

Making It Happen

How Do I Choose the Right Intervention?

Choosing a treatment path for your child may feel overwhelming. Remember to work closely with your child's treatment team and explore all of your options. The two articles that follow may provide helpful information for you as you choose between methods of therapies for your child.



“Alleviate Stress by Actively Pursuing the Right Intervention” from **Overcoming Autism**

by Lynn Kern Koegel, PhD and Claire LaZebnik

It's scary to have to question your own child's potential, but the best way to relieve your fears is to take action with productive interventions. The first step is to be informed. Talk to people you trust - parents who've been there, experts in the field, doctors you have a relationship with and so on. There are a lot of fly-by-night procedures that prey on distraught parents who will do anything for their child. Make sure that the interventions you're using are scientifically sound and well documented. Make sure they've been tested with many children with autism and that they've been replicated by other experts and clinics. Also, make sure you understand their limitations – some interventions only work on a small number of symptoms or on a small subgroup of children with autism. If you're going to spend time and money for interventions, be informed about the degree and extent of the change they may bring about.

“Understanding Your Child’s Learning Style”

from ***Does My Child Have Autism?***

by Wendy Stone, PhD, and

Theresa Foy DiGeronimo, M.Ed

Finding the right intervention program begins with an understanding of your child’s learning style – which is quite different from the learning style of other children. You probably realize this as you’ve tried to get your child with autism to wave bye-bye using the same teaching strategies you used with your other children – that is, demonstrating the action, providing a verbal prompt by saying “wave bye-bye” and even moving his or her hand to demonstrate what to do. But when that approach didn’t seem to be working, you probably started to think that your child was being stubborn or uncooperative. After all, you’re teaching simple skills using methods that worked very well for your other children. But the reality is that your child isn’t being bad; he or she just has a different learning style from your other children. This difference in learning styles isn’t apparent only when you try to teach children with autism; it’s also evident in the way they learn (or don’t learn) on their own. There are lots of things that children without autism seem to learn effortlessly, without being taught, but that children with autism don’t pick up on as easily. For example, young children without autism somehow learn, without explicit teaching, how to use a pointing gesture to let you know what they want or to indicate where they want you to look. They learn to follow your point or eye gaze to figure out what you’re looking at or what you’re interested in. They figure out on their own how to use eye contact and facial expressions to convey their feelings—as well as to understand the meaning of your facial expressions and tone of voice. Social-communicative behaviors and skills like these just don’t come as naturally to young children with autism and often need to be taught explicitly.

Assembling Your Team

Your child’s team will consist of many different members. They will help you to address all areas of your child’s life and assist you in making decisions about your child’s treatment, education, recreation and health. Below is some helpful information on how to assemble this group of professionals.

Medical team

Your child should be supported by a pediatrician who understands developmental issues and who will serve as your child’s primary care provider. Depending on your child’s needs, other medical team members may include a neurologist, geneticist, developmental pediatrician, gastroenterologist, psychiatrist or nutritionist.

Intensive intervention team

ABA, ESDM, Floortime, PRT, RDI, SCERTS, TEACCH and VB are all intensive interventions. Depending on the intensity of the primary intervention, there may be an intervention leader and several providers or therapists involved in providing the treatment as structured by the leader.

Related services team

Speech and language therapy, occupational therapy, physical therapy, sensory integration therapy and social skills instruction are all related services. All therapists working with your child should be communicating frequently and using a consistent method of teaching.

Hiring therapists

For parents hiring new therapists, you may want to consider the candidate as you would any other job applicant and handle the situation accordingly. Ask for resumes.

Specific Things to Look for on the Resume:

Past experience with children with autism approximately the same age as your child

Amount of experience the therapist has had

Kinds of experience the therapist has had, for example, whether he or she has worked in a school setting or in a private program

Educational background

Membership in professional autism organizations – if so, then he or she is most likely going to conferences, thus enhancing his or her skills in the profession

Conducting interviews

Conduct a “hands on” interview, during which the potential therapist works with your child to implement a skill acquisition program. It is important to see how the potential therapist takes direction and to see how flexible he or she is about changing approaches in his or her teaching. You will want a therapist to potentially be open to new ideas in terms of teaching approaches. It’s a good idea to have him or her bring video of a therapy session conducted with another child. This offers yet another view of his or her teaching skills. If possible, observe the therapist working with another child.

