

Assembling your Team

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, or 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 yours.
- The amount of experience the therapist has had.
- The kind of experience the therapist has had, for example, whether they have worked in a school setting or in a private program.
- Educational background.
- Membership in professional autism organizations. If so, then they are most likely going to conferences, thus enhancing their skills in their profession.

Conducting Interviews

■ Conduct a "hands on" interview, during which the potential therapist works with the child, following instructions to implement a skill acquisition program. It is important to see how the potential therapist takes direction and to see how flexible they are about changing approaches in their teaching. One would want a therapist to potentially be open to new ideas in their teaching approaches. It's a good idea to have them bring video of a therapy session they have conducted with another child. This offers yet another view of their teaching skills. If possible, observe the therapist working with another child.



Check references. Be sure to talk to previous supervisors and to other parents the therapists have worked for. Previous supervisors and other parents 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 the parent and/or the home coordinator feels comfortable with the therapist and confident in their abilities.

Check clearances. Anyone working with your child will need to provide background clearances from the state you live in to establish that they do 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.

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.

Establish Team Communication

■ There are two important ways your team will communicate. One is through a notebook in which each therapist records information after their session with your child. Each therapist reads the information recorded since their last session before their 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.



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 therapists is excluding you, blaming you, or using techniques that do not have measurable outcomes, you should consider looking for another therapist or agency.

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



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Ten Things Every Child with Autism Wishes You Knew

By Ellen Notbohm

Some days it seems the only predictable thing about it is the unpredictability. The only consistent attribute – the inconsistency. There is little argument on any level but that autism is baffling, even to those who spend their lives around it. The child who lives with autism may look “normal” but his behavior can be perplexing and downright difficult. Autism was once thought an “incurable” disorder, but that notion is crumbling in the face knowledge and understanding that is increasing even as you read this. Every day, individuals with autism are showing us that they can overcome, compensate for and otherwise manage many of autism’s most challenging characteristics. Equipping those around our children with simple understanding of autism’s most basic elements has a tremendous impact on their ability to journey towards productive, independent adulthood. Autism is an extremely complex disorder but for purposes of this one article, we can distill its myriad characteristics into four fundamental areas: sensory processing challenges, speech/language delays and impairments, the elusive social interaction skills and whole child/self-esteem issues. And though these four elements may be common to many children, keep front of-mind the fact that autism is a spectrum disorder: no two (or ten or twenty) children with autism will be completely alike. Every child will be at a different point on the spectrum. And, just as importantly – every parent, teacher and caregiver will be at a different point on the spectrum. Child or adult, each will have a unique set of needs.

Here are ten things every child with autism wishes you knew:

I am first and foremost a child. I have autism. I am not primarily “autistic.” My autism is only one aspect of my total character. It does not define me as a person. Are you a person with thoughts, feelings and many talents, or are you just fat (overweight), myopic (wear glasses) or klutzy (uncoordinated, not good at sports)? Those may be things that I see first when I meet you, but they are not necessarily what you are all about. As an adult, you have some control over how you define yourself. If you want to single out a single characteristic, you can make that known. As a child, I am still unfolding. Neither you nor I yet know what I may be capable of. Defining me by one characteristic runs the danger of setting up an expectation that may be too low. And if I get a sense that you don’t think I “can do it,” my natural response will be: Why try?

My sensory perceptions are disordered. Sensory integration may be the most difficult aspect of autism to understand, but it is arguably the most critical. It means that the ordinary sights, sounds, smells, tastes and touches of everyday that you may not even notice can be downright painful for me. The very environment in which I have to live often seems hostile. I may appear withdrawn or belligerent to you but I am really just trying to defend myself. Here is why a “simple” trip to the grocery store may be hell for me: My hearing may be hyper-acute. Dozens of people are talking at once. The loudspeaker booms today’s special. Music whines from the sound system. Cash registers beep and cough, a coffee grinder is chugging. The meat cutter screeches, babies wail, carts creak, the fluorescent lighting hums. My brain can’t filter all the input and I’m in overload! My sense of smell may be highly sensitive. The fish at the meat



counter isn't quite fresh, the guy standing next to us hasn't showered today, the deli is handing out sausage samples, the baby in line ahead of us has a poopy diaper, they're mopping up pickles on aisle 3 with ammonia....I can't sort it all out. I am dangerously nauseated. Because I am visually oriented (see more on this below), this may be my first sense to become over-stimulated. The fluorescent light is not only too bright, it buzzes and hums. The room seems to pulsate and it hurts my eyes. The pulsating light bounces off everything and distorts what I am seeing -- the space seems to be constantly changing. There's glare from windows, too many items for me to be able to focus (I may compensate with "tunnel vision"), moving fans on the ceiling, so many bodies in constant motion. All this affects my vestibular and proprioceptive senses, and now I can't even tell where my body is in space.

