A Parent’s Guide to Autism

XXX Health Group

Table of Contents

Section 1
Autism Overview

“Autism, is part of my child, it's not everything he is. My child is so much more than a diagnosis.” - S. L. Coelho, *The World According to August – One Good Friend*

Chapter 1

History of Autism

The word “autism” has been in use for about 100 years and comes from the Greek word “autos,” meaning “self.” The term refers to conditions in which a person is an isolated self, removed from social interaction.

The first person to use the term was Eugene Bleuler, a Swiss psychiatrist. He started using the term around 1911, to refer to one group of symptoms of schizophrenia.

Leo Kanner, a doctor from Johns Hopkins University, used the term autism in 1943 to describe a group of children he had studied and observed. These children were withdrawn, non-verbal, and exhibited bizarre ritualistic behaviors. He applied the term, Early Infantile Autism.

At about the same time, in the 1940’s, Hans Asperger, a German scientist, identified a similar condition that is now called Asperger’s syndrome.

Early Infantile Autism was perceived as a pre-schizophrenic condition, and solely a childhood condition. Little attention was paid to the developmental and biological aspects of the condition.

Only as recently as the 1960’s were autism and schizophrenia no longer linked in many researchers’ minds, and medical professionals began to have a separate understanding of autism in children. Two psychiatrists published a groundbreaking book, *Early Childhood Autism – Clinical, Educational and Social Aspects* (1966), and psychologist Bernard Rimland published *Infantile Autism: the Syndrome and its Implications for a Neural Theory of Behavior* (1964).

In 1965, Bernard Rimland established the Autism Society of America, one of the first advocacy groups for parents of children with autism. Ruth Sullivan, a teacher, established an educational program for young autistic children and in 1968 was elected the founding President of the Autism Society of America.

In 1980, autism was categorized as a developmental disorder separate from schizophrenia in the Diagnostic and Statistical Manual of Mental Disorders (DSM-III), the reference book used by health care professionals to diagnose mental health disorders.

A more constructive understanding of autism as a developmental disorder has evolved over the years, yet even today ongoing education and awareness programs about the needs of children and adults with autism spectrum disorders are needed.

Chapter 2

What Is The Autism Spectrum

So, what exactly *is* the autism spectrum?

The autism spectrum describes a range of conditions classified as pervasive developmental disorders in the Diagnostics and Statistics Manual of Mental Disorders (DSM).

Different people with autism can have very different symptoms. Autism is considered a “spectrum disorder,” a group of disorders with similar features. One individual may have mild symptoms, one may have much more severe symptoms, but they are both on the autism spectrum.

The wide variation in symptoms among children with autism led to the concept of the term “spectrum disorder.” The forms of autism along the spectrum are thought to overlap considerably.

Autism was not included as a separate diagnostic condition in the DSM until 1952. Until this time, children who exhibited autistic-like symptoms were diagnosed under the “schizophrenic reaction, childhood type label.”

As of the most recent release of the DSM, the DSM-IV, there are five types of autism spectrum disorders specifically identified.

The five disorders classified under the umbrella category officially known as Pervasive Developmental Disorders or PDD, are:

- Autism
- Asperger’s syndrome
- Rett syndrome
- Childhood disintegrative disorder
- Pervasive Developmental Disorder Not Otherwise Specified (PPDNOS)

We will go into further detail on each disorder in subsequent chapters.

Chapter 3
Diagnosis of Autism Spectrum Disorders

How is autism diagnosed?

According to the DSM-IV, a diagnosis of autistic disorder is made when a child displays 6 or more of the 12 symptoms across three major areas:

- Social interaction – such as the inability to establish or maintain relationships with peers appropriate to the level of the child's development
- Communication – such as the absence of language or delays in language development
- Behavior – such as repetitive preoccupation with one or more areas of interest in a way that is abnormal in its intensity or focus

When children display similar behaviors, but do not meet the specific criteria for autistic disorder, they may be diagnosed in one of the other four disorders on the spectrum.

The fifth and final revision to the DSM is expected to be published in May 2013, and is expected to affect how autism and associated disorders are diagnosed. Proposed revisions include changing the name of the diagnostic category to Autism Spectrum Disorders, including Asperger's syndrome, Childhood Disintegrative Disorder and PDDNOS under the diagnosis of Autism Spectrum Disorders rather than defining them separately as is now the case. An additional proposed revision would remove Rett syndrome from the DSM entirely, and thus, from the autism spectrum.

There is no medical test that can diagnose autism. Behavioral evaluations by medical professionals are used for diagnosing these disorders. A typical diagnostic evaluation involves a multi-disciplinary team, which may include a pediatrician, a psychologist, a speech and language specialist or possibly an occupational therapist.

Possible indicators of autism spectrum disorders may include:

- Lack of babbling, pointing or making meaningful gestures by age 1
- Does not speak one word by 16 months of age
- Does not combine two words by 2 years of age
- Loses language or social skills
- Lack of eye contact
- Doesn't smile or interact joyfully
- May seem to be hearing impaired
- Unusual reactions to sensations
- Lack of response to people
- Flapping hands
- Spinning
- Walking on tiptoes
- Extreme dislike of certain sounds
- Extreme dislike of certain textures
- Desire to follow set patterns of behavior
- Desire to keep objects in a certain physical pattern
- Repetitive behavior
- Ritualistic behavior
- Lack of interest in or lack of ability to play with other children

All children are different, especially on the autism spectrum, and so very few, all or some of the above characteristics may or may not apply.

Chapter 4
Statistics

The Centers for Disease Control and Prevention recently released their newest numbers with regard to autism rates in the United States.

1 in 88 children in the United States has autism or an autism related disorder, which marks the highest estimate to date, and a 78% increase over the past decade.

Among boys, the rate is 1 in 54, which is almost five times that of girls, who have a rate of 1 in 252.

