I’ve learned to advocate even more effectively for my needs.” — Autistic Adult

“The school, with a strong ABA component, has helped her learn to communicate her needs, establish friendships, and reduce her self injurious behaviors to the point of being able to access an education.” — Parent

“At the age of 2 he began eloping, and typically he ran towards traffic. He was fascinated with zooming cars on roads. We lived our lives in constant fear. We had to install a hotel bolt on our front door, once he learned how to open it, as well as an alarm that sounded when doors opened. We decided to try ABA. Within a month the eloping stopped. ABA therapy helps provide my son the ability to express himself. He is safer now, and I fully credit ABA.” — Parent



2. Positive Impact of Collaboration Among Providers and Families

Collaboration among providers, individuals, and families was noted as a key factor to successful experiences and positive outcomes of ABA interventions. Parents also noted that they were more prepared to use consistent strategies at home when they were involved with the ABA team.

(See quotes on the next page.)

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“My therapist and speech-language pathologist and other members of my care team consult with my ABA therapist. When I noticed specific programming (the things we work on) was causing me to be anxious, I had a discussion with my BCBA. They listened, observed it, and adjusted the programming accordingly.”

— **Autistic Adult**

“His RBTs were like family. I have never felt more trusting. They knew everything about him - his quirks and dislikes. They knew him so well they could tell when he was getting sick or wasn't feeling too well. They helped me to better understand signs of what was working and not working, and they always knew what tactics to try out.”

— **Parent**

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3. Positive Impact of Person-Centered Planning

Person-centered-planning is an important approach that focuses on supporting the individual's goals and preferences rather than trying to “cure” or “fix” the person. A person-centered team includes families, caregivers, and other specialists/therapists working together with the individual receiving services, who leads goal-planning and provides frequent feedback.

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“My current BCBA lets me pick all our target goals or at least approve what we work on. I've sometimes been able to come up with my own programming ideas and even strategy ideas. ABA gives me opportunities to share my perspective and give my input.”

— **Autistic Adult**

“Our BCBA was incredible and ensured that therapy was done in a natural environment that was inclusive of our family.”

— **Parent**

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Additional Considerations

Other opinions identified from the stories submitted by Autistic individuals, parents/caregivers, and professionals with direct ABA experiences:

1. Mixed Reviews

Some people shared that they had mixed feelings about ABA because they noticed both positive and negative outcomes and experiences.

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“I became noticeably less defensive and less reactive in social situations at work that caused me anxiety...but in the long run, it seemed to increase the frequency of my anxiety.” — Autistic Adult

“I believe that ABA can be beneficial, but needs to be done carefully and with a very close watch on the effects that it has in an individual’s life, both positive and negative.” — Autistic Adult

“It’s important to recognize the many possible communicative, sensory, and otherwise Autistic functions of behavior before deeming a behavior as ‘non-functional’ - to approach intervention from a deep understanding of Autism.” — Autistic Adult

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2. Motor Planning Difficulty

Some Autistic individuals have difficulty with motor planning that can impact movement, speech, and behaviors. Being asked to say or do something over and over without control of your body or speech can be incredibly stressful and uncomfortable. When a person has motor planning, motor-speech and other movement issues and receives ABA - their ABA providers should collaborate with speech and language therapists and occupational therapists.

3. Considerations for Non-Speakers, Prepared by Non-Speakers

“Non-speaker” is a term for people who cannot rely on verbal speech to effectively communicate. This represents 25%-40% of people with Autism. Some non-speakers are unable to speak because of a motor/movement issue that also makes it difficult for them to control their body movements.

Together, these challenges can make ABA difficult, not because they don’t know the correct response to a direction - but because they are unable to respond verbally or control their body movements to demonstrate their understanding. **ABA providers must presume competence in non-speakers.** It is important not to mistake a motor disorder for intellectual disability.

Section 3: An Overview of ABA Therapy

Understanding ABA Therapy

Applied Behavior Analysis (ABA) is a therapy that focuses on teaching new skills and improving behaviors that interfere with an individual's quality of life. ABA practitioners use evidence-based practices to address skills and behaviors, such as self-help skills, communication skills, social behavior, challenging behaviors, and more.

