About Autism: What You Need to Know
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Goal: To acquire a basic understanding of what autism is and understand the challenges and strengths possessed by people with autism.

What is Autism

Autism is a general term used to describe a group of complex neuro-developmental disorders also known as Pervasive Developmental Disorders (PDD) or Autism Spectrum Disorders (ASD). These disorders are characterized, in varying degrees, by challenges related to:

- Communication
- Social Interaction
- Restrictive or repetitive behaviors and interests

People with autism may also experience other difficulties including medical issues, differences in coordination and muscle tone, sleep disturbances, altered eating habits, anxiety or disordered sensory perceptions.

Keep in Mind

- Autism is a neurological/biological disorder, not a psychological or emotional condition.
- The features, abilities and severity of symptoms vary considerably among people with autism.
- Always assume intelligence, teach competence, promote independence and be respectful.

Did You Know

- Autism now affects 1 in 88 children and 1 in 54 boys.
- More children will be diagnosed with autism this year than with AIDS, diabetes and cancer combined.
- Autism is the fastest-growing serious developmental disability in the U.S.
- Boys are four times more likely than girls to have autism.
What Causes Autism?

Not long ago, the answer to this question would have been “we have no idea.” Research is now delivering the answers. We now know that there is no one cause of autism just as there is no one type of autism. Over the last five years, scientists have identified a number of rare gene changes, or mutations, associated with autism. A small number of these are sufficient to cause autism by themselves. Most cases of autism, however, appear to be caused by a combination of autism risk genes and environmental factors influencing early brain development.

Although autism appears to have its roots in very early brain development, the most obvious signs and symptoms tend to emerge between two and three years of age. Often parents are the first to notice that their child is showing unusual behaviors such as failing to make eye contact, not responding to his or her name or playing with toys in unusual, repetitive ways. Sometimes an autism spectrum disorder is diagnosed later in life, often in relation to learning, social or emotional difficulties.

What’s Different About People with Autism?

Things that may make a person with autism different can also be seen as exceptional abilities. It is important to think of him or her as intelligent, even if language or behavioral difficulties do not reveal this in the way you expect. Characteristics of someone with autism can be seen as both challenges and strengths. For example, a child who seems inflexible or rigid may also be the one who is the best at following the rules of your program.

People with autism may display some or all of these characteristics:

- Difficulty understanding language, gestures and/or social cues
- Limited or no speech
- When there is speech, it can be repetitive or relate primarily to one particular topic
- Limited or no eye contact
- Difficulty participating in back-and-forth conversations or interactions
- Social awkwardness
- Intense interest in unusual topics or objects
- Repetitive behaviors, such as pacing or lining things up, spinning, hand flapping or rocking

Autism Spectrum Disorders per DSM IV

- Autism
- Asperger Syndrome
- PDD-NOS (Pervasive Development Disorder – Not Otherwise Specified)
- Rett Syndrome
- Childhood Disintegrative Disorder

Note: There are planned revisions to the definition of autism spectrum disorder (ASD) in the upcoming 5th edition of the Diagnostic and Statistical Manual of Mental Disorders (DSM-5), scheduled for publication in spring 2013. Please visit Autism Speaks www.autismspeaks.org for regular updates.
• Sensitivity to light, sound, smell, taste or touch
• Abnormal fears and/or lack of appropriate fear for real dangers
• Difficulty managing transitions, changes in routine, stress and frustration
• Strong visual skills
• Good rote learning and long-term memory skills (math facts, sports statistics, etc.)
• Adherence to the rules
• Honesty
• Intense concentration or focus, especially on a favorite activity
• Ability to understand and retain concrete concepts and patterns
• Strong interest and/or ability in mathematics, technology, music and art

Tips for Communication with People With Autism

• Speak calmly.
• Use direct, concrete phrases.
• Instructions should contain no more than two steps.
• Allow extra time for the person to respond.
• Avoid using phrases that have more than one meaning, like “cut it out.”
• Avoid touching. If necessary, gesture or gently guide the person.
• Be alert to the possibility of outbursts or unexplained behavior. If the person is not harming themselves or others, just wait for these behaviors to subside.

