

Ten Things Every Autistic Child Wishes You Knew

Note: this is not to be confused with "10 Things the STUDENT with Autism Wishes You Knew" by Ellen Notbohm. This is a different list of things. It is focused wider on children, not just students. -Ed.

1. I am first and foremost a child. There is more to me than a one-word description like "autistic." I know you know this. Why would you not? So, do not be concerned about calling me autistic even if others say it is wrong. It makes no difference to me if you say I am an autistic child or a child with autism. What you do about me is far more important than what you say about me, anyway. Please pay attention to my real problems and not ones made up by some adults. I already have enough problems as it is. There is no need to make up ones to add on.

If I have autism, then I am disabled by it. Saying that famous or unusual people like Einstein, or Mozart, or Van Gogh were autistic says autism is not a disability. Those people were not disabled. I am. You do not help me by pretending or telling others that I am not disabled, even if that makes you feel better. I am dependent on the public's support. Telling people that I am not disabled, only "just different", threatens my care. Please take autism seriously so others will, too.

2. 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 his 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 I may appear withdrawn or belligerent to you but I am really just trying to defend myself.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. Musak 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 overstimulated. 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.

3. 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.

4. I am a concrete thinker. This means I interpret language literally. For example, to me it could mean that I think about concrete. It could also mean that I am made of concrete. 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."

You may use the word "like" or "as" to help me learn to compare, but do not exaggerate. If something is described "as cold as ice", it should really be that cold. Pick words carefully. "High as a kite" is not the same "high" as in being drunk, yet the expression is used to compare the two. "I play the shoe horn" is not funny to me. It is confusing. It is difficult to understand expressions that play on the different meanings of the same word. Idioms, puns, nuances, double entendres, inference, metaphors, allusions, hyperbole or exaggeration, sarcasm and much of other people's humor are lost on me. I have a sense of humor. I find different things funny.

5. 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.

6. Because language is so difficult for me, I am visually oriented. Please show me how to do something rather than just telling me. And please be prepared to show me many times. Lots of consistent repetition helps me learn. Speech and language therapists and behavior specialists knowledgeable about autism can provide a range of learning aids tailored for me. Contact my local school district or disability agency to help you find them.

7. 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. The autism needs fixing, not me. 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.

8. 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?"

9. 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. It is my situation and my autism that needs to be fixed, not me.

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.

10. If you are a family member, please 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. Understand my autism is a disability. Autism the disability is not some wonderful gift. It cripples. It confuses me when you say my suffering is a good thing I should like. But autism is treatable and I may be able overcome being disabled. To find out more about treatment and recovery contact one of these two sources:

. Autism Research Institute
<http://www.autismwebsite.com/ari/index.htm>

. Generation Rescue
<http://www.generationrescue.org>

Look past what you may see as limitations.

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.

[This "Ten Things. . ." list by the Schafer Autism Report is derivative of one created by Ellen Notbohm, "Ten Things Every Child With Autism Wishes You Knew", which has been rewritten for publication here.

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