

# Parenting the Autistic Child

Diana Alago



## **"Before I Go To Sleep..."**

Mommy, don't you cry now and Daddy don't you weep.

I want to whisper something before I go to sleep.

I know that when I came here I looked perfect in every way.

And you were so proud, Daddy; when you held me on that day.

And Mommy, when you kissed me and wrapped me up so tight,

I knew that I belonged here and everything was right.

But then I stopped talking and began to slip away,

I saw your worried faces as you knelt by me to pray.

And Daddy, I always notice how you wipe away a tear,

When you watch the other children as they run and laugh and cheer.

I may not be able to tell you how much I love you so,

Or even show you how I feel and what I really know.

But when you hold me, Mommy, at night when all is still,

I feel the love you have for me and I know that all is well.

And Daddy, when you take me to the park to run and play

I know that you still love me though the words I cannot say.

I want to tell you something before I go to sleep.

I may be sort of direct and you may not understand,

I know that I am not that little child that you and Daddy planned.

But I love you both so very much and I know you love me too,

And if I could only speak my heart, you would feel my love for you.

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I know the future is unknown and you will always have to be,

The ones who love and listen and take good care of me.

I know that you are frightened and you shed so many tears,

And if I could I'd wipe them dry and take away your fears.

So Mommy, don't you cry now and Daddy please don't weep.

I want to say...I love you both, before I go to sleep.

- Written by Sally Meyer 2000

Sally Meyer's poem "Before I go to sleep..." exemplifies a parents' grief. Sally Meyer is the mother of Dylan who is an autistic child. Parenting is a life-long job that requires love and dedication. It is a job that is filled with love, joy, challenges, obstacles, and lessons for all involved. For most the joy is so impact full that in the end the joy overrides all of the challenges and heartaches that come with each challenge. Every parent faces challenges and has difficult decisions to make throughout the course of a lifetime however; the last four decades have proven to be tumultuous for parents of children diagnosed with Autistic Disorder. Due to lack of informational resources, research, standards and guidelines for treatment, as well as access to education and day care, parenting a child diagnosed with Autistic Disorder in the United States is substantially more challenging than parenting a child with other developmental disorders and moreover parenting a healthy child.

As a mother of three, my experience as a parent has been the most amazing journey. I can say that each stage of life with each of my children from the moment of birth has been a different challenge. For those with more than one child, multitasking between different worlds is an additional challenge. The lessons I've learned have shaped the way I view the world today. Some of those lessons have been learning unconditional love, patience, perseverance, and accepting of what is. Unfortunately learning did not come easily, it was through all of trials and tribulations and finding myself at the brink. Parents must be strong for themselves and ultimately for their

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children. It is easy to give up since most of the lessons you teach take a very long time to be absorbed. Some children listen and others learn by trial. Learning acceptance is important when you have children since rarely do things go as you planned, you'll learn to improvise and make the best of every situation for them. The good news is that as long as you never give up, and you truly give it your all, you will never fail.

The process of parenting consists of nurturing, teaching, protecting, supporting both psychologically, and financially, and guiding throughout the course of your life.

"God sends children to enlarge our hearts, and make us unselfish and full of kindly sympathies and affections." – Mary Howitt

Through the enormity of responsibility for another, lessons of unselfishness and unconditional love arise as Mary Howitt states. The most valuable of all lessons is learning how to view the world from the eyes of another. The "building blocks of parenting are Modeling; Trust; Respect; Love; Discipline; Communication; Honesty; Positive Statements; Time, Attention, Concern" ("Building Blocks of Parenting", The Process of Parenting).

**Modeling** is leading by example. Parenting in the lead is easier said than done since none of us are perfect and we are all here to learn. As a parent of three, I can say that modeling the example can sometimes be challenging. Unfortunately we can't go back in time when we arrive at this point and who knew, that your life would have spectators. Do as I say and not as I do, really doesn't work but if you are honest and you try and you push and you stay on top of knowing and understanding their worlds, one day all of the words you spoke over the years will come back to you, even if comes back with words like "mom, you were right. I didn't listen and ...." **Trust** is important in every close relationship. If a parent is confident in themselves their children will trust them. Confidence and control exude the feeling of safety. The feeling of safety leads to trust. Children who feel safe and feel supported are more confident themselves and are therefore more likely to succeed than those who do not feel protection and support from their parents. As a parent and human being I am not always confident, but I've learned

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that success comes when you master your inner self and control what you feel enough to exude confidence and strength when most needed. **Respect** your child and they will respect you. Children need to be treated with respect and in return they will treat others with respect. Respect does not come naturally it is something that needs to be taught. **Love** alone is not enough. Love must be openly expressed with words and actions. Parents who discipline with love are more effective than that of parents whose words and actions do not display love and affection. **Communication** is the key to every successful relationship. Keeping the lines of communication in a constant and opening your doors will help the relationship succeed. The key is to listen intently and understand them without judgment and advising as best as you can. **Honesty** is important in every relationship, without honesty it is difficult to trust. Parents should model attributes that they wish to see their children develop. Parents should be honest with themselves and their children. Honesty will provide inner strength that will empower children to be who they are. **Positive Statements**, positive reinforcement fosters strong self worth and builds confidence. Parents should use positive reinforcement instead of negative terms. Negative terms produce low self worth and sometimes an individual will eventually live up to those negative terms creating a self fulfilled prophecy. **Time, Attention, and Concern** is key to building a loving, honest, communicative relationship. Quality time, positive attention and absolute concern for a child is imperatively important to development and the bond created between a child and his/her parents. If you don't make time for them you will lose trust, and communication will be difficult. Giving time shows them that you love them and that you will be there no matter what happens.

The basic building blocks are a huge undertaking especially when considering the time frame of a life time. These building blocks are based on parenting a healthy child. What is a healthy child? A healthy child is a child who is growing and developing within a range of reasonable time according to international growth standards developed by the World Health Organization. "Developmental milestones can be described as a set of functional skills or age specific tasks that an average child is able to do when he reaches a specific age" (Parenting Tips, Iloveindia.com). Functional skills consist of motor skills, learning skills, cognitive, thinking, and social skills. What happens when your child is diagnosed with Autistic Disorder? The above "building blocks" will change drastically as

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communication between the child and the rest of the world is severely impaired. Strong focus on the lines of communication is necessary to connect.