This spike in the prevalence of autism and related disorders raises questions about whether it is a true increase or a result of greater awareness that has led parents, teachers, and even health-care providers to see symptoms of autism in children who would not have received the diagnosis a generation ago.

Doctors have become more educated and aware, and are therefore better at diagnosing the condition, so the increase may be due in part to better detection.

Autism advocates use this new data to call for more research to identify the causes of autism-spectrum disorder and for more services for those affected by it.

It is important to remember that autism comes in all shapes and sizes, that the spectrum is very broad, from severe, low-functioning cases to those that are very high-functioning. With the rising numbers of diagnoses, autism is something that will eventually touch all of us in some way. Education and awareness are critical as society adapts to meet the needs of this growing population.

Section 2
Autism Spectrum Disorders

“Not everything that steps out of line, and thus ‘abnormal,’
must necessarily be ‘inferior.’”
-Hans Asperger

Chapter 5
Rett Syndrome

Rett syndrome, named for Dr.Andreas Rett, is a rare and unique developmental disorder that is first recognized in infancy and is almost always seen in girls. Rett syndrome causes problems in brain function that are responsible for cognitive, sensory, emotional, motor and autonomic function.

Rett syndrome symptoms present themselves after a period of seemingly normal development. At anywhere from six to eighteen months of age, a slowing down or stagnation of skills takes place, followed by a period of regression. As the syndrome progresses, the child loses purposeful use of her hands and the ability to speak.

There are several types of Rett syndrome:

- Atypical
- Classical (meets the diagnostic criteria)
- Provisional (some symptoms appear between ages one and three)

Rett syndrome is associated with mutations on the X chromosome on a gene called MECP2. This condition affects about 1 out of 10,000 children. Rett syndrome is extremely rare in males.

Since the MECP2 mutation can be seen in other disorders, the presence of this mutation is not enough in itself to diagnose Rett syndrome. Diagnosis requires either the presence of the mutation, fulfillment of the diagnostic criteria, or both.

An infant with Rett syndrome will usually exhibit normal development for the first 5 to 18 months. When symptoms present, they range from mild to severe and may include:

- Apraxia – the inability to perform motor functions

- Breathing problems
- Change in development
- Excessive saliva and drooling
- Floppy arms and legs
- Scoliosis
- Shaky, unsteady or stiff gait, or toe walking
- Seizures
- Slowing of head growth, beginning at 5-6 months of age
- Loss of normal sleep patterns
- Loss of purposeful hand movements
- Loss of social engagement
- Severe language development problems

There is no cure for Rett syndrome. Treatment is symptomatic and requires a multidisciplinary approach. Medication may be used to treat breathing irregularities and motor difficulties and occupational therapy can help children develop skills needed for performing self-directed activities. Physical therapy may help prolong mobility, and speech-language therapy can help patients use non-verbal means of communication and improve social interaction.

Chapter 6
Childhood Disintegrative Disorder

Childhood Disintegrative Disorder, also known as Heller's syndrome, is a rare type of autism spectrum disorder. It is a condition wherein children develop normally until age 2 to 4 and then lose language, motor, social and other skills that they had previously learned.

The loss of skills may be gradual, but more often occurs rapidly over a period of six to nine months. Behavioral changes, such as anxiety, unprovoked anger or agitation, are followed by loss of skills and often loss of bladder of bowel control. Children may stop speaking altogether, or revert to single words and often withdraw into themselves, rejecting social interaction.

This disorder is much like autism, yet typically occurs later than autism and involves a more dramatic loss of skills. Childhood Disintegrative Disorder is far less common than autism.

The diagnosis of this disorder requires extensive and profound losses in motor, language and social skills. The cause of Childhood Disintegrative Disorder is unknown, though research findings suggest that it may arise in the neurobiology of the brain.

For a CDD diagnosis, a child must show loss or regression in at least two of the following:

- Receptive language skills (language understanding)
- Expressive language skills (spoken language)
- Social or self-help skills
- Peer interaction
- Motor skills
- Bowel or bladder control, if previously established

CDD is an extremely rare disorder. About 1 in 100,000 children are thought to have it. Newer research shows that CDD is about four times more common in boys.

Treatment for CDD is similar to that of other autism spectrum disorders. Speech and language therapy, occupational therapy, social skills development and sensory integration therapy may all be used if appropriate.

Sadly, the prognosis for children with CDD is very poor. Once skills are lost, they are not usually regained. Only about 20% of children with CDD reacquire the ability to speak, and most remain dependent on full-time caregivers or are institutionalized.

Chapter 7
Autistic Disorder

Autism, Classic Autism, Autistic Disorder, or Kanner’s Autism

In the 1940's, Dr. Leo Kanner was among the first to describe the condition now known as autism. Before his work, doctors labeled such children as mentally retarded or emotionally disturbed. Autistic people show the three hallmark symptoms in varying degrees.

Autism first appears during infancy or childhood, and is not distinguished by a single symptom, but rather by a characteristic triad of symptoms.

Autism is characterized by delays or abnormal functioning before the age of three years in one of the following categories: (1) social interaction (2) communication (3) restricted, repetitive and stereotyped patterns of behavior, interests and activities.

Social interaction deficits may manifest in a lack of social or emotional empathy, the absence of a desire to share enjoyment and interactions with others, or a noticeable lack of nonverbal communication such as body language, eye contact and gestures.

Deficits in communication include the inability to sustain or initiate conversation with others or the lack of attempts of communication at all, a lack of age-appropriate imaginative play, and/or a lack of development of useful speech.

Stereotyped and repetitive behaviors include adherence to inflexible and rigid routines and rituals, fascination with objects or preoccupation with stereotyped patterns of interest characterized by unusual intensity or focus, and repetitive motor movements (flapping, etc.).

Many autistic individuals also experience sensory processing and regulation issues. Autism is a spectrum disorder due to the fact that the severity of impairment in each of these areas varies so widely in each individual.

