

10 Things the Student with Autism Wishes You Knew (...and it makes sense for other kids too!)

By Ellen Notbohm

Author's note: When my article Ten Things Every Child with Autism Wishes You Knew was first published in November 2004, I could scarcely have imagined the response. Reader after reader wrote to tell me that the piece should be required reading for all social service workers, teachers and relatives of children with autism. "Just what my daughter would say if she could," said one mother. "How I wish I had read this five years ago. It took my husband and I such a long time to 'learn' these things," said another. As the responses mounted, I decided that the resonance was coming from the fact that the piece spoke with a child's voice, a voice not heard often enough. There is great need - and I hope, great willingness - to understand the world as special needs children experience it. So the voice of our child returns now to tell us what children with autism wish their teachers knew.

1. Behavior is communication. All behavior occurs for a reason. It tells you, even when my words can't, how I perceive what is happening around me. Negative behavior interferes with my learning process. But merely interrupting these behaviors is not enough; teach me to exchange these behaviors with proper alternatives so that real learning can flow.

Start by believing this: I truly do want to learn to interact appropriately. No child wants the negative feedback we get from "bad" behavior. Negative behavior usually means I am overwhelmed by disordered sensory systems, cannot communicate my wants or needs or don't understand what is expected of me. Look beyond the behavior to find the source of my resistance. Keep notes as to what happened immediately before the behavior: people involved, time of day, activities, settings. Over time, a pattern may emerge.

2. Never assume anything. Without factual backup, an assumption is only a guess. I may not know or understand the rules. I may have heard the instructions but not understood them. Maybe I knew it yesterday but can't retrieve it today. Ask yourself: Are you sure I really know how to do what is being asked of me? If I suddenly need to run to the bathroom every time I'm asked to do a math sheet, maybe I don't know how or fear my effort will not be good enough. Stick with me through enough repetitions of the task to where I feel competent. I may need more practice to master tasks than other kids.

Are you sure I actually know the rules? Do I understand the reason for the rule (safety, economy, health)? Am I breaking the rule because there is an underlying cause? Maybe I pinched a snack out of my lunch bag early because I was worried about finishing my science project, didn't eat breakfast and am now famished.

3. Look for sensory issues first. A lot of my resistant behaviors come from sensory discomfort. One example is fluorescent lighting, which has been shown over and over again to be a major problem for children like me. The hum it produces is very disturbing to my hypersensitive hearing, and the pulsing nature of the light can distort my visual perception, making objects in the room appear to be in constant movement. An incandescent lamp on my desk will reduce the flickering, as will the new, natural light tubes. Or maybe I need to sit closer to you; I don't understand what you are saying because there are too many noises "in between" - that lawnmower outside the window, Jasmine whispering to Tanya, chairs scraping, pencil sharpener grinding.

Ask the school occupational therapist for sensory-friendly ideas for the classroom. It's actually good for all kids, not just me.

4. Provide me a break to allow for self-regulation before I need it. A quiet, carpeted corner of the room with some pillows, books and headphones allows me a place to go to re-group when I feel overwhelmed, but isn't so far physically removed that I won't be able to rejoin the activity flow of the classroom smoothly.

5. Tell me what you want me to do in the positive rather than the imperative. "You left a mess by the sink!" is merely a statement of fact to me. I'm not able to infer that what you really mean is "Please rinse out your paint cup and put the paper towels in the trash." Don't make me guess or have to figure out what I should do.

6. Keep your expectations reasonable. That all-school assembly with hundreds of kids packed into bleachers and some guy droning on about the candy sale is uncomfortable and meaningless to me. Maybe I'd be better off helping the school secretary put together the newsletter.

7. Help me transition between activities. It takes me a little longer to motor plan moving from one activity to the next. Give me a five-minute warning and a two-minute warning before an activity changes - and build a few extra minutes in on your end to compensate. A simple clock face or timer on my desk gives me a visual cue as to the time of the next transition and helps me handle it more independently.

8. Don't make a bad situation worse. I know that even though you are a mature adult, you can sometimes make bad decisions in the heat of the moment. I truly don't mean to melt down, show anger or otherwise disrupt your classroom. You can help me get over it more quickly by not responding with inflammatory behavior of your own. Beware of these responses that prolong rather than resolve a crisis:

- Raising pitch or volume of your voice. I hear the yelling and shrieking, but not the words.

- Mocking or mimicking me. Sarcasm, insults or name-calling will not embarrass me out of the behavior.
- Making unsubstantiated accusations
- Invoking a double standard
- Comparing me to a sibling or other student
- Bringing up previous or unrelated events
- Lumping me into a general category ("kids like you are all the same")

9. Criticize gently. Be honest - how good are you at accepting "constructive" criticism? The maturity and self-confidence to be able to do that may be light years beyond my abilities right now. Should you never correct me? Of course not. But do it kindly, so that I actually hear you.

Please! Never, ever try to impose discipline or correction when I am angry, distraught, overstimulated, shut down, anxious or otherwise emotionally unable to interact with you.

Again, remember that I will react as much, if not more, to the qualities of your voice than to the actual words. I will hear the shouting and the annoyance, but I will not understand the words and therefore will not be able to figure out what I did wrong. Speak in low tones and lower your body as well, so that you are communicating on my level rather than towering over me.

Help me understand the inappropriate behavior in a supportive, problem-solving way rather than punishing or scolding me. Help me pin down the feelings that triggered the behavior. I may say I was angry but maybe I was afraid, frustrated, sad or jealous. Probe beyond my first response.

Practice or role-play - show me-a better way to handle the situation next time. A storyboard, photo essay or social story helps. Expect to role-play lots over time. There are no one-time fixes. And when I do get it right "next time," tell me right away. It helps me if you yourself are modeling proper behavior for responding to criticism.

10. Offer real choices - and only real choices. Don't offer me a choice or ask a "Do you want...?" question unless are willing to accept no for an answer. "No" may be my honest answer to "Do you want to read out loud now?" or "Would you like to share paints with William?" It's hard for me to trust you when choices are not really choices at all.

You take for granted the amazing number of choices you have on a daily basis. You constantly choose one option over others knowing that both having choices and being able to choose provides you control over your life and future. For me, choices are much more limited, which is why it can be harder to feel confident

about myself. Providing me with frequent choices helps me become more actively engaged in everyday life.

Whenever possible, offer a choice within a 'have-to'. Rather than saying: "Write your name and the date on the top of the page," say: "Would you like to write your name first, or would you like to write the date first?" or "Which would you like to write first, letters or numbers?" Follow by showing me: "See how Jason is writing his name on his paper?"

Giving me choices helps me learn appropriate behavior, but I also need to understand that there will be times when you can't. When this happens, I won't get as frustrated if I understand why:

"I can't give you a choice in this situation because it is dangerous. You might get hurt."

"I can't give you that choice because it would be bad for Danny" (have negative effect on another child).

"I give you lots of choices but this time it needs to be an adult choice."

The last word: believe. That car guy Henry Ford said, "Whether you think you can or whether you think you can't, you are usually right."

Believe that you can make a difference for me. It requires accommodation and adaptation, but autism is an open-ended disability. There are no inherent upper limits on achievement. I can sense far more than I can communicate, and the number one thing I can sense is whether or not you think I "can do it."

Expect more and you will get more. Encourage me to be everything I can be, so that I can stay the course long after I've left your classroom.

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