17 Things People on the Autism Spectrum Wish Others Would Stop Saying

Mohini Kundu

As a society, we’ve taken some significant steps towards greater acceptance of individuals with autism spectrum disorder in recent years — from mainstream television portraying characters on the spectrum, to large corporations finding ways to better support the community. But despite increasing information and awareness, many people still may not know how to respond to an autism diagnosis in a way that reflects true understanding of the community and the experiences of those on the spectrum.

Even the things that are becoming more commonly known about autism — for example, the difficulty for some people on the spectrum to maintain eye contact or navigate social situations — can be detrimental to the community in the form of generalizations and stereotypes and ignoring an autistic individual’s unique experience.

To help foster more understanding, we asked our readers on the autism spectrum to share things they’ve heard that they wish others would stop saying.

Here’s what the community had to say:

1. “I really wish people would stop saying, ‘Oh, but you’re so normal.’ When people say this, it feels like it is discrediting all the work I have done to get to the point where I am almost ‘normal.’”
2. “I won’t have my child vaccinated. The risk of autism is just too high!’ Both myself, my younger brother and my son are on the spectrum. It’s so lovely to hear, on a regular basis, that parents would rather potentially expose their precious children to deadly diseases than have them ‘end up’ like me.”

3. “I wish people wouldn’t say, ‘Oh, but aren’t we all a little autistic?’”

4. “I hate it when people say I’m ‘acting crazy’ and ‘You need to calm down.’ Sensory overload isn’t fun, and even at my age, it still happens more often than not. It doesn’t make me ‘crazy,’ and I’m not overreacting. I just get overwhelmed.”

5. “I just asked my 9-year-old son, and he said he wished others would stop telling him to stop making his clicking noise because he likes the way it gives pressure in his mouth and he feels calm. He wishes other people better understood how he gets calm.”

6. “When I’m trying to explain the anxiety I feel about crowded places and loud noise and people minimize it by saying, “Well, yeah, I don’t like that either.” It’s as if I’m making a big deal out of something so menial, but they don’t get how my sensory sensitivities can cause me physical discomfort.”

7. “When people tell me I don’t have feelings or shouldn’t/can’t have emotions. I most certainly do have emotions, it just takes me a little longer to understand them.”

8. “I wish people would stop saying, ‘Are you sure you actually have Asperger’s/ASD?’ People are so quick to judge someone’s current situation, not understanding where they came from and what it took them to get where they are today.”

9. “‘So and so’s son/daughter has autism, but theirs is much more severe than yours.’ Just because you cannot always see it, doesn’t mean it isn’t happening.”

10. “‘You’re incapable of knowing what others are actually saying, thinking, or feeling’ — said the people who hurt me the deepest throughout my life.”

11. “My personal favorite: ‘Oh, I know someone with autism. Person continues to ramble generic stereotypes like a lecture and ignore you as an individual.”

12. “‘I am so sorry you have that.’ There is nothing to be sorry about. Autism is another way that the world is looked at.”

13. “‘You must be like Rain Man, then!’ No. I’m legit not.”

14. “My kid wishes other kids would stop using the word ‘autistic’ as an insult.”

15. “A schoolteacher told me my Asperger’s is an ‘excuse.’”

16. “‘Can you please look me in the eye?’ No, I can’t.”

17. “My 11-year-old daughter said, ‘I don’t like it when people say I can’t do something. I can do anything. It might be harder and take longer because my brain needs more time, but I can do it.’”

Reprinted from: www.themighty.com
Despite all of the adults being diagnosed with ASD there are still fewer books about ASD and adulthood than there are about ASD in young children. Fortunately, this is starting to change and more professionals are finding out that autism follows you all through your life for better or for worse.

Dr. Theresa Regan, a neuropsychologist, has written a very thorough and compelling analysis of adulthood on the Spectrum starting with an explanation of ASD and the importance of a good, correct diagnosis. The author is keenly aware of the legions of adults (including myself!) who go for years until they get the right diagnosis which often makes a huge difference in their lives.

Subsequent chapters cover communication, social functioning and relationships, independent living (including skills such as money management, food preparation, grocery shopping, etc.), employment and so much more. Dr. Regan also considers issues relating to older adults such as utilizing the health care system, not an easy task by any means, mental health issues, and resilience and the ability to navigate everyday life and to solve problems as they arise.

