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AUTISM

When people laugh,
they don't see the hurt;
but I do.
It's MY CHILD...

When people speak
such unkind words,
they don't see the pain;
but I do.
It's MY CHILD...

When people turn away
because they don't understand,
I do.
It's MY CHILD...

So many tears,
so many broken hearts,
they don't feel;
But I do.
It's MY CHILD...

A simple smile,
just one kind word
could ease the hurt.
Oh, don't they see;
I do.
It's MY CHILD...

Please understand
my fervent plea;

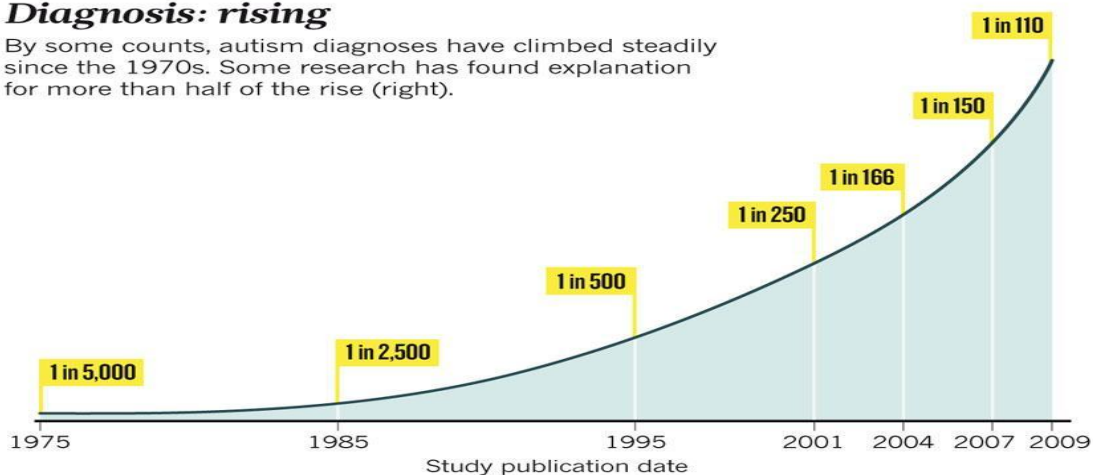
Think before you speak.
It could be YOUR CHILD...

~Written by Fran Sanzone

The day most people find out they are going to be a parent is one of the happiest days of their lives. From that moment most begin the process of preparing themselves for parenthood. "Will I breast feed or bottle feed?" "Cloth or disposable diapers?" "Day Care or Au pair?" These are all normal questions that most parents must decide. Autism unfortunately is not a choice parents make for their children. Today, it is estimated that one in every 110 children is diagnosed with autism, making it more common than childhood cancer, juvenile diabetes and pediatric AIDS combined. An estimated 1.5 million individuals in the U.S. and tens of millions worldwide are affected by autism. Government statistics suggest the prevalence rate of autism is increasing 10-17 percent annually. There is no established explanation for this increase, although improved diagnosis and environmental influences are two reasons often considered. Studies suggest boys are more likely than girls to develop autism and receive the diagnosis three to four times more frequently. Current estimates are that in the United States alone, one out of 70 boys is diagnosed with autism. (Autismspeaks.org) Having a child that is healthy is a blessing. I know firsthand about this, having been blessed with three healthy children of my own. However, having family members and friends who are parents of autistic children, I have witnessed the joys and pains of having a child with this disability. While everyone else is cooing over their child's first words which turn into sentences, autistic children's first words may not come until much later than the normal child. The parent of a child with autism waits and worries when their child shows no signs of those first words.

Diagnosis: rising

By some counts, autism diagnoses have climbed steadily since the 1970s. Some research has found explanation for more than half of the rise (right).



Between 1975 and 2009 the number of children diagnosed with autism has risen. The exact reason for this is unknown. Some have speculated that this increase is due to greater awareness of the condition. Others feel that earlier cases of autism had been misdiagnosed as early onset schizophrenia or mental retardation.