Some characteristics of autism include communication issues, echolalia (repetition of words of phrases spoken by others), stereotypical behaviors such as hand flapping, rocking or head banging, lack of eye contact, an inability to engage in meaningful social interactions.

Chapter 8

Asperger’s syndrome

Dr. Hans Asperger, a Viennese pediatrician, wrote the first paper on the condition in 1944. He had been working with four children, ages 6 to 11, who had similar peculiarities. They were each passionately interested in one narrow subject, and would talk on and on about it.

Dr. Asperger believed these "little professors" had problems understanding other people. For example, they were clueless when their audience was becoming bored as they lectured about obscure subjects. They did not notice that people were yawning, looking at clocks, or trying to switch the topic. In addition, although the children could memorize facts about their subjects, they often had little understanding of it. They tended to be overly logical and rigid, sometimes moralistic in their viewpoints. They had trouble understanding metaphors. If a mother said, "I'm going to hop down to the store," her son with Asperger Syndrome expected her to leap like a rabbit.

As Dr. Asperger and others after him continued to study the syndrome, they were able to pinpoint other traits "Aspies" have in common. Some are clumsy and uncoordinated. They have trouble with self-care and tasks like tying their shoes or buttoning. Others have problems controlling their voices. They speak too loudly or in whispers; they have unusual inflections or monotones.

Many Aspies have trouble with sensory integration. They may overreact to loud noises or bright lights. They may cope with the stress by repeating certain behaviors to soothe themselves. Self-soothing may include elaborate rituals or "rules," such as wearing a certain item of clothing all the time or always eating from the same menu.

The trait that causes Aspies the most difficulty in life is their inability to pick up other people's social cues and to respond appropriately. Unlike autistic people, Aspies often are interested in other people and want to make and keep friends. However, they have to learn social interactions on an intellectual level instead of just picking them up naturally the way others do.

In 1994 Asperger’s syndrome became part of the The Diagnostic and

Statistical Manual of Mental Disorders (DSM).

In order to be diagnosed with Asperger Syndrome, a person must show **two** of these problems:

- "Marked impairment" regarding nonverbal social cues (doesn't make eye contact, doesn't understand others' body language, etc);
- Failure to make friends;
- Lack of appropriate social and emotional responses to others; or
- Inability to spontaneously share enjoyment, interests and achievements with other people.

In addition, the person must show **one** of these behaviors:

- An abnormal and intense interest in one subject;
- Adherence to a strict set of rules, routines and rituals;
- Repetition of certain mannerisms like hand flapping, hair twisting or even whole body movements
- An obsession in the parts or mechanics of objects.

Asperger Syndrome is one of five Pervasive Developmental Disorders within the spectrum of autism. It is a lifelong condition and occurs in boys four times as often as girls.

Chapter 9

Pervasive Developmental Disorder-Not Otherwise Specified (PPD-NOS)

With PPD/NOS, symptoms don't fall neatly into place. A diagnostician cannot absolutely declare that the person has Asperger Syndrome or autism because some of the symptoms are missing, are in the wrong combination or are very mild. This is a "catch-all" diagnosis or an umbrella term sometimes used until a more precise diagnosis can be made.

PDD-NOS is the diagnosis applied to children or adults who are on the autism spectrum but do not fully meet the criteria for another autism spectrum disorder. As with all forms of autism, PDD-NOS can span a wide range of intellectual ability and its defining features are significant challenges in social and language development.

As a diagnosis, PDD-NOS is relatively new, dating back only 15 years or so.

According to the DSM-IV, the criteria for a diagnosis of PDD-NOS is as follows:

"This category should be used when there is severe and pervasive impairment in the development of reciprocal social interaction associated with impairment in either verbal or nonverbal communication skills or with the presence of stereotyped behavior, interests, and activities, but the criteria are not met for a specific Pervasive Developmental Disorder, Schizophrenia, Schizotypal Personality Disorder, or Avoidant Personality Disorder. For example, this category includes “atypical autism” – presentations that do not meet the criteria for Autistic Disorder because of late age at onset, atypical symptomatology, or subthreshold symptomatology, or all of these."

Some studies suggest that PPD-NOS can be broken down into three different subgroups:

- A high-functioning group whose symptoms largely overlap with those of Asperger’s syndrome, but who differ in terms of having a lag in language development and mild cognitive impairment.
- A second group whose symptoms closely resemble those of autistic disorder or classic autism, but do not fully meet all of its diagnostic signs and symptoms.
- A third group who meet the diagnostic criteria for autistic disorder but whose stereotypical and repetitive behaviors are noticeably mild.

Section 3
Parenting An ASD Child

"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 Nothbohm, author of *Ten Things Every Child With Autism Wishes You Knew*

Chapter 10
Advice for Parents Upon Diagnosis

Raising a developmentally different or disabled child presents unique challenges for most parents. These challenges begin as soon as you realize that your child is not “normal” or “typical.” Most parents experience a period of mourning or grief. Upon diagnosis, parents of autistic children have a great deal to learn - about autism itself, about their child’s individual diagnosis and about how to parent a special needs child. You may feel confused, overwhelmed, sad, or all of the above.

“When a child is diagnosed with an autism spectrum disorder, their parents or primary caregivers must become experts overnight in order to effectively support and advocate on behalf of their child.” – *Autism: Perceptions & Reality* (The Autism Foundation, 1996)

If you have a child with autism, it is important to get support. If your friend or family member has a child with autism, it is important to give support. The day-to-day care of a special needs child can be incredibly stressful. Constantly advocating for your child and making sure your child gets the help he or she needs, can be exhausting.

