

# Making Informed Decisions: Understanding and Navigating Applied Behavior Analysis (ABA)

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# **Section 1: Introduction**

The Autism Society of Greater Akron's mission is to create connections, empowering everyone in the Autism community with the resources needed to live fully in Medina, Portage, Stark, Summit and Wayne counties. We know that each member of the Autism community's experience is unique. No two people in the Autism community share identical experiences, strengths, support needs, hopes, and dreams. We also know that families and individuals struggle to access, understand, and trust information that helps them navigate services and support.

# Language Considerations for this Document

Autism and the experiences of being Autistic are myriad and unique; Given the variety of individual experiences and preferences, we always recommend asking an individual how they prefer to describe their identity. The Autism Society of Greater Akron honors and recognizes that both identifiers are valid for individuals. Our practice is to start written materials with person-first language and use identity-first language as a secondary reference after the opening use.

The Autism Society of Greater Akron believes the shift to a capital A is a broader representation of a culture, identity and diverse neurotype – as well as the community itself. It can improve understanding of the diverse needs and perspectives within the Autism community, leading to increased access, inclusion, and meaningful support for people with Autism and their loved ones in our society. The documentation will capitalize "Autism" in all instances.

# What is ABA?

Applied Behavioral Analysis (ABA) is a type of behavioral therapy that incorporates psychological principles of learning theory and behavior modification. ABA has been a topic of interest in the Autism community for years. With a complicated and controversial history, strong "pro-ABA" and "anti-ABA" viewpoints, and a focus on neurodiversity-affirming practices, many individuals and families are unsure how to determine if ABA is an option for themselves or their loved ones.



## **Document Purpose**

#### This resource is intended to:

- **Provide an understanding** of ABA, its history, purpose, and practice
- Give insight into diverse perspectives and individual experiences on what leads to positive or negative outcomes.
- Support individuals and families to advocate for the highest quality of care across Autism services and supports, whatever that may be for you.

Nothing in the following document should be construed as an endorsement nor an opposition to ABA therapy. Ultimately, the Autism Society of Greater Akron's Making Informed Decisions policy has always acknowledged that no single service or intervention is likely to meet the needs of every individual with Autism. Whichever services are chosen, they should promote self-determination, enhance inclusive community engagement, and result in improved quality of life.

## Why did the Autism Society create an ABA Commission?

In recent years, the practice of Applied Behavior Analysis (ABA) has been challenged by individuals expressing concerns about its methodology and impact on individuals with Autism. The contrast between these criticisms and the advocacy of ABA proponents has led to considerable confusion for those who are trying to determine the most beneficial intervention for themselves or their child.

The ABA Commission was formed to assess current opinions about ABA through a series of conversations with people with varied, but direct experiences with ABA. In the context of the diverse opinions that were expressed, the Commission sought to re-examine the purpose and methodologies that comprise ABA, with the goal of providing potential recipients and families with thoroughly impartial decision-making guidance.

When there is conflict within the community, we must acknowledge the good, bad, and the areas we don't understand from a place of respect and a willingness to learn.

We are in this community together, but our experiences are vastly different. What connects us is that at our core, we want the same thing - a world where everyone in the Autism community is connected to the support they need, when they need it.

# **Historical Concerns**

Concerns regarding ABA range from concerns about individual practitioners to concerns about the field of behaviorism as a whole. Some concerns are rooted in ABA's early history, connecting the practice of ABA with conversion therapy and the use of aversive punishment procedures. Other historical concerns cite that ABA was initially presented as a treatment designed to make Autistic individuals indistinguishable from their non-Autistic peers. During that time, ABA was primarily considered to be a treatment to address speech and language concerns in Autism, and was often practiced with little collaboration from speech-language pathologists. Read more about scope of practice and the importance of collaboration in sections **2** and **3**.