In 1943, Dr. Leo Kanner first described autism in a small group of children who demonstrated extreme aloofness and total indifference to other people. Additionally, the children made little eye contact and had severe language deficits associated with the apparent lack of desire to communicate. They reacted to the environment in very unusual ways and demonstrated no pretend or imaginative play. While observing the children he came up with the word autism, which is derived from the Greek word auto meaning self. Around the same time, Hans Asperger was studying families with children who exhibiting the same symptoms as the children in Kanner's study except their language delays were not as severe. No one knows what causes autism. There isn't a blood test or any other biological marker nor does it have any effect on an individual's life expectancy. Autism Spectrum Disorder (ASD) is defined as a group of developmental disabilities that can cause significant social, communication and behavioral challenges. People with ASDs handle information in their brain differently than others. Not everyone with autism displays the same severity of symptoms, but they will all fall under the spectrum of Autism. This spectrum includes:

- Classic Autism, also referred to as Kanner's autism. This is the most common form of autism. Those under this spectrum tend to have significant language delays, intellectual disability and abnormal behavior. This is the most severe form of autism. Those with classic autism have problems talking and relating to people. They can be hypersensitive to their environment. Certain sounds, colors and textures can upset them. They compulsively cling to rituals, such as eating the same foods or watching the same TV show every day at the same time. Changes in routine can upset them.
- Asperger's Syndrome, named after the Viennese pediatrician Hans Asperger, is a developmental disorder that affects a person's communication and social skills but does not trigger language delays. Unlike classic Autism, "Children with Asperger's Disorder may be only mildly affected and frequently have good language and cognitive skills. To the untrained observer, a child with Asperger's Disorder may just seem like a normal child behaving differently. (www.autism-society.org) People with Asperger's can be socially awkward, may not understand conventional social rules or may show a lack of empathy. They may make limited eye contact,

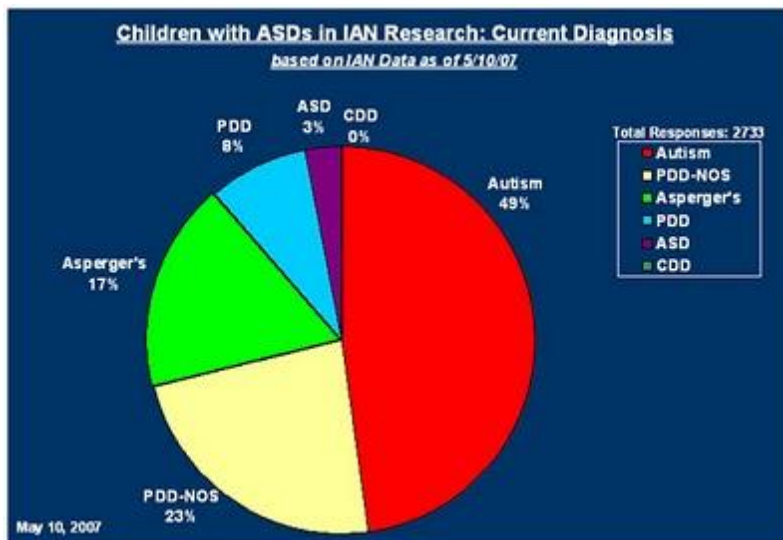
seem to be unengaged in a conversation and not understand the use of gestures. They also have average or above-average intelligence. People with Asperger's tend to lead a typically normal lifestyle-socializing, attending school, graduating from college and some even live on their own. It has been said that geniuses like Sir Isaac Newton and Albert Einstein showed traits of Asperger's syndrome.

- Rett Syndrome is a rare genetic disorder that affects the way the brain develops. It occurs almost exclusively in girls.
- Childhood Disintegrative Disorder Childhood disintegrative disorder, also known as Heller's syndrome, is a condition in which children develop normally until ages 2 to 4, but then demonstrate a severe loss of social, communication and other skills. Like autism, childhood disintegrative involves normal development followed by significant loss of language, social, play and motor skills. However, childhood disintegrative disorder typically occurs later than autism and involves a more dramatic loss of skills. In addition, childhood disintegrative disorder is far less common than autism.
- Pervasive Developmental Disorder NOD (not otherwise specified) also known as atypical autism, is usually used to describe those individuals who do not meet the criteria for having classic autism or Asperger's. PDD-NOD is usually given as a diagnosis when patients exhibit some signs of autism but these signs are too mild to be fully classified as autism.

Early warning signs of a child possibly having Autism are:

- not responding to their name by 12 months
- not pointing at objects to show interest
- not playing "pretend" games (pretend to "feed" a doll for example) by 18 months
- avoiding eye contact
- preferring to be alone(I would say “ not eliciting maternal/Paternal interaction).
- having trouble understanding other people's feelings or talking about their own feelings
- having delayed speech and language skills
- repeating words or phrases over and over (echolalia),are obsessed with the clapping their hands, rocking their body, or spinning in circles.

