



Finding a Quality ABA Provider *A Parent Perspective*

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Updated July 2016*

The purpose of this article is to discuss important things to consider when evaluating an ABA provider for treatment. It will not address school based educational programs that may use ABA techniques and principles as part of the services offered. Schools may also offer psychology services, counseling, occupational therapy, speech therapy, physical therapy, and nursing services when required as part of an education program. This article will focus upon *medically necessary ABA services as part of a treatment program* for autism spectrum disorder. The views in this article are my own and do not necessarily reflect the views of any organization with which I am, or have been, affiliated.

Introduction

Applied Behavior Analysis therapy for autism is widely considered to be an evidenced-based and effective treatment for autism, and it is endorsed by the American Academy of Pediatrics and several other major medical societies and institutions. ABA therapy is complex and can be expensive if intensive therapy hours are required. Most importantly, your ABA provider will have a great deal of influence upon building the foundation for the life-long functionality of your child, so the quality of the ABA intervention is very important. Early intensive behavioral intervention or “EIBI” ABA therapy is not intended to last indefinitely – your provider will need to work with you and the school of your choice to transition, or to “braid” programming when the educators need to take over a portion of, or all of, the child’s interventions. Your provider will need to be sure that your family has the tools at home to support the interventions in the treatment program. Therefore, it is extremely important that parents are educated consumers when evaluating ABA providers.

ABA is an effective treatment for autism across the life-span. After EIBI, ABA programs will vary more widely in number of hours, the number and kinds of treatment goals addressed, and the expected outcomes. An adult’s program will be very different from a teen’s, from a child’s and from a preschooler’s programs. Services may vary from one-to-one therapy to group therapy to consultation-only programs. Since ABA is a treatment that is tailored to each individual, no two programs will be alike.

At a time when a parent may feel vulnerable and desperate, how does a parent select a quality ABA provider? Take a breath, take a step back and take some time to set the stage for successful treatment.

1. Learn about ABA

Knowing some basics about what ABA is, and what it is not, is important. If you do not know some basics, how do you know what questions to ask or what kind of service to expect? It is very important that parents go to *objective, reliable* sources to do research about ABA. Don't select ABA as a treatment because "everybody says you have to do it". It is a family commitment, and it is not the only intervention that parents may choose. ABA treatment should not be approached with an attitude that "I will drop my kid off and the ABA provider will fix him". With a little research, you can know more to decide for your family what is right for you.

Resources:

- Autism journals and magazines – search for articles about ABA.
- The internet – find sources that are credible – there is a lot of misinformation on the web
- Look at the websites for Autism Speaks, the Autism Society of America, the Autism Society of Indiana (ASI), the Indiana Resource Center for Autism, The National Autism Project, medical school affiliated autism programs, such as The Cincinnati Children's Hospital Kelly O'Leary Center for Autism, among others.
- Take provider websites and publications with a grain of salt – they are trying to market to parents and clients – check their information with objective sources, not competitors
- Take a seminar or training session on ABA from the Indiana Resource Center for Autism or other autism advocacy group
- Thoroughly read and understand the Behavior Analyst Certification Board (BACB) website's articles for consumers and their health plan guidelines, see www.bacb.org.

Your child's physician *should* also be able to assist you in finding credible resources on ABA and in finding quality ABA providers in your area. Unfortunately, many physicians are unaware about current treatment standards for autism, ABA, and the quality of the ABA providers in your area. Parents need to continue to advocate with our local children's hospitals, pediatricians, psychiatrists, and health care systems to increase the capacity of local physicians who can appropriately diagnose, treat and manage ASD patients, including referrals to ABA providers that have been vetted.

2. Finding ABA Providers to Evaluate

Now that you know more about ABA, and you and your child's physician have decided it is the right treatment for your child, it is time to evaluate several ABA providers.

