

TEN THINGS EVERY CHILD WITH AUTISM WISHES YOU KNEW

Freelance writer and consultant Ellen Notbohm is a columnist for Autism/Asperger's Digest and co-author of 1001 Great Ideas for Teaching and Raising Children With Autism Spectrum Disorders (Future Horizons). She favors "common sense" approaches to raising her sons with autism and AD/HD. She lives in Oregon. This article was featured in South Florida Parenting Magazine

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 or her behavior can be perplexing and downright difficult. Today, the citadel of autism, once thought an "incurable" disorder, is cracking around the foundation. Every day, individuals with autism show us they can overcome, compensate for, and otherwise manage many of the condition's most challenging aspects. Equipping those around our children with a simple understanding of autism's most basic elements has a tremendous effect on the children's journey towards productive, independent adulthood. Autism is an extremely complex disorder, but we can distill it to three critical components: sensory processing difficulties, speech/language delays and impairments, and whole child/social interaction issues.

Here are 10 things every child with autism wishes you knew.

1. I am a child with autism. I am not "autistic." My autism is 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)?
2. My sensory perceptions are disordered. This means the ordinary sights, sounds, smells, tastes and touches of everyday life 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 I may appear withdrawn or belligerent to you, but I am really just trying to defend myself. A "simple" trip to the grocery store may be hell for me. My hearing may be hyperacute. Dozens of people are talking at once. The loudspeaker booms today's special. Muzak 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'm too nauseous. Because I am visually oriented, this may be my first sense to become over-stimulated. The fluorescent light is too bright. It makes the room pulsate and hurts my eyes. Sometimes the pulsating light bounces off everything and distorts what I am seeing. The space seems to be constantly changing. There's glare from windows, moving fans on the ceiling, so many bodies in constant motion, too many items for me to be able to focus - and I may compensate with tunnel vision. All this affects my vestibular sense, and now I can't even tell where my body is in space. I may stumble, bump into things, or simply lay down to try and regroup.

3. Please remember to distinguish between won't (I choose not to) and can't (I'm not able to). Receptive and expressive language are both difficult 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's much easier for me to comply.
4. I am a concrete thinker. I interpret language 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, "It's pouring cats and dogs," I see pets coming out of a pitcher. Please just tell me, "It's raining very hard." Idioms, puns, nuances, double entendres and sarcasm are lost on me.
5. 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. There's a flip side to this: I may sound like a little professor or a 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, television or the speech of other people. It's called echolalia. I don't necessarily understand the context or the terminology I'm using, I just know it gets me off the hook for coming up with a reply.
6. Because language is so difficult for me, I am very visually oriented. Show me how to do something rather than just telling me. And please be prepared to show me many times. Lots of patient repetition helps me learn. A visual schedule is extremely helpful as I move through my day. Like your day planner, it relieves me of the stress of having to remember what comes next, makes for smooth transitions between activities, and helps me manage my time and meet your expectations.
7. 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 or 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'll find them. There's more than one right way to do most things.
8. 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 don't 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, I may be delighted to be included.



Excellence in Child Development Since 1994.

9. Try to identify what triggers my meltdowns. This is termed "the antecedent." Meltdowns, blowups, 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.

10. If you are a family member, please love me unconditionally. Banish thoughts such as, "If he would just ..." and "Why can't she ... ?" You didn't fulfill every last expectation your parents had for you, and you wouldn't like being constantly reminded of it. I didn't choose to have autism. Remember that it's 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'm worth it.

It all comes down to 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. I may not be good at eye contact or conversation, but have you noticed I don't lie, cheat at games, tattle on my classmates, or pass judgment on other people?

You are my foundation. Think through some of those societal rules, and if they don't make sense for me, let them go. Be my advocate, be my friend, and we'll see just how far I can go.

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.