What is Autism? There are 5 different variations of autism, according to the American Psychiatric Association, Autism also known as Autistic Disorder is considered one of five variations of the Autism Spectrum Disorder. The variations of disorders are Autism, Aspergers Syndrome, Rett's Syndrome, Childhood Disintegrative Disorder and Pervasive Developmental Disorder, Not Otherwise Specified.



**Autistic Disorder** is diagnosed when there are symptoms that show that there is an indicative hindrance of development in three key principalities of development, verbal communication, social interaction, and a display of physical repetitive behaviors, such as banging the head on a wall. Many children with the Autistic Disorder also have other medical problems; the most common is intestinal illnesses and severe allergies to foods. The Autistic Disorder is more likely in boys than it is in girls. The Autistic Disorder is considered a *severe* form of the Autistic Spectrum Disorder and is typically low functioning. There are children who have milder forms of the autistic disorder are high functioning. Low functioning means that the child has severe impairments and requires a higher level of care. High functioning means that the impairment(s) are mild and the child requires less care and is able to care for himself/herself to a degree, degrees vary. **Asperger's Syndrome** is diagnosed when there are symptoms that show that there is a hindrance of development in social interaction, and a lower level of repetitive activity such as hand flapping. There is obsessive behavior but it is more likely in areas of interest instead of objects. Patients diagnosed with Aspergers do not experience mental setbacks and commonly do very well academically. Asperger's is considered a milder

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form of Autism Spectrum Disorder and is high functioning. **Rett's Syndrome** is diagnosed when there are symptoms that show a noticeable diminishment of head growth, retrogression of speech, and motor control, typically displayed between birth and five years of age. Rett's is more common in girls than in boys. **Childhood Disintegrative Disorder** is diagnosed when there is growth regression; similar to Rett's however, regression is only in the psychological aspect, and not in the physiological aspect of symptoms. This diagnosis is rare. **Pervasive Developmental Disorder, Not Otherwise Specified** is diagnosed when there are signs of autistic like symptoms but no definitive proof.

Autistic Disorder is the most severe and the least functional from the 5 disorders classified as Autism Spectrum Disorders. There are no standard behavioral or medical symptoms; every child diagnosed with Autistic Disorder has different behavioral and medical symptoms. Some of the following are common characteristics of the Autistic Disorder: Social Development is deeply affected; some symptoms include lack of eye contact, preference of being alone, and inability to interact with others. Communication is impaired, symptoms include mild to severe language impairment, uncommon or odd speech patterns, inability to hold conversations with others, inability to pretend, and some children cannot communicate verbally at all. Since motor skills are typically impaired there is no physical communication either, it is likely that body language would be misinterpreted. Applied Behavioral Analysis Therapist Michelle Badagliacca emphasizes that "It is up to the parent to guide the child in communication and to engage with the child on the child's level instead of using normal forms of communication." Behaviors include: Self injury such as head banging, biting themselves and others, and self mutilation. A 2007 study reported that self-injury at some point affected about 30% of children with ASD."(Wikipedia). Physical repetitive behaviors such as body rocking, hand flapping, or odd hand and body gestures. Intense preoccupations with objects or parts of objects, common traits are lining up, stacking, or spinning objects. It is also common for the Autistic child to be detached or aloof, or have no interest in the world around them. Resistance to change is common including things like wearing the same clothing, eating certain foods etc. Tantrums, hyperactivity and aggressive behaviors are not uncommon if a daily routine changes in any way or if

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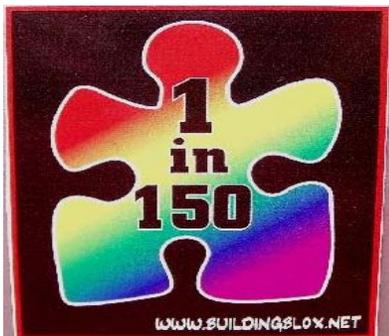
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the child is experiencing pain or discomfort. Since physical and verbal communication is impaired, the parent would have to have the child constantly tested for problems or teach the child how to communicate when something doesn't feel good. This is challenging, often parents require professional help to do this.

“These officers will take the children of the better guardians to a nursery and put them in charge of nurses living in a separate part of the city; the children of the inferior guardians, and any *defective* offspring of the others, will be quietly and secretly disposed of.” – Plato

In Plato's time, autistic children would be considered “defective offspring.”

Documented symptoms go back to the 1700's. The Autism syndrome diagnosis identified as an abstracted mental illness, has been around since the 1960's however although there has been research, there is still a lot to be desired. Not enough to help the medical community to create standardized treatment that has been well researched that can provide some stability and hope for these parents. When Autism was first introduced as a diagnosis it was believed that the cause was maternal deprivation, meaning lack of love, bonding, and/or connection from a baby's mother. Imagine, believing that you as the mother are the cause of a dreadful disorder bestowed upon your child. That idea alone can cause severe stress and depression. Today, these families are often judged, made fun of and rejected from society. What kind of society are we? A not so nice society. There are more families living with this disorder than what may be assumed.



Today, 1 in every 150 births is a child with some form of autism. According to the Autism Society of America, “1 percent of the population of children in the U.S. ages 3-17 have an autism spectrum disorder.....1 to 1.5 million Americans live with an autism spectrum disorder.”(Autism Society of America, Autism-Society.org). Autism affects boys more than girls, 1 in every 90 boys is diagnosed with

some form of Autism.

