

By Michele Trivedi

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Michele Trivedi is a former health services executive and is a parent of an adult with autism. She has over 18 years of experience working with and evaluating ABA providers for her child, including hiring her own front-line technicians and BCBA's, running her own home program, billing her own insurance claims, and utilizing both home and center-based providers. Her child has done intensive, comprehensive ABA and part-time, focused ABA programs. She has used both Lovaas and Verbal Behavior based ABA programs. She has also secured ABA training and consultation 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 comprehensive autism health insurance reform law. Her child was the first child in the nation to receive coverage for autism treatment and ABA therapy under such reform. Michele was the sole consumer representative appointed by the Indiana Department of Insurance's Commissioner to develop "Bulletin 136," the state's enforcement document for the autism coverage reform law.

Michele has volunteered with various autism organizations for the past 18 years to assist families with securing health insurance coverage for ABA. In 2013, Michele joined the staff of The Arc of Indiana part-time to establish The Arc's Insurance Advocacy Resource Center (INARC) to assist persons with autism and other developmental disabilities to navigate their health insurance options.

Choosing an ABA provider is an important decision. I hope this article will help you learn from other parents' experiences. 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.

The purpose of this article is to discuss important things to consider when evaluating an ABA provider. This article will focus on medically necessary ABA services as part of a health insurance, Medicaid, or private pay treatment program for autism spectrum disorders. It will not address school based educational programs that may use ABA tools, techniques and principles as part of the services offered.

Applied Behavior Analysis therapy is widely considered to be an evidenced-based and effective clinical treatment for autism and is endorsed by several 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 educational program of your choice to transition, or to “braid” programming when 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. Your provider may need to have the skills to “grow” with your loved one and provide quality care as he or she ages or transition them to another provider. 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 ABA treatment program will be very different from a teen’s, from a child’s and from a preschooler’s programs. A treatment program for a severely affected individual will be very different than the program for a person who is moderately or mildly affected. Services may vary from one-to-one therapy to group therapy to consultation-only programs across the spectrum and over time. **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.

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/her.” ABA providers should not promise this either. With a little research, you can know more to decide what is right for your family.

Resources

- Find sources that are **credible** – there is a lot of misinformation on the Internet. Look to respected University based medical centers, professional societies in medicine and behavior analysis such as the Behavior Analyst Certification Board (BACB), Association for Science in Autism Treatment (ASAT) for example.
- 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, and medical school affiliated autism programs, such as The Cincinnati Children’s Hospital Kelly O’Leary Center for Autism, Kennedy Krieger Institute, among others.
- Take provider websites and brochures with a grain of salt. They are trying to market to parents, clients and referral sources. Check their information with objective sources, not with a competitor ABA program.
- Take a seminar or training session on ABA from the Indiana Resource Center for Autism or other autism advocacy group conference; make sure the seminar is about the medical applications of ABA and is given by a BCBA or BCBA-D.
- Thoroughly read and understand the Behavior Analyst Certification Board (BACB) website’s articles for consumers and their health plan guidelines, at bacb.com

Your child’s physician *should* also be able to assist you in finding credible resources and 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, insurers and health care systems to increase the capacity of local physicians who can appropriately diagnose, treat and manage autism, **including referrals to ABA providers that have been properly vetted**. If you are simply given a list of ABA providers in your area, they may not have been vetted. ABA providers are NOT regulated by the state of Indiana – ask your diagnostician if they have vetted the ABA providers on the list.

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 providers.

Indiana passed a new state law in 2021, effective July 1, 2021, that requires ABA therapists to be licensed. However, it may take up to two years for the license board to start issuing licenses. Therefore, parents must still be in the mode of “buyer beware” until the license board is fully functional.

There is also a state law that prohibits anyone from calling themselves 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 may not be subject to any standards or oversight unless they are licensed in another clinical area. If they are licensed in another clinical area, such as social work, counseling 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. **You must ask for them to verify in writing that they have such education, experience and competence.**

“General experience in the field of autism,” “general experience” in social work or psychology, or a degree or license in 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. If they are not a BCBA, they are not overseen by the national certification board (BACB), so you must find out if they have another oversight board, such as a state licensure board. Since Behavior Analysis is such a large field, make sure such a provider has **extensive experience** working with people 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, supervised experience and practiced competencies. Experience working with people with autism across the spectrum is extremely important. It is also extremely important that the providers have extensive experience working with persons in your loved one’s age group. An ABA provider with no experience working with teens will not be able to provide quality treatment to a teen without extensive mentoring and continuing education.

