

UW AUTISM CENTER

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Finding the Right ABA Treatment By Natasha Lewis Harrington, PsyD

Dr. Harrington is a postdoctoral trainee and autistic self-advocate at the UW Autism Center. She has been involved with the neurodiversity/autism acceptance movement for over a decade and has worked as an ABA therapist. Dr. Harrington brings a combination of professional, personal, and community knowledge to the discussion of how to best support autistic people.

When your child is diagnosed with autism, you are typically advised to seek out a variety of interventions. In particular, professionals are likely to recommend pursuing Applied Behavior Analysis (ABA) therapy as soon as possible. While looking into the best services for your child, it is easy to become confused by the conflicting opinions about ABA, ranging from statements of life-changing benefitⁱ to claims of extreme harm.ⁱⁱ How can we make sense of these conflicting voices?

When ABA is implemented appropriately and respectfully, it can lead to increases in valuable skills such as communication and self-care.ⁱⁱⁱ However, it is also important to listen to the critiques of autistic self-advocates who may have suggestions about ways to improve treatment approaches and help avoid negative ABA therapy experiences. Outdated attitudes and practices are not inherent to the science of ABA (see note below), but some therapists may have learned an approach that does not adequately balance respect for the client's autonomy and unique qualities with the work of behavior change and developmental growth. With a holistic perspective, you can ensure that the powerful tools of ABA lead to the best outcomes for your child. The following questions, based on the input of autistic adults, can help you find a therapist whose intervention approach has, at its center, respect, compassion, and accurate understanding of your child.

Questions to Ask About Your Child's ABA Therapy

(Primarily based on https://tinyurl.com/ABAWikiHow)^{iv}:

Does the therapist consider and respect your child's right to be different in the context of setting goals and objectives for intervention?

• Much of the autistic community advocates for a message of acceptance and neurodiversity, the idea that all kinds of brains are natural and valuable, rather than valuing the illusion of conformity.^v Treatment goals should not seek to needlessly eliminate harmless mannerisms such as hand-flapping and rocking; instead, they should focus on functional skills such as communication and participation in preferred or necessary activities.

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- Many autistic children enjoy playing with toys in unconventional ways, such as lining them up or watching the wheels spin. Conventional play skills can be taught as an additional way to play, but should not be presented as the one "right" way.
- Therapists should not present a tragic view of autism or promise that they can help your child become indistinguishable from other children. Recent research suggests that developing a positive autistic identity can be an important contributor to improved mental health outcomes.^{vi}

Is your child treated as a person with the appropriate rights and needs?

- Autistic children are often held to a higher standard than others. Consider whether therapy goals and expectations would be considered realistic for another child of the same age.
- Children need time to have fun and play freely. Make sure that their day is not filled with taxing therapies. Allow autistic children as much access to healthy, enjoyable activities as you would another child.
- Basic needs for sleep and food should always be considered when planning intervention schedules. Working toward intervention goals should not interfere with needs for naps, adequate nighttime sleep, or with providing children food and drink that they can tolerate, regardless of cooperation.

How does your child react to therapy?

- Cutting-edge therapy is often naturalistic, play-based and enjoyable to the child. Children may be excited to see the therapist and look forward to sessions.
- Frequent distress before, after, or during therapy, especially distress that extends over many days or increases over longer periods of time, is cause for concern. Sessions may be too intense, too frequent, or have goals that are beyond what is currently realistic for your child.
- Therapists should not coach children to look or act as if they're happier than they are.

Is the therapist flexible, open, and inclusive?

- Therapists should be responsive to your concerns and provide you with the information you need to make informed decisions.
- Therapists should include you and your child in selecting goals, including your child's nonverbal/behavioral signs of preferences and discomfort.
- Therapists should be comfortable allowing you to watch their sessions. This is essential when children are school-aged or younger. As your child approaches adolescence, therapists should begin to work with you to evaluate ways to appropriately increase your child's independence, including confidentiality considerations.

Does the therapist try to understand your child?

• An "uncooperative" child may be communicating that the task is too difficult or otherwise distressing. Therapists should identify and address the barriers to success rather than using frequent punishment, silent treatment, or reverting to a battle of wills to make the

child give in. Therapists should be able to provide you with a clear rationale for their strategies.

- A valuable component of modern ABA is changing the environment to increase the child's success and comfort, such as moving away from painfully loud sounds or using earphones. Therapists should use problem-solving to address sensory issues instead of requiring the child to endure unnecessarily painful situations.
- Communication goals should prioritize functional communication such as expressing preferences (e.g., yes and no) and needs (e.g., food or a break).

Does the therapist care about and seriously consider the internal autistic experience?