Common skills and behaviors addressed include:

- play and problem-solving
- self-help skills and activities of daily living (ADLs)
- challenging behaviors and self-injurious behaviors
- social behavior and interaction
- attention and Joint Attention
- occupational/Vocational skills
- language and communication skills*
**in collaboration with speech-language pathologists*

ABA is used in various fields, such as substance use disorder treatment, mental health therapy, and Autism intervention, and can be observed in schools, clinics, home, and community settings.

Common ABA practices 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

Aspects of ABA are also incorporated into the following models:

- 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 Intended Purpose of ABA Therapy as Presented by Industry Professionals:

According to ABA professionals, ABA therapy intends to empower Autistic individuals with the skills they need to live their lives with maximum independence and improve their quality of life. “Quality of life” is a broad concept that includes physical health, psychological state, level of independence, and social relationships.

The goal of ABA is not to “cure” Autism.

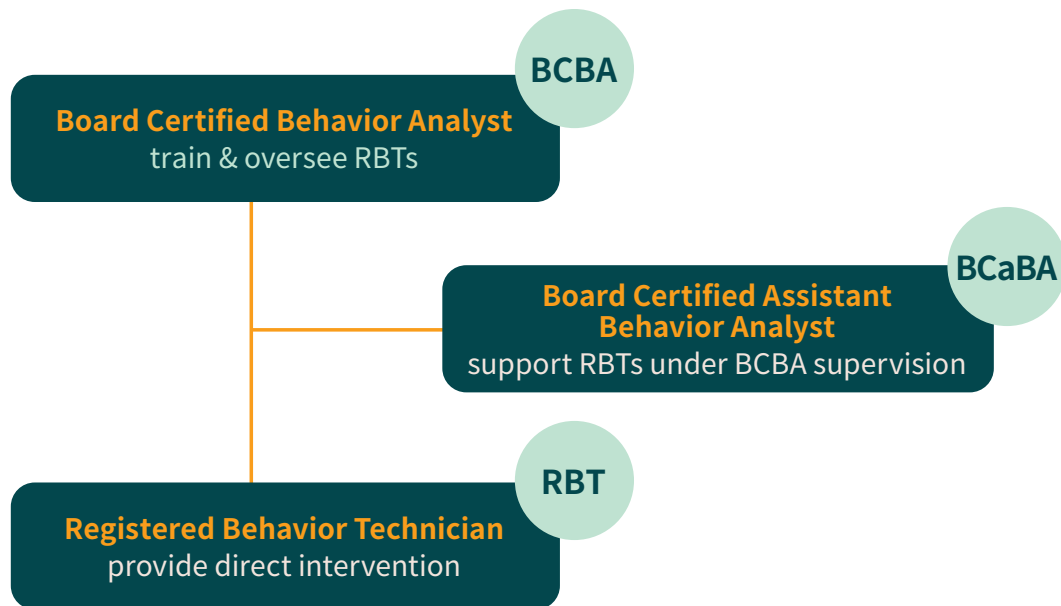
About ABA Providers:

To become a certified ABA provider, a professional completes comprehensive training in the science of Applied Behavior Analysis and must pass a formal board exam to become a Board Certified Behavior Analyst (BCBA). Some ABA is provided by an individual professional, and other ABA is provided by an ABA center with many practicing professionals.

BCBAs train and oversee Registered Behavior Technicians (RBTs) who provide direct services as written and directed by their BCBA supervisor. RBTs must be supervised for a minimum of 5% of ABA hours of service provided. To become a certified RBT, a person must pass certification test from the Behavior Analyst Certification Board (BACB). A BCBA might also work with a Board Certified Assistant Behavior Analyst (BCaBA) who has completed more training than an RBT but less training than a BCBA.

Whether ABA is being practiced by an individual, in a school, or by a team of professionals – therapy goals should always aim to improve a person’s health, independence, and quality of life – with frequent data-tracking, collaboration, and consultation between professionals, the Autistic individual, and their family/caregivers.

(See chart on the next page.)



