

Living with Someone Who Has a Disorder: A Viewpoint of Asperger Syndrome from a Sister

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[Advanced Composition Fall 2012](#)



My little brother was diagnosed with Asperger Syndrome when he was five years old. It's a daily struggle for our family to deal with the effects of the disorder, but it's a part of who he is as a person and while we study ways in which to make his life easier we do not forget that he is a person first.

Asperger Disorder is not simply an extension of Autism but a whole world within itself. It has its own rules, symptoms, and characteristics and does not define those who are diagnosed with it but it's an inherent part of that person and should never be overlooked. When he was about five years old, my little brother Bobby was diagnosed with Asperger's Syndrome, however, it does not define him. It is a daily challenge to live with and to deal with Asperger Syndrome, but it is rewarding because those who are diagnosed with it value the effects of hard work more than anyone else because they have to work harder than anyone else just so they can function in a world where they are considered inferior.

Bobby is twelve years old and knows he's different but does not understand why. When he was younger, his teachers didn't want to separate him from his classmates because the students understood him so well and looked out for him. They helped him with his work and helped him to avoid too much bullying, but once when I was picking him up from school, a couple of girls from his class were walking by. They shied away from him and the car and said "Eww...don't let him near me. He is weird." This may sound traumatizing to most people, as it was to us. Our mother had been assured by his teachers that everything was fine at school and that he was getting along with his classmates, but this was not so. When we

asked Bobby about this he said “Most people act like that to me.” We were confused and hurt because we didn’t know how to help him short of going up to the school and upbraiding the teachers. But that wouldn’t have solved anything because you can’t make people stop picking on others. You may intimidate them or use violence but in the end it doesn’t solve anything. Sometimes when he is bullied, Bobby says that “I think I need Anger Management because I get so angry.” We usually try to laugh it off so that he will start laughing and forget how angry he really is, but in the back of my mind I’m disturbed at both the situation and especially his comment.

Most people have no understanding of Autism, let alone Asperger’s Syndrome, and so they have no idea how hard Bobby has to work in school or how much having Asperger’s Syndrome affects his life. When he was younger, it was a constant struggle with the disorder not only for us but him as well. We blamed his rowdiness and misbehavior on the disorder, and to a point we were right. The disorder causes children to be exceedingly hyperactive and doesn’t allow them to focus very well on one task at a time; at least not without medication such as Adderall or Riddlin. We constantly had to deal with tantrums or fits. They would happen anywhere, and were at least twenty times worse than a typical five or six year old tantrum. Sometimes we had to physically restrain him so that he wasn’t a danger to himself or others. Once he got started on a tantrum it was almost impossible to get him to stop until he made himself sick from crying. Nothing is worse or more embarrassing than having a child with a disorder screaming in the middle of Wal-Mart and having security come over to investigate. I used to resent him at those times, but I would forget about that when he was distressed or in the middle of a tantrum. I can remember times when I would have to lay on the floor with him and whisper to him until he stopped crying.

Asperger’s Syndrome affects Bobby’s performance in school and the subsequent relations with the teachers who are supposed to be helping him. He has always had trouble

IEP: Individualized Education Program/Plan that is required by IDEA law for every student in Special Education.

IDEA: Individuals with Disabilities Education Act of 2004.

reading, no matter how much we work with him. He simply doesn't see the words as we do. We found that he had dyslexia, which often accompanies Asperger Syndrome. His teachers are supposed to help him, but most of the time they haven't got a clue what is going on with him because they ignore him. They do not follow his **IEP** mainly because they do not want to make changes in their classrooms. When he was in kindergarten, first and second grade, the teachers did not even

bother to research Autism or Asperger Syndrome. They did not want to know about their students or help them at all; which is a poor attitude to have when overseeing a student's first three years of school. With teachers such as those, it's no wonder so many students dislike school. They did not help him when he most needed them and they had no intention of coming to an IEP meeting, let alone even read his **IEP**. Nowadays, he has slightly better teachers; at least there is one teacher in every grade he enters who understands what he needs.

Asperger's Syndrome is classified as "high-functioning Autism." It is still within the Autism Spectrum, but a person with Asperger's Syndrome is able to adapt and interact with his or her surroundings. They are more likely than people with Autism to be able to function in mainstreamed society.