Other issues that often accompany autism:

• Seizure disorder
• Tic disorders
• Poor nutrition
• High rates of accidents and injuries

• Gastrointestinal disorders
• Mental health disorders (anxiety, depression, mood disorders)
• Sleep Problems
Tips to Support Children with Autism in Youth Programs:

Be Welcoming and Supportive

- Meet the child where he is and learn from him.
- Respect him as an individual.
- Do not talk about him in his presence as if he isn’t there.
- Set clear expectations and boundaries.
- Be consistent.
- Develop and implement structure.
- Practice and provide repetition to help with understanding and to build skills.
- Expect growth. Keep your standards high.

Develop Strategies to Compensate for Challenges

- Offer preferred seating or placement and allow for additional response time.
- Provide organizational supports like written schedules, lists, visual cues, and specific verbal directions.
- Be aware of a child’s sensory needs. Avoid or prepare for triggers like fire alarms.
- Give breaks for self-regulation.
- With small steps and supports, allow the participant to exhibit success.
- Reward what you want to see with positive reinforcement. Use the child’s interests to engage and motivate him.

Educate and Communicate

- Educate other youth participants about autism.
- Promote acceptance and understanding among peers and staff.
- Support social development with role-playing, modeling, and rewards. Make sure to include typical peers.
- Communicate with family members and caregivers.
- Ask questions and share what works. Problems solve what isn’t working.
- Always keep learning and be creative.

Finally

- Relax and have fun.
- Celebrate success.
- Treasure the individual.
Reflect:

In what ways do you think the unique strengths of people with autism could benefit your youth organization?

_______________________________________________________________________________________

_______________________________________________________________________________________

_______________________________________________________________________________________

People with autism are all unique. One child can have very different strengths, needs and challenges from another. The first goal of someone working with children with autism is to seek to understand.

How do you think you can work best with family, caregivers and the child to understand them?

_______________________________________________________________________________________

_______________________________________________________________________________________

_______________________________________________________________________________________

Resources:


This glossary contains video clips that can help you see what autism “looks like.” It shows the subtle differences between typical and delayed development in young children.

**Autism Speaks Resource Library** [www.autismspeaks.org/family-services/resource-library](http://www.autismspeaks.org/family-services/resource-library)

For those who want to learn more about autism, browse the latest books, magazine articles, educational manuals, software, and much more.


A comprehensive list of autism services and providers by geographic location. You can use this information as a referral tool for families who have children with autism, and as a way to find potential partners in your local area.


*Autism Spectrum Disorders: The Complete Guide to Understanding Autism, Asperger’s Syndrome, Pervasive Developmental Disorder, and Other ASDs* by Chantal Sicile-Kira

*Overcoming Autism: Finding the Answers, Strategies, and Hope That Can Transform a Child’s Life* by Lynn Koegel, Claire LaZebnik
Examples of People First Language
By Kathie Snow

visit [www.disabilityisnatural.com](http://www.disabilityisnatural.com) to see the complete article.

Remember: a disability descriptor is simply a medical diagnosis; People First Language respectfully puts the person before the disability; and a person with a disability is more like people without disabilities than different!

<table>
<thead>
<tr>
<th>Say:</th>
<th>Instead of:</th>
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<tbody>
<tr>
<td>People with disabilities.</td>
<td>The handicapped or disabled.</td>
</tr>
<tr>
<td>He has a cognitive...</td>
<td>He’s mentally retarded.</td>
</tr>
<tr>
<td>She has autism (or a...</td>
<td>She’s autistic.</td>
</tr>
<tr>
<td>He has Down syndrome (or...</td>
<td>He’s Down’s; a mongoloid.</td>
</tr>
<tr>
<td>She has a learning...</td>
<td>She’s learning disabled.</td>
</tr>
<tr>
<td>He has a physical...</td>
<td>He’s a quadriplegic/is crippled.</td>
</tr>
<tr>
<td>She’s of short stature/she</td>
<td>She’s a dwarf/midget.</td>
</tr>
<tr>
<td>He has a mental health...</td>
<td>He’s emotionally disturbed/mentally ill.</td>
</tr>
<tr>
<td>She uses a wheelchair...</td>
<td>She’s confined to/is wheelchair bound.</td>
</tr>
<tr>
<td>He receives special ed...</td>
<td>He’s in special ed.</td>
</tr>
<tr>
<td>She has a developmental...</td>
<td>She’s developmentally delayed.</td>
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<tr>
<td>Children without...</td>
<td>Normal or healthy kids.</td>
</tr>
<tr>
<td>Communicates with her...</td>
<td>Is non-verbal.</td>
</tr>
<tr>
<td>Customer</td>
<td>Client, consumer, recipient, etc.</td>
</tr>
<tr>
<td>Congenital disability</td>
<td>Birth defect</td>
</tr>
<tr>
<td>Brain injury</td>
<td>Brain damaged</td>
</tr>
<tr>
<td>Accessible parking...</td>
<td>Handicapped parking, hotel room, etc.</td>
</tr>
<tr>
<td>She needs... or she uses...</td>
<td>She has problems with...has special needs.</td>
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*Keep thinking—there are many other descriptors we need to change!*

Excerpted from Kathie’s People First Language article, available at [www.disabilityisnatural.com](http://www.disabilityisnatural.com).