BCBA Code of Ethics

BCBAs honor an ethical code that requires them to develop a plan that is always in the best interest of their client. This means compromising when necessary, and always putting their client first. This means compromising when necessary and always putting the client first. It is important for BCBAs to collaborate with other professionals on a client's team because each provider has different areas of expertise. BCBAs should only work within their area of expertise and seek additional training and support from other professionals when needed. Collaboration with professionals from other fields, such as speech-language pathology, occupational therapy, education, psychology, and medicine, is especially important when setting goals and selecting therapeutic targets for clients.

ABA Across the Lifespan

Young Children

ABA is often recommended for young children. ABA can be used to help children with Autism develop important skills in all areas of development, such as thinking, communication, socialization, movement, and daily living. For younger children, therapy should be centered around the child's interests and it should take place in natural home, school, and community settings where the skills being taught are routinely needed (examples include playing with friends, library visit, circle time, etc.)

Older Children and Adolescents

For older children and adolescents, the focus should be on building trust and helping them learn skills that will improve their quality of life, such as self-advocacy. Skills might be related to peer interactions, sibling relationships, or navigating a variety of community-based activities.

Adults

Some Autistic adults have shared a desire to receive ABA therapy. Access to adult ABA services is less common, and there are often barriers to insurance coverage for adult ABA services. In addition, there is a lack of easily accessible information about these services and their outcomes.



“There is no limit on progress. Progress is always possible regardless of age, therefore, in my opinion, there should not be an age limit on ABA.” — Autistic Adult



Individualized Recommendations

The amount of therapy needed should be individualized and there is no set number of hours required. A recent study conducted recently discovered that there was no significant difference in the outcome for young children with Autism who received 15 hours versus 25 hours of early ABA intervention. However, other studies that have looked at this issue have found that the amount of ABA support a child receives per week is directly related to the amount of learning they achieve. Therefore, the type and amount of ABA intervention given to a child should be customized to fit their individual goals, values, and cultural background.

Importance of Collaboration

Collaboration among different healthcare professionals, like occupational therapists, speech-language pathologists, and psychologists, is important in providing the best care for individuals with Autism. All clinicians should work within their area of expertise and communicate regularly to ensure continuity of care.

This document highlights the importance of working together with different types of professionals like occupational therapists, speech-language pathologists, clinical psychologists, psychiatrists, and neurologists. They can help with issues related to communication, language, senses, movement, and other ways to communicate. All clinicians should work within their area of expertise and communicate regularly to ensure continuity of care. If people who aren't trained in specific areas provide ABA, it could have bad effects on Autistic people.

All clinicians should practice within their scope of practice. It is important that clinicians work within their area of expertise. If they are not trained in a certain area, they should collaborate with someone who is. Some BCBA's may have more than one certification (such as speech-language pathologist, occupational therapist, licensed counselor, child development specialist, etc.) which increases their area of expertise. But when a person receiving services has multiple providers, it's important for all providers (including clinicians, educators, and medical professionals) to work together. This helps to ensure consistent care and can help the person learn skills more quickly. It also helps to avoid confusion when different types of interventions are used.



Some good signs of collaboration include:

- Professionals are working together within their own areas of expertise.
- All team members have an equal role in the care of the person receiving services.
- All providers work together and contribute to the person's care across different settings.
- Providers recognize when to refer to a different professional if the person's needs go beyond their area of expertise.
- Team members communicate frequently with each other.
- Progress and potential barriers are discussed often to review and reassess goals.
- The person or their parents are not responsible for communication between therapists. Providers set aside time to communicate appropriately with each other.

Section 4: Conclusion

Making Informed Decisions

The Autism Society of America does not support one specific therapy, intervention, or teaching method for all Autistic individuals. It is important to explore different options and consider what works best for each person based on their individual needs, goals, and preferences. Some people choose not to use any intervention at all. ABA is one of many interventions available, and it is constantly being studied and improved.

