Source: *The Asperger's C-o-n-n-e-c-t-i-o-n*
http://www.theaspergersconnection.org/courses/esimplications/introduction.html
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Asperger's Syndrome: Emotional and Social Implications

Mark was by all accounts a very unusual child. He was clearly extremely bright, with a phenomenal memory. Although gifted in math and science, his grades did not always reflect this fact, apparently because he had a tendency to day-dream. Two things were quite striking about him: first of all, he seemed to know everything there was to know about vacuum cleaners, including their makes, models and mechanics, and secondly, he would approach total strangers, as well as family and acquaintances, to talk relentlessly about his area of interest.

Family members and teachers were understandably perplexed about this odd child. How can we best understand his unusual qualities?

Asperger’s Syndrome!

This mini-course covers the social implications of Asperger’s Syndrome, as well as the emotional difficulties that frequently occur with this diagnosis. The impact on family life is addressed, along with suggestions for working with those with Asperger’s.

Lesson One: Introduction

What is Asperger's Syndrome?

In the Diagnostic and Statistical Manual IV (DSM IV) there is a category entitled "Pervasive Developmental Disorders". Asperger's Disorder (or Syndrome) is one of the five diagnoses under this umbrella heading. Although not stated in the DSM IV, many clinicians use the term "Autism Spectrum Disorder" (ASD) to describe a continuum of related disorders, including autism, Pervasive Developmental Disorder Not Otherwise Specified (PDD NOS), and Asperger's Disorder. Most clinicians feel Asperger's is at the high end of a rather long continuum. It is important to bear in mind that while individuals on the spectrum share certain characteristics, they may look very different from one another. Therefore, the diagnosis of ASD is considered to be a heterogeneous one.

What difficulties do people with ASD share?

There are three main categories of difficulties people on the spectrum have in common. These difficulties are:

1. Impairment is social interaction
2. Impairment in communication
3. Restricted and/or repetitive patterns of behavior, interests and activities.

This course addresses these three categories, with specific attention to the social implications involved.

What is the difference between Asperger's Syndrome and autism?

At this point in time, there does not seem to be a consensus regarding the distinction between Asperger's Syndrome and autism. There does seem to be agreement that people with Asperger's, like those with autism, share difficulties in the three areas mentioned above. There is less agreement about what distinguishes one diagnosis from the other. According to the definition used in the DSM IV, in Asperger's, there can be no delay in the development of language. In other words, although language is disordered, words, phrases, and sentences came in at the expected time. However, Tony Attwood, in his book, Asperger's Syndrome: A Guide for Parents and Professionals[2], has a somewhat different view. He states, "Research suggests almost 50 per cent of children with Asperger's Syndrome are late in their development of speech, but they are usually talking fluently by the age of five." Similarly, Peter Tanguey believes the definition of Asperger's in the DSM IV does not cover enough people, since many, if not most of these children had delays in language development. [24] Another distinction has to do with cognition. In autism, there is an enormous range of intellectual functioning. In Asperger's, cognition is normal, and often gifted in certain areas. Lastly, some clinicians believe that the difficulties with social relatedness are more severely impaired in autism than in Asperger's Syndrome.

Individual Issues

Lesson Two: Impairment in Social Interaction

1. Difficulty Using Non-Verbal Behaviors in Social Interaction

There are several broad categories of difficulties falling under the general heading of impairment in social interaction. First of all, people with Asperger's have difficulty using non-verbal behaviors in social interaction.

Eye contact may be impaired, meaning that the individual may not look at others upon greeting or during conversations and may not respond when others try to catch his/her eye.

It is easy to see why others might inaccurately perceive the individual to be rude or not paying attention.

Social smiling may be impaired. In this case, people with Asperger's may not smile back at someone smiling at them, may not smile during greeting or may not smile in response to something someone else said.

Facial expressions used to communicate may be odd. Sometimes the expressions are limited or flat, sometimes they are inappropriate and at other times are exaggerated.

Again, it is easy to see why others might misread what the individual with Asperger's is thinking or feeling. For example, John, a rather sweet and kind child, broke out into laughter when his brother injured himself. Clearly, his response was inappropriate to the situation and would not be expected from a child his age. Similarly, Nathan, upon learning that a family friend would be arriving for a visit, let out an excited cry, as if this were the most wonderful and extraordinary event that could possibly happen.

Body postures regulating social interaction may be affected. A very common example of this difficulty is that those with Asperger's may not know how to judge social distance and may stand too close.

2. Difficulty Forming Peer Relationships

The second category of difficulties falling under the heading of impairment in social interaction is difficulty forming peer relationships.

Some children with Asperger's seem to **lack interest in others** and may prefer solitary activities. Martin, age 6, was very skilled at building with blocks and Legos. However, when another child would approach to try to join his play, he would become extremely angry, not wanting his play to be disturbed.

Inappropriate overtures towards others or inappropriate responses to the approaches of other people are common occurrences. James, age 5, was fascinated with his next-door neighbor, Ben, a toddler of 18 months. Unfortunately, his way of showing his interest in Ben was hitting him over the head. Another child with Asperger's, Bobby, was somewhat more sophisticated in his technique: his way of showing his interest was throwing his arms around another child in a bear hug.