- Many autistic people find eye contact to be overwhelming, painful, and a distraction from listening. Therapists must consider the costs of their goals instead of only considering the perceived benefit.
- Behavior commonly perceived as distraction, such as repetitive movements or looking around the room, often help autistic people to concentrate better. Therapists should figure out what helps your child learn.
- When your child is upset, therapists should be as compassionate towards them as they would to a typical child.

Is your child receiving the message that they have a right to safety, dignity, and selfdetermination?

- Children should not be taught that they are obligated to hug or kiss others. Therapists should teach assertiveness skills to help children refuse touch that makes them uncomfortable.
- Restraining, trapping, or physically moving an unwilling child should not be a regular approach. If physical intervention is needed in a crisis, the therapist should prioritize addressing the situation so it is not needed in the future. Instances of restraint should be reported to the parent and discussed if the parent is not present.
- Therapy should not rely on external motivation to create a life that the child would not otherwise want to live. It is important that the therapist work toward goals that will be meaningful and rewarding to the child. For example, the therapist should convey the understanding that ultimately, they are not aiming to have your child demonstrate narrow social skills but to use these skills to be able to establish enjoyable friendships with peers. Similarly, the therapist should work toward helping your child communicate about their needs and interests versus having a narrow focus on increased vocabulary that may not be able to be used to communicate.

In summary, understanding the concerns about ABA has the potential to lead to important improvements in the practice of ABA with autistic children.

- First, you can avoid the danger that identified goals will only represent the wishes and convenience of the people around the client without regard to those of the autistic individual.^{vii}
- Second, many autistic adults are concerned about long-term mental health consequences if therapists insist that children endure excessively painful situations

rather than accommodating sensory differences or other unique needs.^{viii} Attending to these concerns within ABA intervention may allow you to avoid these types of negative consequences.

• Third, ABA has a history of misguided interventions that were believed to benefit the child, such as punishing children for harmless behavior in the effort to make autistic children look "indistinguishable from their peers."^{ix} Increasing awareness and understanding of the past can improve present practices and support the most positive outcomes for autistic individuals in the future.

As a parent or guardian, it is important to be aware of this history, and know what to look for in a therapist to make sure that your child's interests are served. Some ABA therapists have a more modern understanding of what is needed to help autistic children thrive, while others may be well-intentioned but focused on making children fit a mold. Many therapists will have a mixture of helpful views and outdated views. You are entitled to insist that therapy respects your child's rights and needs, and to switch therapists if your provider is not responsive to your requests. It can be daunting to think of going back on a waiting list, but finding the right fit is critical for your child's lifelong emotional development.

Note: Many members of the autistic community define ABA differently from professionals. They may state that "ABA is abuse." If an ABA therapist uses an approach that is sensitive to the child's needs, the autistic self-advocates may claim that it's not really ABA.^x However, the scientific term of "Applied Behavior Analysis" is a wide umbrella and encompasses many modern, supportive therapies.^{xi} Applied Behavior Analysis (ABA) therapy can be a valuable tool that provides your child and family with helpful skills and problem-solving strategies.

^{III} Palmen, A., Didden, R., & Lang, R. (2012). A systematic review of behavioral intervention research on adaptive skill building in high-functioning young adults with autism spectrum disorder. *Research in Autism Spectrum Disorders*, 6(2), 602-617.

vii Regan, R. (2014, August 26). A basic problem with ABA. Retrieved from

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ⁱ Padawer, R. (2014, July 31). The Kids Who Beat Autism. *New York Times.* Retrieved from https://www.nytimes.com/2014/08/03/magazine/the-kids-who-beat-autism.html

ⁱⁱ Kupferstein, H. (2018). Evidence of increased PTSD symptoms in autistics exposed to applied behavior analysis. *Advances in Autism, 4*(1), 19-29.

^{iv} WikiHow. (n.d.) Retrieved February 4, 2019 from WikiHow: https://m.wikihow.com/Tell-if-an-Autism-ABA-Therapy-Is-Harmful

v Kapp, S.K., Gillespie-Lynch, K., Sherman, L.E., & Hutman, T. (2013). Deficit, difference, or both? Autism and Neurodiversity. *Developmental Psychology*, 49(1), 59-71.

^{vi} Cooper, K., Smith, L. G., & Russell, A. (2017). Social identity, self-esteem, and mental health in autism. *European Journal of Social Psychology*, 47(7), 844-854.

viii Unstrange Minds. (2014, October 20). ABA. Retrieved from http://unstrangemind.com/aba/

^{ix} The Lovaas Center (n.d.). *Dr. Ivar Lovaas.* Retrieved from http://thelovaascenter.com/about-us/dr-ivar-lovaas/

^x Max Sparrow (2016, October 20). Retrieved from http://unstrangemind.com/aba/

^{xi} Baer, D. M., Wolf, M. M., & Risley, T. R. (1968). Some current dimensions of applied behavior analysis. *Journal of Applied Behavior Analysis*, 1(1), 91-97.