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Some days it seems the only predictable thing about it is the unpredictability. The only consistent attribute — the inconsistency. There is little argument on any level but that autism is baffling, even to those who spend their lives around it. The child who lives with autism may look “normal” but his behavior can be perplexing and downright difficult.

Autism was once thought an “incurable” disorder, but that notion is crumbling in the face knowledge and understanding that is increasing even as you read this. Every day, individuals with autism are showing us that they can overcome, compensate for and otherwise manage many of autism’s most challenging characteristics. Equipping those around our children with simple understanding of autism’s most basic elements has a tremendous impact on their ability to journey towards productive, independent adulthood.

Autism is an extremely complex disorder but for purposes of this one article, we can distill its myriad characteristics into four fundamental areas: sensory processing challenges, speech/language delays and impairments, the elusive social interaction skills and whole child/self-esteem issues. And though these four elements may be common to many children, keep front-of-mind the fact that autism is a spectrum disorder: no two (or ten or twenty) children with autism will be completely alike. Every child will be at a different point on the spectrum. And, just as importantly — every parent, teacher and caregiver will be at a different point on the spectrum. Child or adult, each will have a unique set of needs.

Here are ten things every child with autism wishes you knew:

1. I am first and foremost a child. I have autism. I am not primarily “autistic.” My autism is only one aspect of my total character. It does not define me as a person. Are you a person with thoughts, feelings and many talents, or are you just fat (overweight), myopic (wear glasses) or klutzy (uncoordinated, not good at sports)? Those may be things that I see first when I meet you, but they are not necessarily what you are all about.

As an adult, you have some control over how you define yourself. If you want to single out a single characteristic, you can make that known. As a child, I am still unfolding. Neither you nor I yet know what I may be capable of. Defining me by one characteristic runs the danger of setting up an expectation that may be too low. And if I get a sense that you don’t think I “can do it,” my natural response will be: Why try?

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 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 very literally. 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 “Jamie really burned up the track,” I see a kid playing with matches. Please just tell me “Jamie ran very fast.”

Idioms, puns, nuances, double entendres, inference, metaphors, allusions and sarcasm are lost on me.

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 very 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.

A visual schedule is extremely helpful as I move through my day. Like your day-timer, it relieves me of the stress of having to remember what comes next, makes for smooth transition between activities, helps me manage my time and meet your expectations.

I won’t lose the need for a visual schedule as I get older, but my “level of representation” may change. Before I can read, I need a visual schedule with photographs or simple drawings. As I get older, a combination of words and pictures may work, and later still, just words.
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 and that I need “fixing.” 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.

_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. 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. Work to view my autism as a different ability rather than a disability. Look past what you may see as limitations and see the gifts autism has given me. It may be true that I’m not good at eye contact or conversation, but have you noticed that I don’t lie, cheat at games, tattle on my classmates or pass judgment on other people? Also true that I probably won’t be the next Michael Jordan. But with my attention to fine detail and capacity for extraordinary focus, I might be the next Einstein. Or Mozart. Or Van Gogh.

They may have had autism too.

The answer to Alzheimer’s, the enigma of extraterrestrial life — what future achievements from today’s children with autism, children like me, lie ahead?

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.

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Ellen Notbohm is author of _Ten Things Every Child with Autism Wishes You Knew_, _Ten Things Your Student with Autism Wishes You Knew_, and _The Autism Trail Guide: Postcards from the Road Less Traveled_, all ForeWord Book of the Year finalists. She is also co-author of the award-winning _1001 Great Ideas for Teaching and Raising Children with Autism Spectrum Disorders_, a columnist for _Autism Asperger’s Digest and Children’s Voice_, and a contributor to numerous publications and websites around the world. To contact Ellen or explore her work, please visit [www.ellennotbohm.com](http://www.ellennotbohm.com).