Finding an ABA Provider in Your Area

Check the Behavior Analyst Certification Board (BACB) website, bacb.com, for a list of Board Certified Behavior Analysts in your area. Check your insurance network list, local 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. The closest provider may not be the best for provider for your child.

How do You Tell if a Provider is a “Quality Provider”?

Start with a reliable referral. Your referral source should be a clinician with experience treating autism. Sources for referrals to ABA providers include:

- 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. What setting is best for your loved one may change over time, so you may want to consider a provider that offers home, center and community-based services.

Things to consider for home based providers – therapy delivered primarily in your home:

- 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 school demands in a home program to the same degree as in a center program
- How are skills transferred to other natural settings - school, community?
- Front line workers will not have daily clinical direction or supervision on site by a supervisor
- 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 observe therapy yourself every day
- Daily involvement with therapy is easier
- Concerns about frequency and quality of clinical direction of front line technicians and the therapy
- If lack of clinical direction, 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 or may be difficult to coordinate due to travel issues
- Communication about therapy and daily activities may be easier
- Is the therapy driven by the child's needs or the provider's/owner's needs?
- Home therapy may not be covered by some funding sources

Things to consider for center based therapy – therapy provided *primarily* in a center or clinic:

- 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 are in focused programs
- How are skills transferred to home, school, or 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 "medical" clean (not just "surface" clean), well-maintained, safe; any concerns if your child elopes (easy to leave center undetected, ponds, highway nearby)
- Is the center and therapy designed around the needs of the children or the wants and needs of the staff and/or owners?
- There should be a BCBA on site or accessible at all times for clinical oversight and supervision of technicians and to address any urgent behavioral issues in real time

I have a List of Providers to Interview – Now What?

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

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 and clinical direction of the front line staff will really occur. A well-trained, high quality staff that receives quality clinical direction and 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. With any provider, the safety, security, and clinical needs of the people they serve should be put first.

Things to consider and look for:

- 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.
- Is the provider owned by a Private Equity group? This is an outside group of investors who expect a return (profit) on their investment in a business. If yes, how do they assure quality of care? How do they balance the needs of families and the people they serve with the profit needs of investors? Are BCBA's bonused on billing or quality of care measures? Or both?
- 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.
- Do they have a board of directors for oversight? Are board members compensated in any way? If yes, how? Does the board include clinicians, or do they have a separate clinical advisory board?
- 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, or a small partnership of a few BCBA's, what does this person do when they do not know how to work with a particular child or behavior? When they're 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.
- Ask about the experience of the senior clinical team – how many years of experience is required of a clinical director? If it is not at least 5-7 years, this is a red flag. How many years of experience does the BCBA who will supervise your case have? Who supervises him or her? How many years of experience do they have? In ABA, experience, supervision, on-going training and ethical case load size are the keys to quality.

Ask About Membership in State and National 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 within 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?

Are they members of the national professional organizations for behavior analysts APBA – the Association for Professional Behavior Analysts, or ABAI – Applied Behavior Analysis International? Do staff members regularly attend continuing education opportunities (national or regional conferences, university based conferences)? **If their staff only gets continuing education on-line that is a red flag. ABA is an applied science. It requires practice, which requires interaction with more experienced mentors, experts, researchers and others in the field.**

Ask How They Use Telehealth

Telehealth is when BCBA services are not delivered in person – they are delivered via video conferencing or by telephone to the technician, parent or person with autism. Telehealth can be helpful for several reasons – access to BCBA's in rural areas, in-home consultations where in person observation would be disruptive, and for more immediate response for in-home programs where video technology is established and available.