# **Position on Aversive Punishment Procedures**

The Autism Society of Greater Akron strongly condemns the use of aversives and physical punishment such as contingent electric skin shock. It should be noted that this practice is rare in modern ABA and prohibited by all but one institution. The Association of Professional Behavior Analysts recently published a **position statement** citing that the use of contingent electric skin shock "goes against the profession's overarching ethical principles of maximizing benefits for clients, doing no harm, and treating others with compassion, dignity, and respect (Ethics Code for Behavior Analysts, Core Principles 1 and 2, Behavior Analyst Certification Board, 2020)." The Autism Society of Greater Akron strives to protect inalienable human and civil rights of people with Autism to live freely, without the risk of harm. Our advocacy efforts actively promote abolishing the use of aversive processes, stigmatization, and abuse and neglect by supporting protective policies and legislation.



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

# Outreach

Making informed decisions requires an understanding of multiple perspectives, options, and community experiences. To support individuals and families to make informed decisions regarding ABA, the Autism Society of America hosted a series of virtual Town Hall events. The ABA Town Halls served as listening sessions, featuring the lived experiences and diverse perspectives of Autistic individuals, parents, and professionals. The ABA Commission sought first-person stories and received hundreds of submissions, some of which were shared during live ABA Town Hall sessions. The ABA Commission's selection work group was intentional in selecting speakers and stories that were representative of the diversity of perspectives, identities, and lived experiences across the community. These virtual events provided an opportunity to listen to balanced positions of positive, neutral and negative experiences within each session. While there are no two people who will have shared identical experiences, what emerged were key themes, which are listed below under the categories of common "concerns" and "benefits."

# **Town Hall Outcomes**

Overall, what emerged from our outreach to the Autism community was a wide range of perspectives that reflected both concerns and benefits from ABA. Beyond the practice of ABA, it was widely noted that the goal or purpose of ABA is most critical. ABA, when applied for the purpose of neuronormativity - to promote neurotypical norms or other ways of being to appear less Autistic - was among the most likely to cause negative outcomes, such as trauma-responses, masking, and other adverse mental/emotional/behavioral consequences. Alternatively, those who shared positive experiences with ABA were most likely to identify the purpose of ABA as a way to build skills that support safety and improved quality of life using a person-centered and interdisciplinary approach. It was noted repeatedly that families and individuals who were included in the goal-setting and planning of ABA and whose ABA was provided in the context of a collaborative, interdisciplinary team were likely to experience improved quality of life.

# **Common Concerns**

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

#### 1. ABA therapy's focus on achieving neuronormativity

Many raised concerns that ABA stems from the perspective of neuronormativity. Neuronormativity is based on society's notion that neurotypicality is "right" and neurodivergence is "wrong." When ABA first rose to prominence in the 1990s, one of its stated goals was making children with ASD "indistinguishable from their peers." Concerns regarding neuronormativity highlight the harm of ABA when it is applied with the goal of "normalizing," behaviors. Examples of these practices include forcing eyecontact and "extinguishing" harmless regulatory/self-stimulatory movements. While often unintentional, teaching Autistic individuals to have "quiet hands" or expecting compliance with behavioral norms that ignore aspects of Autistic neurology and culture can have unintended and harmful consequences. Simply, teaching people to change their Autistic behaviors to support the comfort of neurotypical teachers/parents/ providers reinforces ableist views that confuse "different" with "deficit."

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."

"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." "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."

"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

Concerns have been raised by professionals, families, and ABA recipients calling for improved quality control, consistency, and oversight of ABA providers. While BCBAs share common ethical codes and practices standards, there is great diversity among centers and clinicians. Different centers use different approaches and exhibit different values. For example, some may focus on more play-based strategies and others might use greater 1:1 professional directed approaches. Others may focus more on preparing children for less restrictive settings such as a typical classroom. ABA is not a singular "service." How ABA is practiced is dependent on the training, knowledge, clinical judgment, and values of the clinician. It is important that individuals and families become informed consumers and evaluate which center and clinicians provide quality and respectful services that best fit their needs and align with their values.