Most autistic children also have unusual reactions to the way things sound, taste, feel and smell. On top of having autism, people usually have other underlying health conditions like allergies, asthma, epilepsy, digestive disorders, persistent viral infections, feeding disorders, sensory integration dysfunction, sleeping disorders (<http://www.nationalautismassociation.org>)



The above graph charts the percentages of specific disorders within the Autistic Spectrum. These results were taken from a study performed by the Interactive Autism Network (IAN), studying young men and women, living with their families, with disorders that fall within the Autistic Spectrum

The etiology of Autism is still unknown, however, there has been increasing evidence to suggest that environment, genetics and biology play a significant role in the development of autism. Irva Hertz-Picciotto, Ph.D. is an epidemiologist at the University of California who recently conducted a seminar on the environmental factors associated with autism. Our exposure to chemicals within our food and home has changed within the past 10 to 15 years. We are being exposed to chemicals that affect how our brain grow such as Mercury, polychlorinated biphenyls, lead brominated flame retardants and pesticides. These chemicals are present all around us in our everyday lives. Polychlorinated biphenyls (also called Aroclor) could be found in adhesives, plastics and cable installations. Lead brominated flame retardants are used in printed circuit boards manufactured by companies like Dell, IBM and Hewlett Packard. We have all heard about the health benefits of eating fish. However, we are most commonly exposed to mercury by fish consumption. Recent DNA research is zeroing in on sets of abnormal genes that may play a role in this disorder. Scientists have theorized about a connection between gene mutations, impaired brain development, and the onset of autism. Their goal is first to establish the link. For many parents these studies are both welcoming and worry some. For some it means that we are one step closer to possibly finding the cause for autism. For others it means that there are still no answers to explain why their child has this disability.

Making the decision to have a child is momentous. It is to decide forever to have your heart go walking around outside your body.

-- Elizabeth Stone

Research indicates that parents of children with autism experience greater stress than parents of children with other disabilities. An individual with autism may not be able to express their basic wants or needs. Often time's parents are left guessing. Is the child crying because he/she are thirsty, hungry, or sick? When the child's needs cannot be determined both parent and child are often left feeling frustrated. This frustration often comes out in the form of tantrums thrown by the child. Normally, when a child throw a tantrum a parent will know specifically what it is for and know how to proceed accordingly. But when you have a language barrier that prevents you from understanding exactly what's going on the situation can become quite stressful for all parties involved. As stress levels build parents often times find themselves at war with each other.

For most parents of Autistic children having a good family support network is an important piece of their sanity puzzle. Parents of children with Autism tend to have higher levels of stress than those of parents whose children have other developmental problems. Money issues are one of the major stressors that parents of autistic children have to deal with. Once a two-income family the household budget is now cut in half while financial demands have increased. The Father becomes the primary bread winner in the family while the mother stays home to tend to the child. Receiving the proper intervention that is needed in order to become a functional member of society requires constant visits to doctor's offices as well as therapy sessions. Overtime, this can prove to be costly to the family.

Emotionally and physically these parents require a lot of support. Just imagine being a full time worker who leaves to go home and take care of a normal child's wants and needs. After working an eight hour day you return home to cook for your household, do homework and housework before bathing and getting your children off to bed to start it all over with in the morning. Seems stressful right? Now imagine the stress a parent of an autistic child feels being at home full time and on constant watch because there are no boundaries when it comes to autism. While today may be a good day and without incident, tomorrow may bring about new findings and new sensory issues that you were not aware of before.

Lack of communication between parent and child can cause already heightened stress levels to elevate to even greater heights. Mothers, more so than fathers begin noticing that their once vibrant social life is now diminishing. Stacey is the mother to six

year old Tripp. Prior to him being diagnosed with autism, she and her husband made it a point to have monthly date nights. These nights could be as simple as dinner and a movie or more extravagant like a Broadway show. She would also have a girl's night out with her friends to unwind from all the stresses of work and having a young child at home. After Tripp's diagnosis of autism she noticed that the monthly date nights slowly came to a halt. Her girls night out has become a one weekend a year adventure that is carefully planned out.