Difficulty forming friendships is a common fact of life for children with Asperger's. Interestingly, what these children mean by friendship may be decidedly different from what their typically developing peers mean. For example, Nick repeatedly referred to another child in his school, Tom, as his best friend, although no one had observed the two boys talking or playing together. When asked what makes them friends, Nick replied that Tom said hello to him.

Impairment in group play with peers is another common difficulty. Unfortunately, most of the team sports so common to school-age children are terribly difficult for children with Asperger's. Their troubles with social interaction and peer relationships make organized group sports a real challenge. Oftentimes, sports in which individual achievement is stressed (e.g., track, archery, fishing) are more successful.

3. Difficulty in Sharing Enjoyment

The third area of impairment in this section is difficulty sharing enjoyment. Young children with Asperger's are less likely than their typical peers to share objects, such as food or toys, with others. Individuals with Asperger's are not as likely to show other people items in which they are interested. Lastly, they generally make more limited efforts to share feelings of enjoyment with others.

4. Lack of Social or Emotional Reciprocity

The fourth kind of social interaction impairment is a lack of social or emotional reciprocity. This area includes such difficulties as **inappropriate or limited responses to the approaches of others**, as well as **limited offers of comfort** shown towards others.

For example, Max enjoyed going to the supermarket with his mother. He liked to help prepare the shopping list, easily located the items on the shelves, loved to sample the free food often available, and calculated the correct change while in the check-out line. However, when the cashier spoke to him and tried to make small talk, he generally did not look at her, did not answer her questions, and sometimes made a remark completely off the topic, but one that was of interest to him.

Similarly, Bob was walking outside with his mother on a cold winter day, when his mother slipped and fell on the ice. Bob clearly was aware something was not quite right, as he immediately began to scream. What he did not do was ask his mother if she were okay, and offer to help her, as a typical child his age probably would have done.

Lesson Three: Impairment in Communication

This lesson focuses specifically on the social implications of communication difficulties in individuals with Asperger's.

Inappropriate Questions/Comments

The uttering of inappropriate comments or questions can be a serious problem. Sometimes the remarks are inappropriate to the setting. Sometimes the comments are sexually inappropriate. In any case, the remarks or questions do not take into account the impact on the other person involved. For example, Alex was attending a funeral. Oblivious to the impact his question would have on the grieving friends and relatives, he wondered out loud about the process of bodies decomposing. In another example, Michael found himself attracted to a young woman and proceeded to stare at her. When she asked him what he wanted, he told her in sexually explicit details what he was staring at and the specific nature of his interest.

Lack of Symbolic Play

For most children, play is a crucial area of communication and development. Children with Asperger's generally display problems with imaginative or symbolic play. In autism, there is sometimes a lack of symbolic play. Some autistic children do play imaginatively for brief periods of time, but unlike their typically developing peers, they usually cannot sustain and elaborate on the play. In Asperger's, there may be rather elaborate imaginative play, especially in girls. According to Tony Attwood, "Girls with Asperger's Syndrome can create imaginary friends and elaborate doll play which superficially resembles the play of other girls but there can be several qualitative differences. They often lack reciprocity in their natural social play and can be too controlling when playing with their peers... While the special interest in collecting and playing with dolls can be assumed to be an age appropriate activity and not indicative of psychopathology, the dominance and intensity of the interest is unusual. Playing with and talking to imaginary friends and dolls can also continue into the teenage years when the person would have been expected to mature beyond such play."[3]

Some clinicians consider play of paramount importance to the development of the child. Stanley Greenspan, M.D.[9] has developed a treatment technique which he terms "Floor Time." In this approach Greenspan utilizes play to "open and close circles of communication". For example, when one person makes a communicative overture, the expectation is that the other person will respond to this overture in a reciprocal way. He believes play is critical not only for the development of social interaction, but also for the development of logical, flexible and creative thinking.

Literal Thinking

In addition to problems with imaginative play, individuals with Asperger's have a tendency to think in a literal way. Parents and teachers are sometimes astonished to learn

how a child with Asperger's has misunderstood a commonly used term or expression. Idioms are particularly problematic. Individuals with Asperger's often have great difficulty with metaphors and with information that is implied but not stated directly. On occasion, the child's misperception becomes apparent, as in the following examples.

> Edward was told by the staff in his group home that wake-up on weekends was 10:00 a.m. Staff were surprised to see that he was lying in bed awake for hours on week-end mornings. When asked about it, he replied that he was not allowed to get out of bed until 10:00, rather than understanding that he could stay in bed as late as 10:00 if he chose to do so.

Similarly, the same child was told by his mother to put on his winter jacket. He found two winter jackets hanging on the banister, but told his mother he did not know which one was his. To her surprise, he said he could not tell which one to wear because they both had a name-tag with his name on it. In fact, he had been wearing one of the jackets all winter; he had outgrown the other one, but his mother had failed to remove his name from inside.