BCBA clinical direction can be delivered effectively **in certain circumstances** via telehealth. However, it is *not* a substitute for in person observation/assessments and in person clinical direction. Providers who use telehealth for BCBA oversight should have written policies and procedures that they share with you ahead of time about how often and under what specific circumstances telehealth is used. This will differ during COVID circumstances; but all providers should have quality metrics to ensure that telehealth is not overused in place of face to face oversight.

If the BCBA clinical direction offered is *exclusively or predominately* via telehealth, that is, a BCBA is not on site or is rarely on site at a center or will rarely come into the home program, this is a red flag. If a BCBA is not readily accessible in an urgent situation during treatment this is a red flag. (Again, COVID may alter this temporarily.)

Top List of Red Flags From Real World Parent Experiences

1. **Treatment without an assessment.** 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
2. **Lack of thorough background checks.** Centers and home providers should conduct checks on *all* employees who may be on site with patients. BCBAs should be willing to provide their background checks. The background check should be timely, based upon social security number and be nation-wide. Those who victimize children and families are very good at moving from state to state, county to county to avoid detection in less comprehensive background checks.
3. **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. A center-based program should be willing to conduct tours and observations (with parent permission) during normal operations. (COVID considerations may alter the ability to do this for a time).
4. **Filling slots fast.** "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? That takes time and planning.
5. **Playing fast and loose with insurance.** Look for signs that the provider is "crossing lines" in terms of insurance fraud, improper insurance procedures, etc. This might include offers to buy your child insurance if you become a client, giving you financial incentives to start therapy, providing services like babysitting and transportation and "getting 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 completely 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, private school or state curriculum programs.
6. **Insurance prior authorization shenanigans.** How does the provider handle prior authorizations? If the provider recommends 40 hours, for example, but the insurance company says that services should be reduced by 5 hours, does the provider reduce hours if asked by the insurer during the prior authorization process? If yes, this is a red flag. Prior authorization is not a service negotiation, and the provider should recommend what they think is medically necessary – they should not recommend higher hours so that they can "have room to bargain down." This denies you your appeal rights, sends a message to the insurer that the provider "overdoes it" on hours if they are so willing to reduce over the phone, and it is a slippery slope that allows insurers, not clinicians, to drive what becomes the "community standard of care."

7. ***Policies and Procedures Manuals*** - Lack of written policies and procedures for staff and for families is a red flag.
8. ***Conflicts of interest/checks and balances in the business*** - 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?”
9. ***Refuses to give references*** – Be wary if a provider will not give you several references for families who have been with them for over two years or if a provider discourages you from checking references.
10. ***Pressure sales tactics and “bad mouthing” other providers*** – Providers should not discourage you from visiting and interviewing multiple providers or attempt to coerce you in any way into committing to therapy with them right away. Providers should not require you to sign a contract for length of treatment or hours of treatment before starting services or require 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.
11. ***Bad vibes*** - 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).
12. ***Don't ask questions, just trust me*** - Provider is defensive or discourages probing questions. Provider states things such as, “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. You have the right to informed consent and full information before agreeing to treatment.
13. ***“I’m doing God’s work!”*** - Provider cites a particular 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.
14. ***Lack of tech training*** - The technicians do not receive significant training and supervision before working alone with your child. See the BACB Registered Behavior Technician credential at bacb.org. Ask what percentage of front-line staff are RBTs. If the provider does not use RBTs, can they demonstrate that their training is equivalent? The tech should have at least 40 hours of training and pass some sort of competency test that includes observed practice with a client.
15. ***Caseload overload*** - The BCBA has too many people to supervise and does not come to directly observe the program in regularly scheduled intervals that meet BACB guidelines.

16. **On paper but not in practice** - The BCBA schedules clinical direction, supervision, parent meetings, trainings, but does not follow through; what your child does every day doesn't match the treatment plan; their data shows progress that is not demonstrated in real situations
17. **Too much telehealth** - Clinical direction and supervision is only done remotely (video, phone, not in person); overuse of telehealth when in person observation is needed. Covid may temporarily change this expectation.
18. **Data, what data?** - The data collection is disorganized or inaccessible. 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.
19. **No back up** - The BCBA does not have back up for emergencies, illness, vacations or for cases beyond the scope of their experience.
20. **"Guaranteed!"** - The provider or staff offer guarantees – "we will teach your child to talk," "We will get them in school without special education," "ABA cures autism," "We guarantee you will see this result." It is unethical for a clinician or health service to guarantee an outcome in order to entice you to use their services.
21. **Staffing changes – too much OR too little** – If you never know who your loved one will work with from day to day, this affects quality due to treatment fidelity (running the programming as written), consistency, communication and data collection issues. However, if your child goes several months only working with one person, while the consistency may be comforting, that makes generalization of skills more difficult and "fudging data" much easier. Ideally, your loved one will have a team of front-line technicians who are trained to work with him/her who rotate regularly to provide generalization and to check for true progress. Covid may temporarily make this more difficult.