“Buyer Beware”: In Indiana, there is no *state* licensure or *state* certification for Behavior Analysts, “autism consultants”, “autism therapists” or the like. However, there is a state law that prohibits anyone from calling himself or herself a “Board Certified Behavior Analyst” unless they have a certification from the *national* Behavior Analyst Certification Board (BACB). Anyone who is not a BCBA, an Associate Behavior Analyst (BCaBA), or Registered Behavioral Technician (RBT) under the national BACB standards is not subject to review or qualifications with any particular body or oversight agency in terms of ABA treatment for autism. If they are licensed in another clinical area, such as social work or psychology, they should **ONLY** be providing ABA therapy to treat autism if they have **extensive training and experience** in ABA and how it is used to treat autism.

“General experience” in the field of autism, “general experience” in social work or psychology, or a degree or license in an area of specialty other than autism (such as addiction, marriage and family therapy, general child psychology, etc.) may not be enough to have the experience or education necessary to direct and supervise a comprehensive or focused ABA treatment program. Some providers may have a degree specifically in Behavior Analysis, but not be a BCBA. Since Behavior Analysis is such a large field, make sure such a provider has **extensive experience** working with children with autism. All providers should be able to show you documentation of their specific experience in directing and supervising ABA programming for autism treatment.

Behavior Analysis is a large field – it requires specialization and applied, or practiced, competencies. Experience working with people with autism across the spectrum is extremely important.

Finding an ABA Provider in Your Area

Check the Behavior Analyst Certification Board (BACB) website, www.bacb.org for a list of Board Certified Behavior Analysts in your area. Check autism related publications and advocacy lists. Search the web for “ABA treatment for autism” or “behavioral treatment for autism” for names of providers. Remember, “buyer beware” – finding a name or a center nearby is not enough. And the closest provider may not be the best, or even good!

How do you tell if a provider is a “quality provider”?

Start with a Reliable Referral - Sources for ABA Provider Referrals

- Pediatrician
- Developmental pediatrician
- Neurologist or Neuropsychologist
- Psychiatrist or Psychologist
- Speech, occupational, physical therapists

Do I Want a Home or Center Based Provider?

There are advantages and disadvantages to both types of providers, so it is important to consider both, and interview both so that you can assess what is the best fit for your child, family and treatment goals. Whether or not a home or center based program is appropriate may depend upon your family situation, child's age, treatment goals, progress in one setting vs. another, etc. You should work with your physician or psychologist to consider both options.

Home Based Providers - Things to Consider

- Home is the natural environment for young children (toddlers/preschool aged)
- Transition from home-based therapy to school may offer challenges as one cannot simulate the school demands in a home program as well as in a center program
- How are skills transferred to school, community?
- Front line workers will not have daily supervision on site
- Privacy for the family; having people in your home and accessing your home every day
- Professionalism concerns – getting too close to a worker, friendships or relationships that are detrimental to the family and quality of therapy
- Better ability to supervise therapy yourself every day
- Daily involvement with therapy is easier
- Concerns about frequency and quality of supervision of front line technicians
- If lack of supervision and training, quality will suffer greatly
- Support available to the front line technician if there are behavior issues involving injury; if they do not know how to handle a situation; if they have a question of problem how long do you wait for support?
- “Burn out” issues for staff and family
- Substitute staff for absences or turnover may not be available
- Communication about therapy and daily activities is easier
- Is the therapy driven by the child's needs or the providers/owners needs?
- Home therapy may not be covered by Medicaid and other funding sources

Center Based Therapy Providers - Things to Consider

- What access do you have to the center and to observe therapy? Not being allowed in or to observe should be a red flag.
- How flexible is the center in terms of scheduling and with working with your child's school or outside therapy schedule?
- Do you get parent training before therapy starts? During? How often?
- Transportation issues, especially for children who do part time programs
- How are skills transferred to home, school, and community?

