How You Talk About Your Autistic Child

The Top 5 Language Mistakes You (Or Your Friends and Family) Are Making

Autism Acceptance

Many autistic self-advocates are speaking out against the movement to eradicate autism and instead supporting the creation of a society that acknowledges the civil rights of autistic individuals and offers them the same opportunities that neurotypicals have access to. (This is discussed at length in "The Neurotypical Parent's Autism Advocacy Toolkit.")

Some parents unknowingly adopt an agenda for their autistic children that their children never internalize. Parents may push their children toward certain careers or activities they think will help them, pursue aggressive therapies, and try every new medicine or autism "treatment" on the market.

Unfortunately, treating autism as a nasty disease that needs to be fought off in order to live a happy, productive life can have a devastating impact on a child's perception of self-worth. Fortunately, while we may not be able to control autism, we can certainly control our attitudes about it. **Autism advocacy beings with love, acceptance, and respect for your child as an autistic being, not someone who is trapped inside of an autistic body.**

"Autism is a part of me, and it always will be."
-Lydia Wayman

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Even if you have always believed autism is something your child "has," and have been trying for several years to "cure" him or her of it, adopting some very specific language changes can make a big difference in how your child views autism. How you speak about autism around your child can severely impact his or her perception of self-worth, which is why it is useful to examine some common expressions and reflect on the implications of your own language use.

It is easy to talk about your children freely when they are young and oblivious to the words you use, the connotations of those words, and the manner in which you use them. At some point, parents become more careful of the words they use around their children and what they discuss in front of them. It's important for parents to discuss the language they will use to talk about their autistic children and practice that language early on. Children are perceptive, and parents who dismiss their child's ability to absorb and understand their frustrations or low expectations for them may unintentionally encourage poor self-esteem and depression for their children.

Below is a list of common statements people use when discussing autism that many autistic self-advocates condemn. People use this language with the best of intentions, but autistic self-advocates are asking everyone to reconsider how they speak about autism. Underneath each statement is an alternate way to discuss autism that promotes more positive messages to your child and your community. These suggestions can be useful substitutions to help practice autism acceptance within your own household, or respectful ways of correcting or responding to family, friends, or strangers who use non-preferred language.

1. *"He has autism."*

Instead say, "He's autistic."

This is a distinction between person-first language and identity-first language. Within the autistic community, many self-advocates prefer identity-first language. They acknowledge that autism is interwoven with their identity and that referring to it as a separate entity perpetuates the idea that whatever is autistic about them is "bad" and something they should "get rid of." However, there are exceptions to this preference, and it is most appropriate to identify and respect the wishes of whomever you are speaking to or about. It is helpful to use this language when speaking about your child so that he or she doesn't feel guilty about having autism. If your child feels guilty about his autism, something that affects every perception he has, it can lead to daily frustration, embarrassment, and lower self-esteem.

If a family member, friend, or stranger tries to discuss autism like it's a disease your child has, you could say, "Autism isn't something he has; it is who he is. My son is autistic, and that's okay."

2. *"He's very high-functioning."*

Instead say, "He's verbal," or comment on his specific strengths.

Most people use the term "high functioning" to mean that an autistic person can function well in a neurotypical environment. But what does "function well" mean? This phrase typically means that the individual's autistic traits or symptoms are not easily visible to neurotypical people. Primarily, this describes an individual who can communicate verbally. It also means the autistic person doesn't have frequent tantrums in public, exhibit any obvious self-stimulating behaviors (i.e. hand flapping, rocking, physical ticks, loud humming, intense perseverations) or appear to live "in his own world."

So what's wrong with the term "high functioning"? One problem is that it unfairly separates autistic people by offering a simplistic category for those who are different than what has stereotypically come to be known as autism. This impacts society's expectations of them. Many assume that high-functioning autism (HFA) isn't really disabling and even that the label comes with the advantage of possessing a special talent or superior intelligence. These assumptions fail to acknowledge the individual's full neurological condition, which still results in a multitude of obstacles to daily functioning. The assumptions many people have of HFAs can also discourage those autistic people who don't have an extraordinary skill and are expected to navigate their days in the neurotypical world just like every other non-autistic person. Because these people can sometimes "pass" as neurotypical, societal expectations are often higher for them and they typically receive less support than those with more severe symptoms.