"Theory of Mind"

In addition to the problems in communication mentioned above, individuals with Asperger's may have trouble with a concept referred to as "theory of mind". Briefly, this notion, first described by Simon Baron-Cohen[4], refers to difficulty in perspective taking. An example of this difficulty is that individuals with Asperger 's may assume other people have the same knowledge as they do, even when there is no basis for this assumption.

For example, Nick was very interested in movies, frequently talking about the latest movies he had seen. He would discuss the content of movies with anyone who would listen, not recognizing that they could not possibly know what he was referring to, since they had not seen the movie under discussion.

A related matter is the inability many with Asperger's have to recognize how other people are perceiving them. This difficulty contributes to a lack of shame or embarrassment about their behavior.

Can you think of a character who has difficulties with social interaction and communication? What about Data on Star Trek?

The following Star Trek episodes illustrate the difficulties Data has with understanding humor and dealing with the complexity of romantic relationships.

"In Theory" http://stng.36el.com/st-tng/episodes/199.html

"The Outrageous Okona" http://stng.36el.com/st-tng/episodes/130.html

Lesson Four: Restricted and/or Repetitive Patterns of Behavior, Interests and Activities

Preoccupation Unusual in Intensity or Focus

Many people with Asperger's have a preoccupation that is unusual in intensity or focus. They may talk relentlessly about their particular area of fascination, completely unaware of their listener's fading interest. According to Tony Attwood[3], "The most popular special interests of boys with Asperger's Syndrome are types of transport, specialist areas of science and electronics, particularly computers...

Girls with Asperger's Syndrome can be interested in the same topics but clinical experience suggests their special interest can be animals and classic literature." Other common areas of interest are schedules and statistical information, as described in the following examples.

> Daniel went through phases of being intensely preoccupied with different odd interests. One of his first preoccupations was peoples' birthdays. In fact, the first question he would ask upon being introduced to someone was the date of his or her birthday. He had an impressive memory for such information, storing the birth dates of dozens of people he had met. The preoccupation with birthdays seemed to give way after a couple of years to an interest in the hours stores open and close. He would walk down the street, paying close attention if a store's hours were posted out front. Again, he had an incredible memory for such information, which, his mother joked, had a certain usefulness as far as she was concerned. Daniel's next fascination concerned movies. He was not particularly interested in the content of movies or in critiquing them, but rather was preoccupied with the ratings (e.g., G, PG, PG13, R) movies received. Similarly, he liked to create lists of the movies in which his favorite actors and actresses appeared. In addition, he had a unique method of categorizing movies, and was able to rattle off which movies fell under his rather unusual headings (e.g., movies that dealt with the subject of weddings, movies in which horses appeared).

Inflexibility Regarding Routines or Rituals

Of all the impairments common to those with Asperger's, probably the one most likely to cause difficulties for others is inflexibility regarding routines and rituals. This particular difficulty has enormous potential to adversely affect the lives of family and friends as shown in the following example.

> Evan firmly believed that he must watch certain television programs, especially particular game shows. One day a show that he always watched at a particular time was not on; in fact, it was taken off the air several days in a row. This disappointment was apparently more than Evan could bear

> and led to prolonged tantrums. His mother called the television station, inquiring about the status of the show but to her dismay, was informed the show had been cancelled.

In light of the individual with Asperger's difficulties with flexibility, it is helpful for those dealing with him or her to be creative and flexible in their interventions. Certainly, it is important for there to be as much consistency and predictability as possible. If changes are necessary, telling the person in advance, whenever possible, is helpful. Sometimes it is possible to reframe an issue in a different way. For example, Sean was insistent that he eat three meals every day. If the family woke up late and his parents wanted to serve brunch and then dinner, this plan was unacceptable to him. His mother learned that offering him a cracker in the middle of the day and calling it lunch was an acceptable arrangement as far as Sean was concerned.

Another useful technique to consider is to involve the individual with Asperger's in collaborative thinking or negotiation. For an in depth discussion of this approach, the reader is referred to The Explosive Child by Ross Greene, Ph.D[8]. The following interchange is an example of this technique.

Elliot's parents were considering moving him to a new residential home and he was invited to have dinner and meet the staff and students at the new residence. Before returning him to his current placement, his parents' plan was to take him out for dessert while they had dinner. Elliot found this idea unacceptable; in his world, if he were going to be in a restaurant with people eating dinner, he needed to be eating dinner as well (even though he had just had dinner). His response to his parents' disapproval of his plan was to tell them they needed to take him home and then they could go out to dinner by themselves. After explaining to him that this plan did not work for them (logistically, it would have them driving far out of the way), his mother asked him if he had any ideas as to how they might resolve the problem to everyone's satisfaction. Elliot thought a moment and then asked, "Is it okay if I have a piece of bread and a drink?" His mother thought this was a fine idea. Apparently, Elliot considered bread and a drink sufficient to meet his definition of a meal. If his mother had not involved him in the discussion, they would never have been able to come to this resolution.