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Take the building blocks presented previously and modify them to fit a child who has problems with social interaction, communication and behavior. In my experience, handling a healthy toddler can be a challenge. Imagine an uneasy child who cannot communicate. The parent would have to work twice as hard to alleviate any ailments or discomforts. As a parent, I learned that being in tune with your child is so important. Not only is the quality of the care you provide better but it can quickly address things that would otherwise escalate and create very stressful situations. It is not impossible to become attuned but it is something that does not come naturally and sometimes other areas of ones life can distract that interconnection. Becoming attuned requires focus on the child's language, physical language, and facial expressions as well as focus on your internal instincts. Parents, who work, go to school, or have other children to care for may not be as intuitive as those who do not have any other distractions. Add to that constant medical care, children with these disorders often need physical therapy, speech therapy, and ongoing treatment. Special education is required for children with this type of disability as well. There is only one public charter school in New York City for autistic children. There are several private schools; however financing an education may not be an option. Autistic children also need a very highly structured environment since they do not adapt well to change and learn at a much slower pace than the average child. Special medical treatment is needed; the best care comes from a continuity of care amongst a primary care physician, specialists and/or therapists, and teachers. Around the clock care is needed, statistics show that at least one of the two parents of an autistic child leave their daytime jobs to provide continuous care. This is in addition to seeking professional services. Daily challenges are better handled when all family members are educated to assist in the daily care of an autistic child. Successful outcomes are common with early intervention for children between the ages of 0-3.

Every aspect of family life needs to be altered to meet the needs of the family and to successfully raise a healthy autistic child. Everything becomes a challenge. One common characteristic of Autistic Disorder is that the child has difficulty with eye contact and speech and tends to loose focus in conversation if he/he can even provide any audible words. Little things like teaching your child to brush his/her teeth, potty training, eating, walking, playing with other children all become challenging. Keeping a

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child focused to do these little necessary things is challenging and if challenges are not met with perseverance the child's health will suffer. These can be challenging with a healthy child, and more so with a child who has difficulty communicating. At first glance, a family outing may not seem so important however in the spectrum of ones life, an outing can be crucial to mental health and well being. Outings for autistic children need to be handled in an extremely structured manner since change of environment can lead to tantrums and physical behaviors such as head banging and/or biting. Not to mention, judgment from others. Families state that it is hard to go out, and if the child behaves oddly the parents are criticized. A lot of parents complain about behaviors that cause them stress. One father, Karl from Queensland Australia posts daily videos on You Tube. His videos consist of his frustrations and daily experiences with his son who has Autistic Disorder and is unable to attend a regular school. He explains his son's behaviors and how he handles some of the unusual ones. In one video he states that his son picked up a new habit, punching his stomach. His son punches his stomach until it bleeds and then picks at the scabbing and creates this cycle of bruise and infection. He expresses how difficult it is to watch and is learning how to deal with this new habit and trying to get his son to stop. Another mother, Dr. Maier describes being unable to communicate with her 3 year old son. She tried enrolling him in a private school, during the next few weeks she noted that her son was stressed and unhappy everyday. Then the school expelled him for biting. Her son would not speak or look at her. After trying everything possible to connect with him she decided to research Autism. She used his profound interest in animals to teach him colors, numbers, and words. She then discovered that although he does not respond, he was actually listening.

There is no known cause for the Autistic Disorder or any of the other four diagnoses under the Autism Spectrum Disorder. There are some statistics that show links to possible causes however to date there have been no definitive studies that show proof. "It is now known that autism is the result of abnormalities in the brain structure." (Autism, Encyclopedia Britannica). Psychological causes have been ruled out. (Autism, Columbia Encyclopedia). There are no standard treatment guidelines since symptoms vary by child. Parents have to carefully research known facts about the Autistic Disorder

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and carefully choose a doctor. This is not an easy decision since there isn't enough information out there to know if you are making the right decisions.

'It is not enough to feel love for child; you must be able to express your love through your actions' – Judy Ford

For parents of autistic children, the "actions" require careful thought, thorough research, and life altering changes to daily living. One can argue that life altering changes happen to everyone that becomes a parent. This is so, however while the changes may be similar to a degree, parents of autistic children have to go many steps further for simple things like education and day care. The lack of resources and support currently in the United States make those additional steps far more difficult.

Due to the additional care required by a child with autism, parents face substantial ongoing stress that may not otherwise be experienced in families with healthy children or children with other developmental disabilities. Insufficient researched results and lack of definite proof in many aspects of the Autistic Disorder leave families looking for help on their own. Other disabilities such as mental retardation have more support programs for parents and the children alike. Mental retardation is now known as intellectual disability. There is a standard of treatment for intellectual disability, and there are specified tests to determine intellectual disability during gestation and shortly after birth. A simple test during gestation or shortly after birth would give families time to research treatments, day care, education and many of the additional items required for proper care. Many success stories of those who have found treatments that have alleviated many of the behavioral symptoms and some of the physical medical problems have been due to early intervention and constant medical screenings.



Healthcare for Autism

Autistic Disorder has no known cause and no cure. Most children are diagnosed between 18 months and 3 years old as the discovery of growth delay becomes more apparent.

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This reality can be harsh for anyone person who witnessed/experienced a live birth, then lived with what appeared to be normal developmental progress and then a sudden reality shortly after, with a life of autism and an unknown future. Here's a poem I wrote on what I feel the reality of Autism is to a parent.

### **Autism**

The dream of what would've been

Illusion of what should've been

Acceptance is key

To all the wonders inside of he

Difficulty is common

Adjustment is essential

Hidden is something special

Open your eyes to see

Your truths will set you free

I agree that reality to any illness or disability can be a harsh one. Parents of children with autistic disorder are not alone in that arena.

"Reality is hard. It is no walk in the park, this thing called Life." -- **Patty Duke**

Patty was diagnosed as bipolar and manic depressive. Her statement emphasizes the reality of her view of life. Today the reality of Autism is that Autism Spectrum Disorder as a whole is not treated like a medical condition but is treated as a psychological condition. From the research I have conducted, it is certainly more than what meets the

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eye. Unfortunately, science has yet to prove any connections between common medical illness and the autistic disorder. Many families feel that there are several common medical conditions within the autism spectrum disorder. Science is coming close to a cause, in January of 2008 The New York Times reported that DNA testing was conducted in a New England study and found that "a rare genetic flaw that occurs spontaneously near or during conception may sharply increase the risk that a child will develop autism, researchers reported Wednesday." (*New York Times*)

Not everyone believes Autism is real; perception and interpretation play a role. Take a look at this definition. The definition of Autism as stated in the Autism Society Organization's website is as follows: "Autism is defined by a certain set of behaviors and is a "spectrum disorder" that affects individuals differently and to varying degrees." This definition as with any written words can be interpreted in many different ways. If you take out the reference to "spectrum disorder" this definition can easily be interpreted as behaviors that can be treated and modified. Michael Savage, a syndicated talk show host stated that "Autism is a Fraud". He believes that autism is a child that is allowed to act like a fool, a child that has not been taught to have manners. Others feel that it is a money scam for pharmaceutical companies who want doctors to prescribe expensive medications to make millions.

