

## Finding the Right Autism Services for Your Child by Dr. Lucas Harrington, PsyD

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

When parents of autistic children begin researching therapies, they quickly encounter a wide variety of views on what is most important. The autistic community has increasingly been able to make their voices heard regarding the need for services that feel respectful and supportive to the children. Many of these autistic people are part of the neurodiversity movement, which is founded on the idea that despite the associated struggles, autism is a valuable type of brain with its own special strengths and potential. Neurodiversity advocates make the case that autistic people should be encouraged to learn strategies that work effectively with their unique brain rather than being pressured into or rewarded for doing things the standard way. <sup>i</sup>

People often assume that specific types of therapy are automatically good or bad for neurodiversity ideals. In fact, tools of many different fields can be used in ways that are helpful or harmful. As a parent or caregiver, it is important to evaluate therapists on a case-by-case basis to find a good fit for your child, seeking therapies that provide rewarding learning opportunities. A skilled therapist can introduce activities in a way that appeals to your child rather than needing to be forced. 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 Therapy**

## (Primarily based on https://tinyurl.com/ABAWikiHow)ii:

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

• Services should focus on both necessary activities (e.g., going to the dentist, toilet training) and preferred activities (e.g., going to a museum focused on a special interest, playing games that the child appears interested in).



- Treatment goals should not seek to needlessly eliminate harmless mannerisms such as hand-flapping and rocking. While some therapists may view repetitive behaviors as a useless distraction, many autistic people report them to be an important part of their self-expression and life enjoyment.
- It can be appropriate for therapists to introduce conventional play skills in order to broaden your child's repertoire, and to direct your child to activities that they might enjoy sharing with other people. However, many autistic children enjoy playing with toys in unconventional ways, such as lining them up or watching the wheels spin, and it is important to recognize these activities as an equally meaningful way for your child to have fun.
- It is important to find therapists who hold a positive view of autism. Autism should not be presented as a tragedy and therapists should not aspire to 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.<sup>iii</sup>

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 and/or current developmental level.
- Children need time to have fun and play freely. Make sure that their day is not only 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. Services should not interfere with the need for naps, adequate nighttime sleep, or a healthy relationship with food.
- Interventions should not take advantage of basic needs (hunger and thirst, need for connection with a parent, etc.) in order to make the child obey. Goals should be set at a level that the child will voluntarily participate in.

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. They should earn your trust rather than insisting that you defer to their expertise.
- 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 punishment, resorting to silent treatment, or engaging in a protracted battle of wills to make the child give in. Therapists should be able to provide you with a clear rationale for their strategies.
- Problems can often be solved by changing the environment to increase the child's success and comfort, such as moving away from painfully loud sounds or using ear protection. 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 show as much compassion towards them as they would to any other child.

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

• 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 dangerous 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 work on strategies that help your child enjoy mutually rewarding social interaction rather than focusing on behavior that will make them "fit in". Similarly, the therapist should work toward helping your child communicate about their needs and interests, rather than focusing on acquiring vocabulary that may not be useful.

As a parent or caregiver, it is important to know what to look for in a therapist to make sure that your child's interests are served. Some 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 crucial for helping your child thrive.

<sup>&</sup>lt;sup>1</sup> Disabled World. (2021, March 15). *What Is: Neurodiversity, Neurodivergent, Neurotypical.* https://www.disabled-world.com/disability/awareness/neurodiversity/

<sup>&</sup>quot; WikiHow. (n.d.) Wikihow. Retrieved February 4, 2019 from https://m.wikihow.com/Tell-if-an-Autism-ABA-Therapy-Is-Harmful

iii 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.