- Communication about therapy progress, daily activities can be challenging
- Is the center environment too controlled to allow teaching “real world” environments and situations (do they control the lights, sounds, sensory input vs. teaching your child how to cope with real world experiences they will face in the community)?
- Is the center clean (not just surface clean), well-maintained, safe; any concerns if your child elopes (easy to leave center undetected, ponds, highway near by)
- Is the center and therapy designed around the needs of the children or the wants and needs of the staff and/or owners?

3. I Have a List of Providers to Interview - What Now?

Site Visits and Interviews

It is very important to visit centers *personally* and to conduct *in-depth interviews* with all of the providers that you are considering. If the provider is not willing to conduct an in-depth interview, that should be a red flag. Be prepared to “read between the lines” – you are seeing the provider “put their best foot forward” when you are interviewing. It is best for both parents to attend and to decide how you will evaluate providers ahead of time. Blended families should decide ahead of time how to approach the evaluation process and should select more than one parent/caregiver/guardian to attend. Each of you will see and hear different things and you will need to be “on the same page” about the therapy for it to be most effective for your child.

Ask About the Business Model

- Is the provider for profit or not for profit? This may impact how much is invested in training, staff benefits, staff development, and non-billable services for the children.
- Do they have a Board of Directors for oversight? Are they compensated in any way? If yes, how?
- Does a family own the provider business? A married couple? Partners in a personal relationship? What are the checks and balances in place to address potential conflicts of interest? To protect children and families from potential conflicts of interest? What happens to the provider business if these relationships sour? “Just trust us we would never...” is not a sound plan.
- How do they assure that clinical decisions are not inappropriately influenced by business concerns? What are the checks and balances? Do they have a clinical advisory board to provide objective clinical advice? How often are they on-site? Are they compensated? How?

- If the provider business is a lone BCBA, what does this person do when they do not know how to proceed? When they are faced with a child that has issues they have never treated? Who is the back up? What if they are ill and cannot see children for an extended time? What limit do they place on their caseload? If they have no set advisory system or plan, that should be a red flag.

The business model of a provider will affect how many resources they will put into training and retaining high quality staff. It will also affect how much supervision of the front line staff will really occur. **A well-trained, high quality staff that receives quality supervision is the most important factor in the provision of high quality, effective treatment.** The business model may also affect how much is spent on services/supplies for the children that are needed, but cannot be directly billed to insurance companies. It may also affect the cost – generally, for profit health care entities of all types tend to charge higher rates than their non-profit counterparts, and for-profit entities tend to spend less on actual care delivery. With any provider, the clinical needs of the children should be put first.

Ask About Membership in Professional Associations

Ask if their BCBA's are members of the Hoosier Association of Behavior Analysts (HABA) and if the business entity is a member of Indiana Providers for Effective Autism Treatment (INPEAT). Membership in both is an indication of a commitment to on-going education, treatment quality, ethics and continuous improvement of the profession. If they are not members, ask how they contribute to the on-going education and improvement of the profession. If they are not engaged members of HABA and INPEAT, how do they know that they are keeping up with the standards of treatment? How do they know that they are on top of insurance and important policy issues that affect your child's treatment?

Top List of Red Flags (from real world experiences)

- Without conducting an assessment, the provider states that your child needs a full time ABA program, or "x" number of hours, or has a treatment plan "off the shelf" and ready to go. ABA is an individualized treatment. Without an assessment, these decisions cannot be made based upon the clinical needs of the child.
- Lack of thorough background checks – centers and home providers should conduct checks on **all** employees. BCBA's should be willing to provide their background checks. Ask solo BCBA providers for a copy of a recent background check (no older than one year). The background check should be based upon social security number and be nation wide. Those who victimize children are very good at moving from state to state, county to county to avoid detection in less comprehensive background checks.