If you take some time to research the stories of some who live with this disorder you will find that Autism is not a fake, if it was it would be impossible for so many children to have the same symptoms. A search on You Tube with the word Autism will result in many videos of children, their parents speaking about the disorder and the parenting experience, and videos of Adults who are Autistic discussing their experiences.

Researched statistics prove that stress levels are higher for parents with autistic children than parents of children with other disabilities. Let's take a look at one study conducted on stress levels amongst this population.

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In 1989, a study was conducted on the psychological effects of parenting on parents who have an autistic child. The study analyzed 124 children and their parents. 31 children had autistic disorder, 31 had downs syndrome and 62 were developmentally healthy children. The groups were kept consistent for age and sex; measures for age were chronological and mental.

“It was hypothesized that a) parents of autistic children would report greater stress and dysphoria than parents of Down Syndrome and average children. B) the experienced dysphoria was directly associated with parenting stress; c) perceived social support conditioned the relationship between stress and dysphoria differently for each parent.” (*Journal of Autism and Development Disorders*, Vol. 19. 1, 1989). The word dysphoria means anxiety and restlessness.

So in essence these parents are more anxious than other parents because of the perception of “social support.” You can tie the perception of social support to not knowing and not finding anyone who knows who can help or provide guidance. This same study concluded the following: “Numerous empirical investigations have suggested that parenting developmentally handicapped children may have an adverse impact on parents’ well-being” (*Journal of Autism and Development Disorders*, Vol. 19. 1, 1989). To be a successful parent you must take care of yourself. Faced with the unknown and the uncertainties surrounding autism, a parent must focus on keeping their sanity and well-being otherwise they will be useless to their autistic child. There are stories of parents who have killed their autistic children and then themselves unable to cope with the enormity of this disorder. Parents must take time out to research and make decisions that will affect the well being of themselves and their families.

Now what would cause so much stress? Let’s examine some other common experiences within these families. Let’s begin with the behavioral symptoms of the Autistic Disorder. Children with the Autistic disorder have developmental dysfunctions. Let’s begin with motor skills. Autism is a neurological disorder that impairs motor skills such as speech, which affect the ability to communicate as well as the mental functions that allow communication and social interaction.

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In 2006, researchers studied development of motor skills in 56 children with disabilities ranging from ages of 1 year, 9 months and 3 years, 4 months specifically between three groups: Autism Spectrum Disorder, Developmental Delay, and No Motor Delay. The last group is a group of children who have developmental disabilities but do not have any motor delays. This study was conducted by comparing and analyzing these developments using the Bayley Scales of Development II Motor Scale, and the Peabody Developmental Motor Scales 2<sup>nd</sup> Edition. Bayley Scales of Infant Development II Motor Scale is a publication of standardized tests used to assess children who have cognitive or motor delays. Standards were created by the assessment of 1,700 infants, toddlers, and preschoolers between one and 42 months of age with balanced developmental growth of cognitive and motor skills. Peabody Developmental Motor Scales is a publication of standardized tests used to assess motor progress of children during the first two and a half years of life. Standards were created by assessing 2,003 individuals from 46 states with balanced developmental growth of motor skills.

This study focused on identifying distinct characteristics in motor functions which consist of critical movements such as, walking, running, and stepping, along with less critical but important movements such as, writing and holding objects. Analysis done for this study concluded that children with Autism had significant delays in growth as compared to the same population of children with well balanced developmental motor skill growth.

The results identified distinctive characteristics of motor delays within the Autism Spectrum Disorder group and the Developmental Delay group compared to the No Motor Delay group. Although the Autism Spectrum Disorder and the Developmental Delay groups both showed delays in motor skill development the Autism Spectrum Disorder group did not differ significantly. The study concluded that further research is needed to analyze the different characteristics between the two groups. So in essence, children with developmental delays and children with autism spectrum disorder have significant motor delays when compared to normal children thus making physical and verbal communication difficult. Some have this in severe form and some have this in mild form. Severe form would be a child who is not able to connect to anyone by

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communication, verbal and physical. They are unable to display their feelings of pain, anxiety, or fear. Many parents state that their children retreat to themselves and they as the parent must pull them back. One way is facilitated communication; this is communication by leading the autistic person to communicate by using a keyboard. They speak and allow the person to use the keyboard to answer. This discovery was made in the 1980's; it was a phenomenal discovery since before this was accomplished it was thought that autistic individuals did not possess conventional intelligence. Facilitated communication is viewed as controversial. The method was peer reviewed and some medical professionals speculate that autistic individuals are not actually communicating with their own thoughts but with thoughts of the therapist or person facilitating. There are other types of therapies that involve different variations of facilitated communication. Applied Behavioral Analysis Therapist Michelle Badagliacca, points out that "Therapy involves different forms of communication. There are non-verbal forms of communication which consist of gestures, maintaining eye contact, body language, PECS (picture exchange communication system) which is a form of communication that consists of small pictures of activities, rooms, or ideas which a child can use to communicate their needs, imitation, mand training (training the child to request certain things by prompting them to do so)."

An excellent example of successful keyboard facilitated communication is the success story of an adult with autism who wrote a documentary called *Autism is a world*. Her name is Susie Rubin. Susie is unable to speak. Susie walks with spoons 24 hours a day, when asked why Susie states in her facilitated communications that the spoons make her feel safe. Susie has 24 hour care and attends college with a caregiver who takes notes for her. Susie is visually able to write what is on her mind, it is stated that she wrote the entire documentary. During the documentary Susie speaks about her feelings regarding episodes of head banging, she states that the urge is intense and sometimes uncontrollable. She visibly has visual motor impairments as well as habitual practices that are systematic symptoms of sameness.