Stereotyped and Repetitive Motor Mannerisms

An additional category under the heading of restricted and/or repetitive patterns of behavior, interests and activities is that of stereotyped and repetitive motor mannerisms. There are a number of mannerisms in which the individual with Asperger's may engage. These mannerisms include hand or finger flapping, rocking, or complex whole body movements such as spinning or jumping. These behaviors differ from tics in that they are voluntary movements in the motor sense; voluntary in this case does not imply that they are easily stopped. In fact, there is considerable support for the notion that these movements have a calming or regulatory effect on the nervous system. An unfortunate consequence is that these behaviors call attention to the oddness of the individual, often resulting in teasing or ostracism.

Lesson Five: Additional Characteristics Sometimes Present

Aggression

Aggression may occur against others or against the self (in which case it is often called self-injurious behavior or SIB). Some children, when extremely agitated, may lash out physically at others by hitting, kicking or biting. Other children, more prone to SIB, may do such things as head bang or bite their hands.

Sensory Difficulties

Many people with autism and Asperger's Syndrome have unusual reactions to sensory experiences, i.e., experiences related to the senses of touch, hearing, vision, smell, and taste. According to Bernard Rimland[22], "About 40 per cent of children with autism have some abnormality of sensory sensitivity." Tony Attwood has concluded that, "There is now evidence to suggest that the incidence may be the same for Asperger's Syndrome."[2] The senses of touch and hearing are most commonly affected; certain kinds of touch, especially light pressure, and certain sounds may be experienced as intolerable. This difficulty is known as sensory defensiveness. Interestingly, while people with autism and Asperger's Syndrome are usually hypersensitive to sensory input, at other times they may be under-reactive, particularly to pain and changes in temperature. It is not uncommon for over-reactivity and under-reactivity to co-exist in the same individual. The following examples illustrate these points.

One youngster became so agitated by the sound of the vacuum (over-reactive) that every time the house cleaners arrived, he attempted to push them out the door. Some people react to sounds others do not even perceive to be present (over-reactive); a common example of this is fluorescent lights which many individuals with Asperger's find extremely disturbing. Children have been known to sleep between the mattress and the box-spring (under-reactive), apparently craving the sensory input.

A number of adults with autism or Asperger's who speak and write about the nature of their own experience stress the overwhelming importance of sensory issues to their functioning. Temple Grandin, arguably the most famous person with autism in the world, holds a doctorate in animal studies and teaches at Colorado State University. She has developed a "squeeze machine", a kind of holding device that allows her to control the amount of pressure exerted on her body. She talks about the calming effect this device has on her when she feels stressed. [7]

Similarly, many children with autism spectrum disorder crave swinging, apparently finding it soothing and organizing to their nervous systems.

Certain clinicians, for example, Stanley Greenspan, M.D., consider sensory difficulties of overriding importance in developmental disorders and believe a number of the symptoms occur in response to the underlying sensory issues. [9] For example, it is no wonder a

young child withdraws if he is overwhelmed by the touch of his parents or if he finds loud noises unbearable.

Attentional Difficulties

There are several different kinds of attention, some of which tend to be impaired in individuals with Asperger's or autism. In particular, there are often problems with shifting attention, the ability to shift attention in a flexible way from one subject to another. According to Judith M. Rumsey, "Autistic children may engage in over-focused, repetitive play for lengthy periods of time, underreacting to distractions in the environment... These observations suggest good sustained attention, but deficient flexibility in shifting attention"[23]. Similarly, Hans Asperger referred to the distinction between active and passive (distractibility from outside) attention. In autism spectrum disorder, the problem tends to be more one of active attention. Asperger states, "Autistic children...are not interested in directing their attention to outside stimuli... They follow their own ideas, which are mostly far removed from ordinary concerns, and do not like to be distracted from their thoughts"[1]. A related matter is that of relevance, the ability to judge where it is important to focus one's attention. Francesca G.E. Happe states, "Autistic individuals are unable to calculate what is relevant in the normal way, hence the observation that the focus of their attention seems peculiar"[10]. Thus, one could say they often cannot see the forest for the trees.

Unfortunately, it is not uncommon for students with Asperger’s to have considerable difficulty with schoolwork and homework, because of their attentional problems. This difficulty often exists despite superior intelligence. In one striking example, Jill, a fifteen year old with Asperger's, had an I.Q. in the superior range, but was failing almost all of her high school subjects. Her difficulties were not due to a lack of effort on her part. Unfortunately, almost every time she sat down to study or write, she became flooded with her own rather unique thoughts.

Sleep Problems

The incidence of sleep difficulties in this population seems to be extremely high. Many parents of children with autism or Asperger’s complain that this problem is one of the most serious they face. Unfortunately, when the children are unable to sleep, they do not usually remain quietly in bed. They are often up and out of bed, making noise, interfering with their parents’sleep and requiring adult supervision.

Lesson Six: Social or Emotional Difficulties Frequently Occurring with the Diagnosis

Hyperactivity

There has recently been considerable interest and research into the possible connection between autism spectrum disorders and Attention Deficit Hyperactivity Disorder (ADHD). This interest includes both the similarities in symptoms as well as genetics. According to Richard Perry[19], hyperactivity, inattentiveness and impulsivity can be present in a number of childhood onset disorders, including ADHD as well as autism spectrum disorders. A recently published book on this subject is The ADHD Autism Connection by Diane M. Kennedy[14]. Tony Attwood has also written on the subject, noting, "Children with Attention Deficit Disorder (ADD) are often considered as having some characteristics indicative of Asperger's Syndrome. Although they are two distinct disorders, they are not mutually exclusive and a child could have both conditions"[3].