Check references. Be sure to talk to previous supervisors and other parents for whom the therapist has worked. They are often good sources for finding additional therapists.

Consider a probation period. The therapist should be hired for a probation period, during which sessions are videotaped or observed directly until you and/or the home coordinator feel comfortable with the therapist and confident in his or her abilities.

Check clearances. Anyone working with your child will need to provide background clearances from the state you live in to establish that he or she does not have a criminal record. If you have chosen a home-based intervention program for your child, you will probably be required to submit copies of those clearances to the state, county or local agency providing services.

“When to Be Concerned About a Therapist”

from **Overcoming Autism** by Lynn Kern Koegel, PhD and Claire LaZebnik

There’s plenty of evidence showing that children with autism do better when parents are actively involved in the intervention and when programs are coordinated. Find programs that encourage you to be involved – you should be learning all the procedures and coordinating your child’s program across every environment. You can’t do that if you’re being shut out. If a treatment provider tells you that you can’t watch the sessions or that your child does better when you’re not there, this is a RED FLAG. It may be reasonable for a therapist to request a few sessions alone to bond with the child, but more than that just doesn’t make sense and the therapist needs to communicate fully with you so that you know exactly what’s going on at all times. If a clinician tells you that she’s not documenting any type of changes, be concerned – the only way to evaluate whether a treatment program is working is to analyze the changes your child is making. Also be wary of any therapist who says that he’s working on the “parent-child bond,” and that fixing your relationship with your child will improve her behavior. In other words, if your therapist is excluding you, blaming you or using techniques that do not have measurable outcomes, you should consider looking for another therapist or agency.

Managing your team

Participate in training. Be part of the team. Your participation in team training is vital so that you can increase your skills to successfully parent your child and understand the goals and techniques of his or her program. Knowing the techniques and objectives of your child's intervention program will allow you to closely monitor his or her progress and guide and evaluate the members of your team. Intensive intervention programs often start with a one or two day training course where individual therapists are trained by the primary intervention leader.

Establishing team communication

There are two important ways your team will communicate. One is through a notebook in which each therapist records information after his or her session with your child. Each therapist reads the information recorded since the previous session before the next session with your child. Parents and supervisors can add information to the notebook as needed. The other way is through team meetings. Team meetings are often held at the home of the child, especially in the case of intervention programs that are home-based. These meetings should include as many members of your team as possible. This will ensure that your therapists are up to date on every aspect of the program and that they are all working with your child in consistent ways. At team meetings, you will discuss what is working, as well as areas in which there have not been progress, so that you can determine whether to make changes and what those changes should be. Teams usually meet once a month, but may meet more or less often as needed. Many team meetings include time for therapists to observe each other in action with your child and receive feedback on their techniques.

“Making Therapies Work for the Entire Family”

from **Overcoming Autism** by Lynn Kern Koegel, PhD and Claire LaZebnik

Always be sure you select interventionists who will view the family as teammates and will include you in the determination of target goals – your child needs to learn skills that will help the family function, fit into your lifestyle and be compatible with your cultural and religious values. For example, a clinician may feel that it's important to work on answering the phone, while the family may feel that toilet training is a much more pressing and immediate goal. Both goals may well be valid, but the family needs to have a say in prioritizing them. Similarly, studies show that families who are required to implement drill type interventions have greater stress than when less rigid interventions are incorporated into daily family routines. How well the family functions as a whole is just as important as how well the child with special needs is doing and it's your responsibility to work toward both kinds of success.

There are also currently apps and other technology resources out there that help parents manage their team and keep everyone informed and connected. One resource is My Autism Team (myautismteam.com), a social network that allows all professionals and family members involved in the care of an individual with autism to communicate and provide updates. Search the Autism Speaks Autism Apps database at autismspeaks.org/autism-apps for similar tools!

Technology and Autism

Technology such as iPads, computers and smart phones have become valuable tools in the treatment and daily lives of individuals with autism. These devices can assist in areas ranging from behavior tracking to communication and more. There are many options for how to use technology to benefit each individual. Discuss the use of technology for your child with your treatment team.