*-Autism Is A World*. Dir. Gerardine Wurzburg. Perf, Susie Rubin CNN, 2004. DVD

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One of the worst feelings as a parent is not being able to comfort your child. Skilled parents learn how to become attune with their children however this state of achievement does not always come naturally; it takes a level of focus and intuitiveness that can be learned. Most parents learn as they go since there is no handbook, you may find a lot of literature however every child is different. An autistic child cannot afford a parent who learns as they go. Not only would it benefit the child for a parent to learn how to communicate non verbally or visually but the entire family will benefit and therefore our entire society as a whole. Parents of autistic children should seek professional assistance to initiate communication.

Behavioral issues present to be the biggest problem according to a study on stress levels of parents which was published in the July 2009 issue of the journal *Autism*. 73 pre-school aged children were studied, 51 with autism and 22 with other developmental delays. In this study, all children required more care than would a healthy child. While this is a fact, the group of autistic children had severe behavioral issues and presented parents with higher stress levels due to the lack of verbal and physical communication. On a scale of zero to four, the autistic group scored 2.3 while the second group scored 2.04. The study found that parents of the autistic children reported higher levels of distress. This could be because some of the behaviors include temper tantrums, self injury, difficult to understand language patterns, head banging & hand flapping at inappropriate times. Children with Autistic Disorder also have difficulty with sleep and intestinal allergy problems.

Lee Grossman, president and CEO of the Autism Society stated "one reason that parents of children with autism may be so stressed is that every child with autism is different, so there's no standard treatment of care. Parents don't have many avenues to go for support". (qtd. In. Gordon)

If the pretention is that Autism is not real and these children just need a good spanking, how could you explain difficult to understand language patterns? Susie Rubin explained that the impulse to bang her head on the wall was at times uncontrollable. Susie's care

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givers gave her a helmet so she can place it on her head once she feels the impulse. Susie is an advocate for the disabled and is a low functioning Autistic person. (Rubin)

Why else are these parents experiencing on going stress? Lets take a look at some other statistics.

"[Sleep is] the golden chain that ties health and our bodies together."

-- Thomas **Dekker**

Sleep disorders are also prevalent. It is easy to imagine lack of sleep causing stress. As Thomas Dekker states it affects our overall health and our bodies. I know that waking up every three hours to care for a newborn is exhausting and over the course of the time it takes a newborn to adjust to a schedule it can take a toll on you, this is typically between 3 months and a year and some children require bed rituals to wean off of sleeping with their parents for a longer period of time. My son was 5 when he learned how to fall asleep by himself. The difference with a healthy child, is that at least you know that the baby or the child will eventually outgrow these sleep patterns and there is an end in sight. Imagine seeing no end? The thought alone causes me stress. Although I do agree that for that period of time you could learn how to function however, I am not sure that adjustment would last forever. I think eventually it takes a toll on your overall health.

In 2004, researchers from the Weisskopf Center for the Evaluation of Children in University of Louisville conducted a study on sleep difficulties in children with Autism. The parents of 210 children with Autism were surveyed. The average age was 8; the age range was between 2 and 16. There were 169 males and 32 females. "The highest statistics of sleep disturbances were in difficulty falling asleep, restless sleep, unwillingness to fall asleep in own bed, frequent awakenings and difficulty arising." (266)

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CURRENT MOOD:



It was determined that sleep problems are common amongst the population of autistic children. Problems consisted more in falling asleep and awakening, the report concluded that the majority of children were sleeping 8-9 hours but not peacefully and not easily. Unfortunately when the child does not sleep, neither do the parents. The study was able to link negative sleep problems to behavioral problems as well as medical problems.

Nutrition is also challenging for parents of autistic children. One of the behavioral symptoms is sameness, many parents report that their children like to repeatedly eat the same foods. In addition, a large number of children with the autistic disorder experience stomach or intestinal problems and/or severe food allergies.

"The only way to keep your health is to eat what you don't want, drink what you don't like, and do what you'd rather not." - **Mark Twain**

Mark Twain was right about not wanting to eat healthy foods. When you decide to switch over from unhealthy to healthy, it can be a difficult transition since unhealthy foods are usually loaded with sugars and preservatives that taste good while the taste of healthy food isn't always as appealing to the taste buds. As a parent, controlling the house diet is a huge responsibility. The best way to change the family diet is to buy healthy choices for the entire family, if everyone is joining in the change it can help to ease children into the right choices. The family change may not be helping in easing an autistic child into change since most are unaware of the world around them. Although Autistic children may not communicate well, they are similar to healthy children in terms of being picky eaters; this may be due to the physical problems. Many advocates suggest that children with Autistic Disorder be seen by a primary care physician regularly for physicals that can outline any underlying medical problems.

There is a huge controversy surrounding diet and autism. In 2008, a study was conducted on 77 children. 44 were diagnosed with Autism Spectrum Disorder and 31 were children were healthy with typical development. The researchers requested food

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diaries, which consisted of everything consumed in a period of 3 days. Parents submitted information about height, weight and dietary restrictions if any. Training on food diaries was administered to all parents, as well as support and assistance during the duration of the study. Labels containing all of the ingredients were also requested as well as homemade recipes when applicable.

Certified Bio-nutritionists examined the food diaries by using the Nutrition Data Systems for Research Database. The database does not include portion standards. Portion size averages were estimated and compared to published average food quantity per serving per child. The Nutrition Data System for Research is a Windows based database that was created by the Nutrition Coordinating Center at the University of Minnesota. It was designed to collect, calculate and analyze dietary data in the form of, dietary recalls, written dietary records, record-assisted recalls, recipes and menus. Portion size was evaluated by measuring each serving with the Dietary Reference Intake system. Dietary Reference Intake is a system of recommended nutrition guidelines created by the Institute of Medicine of the U.S. National Academy of Sciences.

From this survey, researchers concluded that children with Autism Spectrum Disorder consumed less calcium, more vitamin B6, and vitamin E when compared to children who are developing typically. This was due to parental restrictions and medical problems in the intestines. Bowel problems have been recognized to be common amongst children with Autism Spectrum Disorder. The nutritional deficiencies prompted for recommended attention to diets, by providers and parents.