One nine year old boy with Asperger's, Jeremy, displayed severe symptoms of hyperactivity. He could barely contain himself when in his therapist's office, preferring to remove all the books from her bookshelf and trying to race down the hallways.

Another possibility is that of misdiagnosis. Richard Perry, in his article entitled "*Misdiagnosed ADD/ADHD; Re-diagnosed PDD"*[19], notes that some children originally diagnosed with Attention Deficit Hyperactivity Disorder (ADHD) have later been re-diagnosed with a diagnosis on the autistic spectrum.

Attwood summarizes the similarities and differences between the two diagnoses in the following way: "Perhaps the central feature of Asperger's Syndrome is the unusual profile of social and emotional behavior... with ADHD, the children tend to know how to play and want to play, but do so badly... children with ADD have a diverse range of linguistic skills and interests, while there is a distinct language and interests profile for those with Asperger's Syndrome. Their interests tend to be idiosyncratic and solitary, in contrast to those children with ADD whose interests are more likely to be conventional for children of that age. Children with both conditions prefer and respond well to routines and predictability, can experience sensory sensitivity and have problems with motor coordination... Both conditions can be associated with impulsivity but this feature tends to be less of an issue with Asperger's Syndrome... The child with ADD has a propensity to have problems with organization skills... With Asperger's Syndrome, the profile includes unusual aspects of organizational skills such as unconventional means of solving problems and inflexibility"[2].

Obsessive-Compulsive Traits

As noted in Lesson Four, inflexibility regarding routines and rituals is a very common characteristic of people with autism and Asperger's Syndrome. In Leo Kanner's writings about autism in 1943, he referred to the child with autism as having an "obsessive insistence on sameness"[13].

While many individuals with autism spectrum disorder display inflexibility and rigidity, sometimes the symptoms are extreme and may warrant an additional diagnosis of Obsessive-compulsive disorder (OCD). According to Luke Tsai, "...it is conceivable that some higher-functioning autistic people's quasi-obsessive behaviors reflect true symptoms of a co-existing OCD"[25]. He describes the case of a woman with Asperger's who needed to check her doors and stove many times a day. Similarly, Tony Attwood describes a man with Asperger's who needed to wash his hands very frequently because he feared contamination by germs[2]. In these two examples, the extreme nature of the symptomatology and the fact that the individuals involved were troubled by their rituals support the diagnosis of OCD.

A commonly asked question is how to make a distinction between obsessive-compulsive symptoms and the unusual preoccupations of many people with Asperger's. In general, people with OCD realize their behavior is odd and are upset by their inability to control their symptoms. Attwood states the special interests of people with Asperger's are "different from a compulsive disorder in that the person really enjoys their interest and does not try to resist it"[2]. As Jane, an adult with Asperger's said, "It's fun!".

There is considerable controversy in the field about whether people with autism or Asperger's who have milder ADHD or OCD symptoms should be diagnosed with multiple disorders. In other words, does the person have Asperger's Disorder with hyperactive traits or is it preferable to diagnose him with Asperger's as well as ADHD? Does he have Asperger's Syndrome with obsessive-compulsive characteristics or Asperger's plus OCD? Some clinicians feel that autism spectrum disorder, including Asperger's Syndrome, is a broad category encompassing a wide variety of symptoms, with some individuals displaying more of some symptoms than others. On the other hand, other clinicians worry that many symptoms which respond well to psychopharmacological treatment may go untreated if not specifically diagnosed.

Anxiety

Anxiety appears to be extremely common among people with autism and Asperger's Syndrome. As one might expect, there are certain situations that typically lead to anxiety in this population. These situations include such things as changes in routine, interference with rituals, things not happening in the expected way, failing at tasks, and sensory overload.

Interestingly, for some people on the spectrum, it is the "little" things which seem to cause the most distress, while more major changes may be experienced with less disruption. Evan, the boy who became overwhelmed with a change in television programming, looked forward with eager anticipation as his family prepared to move to a new house and, in fact, did quite well before, during and after the move.

If anxiety builds up to a critical level in any individual, a tantrum may be the end result. Unfortunately, for a child on the spectrum, a tantrum may be an overwhelming and prolonged event. Furthermore, the techniques often used with typically developing

children may not work and may even prolong the difficulty. Trying to talk the child through the experience or reasoning with him are usually not effective. In addition, after the tantrum has subsided, trying to process with the child what happened and why may even contribute to the return of anxiety as well as the tantrum. Brenda Smith-Myles has referred to this phenomenon as "recycling"[12].

Clearly, it is preferable to be proactive in preventing tantrums whenever possible, rather than trying to stop them once they have begun. In a proactive approach, thought is given beforehand to the kinds of things likely to provoke a tantrum in any particular individual and either trying to avoid them or preparing for them. For example, for a person greatly upset by change, one approach is to try to keep things as consistent and predictable as possible. When changes are unavoidable, if they are known in advance, it is often helpful to prepare the individual for this fact. Another approach is to teach the individual in a gradual, but systematic way, techniques for dealing with the changes and disruptions in life.

