

How much do you know about autism

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What is the fastest growing type of developmental disorder in the United States? What strikes one in every 166 children, making a once obscure disorder now more common than Down Syndrome? What robs individuals of the ability to communicate and interact in a typical way?

If you answered *autism*, you are correct. If you didn't know, you are not alone. Until my daughter, Bethany, was diagnosed with autism, my only knowledge of autism came from the movie *Rainman*.

April is Autism Awareness month. Let me tell you a little about this disorder that has so dramatically affected my family and our life.

What is autism?

Autism is a complex brain disorder resulting in social, behavioral and language problems. Individuals with autism have difficulty communicating and forming relationships. They may be preoccupied and engage in repetitive behaviors. Autism is usually diagnosed in children between the ages of one and five years, and boys are four times more likely than girls to have autism.

The cause of autism is not known, although most researchers agree that there is a genetic vulnerability which is then triggered by something in the environment. The exact genes are not known, nor are the specific environmental triggers.

The hallmark characteristics of autism are impaired speech and social development. Individuals with autism often have repetitive behaviors (such as flapping their hands or repeating nonsensical phrases), require a rigid routine, have difficulty engaging in imaginative play, and may not understand real dangers such as traffic or falling from a height.

That describes some of the behaviors associated with autism, and because there are no medical tests yet available to diagnose autism, it is considered a behavioral disorder. However, there is a very physical side to it. Many individuals with autism have gastrointestinal disorders, immune system abnormalities, sleep disruption, and food sensitivities and other allergies. Studies also reveal that many individuals with autism have higher than normal levels of heavy metals such as mercury in their body. Mercury and other heavy metals are known to poison the nervous system, including the brain.

Another area affected by autism is called "sensory integration." This means that the

way people with autism get information from their senses is different. They either get too much or too little information, and once that input is received in the brain, it might not be interpreted correctly. As a result, people with autism are frequently very sensitive to noise, light, touch, motion, or taste. Or they may be under sensitive and inadvertently hurt themselves because, for example, they cannot feel pain.

To add to the complexity, autism is a "spectrum" disorder, meaning there is a wide variety of individuals who can be diagnosed with autism. Some have mild symptoms and are able to live independent lives. Others are so severely impacted they never develop speech, cannot communicate basic needs, and require 24-hour care throughout their lives. As you might expect, most fall somewhere in the middle, with varying degrees of ability and disability, independence and dependence.

The character Rainman is known as an autistic savant, or, a person with remarkable ability in an area such as mathematical calculations or amazing recall of obscure facts (such as what the weather was on a particular date). This mixture of genius ability and severe impairment is rare.

Many individuals with autism have normal or even gifted IQs, although it can be difficult to measure due to the impairments in speech and communication. Mental retardation is no longer commonly associated with autism.

I like to describe a person with autism as someone like you or me who simply has not developed the ability to communicate in a typical way and who perceives the world uniquely. My daughter, Bethany, seems more like Helen Keller than Rainman! It is just a matter of breaking through the barriers to reach her.

What hope is there?

Once considered untreatable and hopeless, we now know that many individuals with autism can make great improvement and some even "recover"—they lose their diagnosis of autism!

Not knowing the cause of the disorder makes it confounding to treat. The most effective intervention today is two-pronged: biomedical and behavioral.

The biomedical intervention includes restricted diets, supplemental nutrition, removal of heavy metals, immune system regulation, and removal of toxic chemicals such as pesticides, cleansers, and fragrances from the person's daily environment.

On the behavioral side, an intensive therapy known as Applied Behavioral Analysis (ABA) is coupled with speech therapy, occupational therapy, physical therapy, music therapy, and special education. Two keys to successful behavioral intervention are to *start early* and make it *intense!* Children with autism should be engaged in a behavioral program for 30-40 hours per week.

I participated in a study that was trying to identify the most effective treatments for autism. To my astonishment it listed more than one hundred biomedical and behavioral interventions, some of which I'd never heard of! While it is encouraging to know there are alternatives to try if one intervention is ineffective, it is also overwhelming to figure out where to start, and sometimes it is impossible to determine what is good science and what is snake oil.

How does autism affect my work life?

Bethany was diagnosed with autism in 1999 at the young age of 19 months. She was not developing language, she rarely made eye contact with anyone, she hid behind the sofa at daycare, she screamed and wept when she ate because her mouth was so sensitive to textures, and she couldn't go outside without sunglasses. That's the short list to describe Bethany at age one!

We started intensive therapy immediately. Bethany is now six years old and in kindergarten. She now makes good eye contact, loves to watch and imitate other children, will initiate playing "get you" games with her older brother, makes choices about activities and foods she prefers, has lost her sensitivity to food textures, is better able to tolerate loud noises and bright light, and is being taught regular kindergarten class material in a special education setting. It's been an arduous journey, and there are many more miles to go, but Bethany's progress is real!

I am frequently away from work to attend therapy sessions, medical appointments, or administrative meetings related to school, state services, or insurance. Through a special Family Leave of Absence (FLOA), my employer, Intel, gives me the flexible schedule required for me to manage my daughter's complex care.

Meanwhile, my husband, Kenny, quit his full-time job two years ago to be Bethany's primary care provider. He takes her to therapy appointments and school, manages her special diet, handles all the nutritional supplements (that alone takes 12 hours a week!), and does 1:1 therapy with her himself when there is a gap in our provider schedule.

We can't predict the future for Bethany, but thanks to the intensive intervention she has received and Intel's support for my caregiver role, she is progressing. We remain hopeful that Bethany will grow to her full potential!

For more information about autism:

Autism Society of America: <http://www.autism-society.org>

Autism Research Institute: <http://www.autism.org/Unlocking>

Autism: <http://unlockingautism.org>

Autism Clock: <http://www.fightingautism.org/clock/index.php>

Book: *Children with Starving Brains*, by Jacquelyn McCandless, M.D.

"Red flags" of autism (From Autism Society of America):

- Does not babble or coo by 12 months
- Does not gesture (point, wave, grasp) by 12 months
- Does not say single words by 16 months
- Does not say two-word phrases on his or her own by 24 months
- Has any loss of any language or social skill at any age.
- Insistence on sameness; resistance to change
- Difficulty in expressing needs; uses gestures or pointing instead of words
- Repeating words or phrases in place of normal, responsive language
- Laughing, crying, showing distress for reasons not apparent to others
- Prefers to be alone; aloof manner
- Tantrums
- Difficulty in mixing with others
- May not want to cuddle or be cuddled
- Little or no eye contact
- Unresponsive to normal teaching methods
- Sustained odd play
- Spins objects
- Inappropriate attachments to objects
- Apparent over-sensitivity or under-sensitivity to pain
- No real fears of danger
- Noticeable physical over-activity or extreme under-activity
- Uneven gross/fine motor skills
- Not responsive to verbal cues; acts as if deaf although hearing tests in normal range.