Several of our contributors across roles also expressed concern that ABA is sometimes the only intervention approach that is covered by insurance, which ultimately limits a person's options and choice in the matter. Many see ABA as one treatment option among many other available treatments, and that no single treatment will benefit everyone. This becomes a systemic challenge with policy needs in order to reform.

"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** 

#### 3. Lack of Collaboration

A common concern raised by Autistic ABA recipients, families/caregivers, and professionals within the field points to a lack of collaboration in goal setting, servicedelivery, and progress monitoring/evaluation. Several described their experience of ABA as "one-size fits all," noting a lack of respect for individual and family values, culture, and belief systems. There are many complexities within Autism and language development, communication, and motor-planning that require collaboration with speech-language pathologists and occupational therapists.

A multi-disciplinary team is also needed to address medical needs, such as epilepsy, gastrointestinal problems, sleep disturbances, among others-and psychological and psychiatric needs and co-occurring conditions. Collaboration with clinical

psychologists, psychiatrists, neurologists, and primary care providers is also warranted to address medical and psychiatric conditions associated with Autism, such as epilepsy, gastrointestinal problems, sleep disturbances, ADHD, anxiety, and depression among others. This is especially important considering data demonstrating the high rates of suicidal ideation and attempts associated with Autism.

"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 neurodiversityfriendly 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. Speech-language pathologists 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** 

## **Common Benefits**

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

#### 1. Improved Skill-Building

Individuals who submitted their experiences to the Autism Society's ABA commission shared a number of benefits related to improved skills. Skill areas that were most frequently mentioned as areas in which ABA contributed to improvement include coping and adaptive skills to replace self-injurious behaviors, improved responses to sensory distress tolerance, and increased comfort with change and unpredictability, communication, social skills, self-help skills supporting activities of daily living, and selfadvocacy skills (including stating one's needs and preferences, and refusal skills such as saying "no" instead of people-pleasing).

(See quotes on the next page.)

"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

Individuals who expressed positive benefits from ABA were more likely to have experienced a collaborative team approach, and often credited this collaboration to their / their loved one's success. It was repeatedly noted that ABA was most effective for an individual when ABA providers worked alongside family members, educational providers, and specialists including speech-language pathologists and occupational therapists and other providers. Parents celebrated the impact of a consistent approach between families and providers, noting the importance of parent communication and collaboration.

"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** 

#### 3. Positive Impact of Person-Centered Planning

Person-centered planning is a practice where the focus of an intervention is to help the person achieve what they want in life or to support whatever they are trying to accomplish. The focus is not on trying to "cure" the person. It means accepting them and what they want, and letting the person receiving services be the center, or leader, of goal-planning and service delivery. Some examples of person-centered intervention practices include seeking feedback after a session - through multiple modes of communication - or in whatever way works best for the individual. Person-centered planning requires a team approach, with families, caregivers, and other specialists/ therapists working together.

"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** 



# **Additional Considerations**

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

#### **1. Mixed Reviews**

In addition to these common benefits and concerns, some ABA-recipients expressed mixed reviews of ABA, recognizing improvements that they saw in themselves, but noting that there was a cost to those improvements.

"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** 

#### 2. Motor Planning Difficulty

Problems in praxis or motor planning (also referred to as apraxia or dyspraxia are at the heart of the lack of speech in many—perhaps most—non-speaking Autistic individuals. Since this is a motor speech disorder that affects voluntary movement patterns, attempts to get the Autistic individual to imitate words (or in the case of limb apraxia to imitate actions, on demand, is to put Autistic individuals in the least advantageous position to perform the task. Being repeatedly asked to say or do something that they could not say or do on command, caused significant discomfort and stress in some of the Autistic individuals who participated in our outreach regarding ABA. Ignoring motor planning issues, or addressing them in inappropriate ways, has been a major scope-of-practice concern in ABA practice. Collaboration with speech-language pathologists regarding motor speech issues, and occupational therapists in the treatment of movement disorders, is essential.