■ Please remember to distinguish between won't (I choose not to) and can't (I am not able to). Receptive and expressive language and vocabulary can be major challenges for me. It isn't that I don't listen to instructions. It's that I can't understand you. When you call to me from across the room, this is what I hear: "*&^%\$#@, Billy. #\$\$%^*&^%\$&*....." Instead, come speak directly to me in plain words: "Please put your book in your desk, Billy. It's time to go to lunch." This tells me what you want me to do and what is going to happen next. Now it is much easier for me to comply.

■ I am a concrete thinker. This means I interpret language very literally. It's very confusing for me when you say, "Hold your horses, cowboy!" when what you really mean is "Please stop running." Don't tell me something is a "piece of cake" when there is no dessert in sight and what you really mean is "this will be easy for you to do." When you say "Jamie really burned up the track," I see a kid playing with matches. Please just tell me "Jamie ran very fast." Idioms, puns, nuances, double entendres, inference, metaphors, allusions and sarcasm are lost on me.

■ Please be patient with my limited vocabulary. It's hard for me to tell you what I need when I don't know the words to describe my feelings. I may be hungry, frustrated, frightened or confused but right now those words are beyond my ability to express. Be alert for body language, withdrawal, agitation or other signs that something is wrong. Or, there's a flip side to this: I may sound like a "little professor" or movie star, rattling off words or whole scripts well beyond my developmental age. These are messages I have memorized from the world around me to compensate for my language deficits because I know I am expected to respond when spoken to. They may come from books, TV, the speech of other people. It is called "echolalia." I don't necessarily understand the context or the terminology I'm using. I just know that it gets me off the hook for coming up with a reply.

■ Because language is so difficult for me, I am very visually oriented. Please show me how to do something rather than just tell me. And please be prepared to show me many times. Lots of consistent repetition helps me learn. A visual schedule is extremely helpful as I move through my day. Like your day-timer, it relieves me of the stress of having to remember what comes next, makes for smooth transition between activities, and helps me manage my time and meet your expectations. I won't lose the need for a visual schedule as I get older, but my "level of representation" may change. Before I can read, I need a visual schedule with photographs or simple drawings. As I get older, a combination of words and pictures may work, and later still, just words.

■ Please focus and build on what I can do rather than what I can't do. Like any other human, I can't learn in an environment where I'm constantly made to feel that I'm



not good enough and that I need “fixing.” Trying anything new when I am almost sure to be met with criticism, however “constructive,” becomes something to be avoided. Look for my strengths and you will find them. There is more than one “right” way to do most things.

■ Please help me with social interactions. It may look like I don't want to play with the other kids on the playground, but sometimes it's just that I simply do not know how to start a conversation or enter a play situation. If you can encourage other children to invite me to join them at kickball or shooting baskets, it may be that I'm delighted to be included. I do best in structured play activities that have a clear beginning and end. I don't know how to “read” facial expressions, body language or the emotions of others, so I appreciate ongoing coaching in proper social responses. For example, if I laugh when Emily falls off the slide, it's not that I think it's funny. It's that I don't know the proper response. Teach me to say “Are you OK?”

■ Try to identify what triggers my meltdowns. Meltdowns, blow-ups, tantrums, or whatever you want to call them, are even more horrid for me than they are for you. They occur because one or more of my senses has gone into overload. If you can figure out why my meltdowns occur, they can be prevented. Keep a log, noting times, settings, people, activities. A pattern may emerge. Try to remember that all behavior is a form of communication. It tells you, when my words cannot, how I perceive something that is happening in my environment. *Parents, keep in mind as well: persistent behavior may have an underlying medical cause. Food allergies and sensitivities, sleep disorders, and gastrointestinal problems can all have profound effects on behavior.*

■ Love me unconditionally. Banish thoughts like, “If he would just.....” and “Why can't she.....” You did not fulfill every last expectation your parents had for you and you wouldn't like being constantly reminded of it. I did not choose to have autism. But remember that it is happening to me, not you. Without your support, my chances of successful, self-reliant adulthood are slim. With your support and guidance, the possibilities are broader than you might think. I promise you – I am worth it.

And finally, three words: Patience. Patience. Patience. Work to view my autism as a different ability rather than a disability. Look past what you may see as limitations and see the gifts autism has given me. It may be true that I'm not good at eye contact or conversation, but have you noticed that I don't lie, cheat at games, tattle on my classmates or pass judgment on other people? Also true that I probably won't be the next Michael Jordan. But with my attention to fine detail and capacity for extraordinary focus, I might be the next Einstein. Or Mozart. Or Van Gogh. They had autism too. The answer to Alzheimer's, the enigma of extraterrestrial life -- what future achievements from today's children with autism, children like me, lie ahead? All that I might become won't happen without you as my foundation. Be my advocate, be my friend, and we'll see just how far I can go.

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