Some advice for parents of children with autism:

- Educate yourself. Learn all you can about your child’s specific disorder and about what current therapies are recommended, what medications may be helpful and what current research findings are.
- Build a support system. The autism community has numerous local and national groups and parent organizations, online support groups, community groups and activities. Ask your pediatrician for referrals or join an online chat groups for parents of children with autism.
- Take care of yourself and your relationships. Make sure to put your emotional health first. Time away by yourself and time away

with your partner is crucial for your well-being, and for making sure you are able to be the best possible parent.

- Get professional help. Your family may need help with the stress of caring for your special needs child, you may need help managing your family dynamic with other children, and a therapist will be able to provide the help you need.
- Become involved with other parents of autistic children. A support group is where you will find other parents who understand, who “get it,” who won’t judge, who can provide quality advice, and where you will find a place where you do not have to feel different or alone.

Chapter 11
Understanding and Managing Behavior

Your child with an autistic spectrum disorder will at times display perplexing, frustrating, frightening, hilarious, joyous and rewarding behavior – perhaps all in the same afternoon! Being as prepared as possible, and being able to plan for and control your reactions to your child's behavior will help both of you a great deal. Below are some tips to help understand and manage the behavior of your special needs child.

- Modify the environment. Creating a safe environment is critical since some of your child's behaviors may have the potential to be dangerous. Take precautions around your home to ensure your child's safety, and when in strange environments, take safety into consideration first and foremost.
- Establish routines and a stick to a schedule. Children with autism crave consistency and do best when they have a highly structured schedule. Set regular times for meals, therapy, school, and bedtime. Try to keep disruptions to the routine to a minimum, and if there needs to be a schedule change, prepare your child in advance.
- Be consistent. Be consistent in the way you interact with your child and in the way you handle challenging behaviors. Be consistent with praise and positive information. Children need continual and direct guidance on expected behavior.
- Consider possible sources of behavior. By carefully observing your child, and watching for nonverbal cues, you may be able to figure out what is setting him off. Oftentimes, throwing a tantrum is your child's way of communicating his frustration and getting your attention.
- Avoid or remove overwhelming sensory input. Avoid overwhelming sensory settings, with too much noise, activity or large crowds and when that is not an option, utilize ear plugs, or distracting or soothing toys or games.
- Seek out positive outlets for sensory input or unusual behaviors. Climbing on the furniture may not be safe or acceptable, but a playground or climbing gym provides an appropriate place for

that behavior. Your child may be craving sensory input that can be provided in appropriate and positive ways.

- Modify your expectations. Sitting through a long meal or activity may not be possible for your child, but starting with small goals can build toward a larger goal.
- Reward the behavior you want them to display. Positive reinforcement works wonders. Praise your child when she acts appropriately, or masters a new skill. You may consider implementing a reward system, using stickers, screen time, play time – whatever is desirable and appropriate for your child.
- Make time for fun. Come up with ways to have fun together, in an unpressured environment, where you both benefit from enjoying one another's company.
- Work on staying calm and finding gratitude, joy and humor each day.

Chapter 12
Parenting An Asperger's Teen

Parenting teenagers is a tricky business – it is like riding an emotional roller coaster – it is frustrating, terrifying, exhilarating, often joyous and always tenuous. Parenting a teen with Asperger's Syndrome is all that and much, much more.

Children with AS can be difficult to parent and to love when they are young, and adding adolescence to the mix can make an already challenging parenting situation radically more so.

Reaching out to other parents with AS children is to your benefit, for a sense of camaraderie, support and sharing of experiences and "best practices." As the parent of an AS teen, support from family, friends, church groups, understanding school staff, and support groups can be rewarding and comforting, and can help preserve your sanity.

Some tips that parents of teens with Asperger's Syndrome may find helpful include:

- Even though they are no longer young children, your teen will still need structure, downtime and preparation for transitions. Keep doing what worked when they were younger, modifying as it their needs grow and change.
- Remember your teen's chronological age may not accurately reflect his social or emotional one, and adjust expectations accordingly. You would not want to put a 14-year old behind the wheel of a car, for example, even if his chronological age is 18.
- Communication methods may need to change. Impersonal, written communication is easier for AS teens to absorb – email and texting may be highly effective means of communication.
- Pick your battles. Set and enforce only your bottom line rules and expectations – those involving matters of safety and respect.
- New, multiple stressors in the teen years, such as increased academic, social and peer pressures, may add to anxiety or depression in your AS teen. Consult your teen's health

professionals – medications may need to be introduced or adjusted.

- Forgive yourself for not having the perfect child and for not being the perfect parent. Allow yourself the comfort of knowing your teen is a different and that it is neither your fault nor his.
- Continue to stay patient and calm and do the best you can, even when your AS teen is especially distant, surly or acting out.
- Have a unified front as parents, whether divorced or together, with regard to treatment and rules for your AS teen. Attend team meetings and therapy sessions together as often as possible.
- Transition planning for during and after high school is extremely important. The transition part of the IEP is critical for addressing the skills a teen will need to acquire while in high school in order for future independent living.
- Remember that social skills are far more essential for success than is academic achievement. Make sure that your child's IEP provides for social skills learning, or seek out a practical social skills group especially for teens.
- Realize that not all teens are ready for a residential college, and work with your education professionals to assess your teen's post high school education options.

Bear in mind that while your Asperger's Syndrome teen presents certain unique challenges, parenting any teenager is not easy. Simply knowing you are not alone in your struggles, seeking help when you need it and commiserating with other parents makes the rough teen years a little bit easier.

Chapter 13
Diet and Nutrition

Some parents of autistic children have found that special diets seem to lead to very noticeable changes in their child's behavior and learning progress. Popular approaches include lactose-free or gluten-free, casein-free (GFCF) diets, or a combination thereof.

Gluten is a type of protein found in wheat and other grains. A great many foods contain gluten, including bread, cereal, crackers, pasta, cookies, sauces, and candy, to name only a few.

Foods containing casein include cow's milk, goat's milk, butter, cheese, sour cream, yogurt, ice cream, margarine and soy cheese.