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

"Non-speaker" is a term for individuals who cannot use speech to effectively communicate including minimal and unreliable speakers. Studies estimate that between 25% to 40% of people with Autism are non-speakers.

The problem with ABA for non-speakers is that the same motor dysfunction that prevents people from speaking, prevents them from reliably touching the right answers in ABA lessons. A 2021 study found dyspraxia, the dysfunction in purposeful motor movements, in 87% of people with Autism (Zampella et al., 2021). Non-speakers first need to be taught purposeful motor movements, such as the gross motor skill of swinging an arm, to then choose an answer.

**ABA providers must presume competence in non-speakers.** It is critical not to mistake a motor disorder for intellectual disability. Presuming competence would increase expectations and lead to teaching the gross motor movements needed for spelling on a letterboard and typing on a keyboard.

# **Section 3: An Overview of ABA Therapy**

# **Understanding ABA Therapy**

Applied Behavioral Analysis (ABA) is a type of behavioral therapy that incorporates psychological principles of learning theory and behavior modification. ABA practitioners use evidence-based practices, such as positive reinforcement to teach new skills and improve behaviors that interfere with the individual's quality of life.

#### 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*

In addition to Autism intervention, ABA is used in various fields, such as organizational behavior management, substance use disorder treatment, mental health therapy and more. In the field of Autism, ABA practices 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:

The intended purpose of ABA, when utilized within the Autism community, should be to empower Autistic people to live the lives that they want to live, with maximum independence and self-determination. ABA focuses on supporting individuals to learn adaptive skills in a wide variety of areas, including communication, social skills, vocational skills, coping skills, and daily living skills. Ideally, the ultimate goal is to maximize the quality of life for Autistic people and their families, which is largely defined as Autistic people having the skills that allow them to choose from a variety of options for their life, regardless of what their support needs are. A high-quality life is the desired outcome of behavior analysis intervention. Quality of Life (QoL is defined by the Word Health Organization as an "individual's perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards, and concerns." Quality of life is a broad concept and includes physical health, psychological state, level of independence, and social relationships. Although QoL is measured by an individual's perception, there are some outcomes including employment, literacy, and social connectedness that are generally accepted as impacting QoL for most individuals, including individuals with Autism. Behavior analysts must also ask Autistic individuals what is important to them and how they define their QoL. What intervention do they desire to increase their QoL? The answers to these questions should be incorporated into any behavior analysis intervention plan, and used as a measure of success.

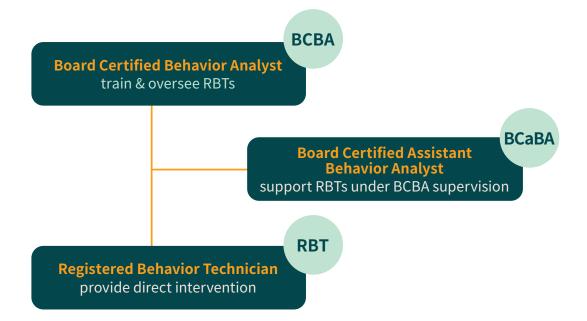
- Goals and intervention procedures are guided by an objective assessment of the person's independence and behavior, with consideration of the individual and family values and cultural context of the behavior. Communication and transparency are key to ensure that the Autistic individuals' wellbeing is prioritized. Therapy goals should always be selected such that the person's health, independence, and quality of life are improved. Therapy decisions are informed by consistent, ongoing, and objective assessment and data-tracking, through multi-disciplinary collaboration and consultation with both the Autistic individual and their family.
- Because generalization is an important dimension of ABA intervention, service delivery should occur in a center, within a family's home, in the community, in the workplace, or any other natural setting.
- Comprehensive intervention should emphasize skill acquisition and teaching foundational skills, in order to facilitate natural learning and independence of the individual. Behavior reduction may become a focus when there are behaviors present that are creating risk of harm, are directly interfering with learning, or are impeding the Autistic individual's ability to participate in the community.