While Autism primarily affects the parents, it doesn't stop there. Autism is a disability that affects the entire family, friends and community. Parents of children with autism often find themselves in need of both emotional and physical support. Fathers are more likely to hide their feelings while mother's become very emotional. Robin, mother to five year old Justin, recalls a time when she cried herself to sleep almost every night. During the early days, she recalls the numerous doctor visits that she attended, trying to get a proper diagnosis and plan of treatment. At the end of these days, after Justin and her boyfriend were sleeping. She would roll on her side and the tears would flow. "Why me?" was one of her most nagging questions. She often wondered why she never saw him show emotion over this. She soon came to the realization that men and women differ in the way things are handled. His stress would come out in the form of angry tirades. Once, she said, he became livid when he came home and realized that there weren't any more cookies left in the house. While there were plenty of other snacks, not having cookies sent him over the edge. Stacey recalled a similar incident she had when she was returning from the supermarket and pulled into her driveway. All of sudden this overwhelming rush of emotion came over her and she began crying hysterically. She tried pulling herself together before she entered the house. Although she was emotional she never wanted her husband or her child to look at her as "weak." When she entered her home her husband automatically sensed that something was wrong and could see in her face that she had been crying. He tried comforting her the best way that he could, with what he thought were words of encouragement. But to her they were not. She didn't want to hear "we are going to be fine." Because she felt they were anything but fine and she didn't understand how this was not affecting him. A few months later she was coming home after being out at her mother's house and walked in a very passionate conversation he was having with his brother about how angry he was at the fact that he is not able to have a normal relationship with his son. Football season was starting and he walked past the park where the junior league was practicing. As he saw the other father's there watching their sons practice he felt cheated because he would never be given the same opportunities in life that these fathers had. Although mother's and father's go through the grieving process differently, at some point they both grieve. And when they do they will not only need the support of each other but also of family and friends.

Call it a clan, call it a network, call it a tribe, call it a family: Whatever you call it, whoever you are, you need one.

~Jane Howard

While Autism primarily affects the parents, it doesn't stop there. Autism is a disability that affects the entire family, friends and community. Parents of children with autism often find themselves in need of both emotional and physical support. Father's are more likely to hide their feelings while mother's become very emotional. I have a friend who is in the process of producing a documentary on Autism from a father's perspective. During the documentary, which takes place during a weekend retreat, he interviews several dads who give their point of views and feelings on having a son with autism. (autisticlikeme.net) The joy that was felt when most of them realized they were going to have a son was seen through their eyes when they recounted that moment in the past. Every man I have ever spoken to has dreamed of having a son of their own to pass the torch to. It is their job to bring them from boyhood into manhood. However, the joy was short lived when a couple of months into the happiest times of their lives they begin to notice little "problems". The eye contact slowly faded. The normal babbling that babies do became little grunts. Some of the men felt like they had been robbed. This was supposed to be their shining moment in life, their chance to show to the world what a man was. Others find it very hard to look at men and their sons and not feel angry and jealous. Simple things like taking their sons to the barbershop for a haircut fuel this anger. The bond that is shared in this moment they will never experience with their own sons.

Robin, mother to five year old Justin, recalls a time when she cried herself to sleep almost every night. During the early days, she recalls the numerous doctor visits that she attended, trying to get a proper diagnosis and plan of treatment. At the end of these days, after Justin and her boyfriend were sleeping. She would role on her side and the tears would flow. "Why me?" was one of her most nagging questions. Once when her boyfriend caught her crying herself to sleep he told her that crying wasn't going to change anything. She wondered why she never saw him show emotion over this. She soon came to the realization that men and women differ in the way things are handled. His stress would come out in the form of angry tirades. Once, she said, he became livid when he came home and realized that there weren't any more cookies left in the house. While there were plenty of other snacks, not having cookies sent him over the edge. Stacey recalled a similar incident when she went was returning from the supermarket and pulled into her driveway. All of sudden this overwhelming rush of emotion came over her and she started crying hysterically. She tried pulling herself together before she entered the house. Although she was emotional she never wanted her husband or her child to look at her as "weak." When she entered her home her husband automatically sensed that something was wrong and could see in her face that she had been crying. He tried

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"Uncertainty and expectation are the joys of life. Security is an insipid thing, and the overtaking and possessing of a wish discovers the folly of the chase."

~William Congreve

"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."

- Ellen Notbohm

For the normal child their parents are the center of their early life. Their physical and emotional closeness is essential to their development. Most parents of Autistic children have to come to terms with the fact that this interaction will not be part of their relationship with their child. Instead parents must find other avenues of contact that will be necessary to aid in the health, development and well being of their child. These avenues are not easy to find and require a lot of patience.

Patience unfortunately is a craft that most of us have not mastered. When you become a parent you get, whether you want it or not, a crash course in it. The regular trials and tribulations of parenthood can prove to be stressful when dealing with a normal, healthy child. For the parents of an autistic child these stressors can be overwhelming.