Clip and Take with You – Sample Interview Questions to Ask an ABA Provider Add Your Own Based on Your Loved One's Needs

1. 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, Association for Science in Autism Treatment or the National Autism Project?
 - Do you assist with verifying insurance coverage? What happens if there is a mistake – we are told services are covered and then claims are denied because ABA is not a covered service in the plan? Do you assist to fight for coverage? Are services cut off immediately or do you allow for a transition period to school or other services?
2. Describe the training program that your front-line technicians go through before they are permitted to work with a child? Do you use only RBTs? If not, why not? How do you tailor training to each child's specific program? How many fail your training program and are let go? (If none, this is a red flag. They may not be well trained or tested.

3. Verify credentials – BCBAs, BCaBAs, are your front line people RBTs? (Registered Behavioral Technicians, credential available since 2014). You can verify credentials at bacb.org by name and state.
4. How often are front line technicians directly observed by the BCBA?
5. How long are front line technicians in training before they are allowed to work with a child?
6. 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 easy to manage but not best practice?
7. Verify that background checks are done on all staff who are in the building with the children, including administrative 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?
8. If a center – what would a typical day for my child be like? Should describe tailored program with some group activity (with individualized treatment goals) if age - and developmentally-appropriate – if they describe a schedule or plan that all the kids adhere to, with same/similar goals, regardless of age, ability, etc. that is a red flag.
9. 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? Describe your checks and balances to protect children and families.
10. How do you assess progress? Do you use validated tools endorsed by the BACB or National Autism Project?
11. 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?
12. Do you have exclusion criteria? Are there children/ages/behaviors that you do not feel comfortable treating? If they say they will treat anyone that is a red flag. You should be told exclusion criteria up front before starting services.
13. 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? If the BCBAs have less than 3 years of experience and they are *not supervised by more experienced BCBAs* or mentored by another more experienced clinician, that is a big red flag.
14. Training, continuing education and professional associations – what organizations are you members of? How do you ensure continuing education for your staff that is NOT on-line only?
15. For young children - How many children are discharged from services every six months without insurance company demand to end/reduce treatment? This is one indicator of success in treating young children.

16. 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. Are appeals handled in house or delegated to a billing company? If delegated, how does the billing company handle medical necessity appeals, since they are not clinicians? The right to appeal belongs to the patient (or parent for a child who cannot make this decision). Appeal decisions should not be made by the provider without your knowledge or consent.
17. How does the provider handle prior authorizations? If the provider recommends 40 hours, for example, but the insurance company says that services should be reduced by 5, 7 or 10 hours, does the provider reduce hours if asked by the insurer during the prior authorization process, without discussing this with you? If yes, this is a red flag. **Prior authorization is not a service negotiation, and the provider should recommend what they think is medically necessary – they should not recommend higher hours so that they can “have room to bargain down.”** This denies you your appeal rights, sends a message to the insurer that the provider “overdoes it” on hours if they are so willing to reduce over the phone, and it is a slippery slope that allows insurers, not clinicians, to drive what becomes the “community standard of care.”

Do not be afraid or embarrassed to ask questions or to expect answers. You have the right to informed consent and to make a fully informed, independent decision about medical treatment without coercion or misleading information of any kind.

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 continuously 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. In fact, your insurer must assist you in finding a new network provider who is currently taking new patients. A provider should never make you feel that you do not have a choice. They should never pressure you to stay with their services.

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 even harm him or her. 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!

Questions? Contact Michele at mtrivedi@arcind.org, 317-977-2375 or 800-382-9100.

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