The goal of ABA is not to "cure" Autism but rather to help Autistic persons reach their full potential, achieving the highest level of independence and quality of life.

# About ABA Providers:

Professionals who study and practice the science of ABA are Board Certified Behavior Analysts (BCBAs) through the Behavior Analyst Certification Board (BACB). Other professionals, such as speech and language pathologists, psychologists, and teachers, may have varied levels of training in ABA. While other professionals may use ABA practices, BCBAs have comprehensive training in the science of Applied Behavior Analysis and have passed a validated board exam in the practice of ABA. Behavior analysts are also guided by the ethical code of the national board. It is important to note that BCBAs, like any professional, may differ in their clinical skills and values, which may lead to variations in practice.

ABA is commonly implemented utilizing a tiered-delivery system. In the home, in schools and clinics, BCBAs train and oversee Registered Behavior Technicians (RBT) who provide the direct intervention, following written protocols developed by a BCBA.



- RBTs must be supervised for a minimum of 5% of ABA hours of service provided.
- RBTs must pass a competency assessment where their skills are directly observed by a BCBA and a certification examination that is administered through the Behavior Analyst Certification Board (BACB.)
- In a school setting, BCBAs can be members of an interdisciplinary team and provide varied levels of support and training to their colleagues in the use of ABA.
- The use of ABA in the school setting varies from state to state, with some schools offering comprehensive ABA services and others offering limited or specific procedures in addition to other educational programming.

#### **BCBA Code of Ethics**

Board Certified Behavior Analysts (BCBAs) are required to uphold their ethical code by developing a treatment plan that is always in the best interest of their client. The code specifically states that "behavior analysts collaborate with colleagues from their own and other professions in the best interest of their clients and stakeholders. Behavior analysts address conflicts by compromising when possible and always prioritizing the best interest of the client" (Behavior Analyst Certification Board, 2020).

To provide the highest quality of services, it is critical that ABA providers collaborate with other providers on a client's team. Each clinician has varying levels of expertise and knowledge outside of behavior analysis, therefore, it is outlined in the BACB ethical code that BCBAs are only to practice within their scope of competence, and are therefore required to seek out additional training and support from various sources, including from other clinicians in related fields. Collaboration regarding goal setting and the selection of therapeutic targets are especially important in highly specialized disciplines such as speech-language pathology and occupational therapy, and may also include education specialists, psychologists, physicians, and other professionals.

## **ABA Across the Lifespan**

ABA is frequently recommended for young children. Service delivery models for these children may differ from other populations due to the unique needs of this group. The developmental needs of each learner should be considered across all five domains of development (cognition, communication, motor, socialization, and adaptive functioning). Children in this age group are acquiring many foundational skills that are necessary prior to evidencing a fundamental change in language and relationships with others. The initial emphasis for intervention within this group should be to establish a relationship centered around a child's preferences.

Since the intended goal for all children is to play, engage, and have a high-quality of life, these same elements are present within ABA intervention. Therapy should be playbased, motivating, functional, and frequently occur in the many naturalistic contexts that children participate in (i.e., circle time, library time, playing on the floor, etc.) to promote generalization and conceptualization instead of rote or memorized skills. For younger children, families are routinely included into therapeutic sessions in order to teach interventions to families so that the newly acquired skills can be carried over into the home, community, and educational environments.

# **Older Children and Adolescents**

Teaching is structured utilizing a combination of naturalistic interventions and/or more structured teaching opportunities. One of the primary goals is to establish a relationship of trust and fun between the direct service providers and the person with Autism. Therefore, there should be a large emphasis placed upon skills which build self-advocacy and lead to improved quality of life. It is also important to focus on generalization of learned skills, which may require support within the community, with peers, siblings, or outside groups.

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. Furthermore, data on these services is not readily available.

