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ASPERGER SYNDROME

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What is Asperger Syndrome?

Hardly a day goes by without a new article or television special somewhere in the world about Asperger Syndrome (AS). The symptoms of AS were first described in 1944 in an obscure wartime European medical journal article by Hans Asperger, a Viennese child psychiatrist. AS was given its name by an English researcher, Dr. Lorna Wing, in the early 1970s when she ran across Dr. Asperger's article and named the syndrome in honor of the first doctor to identify the traits of this condition. When AS was first identified, it was believed that it affected about one person in every 10,000. But in actuality it now has been shown that at least 1 in 500 can be properly identified with AS. In fact, the current numbers are showing closer to 1 in 200, or perhaps even less.

Asperger's Syndrome is considered to be at the higher end of the Autistic Spectrum Disorders (ASD). Individuals diagnosed with AS generally have normal and above-normal IQ scores but the primary features of autism remain: impaired social skills, communication challenges, and difficulties with certain aspects of executive functioning, which involves the skills of planning, multi-tasking, and transferring one skill set on to a different task.

Autism is called a disability, disorder, syndrome or difference, depending on who is using the term, and what label is considered politically correct at the time. There are greater variations between children and adults diagnosed with AS than there are similarities. The multiple features of AS makes it hard for educators,

diagnosing clinicians and experts in the field of ASD's to arrive at commonly agreed-upon criteria in "classifying" persons with AS. The education system, as well as varying governmental agencies, will not accept only a medical diagnosis of AS. Each requires that the individuals pass additional tests to be considered for assistance. For this reason, it is best to really understand how AS manifests itself in the individual you are considering, and then aim your discussions to the goal you desire to achieve.

AS has been called an “epidemic” by many because of the substantial increase in AS individuals in the last ten years. However, in spite of the large increase in diagnosed cases, AS still remains a relatively unknown or “hidden” disorder. There is no identifiable physical characteristic, no race, no social status, no geographic location, and no education level that will help in the diagnosis of AS. Since this is basically a different way of thinking, there is no surgery and no medication that will “cure” it (medication may be prescribed for some of the co-existing conditions, but at this time there is nothing that will work on AS alone). It is a lifelong characteristic. It affects different people in different ways.

But the positive traits of Asperger’s Syndrome should also be considered. These individuals have been known to be extremely creative, and are responsible for many of the outstanding discoveries of mankind. Although the actual syndrome was unknown by a vast majority of professionals until just in the last decade or so, by reading over information concerning Albert Einstein, Leonardo da Vinci, Vincent Van Gogh, Thomas Thoreau, Ansel Adams, and Thomas Jefferson, it is easy to recognize the AS traits. Temple Grandin has become famous for her designs of humane cattle chutes, and she has willingly shared her autistic experiences with many audiences. These individuals will not be contributing to the “politically correct” agendas of so many, for they focus on the facts and the truth. With considerable concentration on details, and willingness to pursue one specific topic in spite of peer pressure, these are the individuals who “think outside the box” and are the very ones giving mankind the spark to continue forward. As AS author Jerry Newport says, “Life is NOT a label”, and the opportunities exist for an AS individual as much as for anyone else in the United States.

Are you looking for assistance for you or your child in school? For a better job for yourself? For assistance with interpersonal relationships problems within your family? For a label and understanding of prior social difficulties? Whatever your purpose, you will need to do much critical thinking and considerable reading before you are ready to really attain your goal. CO-BRASS can assist you on your discovery of AS.



The Official Criteria for Asperger Syndrome

The official definition for Asperger Syndrome can be found in the 1994 edition of the Diagnostic and Statistical Manual of Mental Disorders (DSM) (4th edition), as prepared by the American Psychiatric Association. This is also known as the DSM-IV. Prior to 1994 Asperger Syndrome was not even included in the DSM, which is the “handbook” for all doctors in the United States.

Although this is more of a checklist than a discussion, by reading over this information you should understand the identifying characteristics for this disorder. The summary listed here was taken from Pediatricneurology ([http://www.pediatricneurology.com/autism.htm#Asperger's Syndrome](http://www.pediatricneurology.com/autism.htm#Asperger's%20Syndrome)), so it may sound rather stilted and formal, but so is the DSM-IV.

(A) Qualitative impairment in social interaction, as manifested by at least two of the following:

- 1. marked impairment in the use of multiple nonverbal behaviors such as eye-to-eye gaze, facial expression, body postures, and gestures to regulate social interaction**
- 2. failure to develop peer relationships appropriate to developmental level**
- 3. a lack of spontaneous seeking to share enjoyment, interests, or achievements with other people (e.g., by a lack of showing, bringing, or pointing out objects of interest to other people)**
- 4. lack of social or emotional reciprocity.**

(B) Restricted repetitive and stereotyped patterns of behavior, interests, and activities, as manifested by at least one of the following:

- 1. encompassing preoccupation with one or more stereotyped and restricted patterns of interest that is abnormal either in intensity or focus**
- 2. apparently inflexible adherences to specific, non-functional routines or rituals**
- 3. stereotyped and repetitive motor mannerisms (e.g., hand or finger flapping or twisting, or complex whole-body movements)**
- 4. persistent preoccupation with parts of objects**

(C) The disturbance causes clinically significant impairment in social, occupational, or other important areas of functioning.