In addition to trying to prevent tantrums whenever possible, it is useful to have a plan in place to deal with them should they occur. This approach has more likelihood of success if utilized early in the tantrum; circumventing a tantrum is usually much easier than trying to stop one in full swing. The plan needs to be tailor made to the individual; what works for one person may be quite different from what works for another. It is often useful for teachers to speak to parents about what approaches are helpful in dealing with their children. Undoubtedly, they have had many opportunities to try out different techniques! For some children, removing them from the scene and providing them with "settling"activities may be useful. For example, Frank was often helped by being led to a quiet place where he could look at his calendars and yearbooks. For some children, touch, especially firm pressure, can be a useful technique. On the other hand, for children who are sensory defensive, touch can be too overwhelming. The following example illustrates one approach to containing a tantrum.

Max had been eagerly looking forward to going on the Swan Boats in Boston. One day, his mother planned an outing in which they rode the subway into town, an experience Max loved, and then went on to the boats. Unfortunately, just as they were about to board, the skies opened up in a downpour and the attendant announced the Swan Boats were closing. Max began a full-fledged tantrum, complete with screaming, name-calling and flailing. His mother somehow managed to usher him into the subway station and onto the train, where, naturally, everyone else was also congregating because of the weather! Although the train was extremely crowded, the other passengers gave Max and his mother a wide berth. She sat him down on a seat and knelt before him, placing her face very close to his and cupping his face in her hands. In a soothing voice, she told him repeatedly to look at her and reassured him that he was okay. His sobbing and flailing soon ceased.

Depression

Like anxiety, depression is quite common in people with Asperger's Syndrome. Many individuals develop problems with low self-esteem and depression during adolescence. It is at this time that many become acutely aware of their differences from their peers. Unfortunately, this is also the time in life when fitting in becomes so critical.

Some individuals with Asperger's develop affective disorders, which include true clinical depression and bipolar disorder. There is some data to suggest the incidence of these disorders in Asperger's Syndrome is higher than in the general population. [2] When these disorders do occur, there may be changes in the person's predominant mood or in his view of himself and the world. Vegetative symptoms, e.g., changes in sleep, eating, and activity level, may also occur. Of critical importance is the fact that some individuals with Asperger's and autism display an increase in "autistic" behaviors, for example, stereotyped motor mannerisms, self-injurious behaviors, or aggressiveness, when they become depressed. This fact seems to contribute to the problem of mental illness not being accurately diagnosed in this population, because clinicians sometimes attribute the increased "autistic" symptoms to the autism or Asperger's, rather than to the affective illness. Affective disorders are also more difficult to diagnose in this population because many people with autism spectrum disorders have difficulty communicating their feelings, both in words and in facial expressions. As a general rule of thumb, a significant change from the person's baseline level of functioning should raise questions about the possibility of an additional diagnosis.

In "*Emotional Disturbance and Mental Retardation: Diagnostic Overshadowing*"[21], Steven Reiss, Grant W. Levitan and Joseph Szyszko of the University of Illinois conducted an important study outlining difficulties similar to those described above. They conducted two experiments showing that people with mental retardation were less likely than controls to be diagnosed with emotional disturbances. They coined the term diagnostic overshadowing, meaning that the emotional problems seemed less significant, or were overshadowed in importance, by the presence of mental retardation. Although this study did not include people with autism or Asperger's, it seems highly likely that similar results would occur. The following example illustrates this point.

Tommy, an 8 year old with high functioning autism, was a gentle, rather easy-going youngster and was included in a Montessori classroom. During the fall of 3rd grade, he seemed to become more and more depressed, with increasingly frequent episodes of weeping with no apparent precipitant. His condition continued to deteriorate throughout the fall and by Christmas he required psychiatric hospitalization. By this time, he was weeping almost constantly, had become assaultive, and was trying to escape from his family's home, which was situated near a major highway. In addition, he kept repeating bizarre demands, such as insisting the names of the days of the week be changed to those of the names of the children in his class. After discharge from the hospital, he went to a residential school, where the psychiatrist viewed his symptoms as indicative of his autism. It was not until sometime later that another psychiatrist correctly concluded that Tommy carried the additional diagnosis of bipolar illness.

Family Issues

Lesson Seven: Different Pathways to Diagnosis

There are several different pathways to the diagnosis of Asperger's Syndrome and these are described in detail in Tony Attwood's book, Asperger's Syndrome: A Guide for Parents and Professionals[2]. Some children receive the diagnosis fairly early in life, while some individuals are not diagnosed until well into adulthood. In some cases, children are inaccurately diagnosed with another disorder, (e.g., a language disorder, depression, schizoid personality), and are only later correctly diagnosed with Asperger's. Some children are considered autistic early in life, but progress well enough to ultimately be diagnosed with Asperger's Syndrome.

