

30 Things Parents of Children on the Autism Spectrum Want You to Know

It is estimated that one in 68 children are now diagnosed with an Autism Spectrum disorder, and yet, this diagnosis remains as misunderstood as ever. We simply do not live in a society that is accommodating or even accepting of those who are not “neurotypical.” Fortunately, parents of autistic children are wonderful at communicating who their children are and why. Below are 30 things those parents of children on the Autism Spectrum want you to know.

Information provided
by Applied Behavior Analysis
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Not all autism is the same, and neither is every child with autism.



It's called the Autism Spectrum because autism actually covers a wide scope of complex disorders in brain development. Included are Asperger's Syndrome, "classic" autism and Pervasive Developmental Disorder, among others. The types of autism range in everything from communication skills, anxiety, social interaction, and repetitive behaviors, among other things. As with any kid, a child with autism should be treated as an individual with his or her own set of abilities and preferences.

Just because my kid doesn't look like another kid with autism doesn't mean he's not on the Autism Spectrum.



As one parent wrote on the popular Autism Speaks blog, "Knowing one child with autism doesn't mean anything really — they're all so different. Please don't tell me my son doesn't have [autism] because he looks so different from the other kid you know on the Spectrum."

You can't always see autism.



There is still a shocking amount of ignorance among the general population when it comes to the Autism Spectrum. Many people assume that children with autism have certain identifiable facial features or particular habits. But as it has already been mentioned, every single person with autism is different and mild cases of autism are common. These stereotypes and lack of understanding often make things difficult for parents. It's especially hard in the case of schools, coaches, or other organizations who deny a diagnosis because it is not easily seen.

Our home is safety proofed.



You're probably familiar with baby proofing a house. But while most families can take down the safety gates and doorknob locks once the child ages, families with children on the Autism Spectrum often have these items and more protecting their child from their home's inherent dangers. This is because many children on the Autism Spectrum are prone to behaviors that can bring about self injury.

Autism causes the brain to process things differently.



Children on the Autism Spectrum process differently things others often take for granted. Crowds, loud noises, and bright or blinking lights, among countless other things, can often lead to extreme anxiety or a total meltdown on the part of the child. As one parent of an autistic child stated, "If you are in a supermarket and your child is getting overwhelmed and maybe making a scene, it makes it ten times worse when people around you are giving you dirty looks or making comments."

My child may be nonverbal, but she has a lot to say.



We live in a very verbal society that is ill-equipped for those in our population who are nonverbal. It's estimated that about one-third of those on the Autism Spectrum are unable to speak. Still, it would be a mistake to assume these people do not have ideas, opinions, and other things to say. Some autistic children learn sign language to communicate, while others type or use other tools.

My autistic child has feelings.



A common challenge children on the Autism Spectrum and their parents face is the assumption (by other children, other parents, and even teachers) that because an autistic child cannot verbalize or express their feelings like a neurotypical child might, those feelings must not exist. But nothing could be further from the truth. As one parent bluntly describes, "Even children who don't speak can still hear you. Don't talk to me over my children like they aren't there, especially if you're going to sympathetically tell me what a saint I am for dealing with a horrible situation every day. I'm not a saint. I'm their mother. And she HEARS YOU and understands that you're saying she's a burden to me."

Children on the Autism Spectrum are not dumb.



Kids with autism have the potential to be absolutely brilliant. They're also talented, philosophical, kind, and creative. This is something much of society fails to see, but in truth, the autistic mind is simply wired differently than those not on the Autism Spectrum. Hans Christian Andersen, Emily Dickinson, Albert Einstein, Bill Gates, Michelangelo, Mozart, and Sir Isaac Newton (to name but a very few!) — all are said to have exhibited autistic tendencies.

“Autistic” is not my child’s sole definition.



A child on the Autism Spectrum is first and foremost a child. Autism is simply something that has happened to that child. Make an effort to see someone on the Autism Spectrum for their unique personality, talents, likes and dislikes, not the differences brought about by their autism diagnosis.