During this study, a few other studies were evaluated for informational purposes. Interestingly, two studies regarding the gluten free diet were contradicting to each other and therefore, inconclusive. In 2002, one study conducted found that behaviors improved due to the consumption of a gluten free diet. In 2006, another study found no change in autistic children on the gluten free diet although, energy and protein ingestion seemed to be the same between the gluten free group and the group of autistic children with no dietary restrictions. Although these studies contradict each other many parents such as Jenny McCarthy and Polly Tommey have written books and articles and held

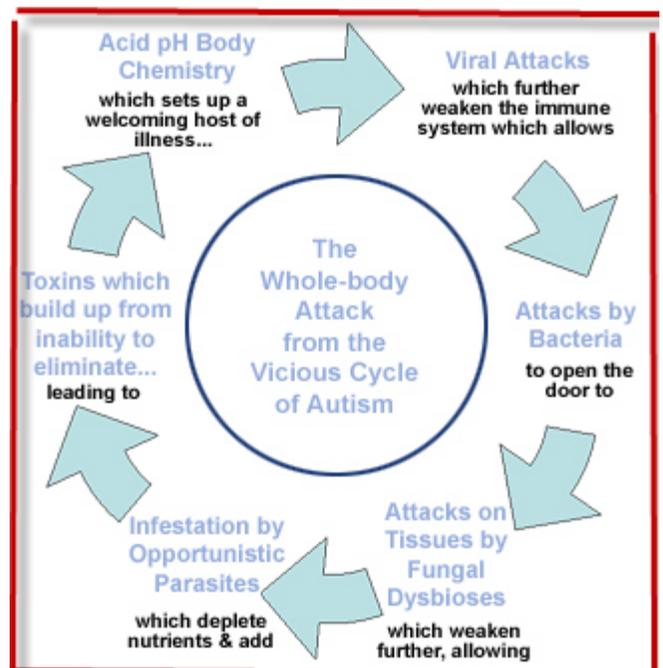
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public speaking events where they state they have cured their children's medical issues and have decreased ASD behavioral symptoms by switching to gluten free diets.

If you were researching diet, this information would be quite confusing since it is inconclusive and contradictory. Parental decisions can be difficult and switching to gluten free foods may be easier said than done, not only is finding the food not easy, gluten free foods tend to be sold in organic and/or whole food supermarkets that are much more expensive. One parent Marie Myung-Ok Lee, resorted to giving her 9 year old son cookies and tea made from Marijuana, at the brink with no where else to turn she decided on medical marijuana to alleviate her sons stomach problems. She reports that her son is now happy and having less intestinal problems. In addition to Autism her son "had two previous surgeries for spinal cord tumor and has inflammatory bowel syndrome". It may sound funny or disheartening for a moment but this decision was probably not an easy one and certainly controversial in its own right. I am not sure I agree however you can't disagree that only extreme stress would bring someone to higher levels in attempting to cure their child of at least one symptom of many in the Autistic Disorder.

Stomach problems, behavioral problems, dietary changes, and communication deficiencies are all conditions that require care from professional providers whether they are medical or psychological providers they all provide services for a fee. Healthcare expenses can be burdensome to any person with a long term illness or a person who needs chronic care management.



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In 2008, researchers analyzed the healthcare experiences, between families of autistic children and families without autism, to determine if having a medical home made a difference. A medical home is an approach to providing comprehensive primary care that promotes communication between individual patients, their primary care physicians, any other treating physicians, and when appropriate, the patient's family, thus creating partnerships for better health.

The study analyzed 300,910 children between the ages of 3 and 17 which were divided into one of three groups: children with autism spectrum disorder, children with psychological healthcare needs, and children with other special healthcare needs. Analysis focused on specific needs, such as, lack of continuous care with a designated primary care physician, difficulty with insurance claim processing, family financial standing with relation to condition, and unfulfilled needs for specialty care or specific ailments.

When comparing the Autism Spectrum Disorder group to the other two groups they concluded the following: Families of children with Autism Spectrum Disorder:

- Experienced more financial hardships.
- Reported that they needed additional income to cover medical expenses.
- Experienced higher employment related issues that forced them to work part-time or become unemployed to care for their children.
- Spent 10 hours or more to provide or coordinate care.
- Paid \$1000.00 or more for medical expenses the year before.
- Children with autism spectrum disorder were commonly incorrectly diagnosed when evaluated for other medical problems, due to the failure of communication between the family and the child, and also, due to the lack of testing since some medical problems are overlooked or dismissed after the diagnosis of autism spectrum disorder. Statistics in this area remain higher than that of the other two groups.
- Children with Autism Spectrum Disorder who had medical homes, suffered a little less than those who did not, since the continuity of care and referral practices were more stable.

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- Large numbers of children in the Autism Spectrum Disorder group had larger out of pocket medical expenses even, those with insurance coverage.

Although the families in the Autism Spectrum Disorder group were not compared to families with healthy children, they still ranked the highest with negative healthcare experiences.

The insurance company dictates the patient responsibility according to the plan and benefits. The large out of pocket expenses are due to limited or no coverage since currently there is no legislation that enforces mandatory coverage for this disorder. Insurance companies can use loop holes to deny coverage simply due to the fact that there is little or no research and no definitive standard for delivery of care. Currently, there are several bills pending review which address all issues surrounding autism rights and insurance coverage. New York State introduced a bill for Insurance Coverage on January 7, 2009, which is currently still pending review. Unfortunately for the time being without legislation, insurance companies can move the cost to the insured which is mostly always the parent and/or legal guardian. So now, you have an autistic child who needs 24 hour care and you were not born wealthy, what is a parent to do? There are federal grants that assist with some things such as education and daycare however this information is not advertised or easily obtained. In my opinion, grants are typically convoluted with legal terms, red tape and a lot of paper work.

Stress often leads to depression. It is not surprising to find depression amongst this population of parents.