"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 ABA intervention varies according to the needs of the individual, the skills being targeted, and recommendations from multi-disciplinary teams. There is no research that specifies a certain number of treatment hours for an individual, nor is there an established minimum number of hours per week. A recent study found no differences in outcome of young Autistic children who received 15 versus 25 hours of early ABA intervention (Rogers et al., 2021). Other descriptive studies have found a clear relationship between the number of hours of ABA support per week received and the amount of learning achieved (Linstead et al., 2017). The type and amount of ABA intervention must be individualized and reflect the goals, values, and culture of the recipient.

# **Importance of Collaboration**

One of the key themes indicated throughout this document, is the importance of collaboration. Collaboration with occupational therapists, speech-language pathologists, clinical psychologists, psychiatrists, and neurologists is essential with respect to issues that fall within their scope of practice. These include those that encompass social communication, language, sensory and motor experiences, and augmentative and alternative communication (AAC). Speech-language pathologists and occupational therapists are among professionals who have expressed significant concerns regarding the lack of collaboration, consultation, and interdisciplinary service delivery in support of Autistic individuals who are receiving ABA services. When ABA is practiced by those who lack training in or understanding in specialized areas of need (as noted above), there can be unintended negative consequences for Autistic individuals.

All clinicians should practice within their scope of practice. If they have not been formally trained in an area, they should work hand in hand with an expert in that realm. Some BCBAs may be dually certified in other areas (i.e., speech-language pathologists, occupational therapist, licensed counselor, child development specialist, etc.), which expands their scope of practice. However, whenever a service participant has multiple service providers, it is critical that all clinicians, educators, and medical providers operate within an interdisciplinary framework. The benefit to this type of in depth communication and collaboration is continuity of care, which can allow for a faster rate of skill acquisition in addition to guarding against confusion when intervention is structured in distinctly different modalities.



## Professionals practicing within their scope of expertise.

- All team members are equal in the participant's care
- There should be significant overlap and contributions from all providers across settings.
- Providers should know when to refer to a different professional if the participant's area of need falls outside of the provider's scope of practice

#### Frequent communication between team members

- Communication regarding progress and potential barriers should continue at a high frequency to regularly review and reassess goals.
- The individual and/or parent should not be responsible for the communication between therapists; rather providers should ensure there is time to thoroughly communicate amongst each other.

# Conclusion

# **Making Informed Decisions**

The Autism Society of Greater Akron does not endorse any one therapy, intervention, or teaching method. There is no "one-size-fits-all" approach or program that will meet the needs of all Autistic individuals. It is important to consider multiple options, and learn about varied perspectives to identify the approach that best meets the needs, goals, and preferences of yourself or your loved one. Know that some individuals choose that no intervention is the most appropriate option for themselves or their family. Keep in mind that ABA practices for people with Autism continue to evolve and improve through ongoing research. ABA is one of many interventions, therapies, supports, and services available to those in the Autism community.

When making decisions about interventions and therapies for yourself or your child, be cautious of providers who make grandiose promises about outcomes or "cures," and seek scientific data to support their claims. It is recommended to discuss any concerns regarding recommendations with trusted individuals who are familiar with your self/loved one. Never hesitate to reach out to neutral parties, seek input from those who have used the services you are considering, or contact the Autism Society of Greater Akron.

**For additional resources or information**, please visit the Autism Society of Greater Akron's website at **www.AutismAkron.org**, or contact our HelpLine to speak to a trained Support Specialist at, **330-940-1441 x1** or **info@autismakron.org**.

## **GREEN FLAGS:**

# If you are considering ABA intervention, here are elements that all high quality providers should incorporate into their practice.