Potty training for example which requires a lot of time and patience can overall prove to be a bonding experience for mother and child but when you are the parent of an autistic child who is four and still has not grasped the concept of potty training your patience can run thin. You are now forced to order special diapers for him to wear because Huggies and Pampers are not made in their sizes. This also causes stress levels to become elevated due to financial constraints within the home.

Once that diagnosis is heard a little piece of you breaks and you begin to play the blame game thinking that it was something that you somehow bought upon your child. The psychological effects of autism many times lead to depression and a decline in health among parents of autistic children. In families where there is a child with autism, there is usually one parent who is the primary caregiver, usually the mother. Because she spends most of her time caring for her disabled child she will most likely stop working to care for the child on a full time basis. This may lead to less social interaction with her peers and often times leads to them becoming withdrawn from society.

Most parents feel a sense of denial when they suspect that their child is autistic. The excuses for their behavior are endless-“he’s lazy,” “he just doesn’t want to talk” “he’s a boy, boys are suppose to act like that” “He just likes everything to be neat, what’s wrong with that?” While all of these excuses are normal and usually are not indicators of autism the accompanying signs should be a red flag. Thinking that their child is autistic is the last thing that a parent wants to imagine. In a way, this signals the demise of the dream that they once had of having a child who they would walk to school for the first day and watch as he waves good by with a smile as he heads into school, returning home a ball of energy as he runs down the day’s events. The reality of that first day of school becomes having a bus pick your child up from home where he will be constantly monitored to and from home, with the day’s events being relayed in a note from the teacher

I can sympathize with the parents of autistic kids because I find that there are times when my patience is at an all time low. My children are old enough that when I get to this point I can say to them, “mommy needs me time” and lock myself in my room to catch up on my shows on DVR, read a book or play a computer game. This sanctuary is not possible for most parents of autistic children who don’t comprehend what it means by “me time.” Most have energy levels that are always on high and have to constantly be watched to ensure that they are not getting into things that may be harmful to them. While there are some parents who have a strongly family support system that allows both parents the opportunity to still work to provide financial support to the household, most families that I know have one parent, usually the mom, who stays at home to take on the caring of the child full time.

As a married mother of three, one being a 5 year old boy with autism, Stephanie finds that there are times she feels like a single parent. Once a manager in a physician's office, she is now a stay at home mom because she has not been able to find adequate childcare. The day care centers that do take children with autism in her area, she finds to be horrid and the centers that she would like to place him in will only take children that are potty trained, which Aidan is not. The household relies solely on her husband's income. In order to support a family of five he often works long hours to bring in the overtime money that is needed to keep the family afloat. Although she understands that this is necessary it can prove to be problematic within their marriage. Jealousy, she states, is sometimes at the root of these problems. While she is at home all day providing support for their three children he gets a break from it all. Her daily routine involves waking up to get her two older children off to school, one middle school and one elementary. Supermarket runs are usually made directly after drop off because it is easier to do in the morning with Aidan because the stores are less crowded and she will not have to worry about him having a meltdown. She will return home to try to prepare that night's dinner before heading out once again to take Aidan to one of his weekly therapy sessions. By the time she is done with that it is usually time to pick up the older two. This is followed by homework and failed potty training all before her husband arrives home for the day, oblivious she says to everything that she does on a daily basis.

I recall going into Circuit City (when it was still around) with my three children and my little cousin who happens to be autistic. My children take stores like Circuit City and Best buy as an electronics heaven and run around testing the sounds on the radios as well as playing the video games that they have set up in the store. On this particular day my youngest decided that he was going to play guitar hero and put the sound up on 50! Well this did not go over so well with my little cousin who proceeded to run, with his hands over his ears, into me with such force that I felt like I was being tackled by a linebacker and not a 3 year old child. His sensitivity to the noise would not allow him to listen to me. In order for me to get him to calm down I had to remove him from the store and take a walk outside with him, which made my shopping very difficult because even though I made my son turn the sound down anyone else in the store could come and do the same exact thing. It's not like there is a sign that can be posted that says, "Autistic child in store, keep noises at a minimum." I have also witness the obsessive behavior that he possesses. My mother is, in her own words, an electronics geek. She has electronics in everyone room of her house. Her living room in particular has the television, cable box, DVR, surround sound and stereo system within the wall unit. Each of these has their own remote control. One day I watched as he meticulously lined the remotes up on the coffee table in the living room. Purposely I moved one and he put it back. I then proceeded to "shuffle" all the remotes when he was about to walk away. Very calmly he turned around and again meticulously rearranged the remotes.