“Depression is a disorder of mood, so mysteriously painful and elusive in the way it becomes known to the self-to the mediating intellect-as to verge close to being beyond description. It thus remains nearly incomprehensible to those who have not experienced it in its extreme mode. ”

- [William Styron, "Darkness Visible"](#)

Depression leads to strained relationships. In 2008 a study on “The Impact of Family and Peer Relationships” was conducted by the Journal of Abnormal Child Psychology.

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The main focus of the study was to examine the “potential impact of family conflict and cohesion, and peer support/bullying on children with Autism Spectrum Disorder.” (Journal of Abnormal Child Psychology)

The study examined 322 families which consisted of 76 with Autistic Disorder, 188 with Asperger Syndrome, 21 with PDD-NOS Pervasive Disorder Not Otherwise Specified, and 37 families with children with a non Autistic Spectrum Disorder or no diagnosis.

“The key findings were that anxiety/depression and the ASD Symptomatology were significantly related, and family conflict was more predictive of ASD symptomatology than positive family/peer influences.” (Journal of Abnormal Child Psychology)

In other words, the study points out that the Autism Spectrum Disorder symptoms are directly related to stress which lead to depression which lead to strained relationships within the family.

In addition to these statistics it has been reported that the divorce rate for this population is currently at 80% while the national divorce average is 35%. The American Academy for Matrimonial Lawyers state that the most common reasons for divorce are Poor Communication, Financial problems, A lack of commitment to the marriage, A dramatic change in priorities, Infidelity. Stress can certainly lead to each of the most notable causes stated above. Although there are no documented researched statistics that prove this theory, it is not difficult to imagine this trend within this population. The core of the family is the marriage, if both parties cannot unite; the marriage may not be able to resist these stressors.

Child Care for an autistic child can be very challenging since children with moderate to severe autism have great difficulty communicating where the parents experience difficulty understanding so others would have greater communication deficiencies. Child care problems lead to employment issues, stable reliable child care is needed for all parents to succeed in any occupation.

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In 2007 a study conducted by the American Academy of Pediatrics which researched child care in the autistic communities with pre-school aged children. The study consisted of surveying 82 children with Autism Spectrum Disorder and 1955 children that were at high risk on the basis of the Parent's Evaluation of Developmental Status."

The results reported the following:

- 97% of pre-schooled aged children diagnosed with autism spectrum disorder were care for in community settings, particularly pre-school and head start, with only 3% in exclusive parental care.
- 39% of the parents of children with autism spectrum disorder reported that child care problems had greatly affected their employment decisions compared to 16% of the children at high risk and 9% who were typically developing.

In multiple variable analyses, the autism spectrum disorder families were 7 times more likely to state that child care problems affected employment than other families, after controlling for household and child covariates. This effect was 3 times higher than the effect of poverty.

Also stated in this report is "households in poverty were 2 times more likely to report that child care problems had a major impact on employment decisions than comparable non poor households" (American Academy of Pediatrics). Impacting these statistics are the family income levels. If a family does not have to worry about paying for the best child care then there are less issues however even those families with high income can find themselves in this situation as medical bills take up higher levels of the annual income. The fact that there is no one set of medical treatment guidelines could cause even further treatment that is not medically necessary leading to time and money wasted. Not only are they facing challenges of where to leave the child safely while they go to work but also the cost of child care. NYC's Head Start is only for families that fall into low income brackets using U. S. poverty guidelines. Public pre-school and kindergarten are free however the rate of discharge for behavior problems is great amongst the autistic population so while

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they are the education service is free they are not equipped with the proper facility or professional education providers to care for children with special needs. There are specialized schools which cater to children with disabilities however there are fewer. Currently NYC only has one public charter school for children who have been diagnosed with any of the 5 disorders under the Autism Spectrum Disorder. Private specialized care for a disabled child is expensive, caregivers for autistic children need to specialize specifically in these types of disorders since the inability to communicate is immense and would impact the quality of care given and other developmental disabilities are different.

In addition, as these children become young adults their educational needs continue. Education continues in transition to postsecondary education, vocational or job training and placement, and comprehensive adult services for individuals. Comprehensive adult services include teaching self care which would hopefully bring about independent living and this may not be the case for all persons in the ASD category, low function may prevent the last transition.

A nationwide study conducted by Easter Seals called "Living with Autism Study" discovered that parental stress also had many other variables. The questions asked were as follows:

- Parents of children living with autism are very concerned about their children fitting into society, with very few feeling their children will be able to:
  - Make his/her own decisions - 14% ASD 65% Non-ASD
  - Have friends in the community - 17% ASD 57% NON-ASD
  - Have a spouse or life partner - 9% ASD 51% Non-ASD
  - Be valued by their community - 18% ASD 50%Non-ASD
  - Participate in recreational activities - 20% ASD 50% Non-ASD
- Children with autism also are less likely than their typically developing peers to have bank accounts - 37% ASD55% Non-ASD
  - Use electronic products like cell phones - 9% ASD 41% Non-ASD
  - MP3 players - 23% ASD 49% Non-ASD

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“Many parents of children with autism report they’re “financially drowning” with concerns for their children’s financial independence seeming to far surpass the worries of typical parents. 74% of parents of children with autism fear their children will not have enough financial support after they die, while only 18% of typical parents share this fear.” (Easter Seals)

They also asked the following questions regarding financial status.

- Drains my families current financial resources 52% ASD 13% Non-ASD
- Will drain my family’s future finances - 50% ASD 10% Non-ASD
- Will cause me to fall short of cash during retirement – 54% ASD 13% Non-ASD

It was also found that only 24% of autistic teenagers have looked for a job compared to 77% teenagers that do not have any disorders. At the same time 76% of parents of autistic children are concerned about their child’s future employment and only 35% parents of typically developing teenagers.

In addition to the many statistics I have provided, there are so many stories of parents who have killed their autistic children and then committed suicide. On September 13, 2008, The Denver Post headline was “Man arrested in fatal shooting of 13 year old autistic son”. The story says that after the shooting Allen Gabe could only sit on the porch stating “I give up.” (Denver Post). That is just one of many horror stories of those who could not cope alone.

There are also success stories. The most notable for this article the story of Susie Rubin. She is an adult with low functioning autistic disorder who requires 24 hour assistance but is able to attend college and has been able to be an advocate for ASD. As a society what can we do to help all families in this situation a success story?