The impact of the diagnosis of Asperger's Syndrome on a family is no doubt partly related to the manner in which the individual was diagnosed. Families who recognize early on that there is something seriously wrong with their child and are given a diagnosis of autism spectrum disorder (and only later learn their child has Asperger's) will experience many of the reactions families with autistic children have. These reactions are described below. Many families, whose children progress far enough to no longer warrant an autism diagnosis, experience considerable relief and pride in their and their childrens'accomplishments. At the same time, they still struggle with complex feelings related to their child's Asperger's diagnosis. If the diagnosis is made in a parent or other relative when a child in the family receives the diagnosis, a different constellation of feelings is often set into motion. In these families, the adult must grapple not only with the diagnosis of a disability in the child, but with coming to terms with his own disability as well.

Because many children with Asperger's Syndrome were originally felt to have an autism diagnosis, the following remarks address the social and emotional issues for the families of children diagnosed with any diagnosis along the autism spectrum (ASD). These remarks generally refer to adult family members, primarily parents and sometimes grandparents. For information regarding sibling issues, the reader is referred to Siblings of Children with Autism: A Guide for Families by Sandra L. Harris, Ph.D.[11]

It is hard to overestimate the impact the diagnosis of ASD has on a family. In Michael D. Power's book, Children with Autism : A Parents' Guide[20], Lillian and Joe Tommasone note, "For many parents, this pain is so searing that even years later, the memory automatically causes tears." All parents wish for healthy children and this diagnosis shatters that hope irrevocably; never mind the fantasy of "perfect" children, it shatters the premise that one has a normal child.

There is generally a kind of anxiety surrounding the birth of a baby that the child be healthy and many of these children early on seemed to be fine. To learn that one does not have the normal little girl or boy one thought one had is an especially painful blow.

Compounding the impact of the diagnosis of ASD is the fact that ASD, unlike some other handicaps, affects multiple and diverse aspects of functioning. There may be impairments of cognition, motor skills, language, behavior, and certainly social and emotional interaction. ASD affects the way in which children respond to and relate to their parents. This is most dramatic in those autistic children who act as if people do not exist. There is nothing more chilling than the gaze of a child who appears not to see. Such difficulties tend to make parents feel helpless and as if they don't matter. Most families become preoccupied with ASD and see it as the central feature of their lives. According to one father, "There isn't an hour that goes by that I don't think about it." Another parent said, "Will I ever be happy again?"

Lesson Eight: Grief and Guilt

Parents must grieve for the loss of the child they imagined they had. Parents have their own particular way of dealing with the situation based on a number of factors, e.g., their personality style, life experiences and support systems, among others. Clearly there are a range of stages and coping techniques, such as denial, depression, anger and rationalization. Most families recognize, at least at some level, that there is something seriously wrong with their child. To at last be given a name for it, can be a relief.

Certainly, having a clearer understanding of what is wrong affords the opportunity to obtain appropriate services, as well as to begin to think about the child in a different, and hopefully more helpful way.

The grief surrounding the diagnosis of ASD is compounded by tremendous confusion and uncertainty. Many parents have little understanding of what the diagnosis of ASD entails. Many have the inaccurate perception that all children with ASD are non-verbal, mentally retarded, extremely remote and possibly self-abusive. Parents must become informed about the varied presentations of ASD. This spectrum is a long one with extremely impaired individuals at one end, but highly capable ones on the other.

While the continuum is long, the potential of any particular child is unclear. The course of the disorder is extremely hard to predict at an early age. Some very impaired looking toddlers go on to become high functioning adults, including adults with Asperger's Syndrome. As one parent said, "The problem is, we don't know if he is going to become a rocket scientist or work in a sheltered workshop."

After learning of the diagnosis on the autism spectrum, the family is forced not only to come to terms with what may be a devastating handicap, but is thrust almost immediately into making many critically important decisions. To champion the child's cause at the same time one must begin to grieve is truly an untenable position. It is as if one must – overnight – and while grieving – become an expert in ASD and its treatment, despite tremendously conflicting opinions. There is considerable support to the notion that the availability of early, intensive intervention offers the best hope for improvement. While this hope leads to a sense of optimism, the message that services must be implemented immediately and intensively can also feel overwhelming.

In addition to decisions about what kind of schooling their child should have, parents must also make decisions about such treatments and services as speech therapy and occupational therapy. What about sensory integration? Auditory retraining? Facilitated communication? Medication? Behavior modification? Many times the approaches seem confusing and even contradictory, with proponents claiming success and even cures. How is a parent, especially one in the midst of grieving, and of desperately hoping for help, supposed to make informed, intelligent choices?

The grief work in the families of children with ASD is an ongoing process. In most families, there are periods of greater and lesser intensity to the grieving. This intensity

may partly relate to developmental issues in the child. For example, birthdays or other rites of passage (e.g. Bar Mitzvahs, graduations) may underscore how different the child is from his typical peers. Grief intensity may also relate to more personal, individual factors. These factors include such things as one's own temperament, history, supports and losses.

In addition to the waxing and waning in the intensity of grief, there is typically an alternation of hope and despair. Each new treatment or program for the child is often accompanied by an increase in optimism in the parents. If the new treatment or program is deemed unsuccessful, despair may follow, only to be replaced by hope once again, when a new plan is implemented.