Foods that *can* be eaten on a GFDF diet include: rice, quinoa, potato, corn, fruits, oil, vegetables, beans, meat, poultry, fish, nuts, eggs, etc.

The gluten-free, casein-free (GFCF) diet has mixed results in the autism community. Some studies have found behavioral improvements in children on a GFCF diet, while others have not found any significant effects from the diet.

There is growing interest and increasing research in the link between autism and gastrointestinal (GI) ailments. A UC Davis Health System study found that children with autism born in the late 1990s were more likely to have gastrointestinal problems, including constipation, diarrhea and vomiting, than autistic children who were born in the early 1980s.

Researchers at Penn State used survey information from parents to conclude that the GFCF diet may improve behavior and GI symptoms in autistic children. One researcher at the New Jersey Medical School's Autism Center found that autistic children were more likely to have abnormal immune responses to milk, soy and wheat than typically-developing children.

New research is being conducted to determine why this diet may help decrease symptoms of autism spectrum disorders, and may include gluten sensitivity, food allergy, or underlying hyperpermeability of the GI tract. According to one theory, children with autism process peptides and proteins in foods containing gluten and casein differently than other people do. This difference in processing may exacerbate autistic disorder symptoms.

Before you consider changing your child's diet, consult with your pediatrician. Medical tests can determine if your child has a sensitivity or allergy to gluten, casein, soy and other foods. You will also want to make sure you are meeting all of your child's nutritional requirements.

Chapter 14
Bullying

Bullying is far too prevalent in our society, and sadly, children with autism spectrum disorders are far more likely than their neurotypical peers to experience it in their lifetime. For example, one study reported that 60 percent of students with disabilities report being bullied regularly compared with 25 percent of all students.

Like any other child, a child with a disability who is bullied may grow angry, resentful, frightened, or apathetic at school, and is at risk for low self-esteem, school avoidance, depression, lower grades, and increased violence.

A recent study surveyed families with autistic and non-autistic siblings from all over the country. Almost two-thirds of autistic children had been bullied at some point, and they were three times more likely than neurotypical kids to have been bullied in the past three months.

Results from this survey indicate that the most common types of bullying are verbal or psychological in nature. However, almost a third of autistic children in this survey also experienced physical bullying.

More disturbing was the fact that over half of the autistic children surveyed had experienced intentional triggering of meltdowns or had been provoked into fighting back. Some particularly cruel bullies find it funny to provoke autistic children who may be more prone to crying or emotional reactions.

Conversely, children with autism are more likely to bully others. Many of these children may be both bully and victim. Some children with autism spectrum disorders may bully unintentionally, as their social skills are less advanced and social cues are often missed on them.

All the hard work that parents, therapists and schools put into helping kids with autism gain social skills and emotional coping skills can be undone by bullying.

Parents need to know that special needs children have resources at their disposal to help with bullying situations. An Individualized Education Program (IEP) is one such resource. The IEP can be a helpful tool in a bullying prevention plan. Every child receiving special education is entitled to a free, appropriate, public education and bullying can absolutely become an obstacle to that education. A child's parents and IEP team members, should work together to make the IEP reflect the child's unique needs in school, including the need to be safe from bullying.

The IEP team can help identify strategies that can be written into the IEP to help stop the bullying. The team may identify an adult in the school whom the child can report to or go to for assistance, and they may determine a process for how school staff will document, report and respond to incidents. Depending on the situation and severity of bullying, shadowing by a school staff member of the student who has been bullied may be appropriate.

Parents need to contact school staff each time they become aware that their child has been bullied. Template letters are available that parents may use as guides for letter writing to school officials. Make sure to document these bullying incidents that you are aware of, and keep copies of the letters you send to your child's school.

Do your homework and know your rights. For example, if bullying is based on a child's disability, it may violate that child's federal rights under Section 504 of the Rehabilitation Act of 1973, Title II of the Americans with Disabilities Act, and the Individuals with Disabilities Education Act.

Specialized peer group programs can be extremely beneficial in a school setting. One parent for example, worked with her child's school to have a group of her son's classmates receive training on how to prevent bullying and speak out on her son's behalf. They called these students peer advocates. If they see bullying, they are to either intervene, ask the bully to stop, or report the situation to an adult.

Parents should remember that 50 percent of bullying situations stop when a peer intervenes. Do not underestimate the power of positive peer advocacy, and do not hesitate to ask your school for help in creating a network of “upstanders” who will not stand by and watch your child get bullied.

Any child can be a target of bullying, but children with disabilities, such as those with autism spectrum disorders, can be especially vulnerable. Parents can take steps to help ensure their child’s safety. Working closely with the school, initiating programs such as a peer advocacy program, using the IEP to their benefit, and knowing the laws that are in place to protect their child are all positive and critical components of anti-bullying efforts.

Section 4
Education and Therapy

"I cannot emphasize enough the importance of a good teacher."
-Temple Grandin

Chapter 15
School and Teaching Techniques

The major treatment for autism spectrum disorders is early and ongoing educational intervention.

The "spirit" of education laws that apply to disabled children is that each child should be educated as an individual. This is a good thing for children with Autism Spectrum Disorders in particular. They need individual treatment because they can range from highly gifted students who excel in academics to children with a variety of learning disabilities and comorbidities like Oppositional Defiant Disorder. The majority usually fall somewhere between the two extremes.

From birth to age three years, federal laws require that disabled children receive early intervention services. These may be speech and language therapy, nutritional counseling, vision and medical services, parental counseling and so forth. Often, a teacher comes to the child's home and works with her one-on-one, although some children receive services in public school classrooms or clinical settings. Children with Asperger’s syndrome often do not receive a diagnosis until after they enter school so they tend to miss Early Intervention programs.

Once a child enters school, parents can require a free evaluation and assessment by a multidisciplinary team. If the team determines the child does not require special education, parents have the right to appeal the decision and get another free evaluation.