At the age of 18 months, Justin's mother knew in her heart that something was not right with her son. Born via c-section as a healthy 7 lb 8 oz baby with all his finger and toes he “was the cutest kid I have ever seen”. As he got older, she began to see signs that maybe something wasn't right with him. Unaware of what Autism was, she missed the signs that could have lead to him being diagnosed earlier and starting treatment. Unlike the other kids his age in the family, when people called his name he didn't respond. He was diagnosed as being a colicky baby (which now she wonders if this was the beginning of his sensory problems) and wasn't hitting the milestones that typical babies were suppose to at his age. Thinking back to that time, she recalls how the simplest things like playing peek-a-boo didn't entertain him. She began to get worried when he wasn't crawling. At the time when most kids were walking, he was beginning to crawl. Diagnosed with Classic Autism he was immediately placed into an intervention program. In this program he was given behavior modification, speech and occupational therapy. Today at the age of 5, he is now able to say full sentence, although sometimes these are hard to understand. When he says “I love you” those three words are the sweetest thing his mother could ever hear. He is able to interact and play with other children as well as interact, when prompted, with other adults. She understands that there is still a long road ahead of them, but despite it all she is happy with the results that she has seen so far. Although he is diagnosed as a low level child with autism Justin's mom, along with the rest of his family, will not let this prevent them from allowing him to lead a normal life. Just this past summer, for instance, he joined his communities T-ball team and has recently signed him up for swimming lessons.

What happens when the stress of dealing with an autistic child gets to be too much? In the case of Jose Stable, 50, the death of his child was the only way out. On November 22, 2006 Ulysses Stable, 12, was found slashed to death in a bathtub in his Bronx apartment. The 911 call was made by his father who statement to the arrived officers was “I've terminated the life of my autistic child.” Neighbors who had witnessed the interaction of the father with the child reported that he was filled with a lot of anger. One neighbor recalled an incident where she had been in an elevator with Ulysses and his dad when the child continually tried to touch her in an agitated way. The father would continuously slam him up against the elevator wall each time he did this. Mr. Stables' anger (which I would say was more extreme stress) was apparent when I encountered him two months before he would take the life of his son. I worked for the neurologist and happened to be covering the front desk that day because we were short staffed. His son has a 1:00 appointment scheduled. At about 1:15 Mr. Stable approached the desk and began cursing at me and yelling that he had arrived on time for his appointment and could not understand why it was that he was still waiting to be seen. No amount of explanation was good enough for him, which left me no choice but to call security on him. This was a very hard decision for me to make because there was a waiting area full of parents and children witnessing this. However, I had to worry about my own safety. As a single father raising a child with autism Mr. Stables' support system was very weak. He was

homeschooling an autistic child which is extremely hard to do. At the time of his death, his father was being persuaded to place him in a private school with the aid of the courts and the children's administration.

On August 2, 2011, one month before he was to start school, Ben Barnhard, 13, was shot in the head by his mother, Psychiatrist Margaret Jensvold, who then took her own life. A letter left stated that "she could not deal with the school system" and that the debt is bleeding her and she was strangled by debt." Although stunned by the killings family members said Ms. Jensvold had become increasingly strained by financial pressure and by fights with the county public school system over the education of her son and their refusal to pay for him to attend private school because they felt that he could be properly educated in a public school setting. As a single mother she was unable to pay for his private school education on her own and refused to send him back to public school. Her mother had agreed to pay for his private school education, which could run up to \$60,000. The day after the killings the school received a check in the mail for \$10,000 from Ms Jensvold's mother.

Always

Unique

Totally

Intelligent

Sometimes

Mysterious

~Care press

While there may be lots of cons in having to deal with an autistic child life is not all bad. From personal experiences, the hugs and kisses and playfulness that they exude just overwhelms you. Once they are broken out of the box the comical side comes out and the laughter returns. The stereotypical views of autistic children are of those not being able to talk and play and do the activities that other children do. This is so far from the truth. The autistic children I know love to play hide and seek, play in the towns little league and are well on their way to becoming the next Michael Phelps. But the road that has been traveled in getting them to this point has not been an easy one. It has been one that is filled with patience, determination and tons of support. Support being a major issue. Parents rely on their family and friends to give them breaks in their lives. Whether this is for a few hours or a few days it is time that is greatly needed and greatly appreciated by these parents. It allows them time to breath, regroup and figure out what the next step would be. For married couples, it allows them a chance to reconnect with each other on a level that doesn't involve the child.