- Frequent conversations with the Autistic individual and/or parents/caregivers to ensure their goals and desires are incorporated
- High frequency of supervision by BCBA during direct service delivery
- Individualization of goals and procedures for the unique individual and family system
- Functional/purposeful goals
- Supervisors and direct staff have a thorough understanding of Autism
- When working with subpopulations (i.e., pediatrics, teenagers, etc.) providers are also well-versed in understanding human development and the unique needs of each group
- Relationship building and genuine care is present (unconditional positive regard)
- Collaboration with educational, therapeutic, and medical teams
- Attending and advocating during IEPs, IFSPs, and medical appointments
- Assessment reports are individualized, thorough, and thoughtful
- Goals emphasize independence and readiness for less restrictive environments for the individual
- Frequent preference assessments and incorporation of the individual's reinforcers into sessions
- Provider is willing to make referrals and/or encourages incorporation of other disciplines for additional guidance regarding specific areas of intervention (e.g. OT for sensory concerns; SLP for guidance regarding speech production, language, and communication)
- Provide accommodates ABA schedule to allow participant / family to pursue additional services
- The participant should be given choices of activities so that they have some control over their sessions

## **YELLOW FLAGS:**

#### If the following elements are observed, additional questions should be addressed with your service provider.

• Frequent staff turn over. This is concern within the ABA industry as whole, and it has increased exponentially with the effects of the pandemic and other factors. Some turnover is to be expected, but it is recommended to ask the following questions.

#### **?** Questions to Pose:

- What is the plan for my sessions if a therapist should leave?
- How long do direct staff typically stay within your agency?
- What attracts employees to want to work here?
- Over-reliance of discrete trial teaching (DTT). DTT is an effective hierarchy in teaching skills by breaking a concept down to a small unit and then adding in more complexity. Often this is equated to the use of flashcards and drills, although it can be used in a naturalistic setting as well.

#### ? Questions to pose:

- In what context do you use DTT?
- Can you modify the process if my child is learning at a faster acquisition rate, to guard against boredom?
- Can you provide me an example of how to utilize DTT within a natural context?

#### • 30+ hours of therapy a week are recommended.

#### (?) Questions to pose:

- What does the breakdown of the hours and the identified goals look like?
- How do you determine frequency and duration recommendations?
- What is the transition plan, to know when we should begin to adjust?
- Talk with provider/agency regarding any how many hours are feasible for you / your family and discuss how these can be scheduled
- My child receives other therapies. Can their ABA be scheduled around these other visits?

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• Provider/agency is owned by stakeholders versus clinician-owned.

#### ? Questions to pose:

- 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:**

ABA providers who make grandiose promises about outcomes or "cures" should be viewed with concern and questioned about scientific data supporting their claims.

If these elements are observed, then these could be red flags for a lower quality provider. Please note that these signs do not necessarily reflect low quality service delivery, but it does raise concerns that the consumer should thoroughly attend to.

- Goals are designed with the intent to "normalize" behaviors for the sole purpose of meeting neurotypical social norms, without regard for the Autistic experience, individual/family values, and cultural considerations
- Non-speakers are not given opportunities to develop reliable methods of communication including AAC
- Majority of teaching is through flashcards/drills
- Data regarding achieving goals is not systematically collected daily and shared with the supervisor and family
- Therapists working directly with the child are not supervised on a regular basis by well-qualified trained professionals
- Goals are developed solely to teach to the assessment and may not be applicable to real situations
- ABA goals are not individualized
- Not teaching conceptual understanding
- High numbers of hours of intervention strongly recommended even if it is not feasible for the family and there is no justification for why fewer hours would not be appropriate
- Not facilitating generalization of goals across people, settings, and stimuli

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- Behavior reduction is not accompanied by teaching skill acquisition
- Inadequate training of direct staff
- Primary goal is for an individual to appear indistinguishable from same-age peers
- 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 a suitable warm-up period, child demonstrates a strong negative reaction to the session or provider
- Family and others notice increased signs of anxiety or adverse behavioral challenges in their child 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 clinicians have you been collaborating with on my child's program?
- Please describe how other professionals' recommendations have been incorporated into my child's program.
- Can you please update me on my child's progress toward their goals
- When is the next supervisor visit?

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