Michael Savage is not the only one who believes Autism is a fake. What additional care does an Autistic child need if Autism was made up by a bunch of parents who can’t  
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handle their children? Or worst a bunch of children who were forced by their parents to lie for money? Dr. Kristina Chew discusses this topic in a Blisstree.com web blog. She points out an online article from MSNBC.com, the title states: "Mom taught her 2 kids to fake retardation, Mother admits coaching children to collect more than \$280,000.00 in benefits" (qtd. in MSNBC). . Then she points out that she found a blog on KevinMD.com that stated "According to Kevin MD, something like this "anecdote" (*sic*)—in which a parent has a child "fake" a developmental disability—may account for the rise in the incidence of autism". In defense she states that she does not believe that parents are desperate enough to fake autism, sounding like the mom of an autistic child. There is one bad apple in every tree; we can't throw them all out because one was rotten. This would mean that countless families have lied for money, what money are they talking about? ASD families have little resources and any resources that are out there are not really publicized. Controversial? maybe. Articles that state autism is a fraud rely on opinions and not on any factual evidence. Find me some facts that state every family is lying.

Claudia Wells published an article in The Other Side web blog called "A Vanishing Diagnosis", she states that ASD diagnosis are not well defined, enough so that one person may be diagnosed with Aspergers by one doctor then mild autistic disorder by another. She may have a good point. From the research I conducted, the terms seem to intertwine at times. Autism and Autistic Disorder are the same however when you compare these terms from various sources from books to medical journals you will find that one or the other is used and some articles seem to separate or confuse the two. I also found that persons diagnosed with Aspergers are sometimes called Autistic however when you read the individual symptoms you will find that the two are very different. I also think that Autism Spectrum Disorder which is the considered the overall category of this disorder is confused with the single diagnosis of Autism or Autistic Disorder. If the medical community isn't consistent how would the rest of us know and understand. This needs clarification since funds can be inappropriately maneuvered for the right causes due to some technical error.

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It is unethical that there is no real support system that includes guidance for parents of autistic children. Since other developmental disabilities have better research on causes and treatment there are more support programs for families in need.

Others may argue that there shouldn't be any resources for disorders that are not established in the medical communities. They may be right however how can we as a society stand by while parents of autistic children are clearly suffering? Success stories prove that early intervention and behavioral therapies do work for some. How long should the world wait? Clearly more research is need but in the mean time we should look to see what works.

While my proposed solution to this problem will not cure autism or provide an easy ride for anyone, I believe it will at least provide resources and support to all parents of Autistic children and thus make society a little better for those fighting hard to survive. I propose a Business Plan for a resource center that provides evaluation and then referrals for focused education, medical professionals for care, psychological support and Community Resources that contain the following:

I propose the following:

- A non profit organization for at least one resource center in every town of every state with specified zone requirements for better access to care.
- The Resource Center
  - Each family will register and complete a medical psychological evaluation for a treatment plan, unique to the diagnosis and individual needs of the child and family. Each family will be assigned a coordinator who will assist in securing evaluations. The coordinator will also be the liaison in the referral process and will assist the family should any problems occur.
  - The evaluation will then provide guidance for the following:
    - Referral to medical facilities and/or professionals for comprehensive medical treatment that specializes in the care for autism spectrum disorder. The care will include wellness

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and prevention care that is delivered at times that convenient for patients and their families. The medical facility and/or professional business office will meet the standards for the implementation of a medical home.

- The medical home will provide a means of communication among autism spectrum disorder health care providers, behaviorists, educators, specialists, hospitals, and other autism spectrum disorder care providers as well as the patient and the family.
- Referral Services for a package of psychological services that contain:
  - Stress Management, which can give each member of the family coping mechanisms for stress relief.
  - Psychological therapy for couples, individual therapy, and family therapy.
  - Support groups – in person and online. Support groups are key for communication between parents who are having similar experiences and know that they are not alone as well as sharing experiences and coping experiences.
- Referral Services for Financial Planning that include education on:
  - Financial aid/charity care for patients with conditions that require chronic care.
  - Education on healthcare coverage do's and don'ts and patient's rights.
  - Budgeting for today, budgeting for the future.
  - Identify any grants that provide financial assistance for experimental treatments not covered by insurance.
  - Identify and assist in applying for grants that provide financial assistance for day care and/or medical care that the family cannot afford.

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- Assist in placement in day care services for eligible children between birth and 2 to enable working families. Eligibility criteria will be based on diagnosis.
- Placement in schools that provide the education requirements for ASD individuals.
  - Assistance in transition to postsecondary education and/or vocational or job training and placement,
  - Assistance in obtaining access to schools that specialize in education on self care and assist in transition to independence for individuals that are deemed capable by evaluation of medical professionals.
- Employment referral services for parents that need part time or flexible hours to care for their children.
- Referrals for Respite services available to parents and caregivers.

Funding for these centers will come from federal and state budgets as well as fundraising and donations. Each center will have a designated professional who will control federal and state spending as well as participate in nationwide fundraising events. Philanthropic organizations will be created for this cause.

Currently there are support groups online and some organizations that help families cope however there are no central resource centers that contain guidance on all topics that relate to all symptoms of the Autistic Disorder or any of the other 4 disorders in the Autism Spectrum Disorder since all 5 are considered a psychological behavioral disorder and not a medical condition. The resource centers will provide access to all types medical professionals should the need arise. The family could easily access referral services and guidance on obtaining some of the resources I have suggested. The Patient Centered Medical Home national initiative would be of help to centralize a patients medical records where all treating medical professionals can work together to provide care. This care is said to reduce unnecessary hospitalizations while providing a higher quality of care.

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In conclusion, although parenting is difficult and the challenges are similar, parenting a child with autism is harder than parenting a healthy child for two main reasons. Without daily support and education the parents alone will not be able to provide the best support possible. My proposed solution will at least provide the support needed. Lack of resources for families in need lead to unemployment and poverty rates and in the end we as the tax payers pay. This solution will not only provide a better quality of life for all involved and all of the surrounding communities but it will also reduce the long term costs to the tax payers in the United States.



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