For most parents of Autistic children having a good family support network is an important piece of their sanity puzzle. Parents of children with Autism tend to have higher levels of stress than those of parents whose children have other developmental problems. Money issues are one of the stressors that parents of autistic children have to deal with. Once a two-income family the household budget is now cut in half while financial demands have increased. The father tends to be the primary bread winner in the family with the mother staying home to tend to the child. In order for the child to receive the proper intervention that is needed in order for him to become a functional autistic parents must rely on constant visits to doctor's offices. Over time, this can prove to be costly to the family.

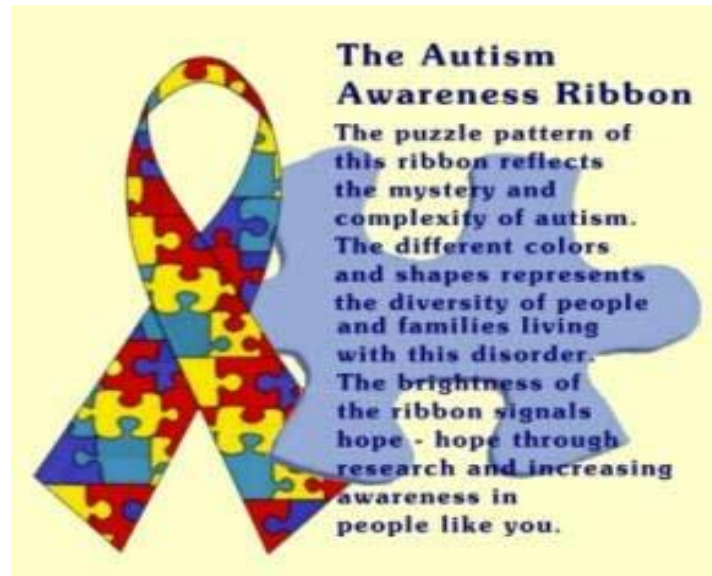


If a little knowledge is dangerous, where is a man who has so much as to be out of danger?

~Thomas Henry Huxley

It is very easy for someone to walk past a parent with a child who is acting out in public and assume that the child is being unruly and has not been properly disciplined. If you are the parent of an autistic child you know this is far from the truth. Most of the parents that I have spoken to have been targets of cruel stares and remarks when their child has had a public outburst. The biased remarks are not often met with kind responses from the parents on the receiving end. Imagine trying to discipline a child without a disability. This is a challenge in itself. Now add Autism into the equation. This now goes from challenging to extremely difficult. Autistic children throw tantrums and behave aggressively when they are disappointed and frustrated like other child do. However because of the disability, autistic children do not comprehend others thoughts and feelings. They do not realize that when you hit someone it causes pain. Some parents may feel that physical punishment is adequate punishment in this situation but it is not. The autistic child can interpret this as acceptable behavior and continue to do it. The best discipline for an autistic child is positive discipline, where the focus is on the child's acceptable behavior and rewards are provided. This way the child is encourage to repeat the positive behavior.

Sounds simple enough but often times it is not. Parents are left feeling frustrated and often times have increased stress levels. I witnessed the interaction between a stranger and a family with autism on a recent family vacation. While we heading back from an island to our awaiting ship the autistic child, who just happens to be a family friend, broke free of his father's hand and headed towards the end of the shuttle boat we were on, curious I assume. His father ran after him and pulled him back and began yelling at him. A passenger on the boat with us, who did not know of his disability told the father that he didn't need to yell at him because he is just a kid who was curious. The outcome was not good for the passenger as the father let out all his frustrations of trying to discipline his child on this lady. It may not have been the best way to handle the situation but after constantly getting backlash from strangers about the care of his child her remarks were the last straw.



A child miseducated is a child lost.

~John F. Kennedy

If you were to ask a parent of a child with autism how hard it would be to get them the proper education, the answer would probably be extremely hard. With most educational institutions making cut backs and laying off their teachers because of lack of funding, the programs that are needed to help the autistic child usually do not come to fruition. The Individuals with Disabilities Education Act (IDEA) is a United States federal law that governs how states and public agencies provide early intervention, special education and related services to children with disabilities. It addresses the educational needs of children with disabilities from birth to age 18. When a child is first diagnosed with autism, it is recommended that Early Intervention is started (usually before the child's 3rd birthday.) After the child's third birthday, services are available through local public school systems. The normal process is to have the child evaluated to see if the disability is a qualifier as defined by IDEA. Once found eligible, an individualized education program (IEP) is written out for the child and followed through at the educational facility that the child is attending.