If the school determines that the child needs special education, parents should find out what is available at that school and in that district. Services can be speech and language therapy, occupational and physical therapy, counseling, vocational education, and assistive technology like special computer software.

Your child with autism is legally entitled to a Free and Appropriate Public Education (FAPE), in the Least Restrictive Environment (LRE.) This means that your child must receive the right supports to be at least moderately successful in as typical a setting as he can handle.

Public schools are required to provide education to children with autism spectrum disorders, and most of these children do attend public school. Depending on your child's needs and abilities, as well as the abilities of your public school, your child will most likely end up in one of these settings:

- Typical public school classroom without special support (mainstreaming)
- Typical public school classroom with support (1:1 ratio and/or adaptations)
- Part-time typical classroom, part-time special needs classroom
- General special needs class
- Specialized public autism class with some mainstreaming
- Specialized public autism without mainstreaming

Public schools generally look at diagnostic criteria that include impairments in communication, difficulty with some social interactions, restrictive areas of interest, sensory oversensitivity, and a consistency in these characteristics over time and in intensity. In the public schools, once students are found eligible for Autism Spectrum support, most get on an Individualized Education Plan (IEP) and are given a case manager. The case manager then becomes their advocate and a voice for them in the school system.

Under IDEA, the Individuals With Disabilities Act, parents and school staff meet together at the beginning of the school year and come up with an "Individualized Education Plan (IEP)." The plan must be written, and include an assessment of the child's current strengths and weaknesses. The IEP must contain measurable goals for the year and list specific special education aids and services. Parents and staff meet periodically to make sure the goals are attained. There should be an IEP case manager who checks the child's work every day and develops new strategies. Most IEPs have contingencies such as allowing extra time for work, giving out shorter or alternate work assignments, providing the child with copies of other students' notes, allowing the child to take tests over or have extra time for them, or allowing the child to take oral instead of written tests.

The success of any program rests on its ability to tailor interventions to meet a child's specific needs. Programs will vary for children in the same classroom, depending on developmental levels, symptoms, medical conditions, response to the program, and parental ability to continue work at home. Programs need to review a child's treatment plan regularly to allow for adjustments according to the child's response and development.

Schools are increasingly using programs that systematically evaluate the child's behavior and identify interventions tailored to each child. This approach is often called applied behavioral analysis (ABA). ABA therapy is based on the concept that when individuals are rewarded for a behavior, they are likely to repeat that behavior.

In conjunction with school education, the first step of ABA is an initial assessment of the child, in which skill needs and strengths are identified. The next step is determining appropriate educational and treatment goals for the child, based on the initial assessment. Each large goal is broken down into the many individual skills needed to achieve the goal. These individual goals are arranged in a step-like manner, to facilitate successful skill building. In the end, a program is developed that addresses many areas of the child's functioning, such as academics, communication, imaginative play, social activities and motor abilities.

Your school can be providing a myriad of interventions, approaches, and programs, but the truth of the matter is that your child's physical placement, teachers and therapists will define his public school experience. A program is only as good as the teacher that implements it effectively with care and compassion.

Chapter 16
What Your Child's Teacher Needs to Know

Your child's teacher can be a great ally in making sure your child is safe and successful in school. The more communication you as parents have with the teacher, the more likely your child will be to succeed in her class.

Make sure that your child's teacher has the knowledge she needs in order to best work with your child.

Your child's teacher will benefit from knowing the following:

- Your child likely needs structure and routine in order to function to the best of his ability. Let her know what his specific routine is so there are no questions or doubts, and encourage her to help you keep your child's routine as predictable as possible.
- When there will be changes to the classroom routine or environment, encourage her to let you know as far in advance as possible, so that the child can be the most effectively prepared.
- Be specific with the teacher about what your child's social difficulties are. If he has a hard time with social cues, nonverbal communication, figurative language or eye contact, let her know so that she more fully understands your child.
- Let her know that you wish to have open lines of communication and that she should not hesitate to contact you with any issues, questions or concerns. When all the adults in a child's life work together, everyone benefits.
- Let her know how your child's disability may manifest itself in her classroom. Give her a description of his specific disorder, let her know what to be aware of so that she can best work with your child and understand his unique needs, strengths and weaknesses.

Chapter 17
Preparing for a Successful IEP Meeting

If you have a special needs child, you are quite familiar with the term IEP (Individualized Education Program), and with the IEP meeting. These meetings take place at least once a school year, and many parents face them with dread and apprehension. This meeting can be intimidating, as the parent has a crucial role as advocate for their child.

If you have gotten to the IEP process, then it has already been determined that your child has a disability and that he or she requires special education and related services.

The IEP itself is a written document developed by the child's "team" of parents and professionals. The plan is to describe how the student learns, how the student best demonstrates that learning, and what teachers and service providers will do to help the student toward better academic achievement.

Parents will want to prepare themselves to the best of their ability to ensure the most productive and successful meeting possible. The child's team convenes at the IEP meeting. This team consists of parents, teachers, therapists, school administrators and any other invited parties.

Some strategies for success that parents may want to employ in preparation for an IEP meeting may include:

- Review current IEP, if there is one, and review what has been successful and what has not.
- Think back to the previous IEP meeting and take note of what part of the discussion you felt least prepared for, so that you can prepare more thoroughly this time.
- Make sure you are familiar with the rules, regulations and laws that apply to your child's special education program - know your rights.