A schedule means nothing to us.



Children on the Autism Spectrum often have a difficult time adapting to changes in routine. Taking a vacation, weekend away, or even just a spontaneous trip to the zoo can be a bit of a challenge. Even the best-laid plans can go awry and cause total havoc.

Please let my child play with your child.



A study done in Australia found that 42% of teens and adults on the Autism Spectrum do not feel comfortable leaving their own home because they often feel others treat them negatively. Not only is this heartbreaking for the affected individuals, it also leads to further misunderstanding and stigma about autism by the general public. Children with autism like to play with their peers, and largely benefit from being included in things like play dates and sports teams.

My kid works harder than any other child her age.



As already mentioned, we do not live in a society that is accommodating to people on the Autism Spectrum. This means that an autistic kid has to work much, much harder to function just about anywhere they go. Behind that hard-working kid are parents, teachers, and therapists who are also working hard to help that child. An autistic child acting like their neurotypical peers has not been cured. He's simply working 100 times harder to keep up, and that's something we should all keep in mind.

There's no need to tag us in every Facebook article about autism.



Parents of children on the Autism Spectrum are research junkies, and do their best to stay up-to-date with each and every advancement in the autism community. Certainly, they know more than the average person. As one parent put it, "There's literally no Facebook article [about autism] we haven't seen. So, before you share it and tag us because we're that friend with the child with autism, take that into account."

On a similar note, please keep your unsolicited advice to yourself.



This is a big one, and parents say it all the time. Please don't offer unsolicited advice about something you probably know very little about to a parent who lives and breathes autism.

We know best when it comes to our autistic children.



All parents know their own children best, but this statement is especially true of parents of children on the Autism Spectrum. Most parents of autistic children have spent countless hours researching and consulting with doctors. They know their children's ticks and the best ways to avoid meltdowns. Autism Speaks advises other parents keep the unsolicited parenting advice to themselves, saying, "Do ask the family whether there's something you can do to help, but be prepared for a 'no.'"

I'm not someone to pity simply because my child has autism.



Autistic children are writing books, making films, creating blogs, and making all sorts of other groundbreaking achievements. Yet, when a parent tells someone their child is autistic, they are usually met with an unnecessary apology or look of pity. Autism is not something to be pitied, and our society's outlook should change to reflect that.

As parents, we aren't looking for an autism cure.



Parents of neurotypical children are often surprised to hear that parents of children on the Autism Spectrum aren't really looking for a cure. Autism is part of their child's life and identity, and they wouldn't be themselves if they weren't autistic. These parents might research to find management tips and tricks (such as diets), but they understand that finding a magical cure to get rid of autism altogether is, for lack of a better word, just silly.

We can't just "get a babysitter."



Generally, when parents need a night away, they hire a babysitter. Simple right? Well, not if you're the parent of a child on the Autism Spectrum. Kids with autism exhibit different behaviors than do neurotypical children. For one, parents leaving isn't just annoying, it's disturbing on an emotional level. That makes it very hard for an autistic child to settle down while a babysitter is running the house.

You can't "catch" autism like you would a cold.



Though we know more about autism today than we ever have before, this is a misconception that parents of children on the Autism Spectrum run into constantly. Autism is not contagious. It does not spread from one person to another. It's as simple as that.

I'm not an autism expert.



If you want to learn more about autism and what it's like to be autistic, there is one reliable source: a person on the Autism Spectrum. Parents of autistic children can tell you what it is like to live with a person on the Spectrum. They are experts on their own child. But the only person who can tell you what it's like to live with autism is an autistic person himself.

My autistic child is not trying to be difficult.



As one parent stated about her autistic son on the popular website Baby Gaga, "He isn't giving us a hard time. He's having a hard time." No child on the Autism Spectrum is trying to behave badly when they experience a meltdown. The biology of autism is complicated and extensive, and much of it cannot even be tested for medically. Children on the Autism Spectrum have trouble with their methylation pathways. Their intestinal tracts do not absorb nutrients well. This impairs their immune system and guts, which then leads to issues in the brain. Because the brain and body of an autistic child do not always work as one, they have to express their pain and frustration in the form of things like meltdowns.