It can be seen as being comprised of several different disorders all rolled into one. Tony Attwood describes the different characteristics that make up the disorder in his wonderful book, *The Complete Guide to Asperger's Syndrome*. He says that

"Children with Asperger's syndrome have the following characteristics:

- Delayed social maturity and social reasoning
- Immature empathy
- Difficulty making friends and often teased by other children
- Difficulty with the communication and control of emotions

- Unusual language abilities that include advanced vocabulary and syntax but delayed conversation skills, unusual prosody and a tendency to be pedantic
- A fascination with a topic that is unusual in intensity or focus
- Difficulty maintaining attention in class
- An unusual profile of learning abilities
- A need for assistance with self-help and organizational skills
- Clumsiness in terms of gait and coordination
- Sensitivity to specific sounds, aromas, textures or touch” (Attwood, 33).

Before the days of more accurate testing, most children who had Autism or Asperger’s syndrome were deemed as unruly, and the issue stopped at that. The parents didn’t know any different they said that “the child would grow out of the phase.” The truth is that they didn’t, they just learned to assimilate. With better testing, doctors and others now know the signs and symptoms of someone who would have Asperger’s Syndrome.

The criterion, provided by Attwood, describes a classic case of Asperger Syndrome. It perfectly describes Bobby and sheds more light on how Asperger’s is a part of him and how it affects his life. He does have extreme difficulty understanding anything having to do with society, such as how appearances matter, or the importance of social skills. He spent years in one type of therapy after another trying to learn social skills. He doesn’t learn or pick up on subtle clues or hints like most people. He has to consciously learn how to say “Hello” in greeting or to even say “please and thank you,” as opposed to “normal” children who learn these skills subconsciously as babies. Just as he doesn’t understand social skills he does not understand emotions. It’s because of this that it’s so hard for him to control his tantrums. He doesn’t know how to express emotion so he becomes frustrated to a degree that he could lash out violently when he cannot make others understand his meaning. The same goes for his

language abilities. People often have a hard time understanding Bobby because his language skills and cognitive development are not on par with his physical development.

Bobby has a one-track-mind. Boys are often teased because single-mindedness is a stereotype of most males; however, Bobby can be a little excessive sometimes. Once his attention is focused on one thing he has to see it through to the finish, and he is remarkably thorough when he puts his mind to a task. He is especially good at organizing. Sometimes we can't walk into a room without him immediately feeling a compulsion to clean or organize it; but when it comes to his own room, there is no messier place, yet somehow he always knows where everything should be, even if he won't admit to it.

Bobby has a hard time with his coordination skills. His right brain and left brain do not work in synchronization, so he cannot do tasks that require the use of both sides of his body at the same time, such as riding a bicycle. The effort required to pedal the bike uses both the right and left sides of the brain at the same time so he can't do it without falling over after about thirty seconds. He also has trouble with fine motor skills, such as tying shoe laces, buttoning a dress shirt, or using eating utensils. Many people who have disorders, such as Asperger Syndrome, Autism, Down Syndrome, etc., have the same troubles. That is why most of them resort to wearing elastic clothes and shoes, and eat foods that rarely require utensils.

Often those with Asperger Syndrome are also diagnosed with a Sensory Processing Disorder. This means that they are often classified as being hyper-sensitive or under-sensitive. Most people on the Autism Spectrum have an aversion to touch, especially with strangers or people they don't know well. This also means that they often having problems with eating disorders because they cannot stand certain textures of food. Temple Grandin, who is a very adamant advocate for Autism, would only eat green Jell-O for a time. For four or five years, the only thing Bobby would eat was chicken tenders, now it's pizza rolls. Often,

they have a very short list of things that they actually will eat. This causes problems for the families because sometimes it can be a drain on finances and it can cause the worry of stunted growth and other health problems when the person doesn't get the nutrients required for normal health.

People with Asperger Syndrome or Autism desperately need social integration skills to help form relationships in every area of their lives; because it is so important to a child with Asperger Syndrome to form friends. They may not understand how to get or keep friends but that doesn't erase the desire to have positive relationships with their peers. Just because they're different does not mean that they don't feel. People with Asperger Syndrome are as human as anyone else. They bleed as we bleed, and they feel as we feel, even if they don't always understand it.

"Not everything that steps out of line, and thus 'abnormal', must necessarily be 'inferior'.

-Hans Asperger

"Autism is a different way of thinking and learning."

-Temple Grandin

Works Cited

Attwood, Tony. "The Complete Guide to Asperger's Syndrome." London: Jessica Kingsley Publishers, 2008. Print.