(D) There is no clinically significant general delay in language (e.g., single words used by age 2 years, communicative phrases used by age 3 years)

(E) There is no clinically significant delay in cognitive development or in the development of age-appropriate self-help skills, adaptive behavior (other than in social interaction), and curiosity about the environment in childhood.

Basic Characteristics of Asperger Syndrome

The official definition in the prior section will give you the most accurate understanding of the Characteristics of AS. But for those of you who would like an easier-to-understand version, this section is for you. Symptoms of AS include: impaired ability to utilize social cues such as body language, irony, or other “subtext” of communication; restricted eye contact and socialization; limited range of encyclopedic interests; perseverative, odd behaviors; didactic, verbose, monotone, droning voice; “concrete” thinking; over-sensitivity to certain stimuli; and unusual movements.

Uta Frith has suggested that there are five main characteristics that identify AS: (1) impaired social relationships, (2) impaired communication, (3) impaired make-believe play, (4) a peculiar pattern of intellectual abilities, and (5) the repetitive phenomena of rituals. By analyzing each of these characteristics we can get a better understanding of how AS can be identified. It is necessary to realize that we are discussing a variety of symptoms with AS, and that not every characteristic will manifest itself in each individual. Some traits may not apply in your particular case.

Impaired Social Relationships

Understanding the concept of friendship and forming close and intimate relationships is difficult for most individuals with AS. As a child with AS approaches school and has an opportunity to be with his/her age peers, it becomes very noticeable that he/she is generally alone. Teachers and other adults consider the AS child a “loner”, and may even tell others that the child is “in a world of his/her own”. But in truth, this child may want desperately to have friends, but is unaware of how to attain friendship—they are lacking the skills and therefore are not successful in their attempts to make friends. While many AS adolescents may have a number of friends, it turns out that very few of them are of the intimate, “bosom-buddy” kind. In actuality, other people would consider those that the AS individual considers “friends” as “mere acquaintances”. Without deliberate, patient instruction by professionals and others about the meaning of relationships, friendship, and sexual bonding, many children and adults remain adrift with unanswered questions about “why” they continue to have difficulty forming such relationships. Even as an adult, without proper training the AS individual may easily make acquaintances, but is still lacking the expertise to change that relationship into friendship, dates, or eventually a spouse.

Most aspies (a term developed by Liane Willey to identify any individual with AS) report being victims of bullying, victimization, abuse, and teasing, much of which may continue into adulthood. An AS individual appears naive and gullible to others. They become targets for such behavior because they stand out from their contemporaries as odd, not being able to understand simple social cues and unwritten rules of social communication and the hidden or "other" meaning of words, phrases, or the facial and body gestures of others. Many aspies do not understand the significance of variations in vocal pitch, pauses, and expectations by others that they "keep up their end of the conversation". In addition they suffer the consequences of remaining on the outside or at the edge of social conversation and the social behavior of their peers.

Since there is a basic non-understanding of social etiquette, the AS individual may become overbearing, domineering, bullying, and controlling as a means to be "in charge" of their environment. The domineering AS adult will have no sympathy for others, and no remorse for any pain or suffering they inflict. This person does not understand that others have different goals or "rules" than he/she does. The anger, frustration, and rage that an aspie experiences may lead him/her to overstep the lines of decency, and touch into abuse, violence, and even illegal activities. It is therefore important to work with a child and help thwart this side of AS before it becomes ingrained into his/her personality.

Other AS adults become very submissive in their actions. They have considerable empathy for others, and are repeatedly apologizing for their actions. They are also unsure how to respond to others in order to actually develop friendships and normal social relationships. But even these quiet AS adults have described being overcome with rage—they feel as if something is taking over their body—they cannot control it. Instead of stifling their emotions, these adults would be happier if they learned how to safely express their feelings in a socially acceptable manner.

An aspie cannot quickly review a social situation and decide on a course of action, but instead must totally review all the "input" and decide how to respond. Others do not realize that the "processing" time is necessary for an AS person, and tend to become aggravated at the slowness in their reactions. It must be remembered that the social awareness that comes naturally for most people must be a learned and well thought out response for the person with AS.

Role playing, guided instruction by other socially savvy children and adults, Social Stories, and the sensitive use of modified cognitive behavioral techniques can make an enormous difference in an AS person's understanding of how to form and sustain lasting relationships. For all such formal instruction, it is critical that the aspie have safe opportunities to practice newly-learned skills with other individuals in a supportive and respectful one-to-one setting, moving gradually into supportive small group settings, testing and generalizing lessons learned into structured

educational, social, community and work environments, and finally generalizing those skills with strangers in the world at large.