When my child is having a meltdown, please stay calm.



Meltdowns occur because children on the Autism Spectrum often feel overwhelmed by their surroundings. Therefore, a sense of calm is required to end the meltdown and restore a child's feeling of control. During a meltdown, the parent will likely be busy trying to calm their child. A helpful person standing by shouldn't approach the parent and child. They can help by trying to make the immediate area as peaceful as possible. As Autism Speaks recommends, "Scan the area around the child for sights and sounds that may have contributed to the meltdown. . . . Is there an alarm that can be silenced? A flashing display that can be temporarily turned off?"

Please be patient with my child.



Children on the Autism Spectrum often have a slew of sensory issues and meltdowns in common. Because no one would expect a family with autistic children to stay home all hours of the day, these meltdowns often happen in stores, at parks, and in other public places. Parents of children on the Autism Spectrum simply want others to understand that these meltdowns are not brought on by bad behavior, and to please remain patient with both the parents and the child. Rolling your eyes or mumbling snide comments are not helpful. It will not change the immediate situation and can even add further stress to both parent and child.

No, I don't just need to discipline my child more.



Meltdowns are not tantrums. They are not the result of a lack of discipline on the part of the parent. Children on the Autism Spectrum have sensory issues. One child may be a sensory avoider, while another is a sensory seeker. And kids with sensory issues do not respond well to physical punishment. Spanking, time out, and yelling are not usually effective tools of discipline for a child with autism. Rather, parents of children on the Autism Spectrum rely on routine and repeated exposure to teach their autistic children rules and boundaries.

We need to hear we are doing a good job.



This is, of course, true of every parent, but it is especially true of parents of children on the Autism Spectrum. Raising a child with autism is a lifelong learning curve. As more and more is learned about the biology of autism, parents must keep up with new therapies and decide if they would be right for their child. For instance, there are new supplements, dietary concerns, and feelings about a new friend or teacher. The list of things to keep parents up at night is a long one.

Don't stop trying to include us.



Autistic children, their siblings, and their parents are simply people, and people like to feel as if they are a part of a community. Though spending the day with a child on the Autism Spectrum may come with a few additional challenges, continue to spend time with them. Ask families to come to the Sunday BBQ, ask questions to better understand, and invite the parents out for dinner and an evening away. If they say no, ask again next time.

We are incredibly lonely.



For all of the reasons already listed, it's easy to see why being the parent of a child on the Autism Spectrum is a lonely experience. Parents are with their children all the time. Many will be with them for the rest of their life. That makes joining a community of friends incredibly difficult. Divorce rates amongst parents of children on the Autism Spectrum is especially high. If you're a friend of a parent of an autistic child, ask that parent if they're okay. Ask if they need something, or if you can help with anything. Showing them they're not as alone as they may feel will go a long way in brightening their day.

Please just listen to us.



Raising a child on the Autism Spectrum is hard and frustrating, and sometimes parents just need to vent to a friend. If you're the chosen friend, listen with compassion. Likely, the parent is just looking to share their battle, and they are not looking for unsolicited advice or opinions.

The rate of autism is increasing.



Current figures say autism affects 1 in 68 Americans, but that number is expected to increase in the near future. Still, there is very little understanding and support throughout communities and amongst organizations and businesses.

We don't need "Autism Awareness," we need "Autism Acceptance."



You've probably seen the bumper stickers, Facebook posts and the t-shirts calling for "Autism Awareness." But as parents of children on the Autism Spectrum continually insist, our society is aware of autism. It's autism acceptance that we need. Though one in 68 American children are now diagnosed with autism, our society still treats autistic individuals and their families as social pariahs. To become a more inclusive society will take advancements in access to services, affordable health care, employment opportunities, Medicaid expansion, fair pay, and more opportunities for quality education.