- Update your notebook! You will want to have a single binder or notebook with all of your child’s information organized and readily accessible. This is an incredibly important resource, one which you will not want to attend the meeting without.
- Do your homework. Obtain and study all school records, research any new information on your child’s disability, get any updates from your child’s health professionals, etc.
- Come prepared with a list of your child’s current level of functioning in all areas.
- Prepare a list of the issues you feel need to be addressed so that you don’t forget anything important, and prioritize issues that are negotiable and those that are non-negotiable to you.
- Make sure you bring the right someone with you. These meetings are anxiety provoking for parents and having someone else who can listen and help take notes and who is a source of comfort to you can be extremely beneficial.
- Don’t be afraid to ask as many questions as you need to, and don’t be afraid to calmly and assertively state your views.
- Consider making a “cheat sheet” for your child’s teachers. A brief description of your child’s disability and how it may manifest itself in their classroom may prove to be a valuable tool.

As your child gets older, you may want to consider his or her participation in these meetings. If your child will be able to self-advocate, help him learn to advocate for himself as early as possible. Observing your advocacy skills will help him learn by imitation. Teach your child to communicate how he learns best and what his needs are. By doing so, you are giving him important life skills and the power to help him succeed.

Navigating the special education system is not easy, and parents have to be vigilant in continuously advocating for their children. You are going to invest a lot of time in the process – as well as blood, sweat and tears – but always remember that you know your child and their special needs best and that you are their best advocate.

Chapter 18

Social Skills

Social issues are a huge factor in the comfort level and satisfaction of all students at school, and in particular for students with autism spectrum disorders because socializing can be a more difficult, and painful, task for them. Many of the stresses autistic students face involve their inability to read social cues as well as other students do; and consequently, they make social mistakes and are often bullied.

General characteristics of social impairment associated with autism spectrum disorders are poor eye contact, a lack of interest in initiating social interactions, a lack of understanding of emotions and how they are expressed and a literal interpretation of nonliteral language such as figures of speech, metaphors and sarcasm.

Social skills training needs vary at different developmental stages. A very young child will need help with basic social rules such as sharing toys, while an adolescent may need help with making friends and navigating dating situations.

Social skills training can be a challenge, but several approaches can work well, including teaching problem-solving methods, weekly social skills training sessions, and video-taping students and letting them see themselves, so that they can gradually make adjustments to their social behavior.

It's critical that caregivers and educators make a concerted effort to teach social skills to children with ASD despite the challenges. Without these skills they may find it impossible to interact with peers one-to-one, or in an informal group. Rather than eagerly anticipating unstructured play periods like other children, they might dread them. They might become anxious and depressed, and might purposefully avoid the very social situations in which they need to become competent.

Teaching social skills to children with autism is a continuously evolving area in behavioral treatment. The Journal of Applied Behavior Analysis frequently includes articles discussing the teaching of interactive play skills, the development of creativity and spontaneity and the development of conversational skills.

In this ever-emerging field of social skills training, a wide variety of interventions are used. Computer technology and special software teach recognition of emotions in facial expressions and tone of voice. Social skills groups are valuable tools and offer opportunities for individuals with autism spectrum disorders to practice skills with one another. Social scripts help provide prompts using scripted phrases or questions.

Research does indicate that there is a need to foster self-awareness and self –esteem as a part of social skills interventions, as these are linked to social motivation and social awareness, in addition to mental health.

Chapter 19
Advocating For Your ASD Child

Friends and family of children with ASD position are involved with children who cannot fend for themselves: children who need advocates to stand up for them. A child's call for help means that they can no longer be "ordinary people" without a choice to make. If they choose to advocate, it means taking on a job that will deeply affect their lives. The task of advocacy takes many forms on the individual to community to societal levels. As one advocate wrote, advocacy can range from "asking a neighbor to turn down a radio to demanding a full-time specialist to help your child in school" to lobbying Washington for more effective services.

Advocacy on the everyday level is often about simply educating people about ASD, a disorder most people have never heard of and may not understand. It is explaining the same things over and over every time a new person enters your child's life. Jonathan is not being willful, selfish and disobedient: these behaviors are a result of his disorder. Sarah wants to make friends with you, she just does not know how. Yes, Taylor is very bright and academically gifted, but he really does need special services at school.

Advocacy can be about always having playgroup at your house so that your child has friends. It can be setting up your home with attractive toys and playground equipment so that other children will want to come over and play with your child. Advocacy on the everyday level can be about not allowing other children to bully your child, even if it means going to PTA meetings and setting up an anti-bullying program at your child's school. It can be a brother or sister standing up for a sibling with patient explanations when others make fun of him.

Some parents find that they have to become an advocate among medical professionals. They work to promote earlier and better diagnosis, treatment and understanding of individuals with autistic spectrum disorders.

Parents of children with ASD also find themselves in the role as their child's advocate in the public school systems. Since special education laws are designed to educate each handicapped child as an individual, parents (as their child's representative) meet with school staff every year to develop an Individual Education Plan for the child. However, they must work through disability laws, not specific autism laws.

Parents often know more about the syndrome than school staff; they certainly come to IEP meetings with superior knowledge about their individual child. Yet parents often meet with resistance when they ask for services for their child. Unless parents have specific knowledge of federal, state and local laws and unless they understand what services are available in their district, they cannot be effective advocates. The school districts officials do not necessarily volunteer such help and information. Usually if parents do not ask for services such as instruction during summer sessions, early childhood intervention, speech therapy, transportation and the like, their child will not receive them. As unfair as it seems, the burden of advocacy is on the parents.

Local chapters of groups such as the Autism Society can provide invaluable help to parents. Some chapters have 24-hour hotlines so you can discuss any problem even as it occurs. Some offer free libraries and/or social programs for families and educational services such as lectures and classes. Some chapters offer unusual options such as sex education classes for children within the autism spectrum.

On a national level, advocacy groups lobby legislatures for more favorable laws for children under the autism spectrum. They operate websites that disseminate information on the latest academic studies, medical breakthroughs and new techniques for helping these children. They raise money for research and public education.

As your child gets older, depending on his abilities, you will want him to start learning to advocate for himself. This concept of self-advocacy is an important one, and the more effectively you can teach your child this skill, the more successful he will be. Being able to express his own needs will make him feel more confident and more understood.