- Lack of proven credentials. Check the BACB website to be sure the provider is certified. If the provider claims to have a degree or credential, verify it. Check all references. A home provider should be willing to arrange an observation of a current client with that child's parental permission.
- "Your child can start therapy tomorrow, or next week" – what about an assessment, training for staff, parent training, writing a quality treatment plan, finding the right staff fit with your child?
- Look for signs that the provider is "crossing lines" in terms of insurance fraud, proper insurance procedures, etc. Offers to buy your child insurance, give you financial incentives to start therapy, provide services like babysitting and transportation and "get insurance to pay for it" should raise red flags. Ask if staff is compensated in any way for bringing in a new client (bonus payment per child, other financial incentives to sign up families). Telling a family that "you can just by-pass the public schools and we can get insurance to pay for your child's education" should raise a red flag. Health insurance pays for treatment, not academics/public school curriculum programs.
- Lack of written policies and procedures for staff and for families.
- In a family-run provider business, lack of checks and balances in terms of finances, child protection, family protection, clinical decision making being independent of inappropriate influence from non-clinical staff or owners. Be wary of personal relationships that may cloud professional conduct and decision-making. If a husband and wife; parent and child; or siblings own or run the provider business, how do they handle staff discipline? Ethical issues? What are the checks and balances? Is it a situation of "take our word, we police ourselves"?
- Provider will not give you several references for families who have been with them for over two years; provider discourages you from checking references.
- Provider discourages you from visiting and interviewing multiple providers or attempts to coerce you in any way into committing to therapy with them right away. Provider requires you to sign a contract for length of service before starting services. Or the provider requires that you get an assessment in order to be on their waiting list – an old assessment is useless for treatment and should not be a requirement to be on a waiting list. You have the right to change medical providers at any time.
- The center seems chaotic, children are alone, staff are congregating in common areas chatting, staff seem stressed or unhappy; all ages of children are mixed together in the same area; privacy and dignity of children changing and/or toileting/going through puberty are not protected or staffed to ensure protection (double staffed).
- Provider is defensive or discourages probing questions; provider states things like "I'm a parent/relative/former teacher of a child with autism, you should trust me" in order to cut off your questions. Provider accuses you of being difficult or emotional for asking probing questions.

- Provider cites a religion or God as endorsing their approach. While providers should have a policy to respect all religions and cultural differences, the use of God or religion as a means to shut down questions or communicate some kind of endorsement of their company and services seems suspect.
- The therapists do not receive significant training and supervision before working alone with your child.
- The BCBA does not come to directly observe the program in regularly scheduled intervals that meet BACB guidelines.
- The BCBA schedules supervision, parent meetings, trainings, but does not follow through.
- Supervision is only done remotely (video, phone, not in person)
- The data collection is disorganized – you should be able to readily see in the data collection what your child is working on and how they are progressing; ask to see a sample of their data collection.
- The BCBA does not have back up for emergencies or for cases beyond the scope of their experience.

Clip and Take with You – Sample Interview Questions to Ask an ABA Provider

Be Sure to Add Your Own

- What is your in-take process?
 - Who conducts the assessment?
 - Which tools do you use to do the assessment? Are they validated instruments accepted by the BACB or the National Autism Project?
 - Do you assist with verifying insurance coverage?
- Describe the training program that your front line interventionist or technicians go through before they are permitted to work with a child? How do you tailor that to each child's specific program? How many fail your training program? (If none, red flag – they are not well trained or tested)
- Verify credentials – BCBA's, BCaBA's, are your front line people RBT's? (Registered Behavioral Technicians, credential available since 2014).
- How often are front line technicians directly supervised by the BCBA?
- How long are front line technicians in training before they are allowed to work with a child?
- How many technicians will be on my child's team? (If only one, without regular rotation, there may be issues with mastery of skills, maintenance of skills and generalization of skills acquired) Ask why the team is set up the way it is. Is it best for quality therapy, or administratively easy?
- Verify that background checks are done on all staff – is it county only or statewide, federal? How often do they check the county, state and federal databases for sex offenders or other crimes that would result in termination?