Feelings of jealousy and anger are common in many families. These feelings may be directed towards other families who do not have to contend with such stresses or towards other families with disabled children whose children are higher functioning or have improved to a greater extent. Many families also experience feelings of anger and frustration towards professionals for a variety of reasons. These reasons include not diagnosing properly, insensitivity, offering false hope or providing inadequate or ineffective treatments or services.

One variant of grief that sometimes occurs in the families of higher functioning children, particularly those with Asperger's Syndrome, is the sense that the child "should" be doing better than he is because he is so bright. There may be feelings of frustration that "normalcy" is so close, yet still out of reach. For some of these children and their families, graduation from high school is a particularly stressful time. For the parents, there may be the sadness that their child is not yet able to be independent the way their typically developing peers are. Finding work is often challenging for those with Asperger's, and support services are usually quite limited for this population.

Guilt

Guilt is another common reaction to the diagnosis of ASD in a child. Fortunately, the medical and professional community no longer hold to the notion that autism is a result of parental failing, e.g., the concept of "refrigerator mothers" postulated by Bruno Bettleheim in his book The Empty Fortress: Infantile Autism and the Birth of the Self[5]. Today, there is widespread acceptance of the fact that ASD is a genetically based disorder. The possible contribution of additional factors, such as environmental toxins, is currently being studied.

This change in perspective, from parental failing to genetic loading, has not eradicated parental guilt, although in most cases it has lessened it. Many parents wonder what they unwittingly did to contribute to their child's ASD. Were they exposed to too much mercury from injections or dental fillings? Was the termite control treatment of their house the culprit?

There have recently been articles in the press on the high incidence of ASD in Silicon Valley. Time Magazine entitled the phenomenon the "Geek Syndrome" in the article "The Secrets of Autism"[17] in May, 2002. This term has led some to speculate that the blame has shifted from “refrigerator mothers” to “geek fathers”. Said differently, believing genetics is the cause does not necessarily eradicate the guilt parents feel. Unfortunately, in some cases, it seems to confirm their fears about having caused or contributed to their child’s disability.

Lesson Nine: Daily Stresses and Others' Reactions

There is yet another aspect to the diagnosis of ASD that further complicates the task most families face. This aspect is that the day to day, hour by hour, moment by moment experience of life with a child on the spectrum may be profoundly affected in very difficult and disconcerting ways.

Unquestionably, there is tremendous variance here. Some ASD children are relatively quiet and docile and in this respect, easier to live with. Others are quite unpredictable, even volatile, and extremely hard to manage. The most simple, mundane things most people take for granted – the natural, unquestioning way people get through the day - parents of ASD children may be unable to do. For example, some children perseverate in ways that turn family life upside down and some become profoundly upset by the way they think things are supposed to be. Some are terrible sleepers and some may be difficult to bring out in public because of behavioral outbursts.

While the parents of ASD children desperately need time away from them, this issue, too, tends to be more complicated than in families with typical children. Babysitters for such children tend to be quite difficult to find. Many teenaged babysitters are unable and unwilling to deal with the challenges such children provide and many parents feel uneasy leaving their child in this situation. Similarly, it is often impossible to impose on one's neighbors, friends, or even family the way many parents do; one cannot simply ask to drop the child by while one goes to the store.

Others' Reactions

The reaction of others often complicates the difficulties parents face. One of the most painful aspects of raising a child on the autism spectrum can be the stares, disapproving looks, and critical remarks from passersby. This issue is often particularly problematic in families in which the children look outwardly normal (and most of them do).

Because they look normal and are usually quite bright, children (and adults for that matter) with Asperger's Syndrome are especially likely to be misperceived as willfully defiant. Many times their "defiant" behavior is due to misreading a situation or being incapable of effectively dealing with frustration. Sometimes parents themselves do not realize their children are not intentionally thwarting authority. Unfortunate confrontations in schools are often due to teachers and school administrators misunderstanding the disorder.

Final Thoughts

Asperger's Syndrome is a heterogeneous disorder. Some individuals with the disorder are quite impaired in their functioning, while others display few limitations. The disorder includes those unable to work, as well as those at the top of their fields. There is also tremendous unpredictability and variability to the disorder. Some days functioning may be much more impaired than others. Consequently, one cannot assume a child with Asperger's has resolved a particular difficulty because he has had an especially good period of functioning. This comment should not be construed to mean individuals with Asperger's cannot overcome difficulties; they certainly can and do. However, the ride to this resolution is often a bumpy one.

Many people with the disorder stand out as being different and are often perceived as weird. Children with Asperger's are often terribly misunderstood and may be the target of teasing and ostracism or even physical violence. The fact that most individuals look physically normal probably exacerbates the difficulty. People tend to be more understanding of those they perceive as having an obvious and recognizable disability.

Despite their lack of social understanding, children with Asperger's are usually very aware of being targeted. Adults can often be enormously helpful by making it clear such behavior is not tolerated. Similarly, children with Asperger's generally are aware when others like them. Consequently, teachers who genuinely like a particular child may find he learns better and is in better control.

In summary, the world is often a confusing and at times overwhelming place for those with Asperger's Syndrome. Understanding the nature of their differences is a critically important step in helping them through this confusing world.

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