Each chapter is enriched by one or more case studies of adults on the autism spectrum learning to cope and to thrive with a still little understood condition that is invisible and often looks like a set of deliberate behaviors rather than a neurological condition needing to be worked around.

I was fascinated by the book and was impressed by the author’s thoroughness and compassion; no condescension or preachiness here—just lots of good, solid information and helpful strategies making this a useful tool for not only clinicians, therapists and family members but the adults themselves so that they can understand themselves better and shine that bright light into their lives.
Autism Society of Michigan

“2018 Workshop
Wednesday, April 18th, 2018
Washtenaw Community College Conference Center
4800 E. Huron River Drive
Ann Arbor, MI
9:00 a.m. to 3:00 p.m.

Morning Speakers:
Dr. Sally Burton-Hoyle, Professor at Eastern Michigan University
Dr. Sally Burton-Hoyle is a Professor at Eastern Michigan University in the Special Education Department. Sally previously held the Executive Director position at ASM. Her brother, Don was on the spectrum.

Anne Carpenter, ASM’s Information & Referral Specialist
Anne Carpenter has worked for ASM for 30 years. Anne creates book, website, and product reviews for ASM’s Newsletters and Website. She was diagnosed at the age of 30 years old with ASD.

Josh Stokes, Speaker & Person with ASD
Josh Stokes offers parents and caretakers a rare look through the eyes of a person diagnosed with Autism. He candidly shares his experiences and how each situation and circumstance he has faced throughout his life as a child and an adult with Autism has made him feel.

The afternoon session will consist of a panel of our speakers, answering and discussing topics from the audience/attendees.

Registration Fees:
*Continental Breakfast Provided/Lunch on Your Own
*Many Restaurants close by

Registrant……..$20
ASM Member…$15
Person w/AD….$10
Student……….$10

Please Register by calling: 517-882-2800 or online at:
https://www.autism-mi.org/events/
By: Anne Carpenter, the Autism Society of Michigan’s Information & Referral Specialist

For many children with autism, the slightest change, such as a rainy day on a day planned for a trip to the zoo or the sudden cancellation of a planned movie outing, can throw one into a major tizzy. Because the change is so sudden and so unexpected, one is at a loss as to how to respond or what to do.

Adele Devine’s charming and reassuring new book, *It’s Raining and I’m Okay: A Calming Story to Help Children Relax When They Go Out and About* is about a little girl who encounters all kinds of things in a one day such as rainy weather, walk signals that don’t work, a long line at the store, a busy cafe, a missed bus, etc. After each seeming mishap the little girl stops, takes a deep breath and everything seems to work out. She has boots and a raincoat, she tries a new pack of snacks at the cafe and likes them and manages to find a bathroom in time when she needs to go.

At the bottom of each page is a set of symbols that represents the situation,(a circle with two arrows representing a change from the ordinary, and calming techniques such as counting, breathing, and making a circle with one’s hand. The parent or teacher can guide the child toward a calmer, more positive response to a tricky situation.

The illustrations are delightful and really show the emotions beautifully. As the reader progresses through the book it is apparent that problems can be solved and one can navigate difficult situations more easily by stopping to take a few deep breaths and finding ways to work things out. This should be in every library’s children’s section and every single school in the land! I wish this book had been around when I was a child and got so upset at the least little thing!
When is it okay to blurt?

If I have a question
Nope...raise your hand

I need to use the bathroom
Nope...raise your hand

If I don’t feel good
Nope...raise your hand

If I have a story to share
Nope...raise your hand

If I’m off topic
Nope...wait til later

If you or someone is unsafe
Yes! tell a teacher right away

If there is an emergency
Yes! tell a teacher right away
7 Steps to Teaching Social Skills

1. Set Realistic Goals
   Clearly define what the behavior is going to look like and make it manageable.

2. Tell Why
   Explain why the desired behavior is important and presume competence.

3. Model the Behavior
   Demonstrate the behavior.

4. Practice
   It takes a lot of practice to change behavior.

5. Prompt
   Set up a natural cue or prompt for the behavior.

6. Reinforce
   Celebrate success!

7. Generalize
   Generalize the skills so a student can get it right with lots of different people.


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