- If a center – what would a typical day for my child be like? Should describe tailored program with some group activity if age- and developmentally-appropriate – if they describe a schedule or plan that all the kids adhere to, regardless of age, ability, etc. that is a red flag.
- What is your business model? Non-profit or for-profit? Family owned? Husband and wife owned? Do you have an advisory board of clinicians? Do you have a board of directors to provide direction and oversight? Is your board compensated in any way? How?
- How do you assess progress? Do you use validated tools endorsed by the BACB or National Autism Project?
- How do you assess when a child is ready to transition to school, or less intensive services and start school or go back to school?
- Do you have exclusion criteria? Are there children that you do not feel comfortable treating? If they say they will treat anyone, that is a red flag.
- Experience of the clinical staff, depth and breadth? Years of experience, number of cases, years doing front line therapy before becoming a BCBA, experience across the spectrum?
- How many children are discharged from services every six months without insurance company demand to end treatment? This is one indicator of success in treating young children.
- How do you handle insurance appeals? Ask for references from families for whom they have done second level and external appeals in the last year. Some providers state that they help with appeals, but then when one arises, refuse to assist parents with second level appeals or external appeals. How successful are you with appeals? If an appeal is in regard to medical necessity, the provider has an ethical obligation to assist, as only the clinician can document medical necessity.

Do not be afraid or embarrassed to ask questions or to expect answers. Ask the provider to put their answers in terms you understand. Like many fields, ABA has its own jargon. Don't be afraid to say, "please explain that to me in a different way". You should expect that a provider would be happy to explain what they do and how they do it in a way that you understand. After all, you are supposed to be a partner in your child's treatment program, just like in any treatment program. As a parent, you have the right, and the responsibility, to ask questions, get full information and to make informed choices about your child's care and treatment.

It is also important to remember that once you select a provider, you should feel free to continue to ask questions and to evaluate their performance and their "fit" with your child and your family. If at any time you do not feel "right" about what you see or hear, trust your gut. You can change providers at any time you wish – that is your choice.

If your ABA is covered by insurance, you will need to be sure that your new provider is on your insurance network, but your network should have enough choices so that you are not forced to stay with any one provider. A provider should never make you feel that you do not have a choice. They should never pressure you to stay with their services.

Some Closing Thoughts, Parent to Parent

I hope this article is helpful in making your decisions. This article is certainly not exhaustive. Trust your gut and your common sense. Take a deep breath and take the time to educate yourself and do your research. While there is pressure to start treatment “right away”, and waiting lists for diagnosis and treatment are frustrating, a poor quality program is not going to help your child, and it may harm him. Taking the time and effort to be an educated consumer will be worth it. A friend once told me, “Autism is a marathon, not a sprint”. Very wise words!

About the Author

Michele Trivedi is a parent of an adult with autism who has over 15 years of experience evaluating ABA providers for her child, including hiring her own front line technicians and BCBAs, running her own home program, billing her own insurance, and utilizing both home and center based providers. Her child has done full-time, comprehensive ABA and part-time, focused ABA programs. She has used Lovaas and Verbal Behavior based ABA programs. Michele was trained to do front line therapy with her child by the Lovaas Institute and Vince Carbone and Associates. She has also secured ABA training by a BCBA for her child’s aides in the public school setting as part of an IEP.

Michele fought the implementation test cases for health insurance coverage for ABA under the Indiana Autism Health Insurance mandate, the nation’s first autism health insurance reform law. Her child was the first child in the nation to receive coverage for autism treatment and ABA therapy. Michele was the consumer representative appointed by the Commissioner of the Indiana Department of Insurance when Bulletin 136 was written to guide enforcement of the autism mandate law.

Michele has volunteered with various autism organizations for the past 15 years to assist families with securing health insurance coverage for ABA. In 2005, Michele joined the volunteer Board of Directors of a non-profit ABA provider serving children and adults. Michele joined the staff of The Arc of Indiana in 2013 to establish The Arc Insurance Project, now The Arc Insurance Advocacy Resource Center, to assist persons with autism and other developmental disabilities to navigate their health insurance options.

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