A label of "high functioning" isn't as descriptive as many people think it is. The name mistakenly groups autistic individuals into a category that assumes they can do everything a neurotypical can with the exception of being a little awkward in social settings. But "high functioning" cannot possibly refer to all of the tasks humans perform on a daily basis. Some autistic people are "high functioning" when it comes to one skill (in other words, they can perform it well by the standards of a neurotypical society), but then "low functioning" when asked to perform a different task. Sometimes they act high functioning one day in a specific environment, but then fail to perform at this level when outside of the home or in a setting with uncomfortable sensory triggers. On the other hand, even autistic people who are identified as "low functioning" can have "high functioning" skills as well. These terms falsely identify autistics and don't do justice to the unique skill sets of people all over the spectrum. The overly simplistic labels of "high functioning" and "low functioning" unfairly and inaccurately divide autistic people.

If someone else says, "Your son must be high functioning," you could respond, "We prefer not to use that phrase because it's not very specific. People would consider him high functioning in some areas and low functioning in others, just like any other non-autistic person."

How You Talk About Your Child

The Top 5 Language Mistakes You (Or Your Friends and Family) Are Probably Making Continued...

3. *"We're lucky we caught it early."*

Instead say, "We are committed to helping him thrive in his environment. We are learning how to make the changes he needs, and he is learning to adapt better every day."

There is a lot of media attention devoted to early interventions for autism treatment. Research suggests that the plasticity of a child's brain allows for "rewiring" opportunities where learning comes easier than it does later in life (although recent studies show that the adolescent brain also mimics some of the same growth opportunities as childhood). Pursuing therapy and support for your child early in life can create healthy learning opportunities when conducted in a loving and accepting environment. But treating autism as something that needs to be "fought off" early on in life perpetuates the idea that it is something bad you are trying to get rid of.

Instead, accept that your child will have more struggles than his neurotypical counterparts, and remain committed to helping support him by learning to adapt to his environmental needs and request appropriate accommodations so that he can participate fully in whatever opportunity he wants to pursue. If your child hears you talk about how happy you are that you "caught it early," and then he feels the effects of his autism later in life, he may feel bad about lingering symptoms (which he experiences even though they may be invisible to others) and think he still needs to be "fixed."

If someone else tells you that, "It's a good thing you caught it early," you could respond with, "We don't like to think of autism as something we 'caught early.' We've just been trying our best to respond to the needs of our son since his birth, like any parent would. We aren't trying to get rid of his autism, but rather help him learn to successfully navigate the world as an autistic."

4. *"We treated her autism. She's cured now."*

Instead say, "We have helped her learn to advocate for her needs," or "We are offering the right supports to help her succeed in the ways she wants to."

Similar to the previous statement, aggressive cure campaigns or constant discussions about treating autism like it's a disease are likely to impact how your child views herself. Many autistic people talk about how autism affects everything they do; it is part of who they are. If your child thinks you are constantly trying to cure her identity, it may be harder to communicate your unconditional love. Tell your child that you love her and are committed to helping her in any way you can to achieve her academic, social, emotional, or professional goals.

If someone else tells you "She's cured now!" you can kindly respond, "She will always be autistic; that is who she is. We aren't trying to cure her, we are helping her advocate for her needs so she can live independently and productively."

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5. *"He's doing great. He doesn't look that autistic anymore."*

Instead say, "He is learning to adapt successfully within the environments of his choosing and advocate for himself."

Again, pressuring your child to shed all visible signs of autism and "pass" as neurotypical suggests that autism is awful and he should be working hard to get rid of it (or at least act like he doesn't have it). Communicating that it is a good thing that your child is not acting autistic means you are praising him for acting like someone else. This facade is extremely wearisome and unsustainable for your child, and your child may feel that he is unable to please you or that he will never be accepted for who he truly is.

If someone else makes a comment like this to you, you can say, "We don't hope that he looks less autistic. We aren't ashamed of autism. We hope that he is comfortable, happy, and capable in his environment."

Learn to Listen

Autistics have spoken on both sides of the self-advocacy issue. Some argue that autism is good and any attempt to prevent or "cure" it is irresponsible and immoral. Other autistics assert that there are real difficulties to living as autistic and that they would readily accept an opportunity to change themselves. Many others lie somewhere in between. Whatever camp you and your child sit in doesn't deny the fact that learning how to advocate for your child's needs is essential to helping him live an independent and productive life. Teaching and modeling how to live a positive, meaningful autistic life will help you and your child embrace what you can't control and truly appreciate your child's identity.

"If we are to achieve a richer culture, rich in contrasting values, we must recognize the whole gamut of human potentialities, and so weave a less arbitrary social fabric, one in which each human gift will find a fitting place.
-Margaret Mead

Jenna Gensic
http://learnfromautistics.com/
https://www.facebook.com/learnfromautistics
Twitter @jennagensic
jennagensic@learnfromautistics.com