The Autism Speaks Autism Apps database contains hundreds of helpful apps divided by age, platform and category. Categories include behavioral intervention, communication, social skills, educational, functional skills and more. Search the database at autismspeaks.org/autism-apps. Many of these apps have been found to help individuals with autism make great strides in their communication skills and abilities to express themselves.

Additionally, technology has been very helpful in allowing families of individuals with autism and their team members to track the child's progress and remain up to date on his or her schedule, improvements, strengths and challenges following treatments and interventions. Examples include:

My Medical App

This app stores complete medical histories for as many people as you wish, helps you keep critical and hard-to-remember information on hand all the time and allows you to track and chart tests results and vital signs and send the records to your doctors with the click of a button.

mymedicalapp.com

TherapyConnectApp

This app was developed by a team of speech-language pathologists and behavioral consultants dedicated to the service of children with disabilities including autism. It is a tool for both therapists/service providers and families who wish to maintain consistent treatment plans that work for their children by allowing the user to monitor the child or client's treatment plan from any iPad.

truetherapydata.com



AutismTrack™

Autism Track is a portable, customizable data tracking tool that empowers caregivers of those with autism to easily track interventions, behaviors and symptoms. Checkboxes allow daily recording of any therapy, medicine or diet.

handholdadaptive.com/AutismTrack.html

You can find additional information on technology and the many ways it can assist individuals with autism at

autismspeaks.org/family-services/technology.

Search the Autism Speaks Apps database for helpful apps for your child at

autismspeaks.org/autism-apps.

Autism and Wandering

Safety is a critical part of all of our lives, whether we are at home or out in the community, alone or with loved ones. Being aware of our surroundings and taking precautions to stay safe is even more important for individuals with autism and their families. Wandering is an especially prominent issue in the autism community. A 2012 study from the Interactive Autism Network confirmed that nearly half of all children with autism have attempted to wander or bolt from a safe, supervised place. Given the frequency of this problem, here are some tips that have been adapted from Autism Wandering Awareness Alerts Response Education Coalition (AWAARE) on how to prevent wandering:

1. Secure Your Home

Consider contacting a professional locksmith, security company or home improvement professional to promote safety and prevention in your home. You may find it is necessary to prevent your loved one from slipping away unnoticed by installing secure dead bolt locks that require keys on both sides, a home security alarm system, inexpensive battery-operated alarms on doors, hook and eye locks on all doors above your child's reach, a fence around your yard, printable STOP SIGNS on doors, windows and other exits, etc.

2. Consider a Locating Device

Check with local law enforcement for Project Lifesaver or Lo Jack SafetyNet services. These locating devices are worn on the wrist or ankle and locate the individual through radio frequency. Various GPS systems are also available.

3. Consider an ID Bracelet

Medical ID bracelets will include your name, telephone number and other important information. They may also state that your child has autism and is nonverbal if applicable. If your child will not wear a bracelet or necklace, consider a temporary tattoo with your contact information.

4. Teach Your Child to Swim

The leading cause of death of individuals with autism who wander is drowning. It is critical to teach your child both to swim and to understand the importance of water safety. Swimming lessons for children with special needs are available at many YMCA locations. The final lesson should be with clothes on. Remember that teaching your child how to swim does not mean your child is safe in water. If you own a pool, fence it. If neighbors have pools, let them know of these safety precautions and your child's tendency to wander. Remove all toys or items of interest from the pool when not in use.

Autism Speaks has a grant program that awards funding to organizations providing scholarships for swimming and water safety lessons for financially disadvantaged individuals with autism. Learn more at autismspeaks.org/family-services/grants/swimming.

5. Alert Your Neighbors

It is recommended that caregivers plan a brief visit with neighbors to introduce their loved one or provide a photograph. Knowing your neighbors can help reduce the risks associated with wandering.

6. Alert First Responders

Providing first responders with key information before an incident occurs may improve response. Informational handouts should include all pertinent information and be copied and carried with caregivers at all times. Circulate the handout to family, neighbors, friends and co-workers, as well as first responders. Always make sure to work with your child's team to express any concerns about safety issues, so that you can work together on a safety plan best suited for your loved one. More information about safety and wandering can be found at: awaare.org, autismspeaks.org/safety and autismspeaks.org/wandering-resources.