If you're trying to decide on a therapy or intervention for yourself or your child, be careful of providers who promise big results or say they can cure Autism. Ask for scientific evidence to back up their claims. Talk to people you trust who know you or your loved one well and get their opinion. Don't be afraid to ask for advice from people who are not involved, get input from others who have used the same services, or contact your local Autism Society. 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 considering ABA, these are some examples of a high-quality provider:

- Talks frequently with the person with Autism and/or their family to make sure their goals and wishes are included
- Ensures a supervisor watches over the therapy often
- Creates goals and methods that are unique to the individual and their family
- Focuses on goals that are helpful in real life
- Have supervisors and therapists who know a lot about Autism
- Understands the unique needs of different groups like kids, teenagers, etc.
- Builds a relationship with the person with Autism and cares about them
- Works with other people like teachers and doctors

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- Attends important appointments and meetings
- Creates reports that are thoughtful and personalized
- Focuses on goals that help the person be more independent
- Asks the person with Autism what they like and try to include those things in the therapy
- Refers the person to other experts if needed, like an occupational therapist for sensory issues or a speech therapist for communication help
- Is flexible with scheduling to allow for other services
- Lets the person with Autism choose some activities during therapy to have more control

YELLOW FLAGS:

If you notice these things, you should talk with your service provider:

- **Frequent staff turn over.** Unfortunately this is a concern within the entire ABA industry, which makes some turnover expected. If you're concerned, you can ask:
 - What is the plan for my/our sessions if a therapist leaves their job?
 - How long do direct staff typically stay in their roles?
 - What attracts employees to want to work here?
- **Overuse of discrete trial teaching (DTT).** DTT is a way of breaking down skills into smaller parts for teaching. Signs of overuse include a reliance on flashcards and drills. If you have concerns, you can ask:
 - How are you using DTT and in what settings?
 - Can you modify the process if the traditional method is too slow for me/my child?
 - Can you give me an example of how DTT can be used in a natural setting?
- **30+ hours of therapy a week are recommended.** If 30 or more hours of ABA are recommended, there are questions to consider asking:
 - How are the number of hours broken down and tied to goals?
 - What is the process you use to determine the frequency and length of therapy recommendations?

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- What is the transition plan: when will recommended hours be reduced, and how will we know when it's time to adjust?
- ABA isn't our only therapy. Can ABA be scheduled around other therapy visits?
Tip: Talk with your provider about how many hours are manageable for you/your family and discuss how these can be scheduled.

- **Provider/agency is owned by stakeholders versus clinician-owned.** If the ABA provider or agency is not owned by ABA clinicians, you can ask these questions:
 - What is the supervision structure?
 - What type of training and how much oversight will my direct technician receive?
 - What if I do not feel a direct therapist is a good match?

RED FLAGS:

The following are signs that could point to a lower-quality service. Please note that these examples may not always reflect a low-quality provider, but if you notice things on this list, play close attention and consider your quality of care.

Always be cautious of providers who make big promises about outcomes or “cures” and question them about the scientific evidence supporting their claims.

- Goals aim to “normalize” a person or their behaviors for the sole purpose of meeting neurotypical social norms or becoming “indistinguishable from their peers”
- Goals ignore the Autistic experience, individual/family goals, and/or cultural considerations
- Non-speakers are not given opportunities to develop reliable methods of communication including AAC
- Majority of teaching is through flashcards/drills
- There is not a system for collecting and sharing data about goal progress and/or achievement between the provider and the individual/family
- Direct therapists are not regularly supervised by a qualified/certified professional
- Goals are developed solely to teach to the test and may not be applicable to real situations
- ABA goals are not individualized
- Conceptual understanding is not being taught

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- High numbers of hours of intervention strongly recommended even if it is not manageable for the family and there is no option for reduced hours or reason why if reduced hours are not offered
- The therapy doesn't help the person apply what they learned to different situations, people, or things
- Reducing unwanted behaviors is not paired with teaching new skills
- Direct therapists/staff do not have enough training
- Parents and family members are not allowed to observe or directly participate in sessions
- There is no plan for peer interactions during therapy sessions
- After an appropriate warm-up period, Autistic individual demonstrates a strong negative reaction to the session or provider
- Family and others notice the person with Autism showing signs of increased anxiety or challenging behavior outside of ABA sessions
- There is little or no collaboration with other providers (e.g. speech pathologists, occupational therapists) and educators

❓ Questions to pose:

- I'm concerned that my child is showing signs of stress. Can I observe their next session?
- What other professionals have you been collaborating with?
- Please describe how other professionals' recommendations have been incorporated into the program.
- Can you please update me on the progress toward their goals
- When is the next supervisor visit?

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.

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**The
connection
is you.™**



Autism Society

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