Get your child involved in his IEP meetings if possible and appropriate. The process of teaching self-advocacy ideally could begin before age 14 when transition planning for life after high school is mandated into the IEP. Providing students with a well-developed sense of self-advocacy through participation in the IEP process should be an integral part of education. Doing so is vital for gaining a greater understanding of how to obtain the required accommodations upon entering the community, in higher education, employment, and relationships through adolescence and into adulthood.

Chapter 20
Therapy Programs

Numerous therapies are used in the treatment of autism spectrum disorders. A wide range of therapy options exists and some are obviously more appropriate for some children than they are for others.

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Equine therapy is one form of experiential treatment used effectively with autistic children and adolescents. Participants are able to address developmental, personal and social needs through a somatically engaging, challenging and enjoyable activity. It has the potential to reawaken the unconscious to the emotional channels of affective empathy with others that seem to be partly or entirely dormant in a person with ASD. Equine therapy has the potential to provide a mind-shaping experience in non-verbal communication for autistic adolescents and young adults.

The experiential treatment benefits of equine therapy are many. A mounted equine experience can influence the development of self-identity and there is an emphasis on touch and rhythm as part of the therapeutic process. The horse, functioning as a co-therapist, provides a living foundation for the participant's growth and development. As a vehicle of experiential treatment, the horse offers immediate, unbiased and nonverbal feedback. Working as a partner with a horse, allows the human therapist a chance to model safe, respectful, firm and consistent limit setting.

The experience of an equine group therapy session requires communication, teamwork and trust – not only trust in the horse, but in the therapist, support staff, peers and in themselves. Developing a relationship with the horse helps teach caring and empathy. In fact, children who seldom express physical affection with humans are often observed hugging and kissing the horses.

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Wilderness therapy is another option and one that has proven to be particularly beneficial to Asperger's syndrome adolescents and teens. In the unique environment of a therapeutic wilderness program, there is the opportunity to be creative and flexible in combining typical interventions as well as incorporating some new ones.

Wilderness therapy programs provide low staff-to-student ratios, constant interventions to help your teen learn to better tolerate stress and frustration and social skills education.

One therapeutic wilderness therapy method often employed is Dialectical Behavior Therapy. Dialectical Behavior Therapy can help teens with Asperger's syndrome learn to model social behaviors, regulate emotions, and tolerate stress.

The teen develops a system of self-balance that allows him or her to accept his/her own decision-making process at any given moment. Often teens with Asperger Syndrome who have used Dialectical Behavior Technique increase their social well-being and decrease their anxiety levels because they learn more appropriate peer interactions.

ASD children need to experience successes –successes in achievement and successes both socially and emotionally. Wilderness therapy provides opportunities for all of the above. A therapeutic wilderness program typically has a small staff to student ratio, an experiential nature, a positive peer culture model, an individualized approach and knowledgeable and trained staff.

The structured setting of a therapeutic wilderness program offers an emotionally safe environment in which social and emotional development can occur. Using nature, a positive community and support system and some degree of challenge can make wilderness therapy highly successful for adolescents with autism spectrum disorders.

Some wilderness therapy programs also offer aftercare support programs. The camp staff work with parents and family members to help students retain the new skills they have gained.

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Assistance dogs are yet another possible form of therapy and support for your ASD child.

To a family with an autistic child, the addition of a specially trained service dog may provide the sense of calm, security and peace of mind that will greatly improve their overall quality of life.

Specially trained dogs are taught specifically to handle the challenges of autism spectrum disorders. These dogs provide a wide range of benefits, such as:

- Serving as a “social bridge” for children – helping them interact socially
- Providing safety and security
- Physically interrupting “stimming” behaviors (spinning, shouting, hitting, arm flapping)
- Alerting parents of potentially dangerous nighttime situations
- Providing improved sleeping habits and reducing stress associated with insomnia or night waking
- Preventing bolting or running away when tethered to the child
- Providing a calming presence to both child and family

Parents whose children are provided with service dogs report decreases in their child’s tantrums and other disruptive behaviors, as well as improvements in their performance of daily routines and participations in social interaction.

On the whole, these dogs reduce emotional agitation and give children a sense of pride and purpose. Canine companions aid autistic children with everyday social challenges and help lower overall stress levels. They bring confidence and calmness and can help children gain success and independence.

Appendix
XXX Programs for Autistic Children

Talisman Academy – Located in Hendersonville, in the beautiful mountains of Western North Carolina, Talisman Academy is a residential academic alternative for adolescents and young adults ages 12 to 20 with Asperger's Syndrome, High-Functioning Autism, and similar spectrum disorders. We focus on improving social awareness and interaction, independence, and academic self-motivation. The academic program is a journey that enables students - who may have struggled in more traditional environments - to seek social confidence and their full potential for life success. For over 30 years Talisman programs have provided life and learning experiences for children with ADHD, Asperger's Syndrome, and other learning disorders. Talisman programs offer students opportunities to develop physical and social competence in an atmosphere that encourages and supports self-regulation and self-direction.

For more information about Talisman Academy visit http://www.aspergersboardingschools.com/ or call (888) 458-8226.

Camp Huntington - Located in High Falls, New York within the Catskill Mountain region, Camp Huntington is a co-ed, residential program for children and young adults with special learning and developmental needs. Our program is designed to maximize a child's potential, locate and develop strengths and hidden abilities. We serve children and young adults with learning and developmental disabilities, ADD/ADHD, Autism Spectrum Disorders, Asperger's syndrome, PDD and other special needs. Your child will enjoy the fun-filled days of summer camp while learning practical social and life skills. We offer a unique program approach of adaptive therapeutic recreation, which combines key elements that encourage progress: structured programming, nurturing care, a positive setting, and academic instruction to meet IEP goals.

For more information about Camp Huntington visit http://www.camphuntington.com/ or call (866) 514-5281