"If I could snap my fingers and be non-autistic, I would not - because then I wouldn't be me. Autism is part of who I am." --Temple Grandin

Temple Grandin, listed as one of the Times top 100 most influential people of 2010 in the heroes, category, was diagnosed as autistic at the age of three. Her intervention was started at an early age thanks to the support system that she had in place which included her parents and teachers. Classified as a “high-functioning autistic” she not only graduated from high school, she has also earned her doctorate in animal science. Dr. Grandin is just an example of the many different levels of autism that are in the world today. While most will require lifelong care, there are those who go on to live full and product lives, depending on the spectrum of their autism disorder.



The Rebecca School, located at 40 East 30th Street, New York, NY 10016

The ongoing debate for most parents is Private institution vs. public school. There are some private institutions, like the Rebecca School in New York whose mission is to

“provide students with a program that meets their individual needs, celebrates their strengths and embraces their passion.” Their goal is to move a student up the developmental ladder to become thinking, relating communicating members of his/her community. This state of the art school has everything that an autistic child needs - music room, two sensory rooms, gym, playground art room and ceramics room. Because the school serves children with disabilities, including autism, the interaction between other children the same age without disability is limited to the home environment. Unfortunately, the Rebecca school is not free (tuition could run up to 70,000 a year) which leaves a lot of low income parents either taking out loans to send their child to the school or opting to send them to public school. The Autism Academy of Learning (AAL), located in Toledo, Ohio, is a year-round public school with programming designed around the needs of students with Autism Spectrum Disorders. Eligibility requirements for admission into AAL require students to be a legal resident of Ohio between the ages of five and twenty-one. The vision of AAL is "The Autism Academy of Learning is structured to provide every student with Autism Spectrum Disorder an appropriate foundation in the areas of academics, behavior, daily living skills, vocational skills, and independence. Our goal is to promote a higher quality of life, and the realization of the full intellectual and social development of students with Autism Spectrum Disorder." Because of the demand for enrollment within AAL, there is usually a lottery process for placement within the school. Once selected, applicants have two weeks to respond or they will be placed back into the lottery pool.



Multisensory or “Snoezelen room” at AAL contains a variety of multi-sensory items ranging from fiber-optics and music to bubble tubes and vibro-acoustic items

Just like in a private school setting, children attending public school are also given an IEP evaluation that is followed through at the school. The difference is that in a public school the child is placed in an inclusion class. From the outside the inclusion class looks no different than any other classroom in the school. However there are a few differences. Inclusion classrooms usually consist of two teachers, a regular teacher and a special education assistant. The makeup of the classroom is usually regular education students and special education students who are taught together. I believe that this setting will help with social interaction amongst the child's peers who are a mixed bag of children like him/her.

Stacey, who is the mother of 6 year old Tripp, chose a private school for her son. She was lucky enough to enroll him in a school that provided her with a scholarship for his education so her out of pocket expenses are minimal. Here he receives his therapy sessions and education but he is also provided with activities that help with sensory issues. While she has seen improvement in his education, such as reading at the third grade level, he still struggles with his social interaction amongst other children who do not have autism. Five year old Justin attends a public daycare where he is in an inclusion classroom. He receives his education with children his age, some with disabilities and some without. His therapy sessions are done with the special education teacher in the classroom who pulls him and two other students into a group. His mother, Robin, has noticed a significant change in his social interaction. He expresses himself more when he is around family and friends. She credits this with the environment of the school. While there are pro's and con's to both settings, ideally I feel that the ultimate goal of the education system needs to be providing a school setting that not only allows children with autism the opportunity to interact with children who do not have disabilities but also provides them with the resources that they require for daily functioning, like a sensory room.



Large Sensory room at the Rebecca School



Small Sensory room at the Rebecca School

While schools like the Rebecca School in New York and the Autism Academy of Learning in Ohio are to be commended for their achievements in the education and social development of autistic children, it still is not enough. There needs to be more schools like these available to the parents of autistic children. Are they out there? Yes. Is this information that is made readily available for parents? No. If Margaret Jensvold and Jose Stable had been given the knowledge and the opportunity to enroll their children into a school like the Rebecca School or AAL without having to worry about paying \$72,000 a year or risk having their child taken away I can only wonder what the outcome for Ulysses and Ben would have been. If I could, I would propose to the department of education a plan of action that would call for the opening of at least one public school in every city for autistic children. Just as they have put into action “No child left behind” I feel that umbrella should be expanded for the autistic child as well.

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