Impaired Communication

AS is characterized by rigidity of thought, black and white thinking, and impulsive behavior (or its apposite - indecision). These individuals tend to take everything very literally, understanding everything just the way it is spoken, no hidden ideas, no idioms, and no double meanings. In addition, a person with AS will listen to the words only, and not recognize the non-verbal methods of communication (gestures, nod, winks, or even facial expressions). From research in the early 1970's has come the term "mind blindness" describing autistic individuals' difficulty in perceiving and understanding the intentions of others.

Many children and adults with AS develop a style of expression characterized by long, fact-filled monologues. In addition they show an apparent disinterest about active reciprocal engagement with other children or adults, leaving their listeners exhausted and exasperated, or very bored. The listener wonders why the AS individual has returned the discussion to their favorite interest no matter how far the conversation has progressed into new topics. As an example, a child that knows the manufacturing process of every toilet in Central Oregon may at first be interesting, but will bore others after an hour or two if they are even still listening and have not walked away. A child or adult with a more common special interest like music, sports or animals seems to fare a little bit better because many other children and adults have an interest in these hobbies. Finding their own age-mates bored with their special interests, AS children often seek out adults to impress with their knowledge and gain the acceptance denied them by their peers. Aspies are more interested in finding a discussion about their favorite topics than they are in social interaction with their age-mates.

An aspie is unaware how they sound to others, and many tend to speak with loud, authoritative, monotone voices. Or, the other alternative is that the person with AS will become exceedingly quiet, not wishing to have a conversation with anyone at anytime. Others incorrectly perceive that the person is bored, mad, or very knowledgeable based on the tone and volume in their voice. The AS person is totally unaware of the unintentional messages he/she is sending to others. They are also unable to "fix" any problems in communication that might arise in any social situation. This lack of social ability often will cause employment problems as an adult.

Many aspies have a tremendous vocabulary and tend to use very long, specific words in rather unusual (but grammatically correct) ways. They tend to write very long sentences, and very comprehensive essays on whatever topic is of interest to them. If the topic is not interesting to the AS individual, you might find an exceedingly short one-sentence response on an essay test paper, or as adults they will simply walk out of the conversation. He/she will find it very difficult to make a

response longer or shorter based on another person's request (e. g. a teacher or professor), but will rather say what they think is important, regardless of length.

AS individuals do have a sense of humor, but it often differs substantially from that of persons who are not autistic. They will understand the humor if the story includes a familiar topic or punch line, one that he/she has already learned. If it is something unfamiliar he/she is totally lost and often the response will simply be blank stare (very reminiscent of Data in Star Trek). It may take a while to process everything, and then the laughter and reaction may be delayed and subdued. But other times, only after explicit information and discussion can he/she join in the laughter.

AS individuals have problems identifying their emotions and the emotions of others, problems that can lead to outbursts of frustration, anger and rage. On the other hand, passive AS individuals withdraw from the same stressful conditions that cause others with AS to be argumentative, "righteous" and persistent in trying to convince others of the correctness of his/her thinking. Since the AS individual is unable to learn social manners by watching others, it is necessary to actually teach them each step of the way. Only with individualized instruction will you avoid the 12-year-old answering the family phone with a gruff "Who's talking?" instead of a more acceptable "Hello".

Impaired Make-believe Play

A child with AS will not enjoy imaginary play with other youngsters. This child is unable to understand the emotions of others, and will instead revert to the safety of "scripts" of movies, videos, or books that he/she has recently seen. An AS individual will have a wonderful memory for facts and want things just the way they were in the original. He/she is a great historian, especially about events that he/she participated in (if you want to review what happened last Tuesday at noon, and who specifically said what, ask your AS child). This child at other times will wish to discuss his/her favorite subject, and therefore will find that older or younger people will be more receptive to his/her feeble social advances than his/her age-peers. This child will continue to use "parallel play" until considerably older than most of his/her peers. Then he/she will grow into the next phase where he/she is desirous of being "in control" of every play situation so that everything will go exactly as he/she prearranged it. He/she is unable to accept anything that is not predicted, and therefore imaginary play is avoided. It is too spontaneous.

Peculiar Patterns of Intellectual Abilities

AS individuals have strong but relatively narrow "obsessive" interests. They may develop them as children and persevere in their pursuit of knowledge in such areas throughout their lives. Other individuals develop strong but successive interests, moving from one intensive preservation to the next. Others don't as much abandon earlier interests as place them in a lower order of importance, but still

maintain a substantial "collection" of areas of expertise which they are often able to temporarily pull up from their past and pursue anew. As the aspie becomes more mature, he/she will often refer to these special interests with the socially acceptable label of "hobbies". Aspies are distinguished from those who are not on the autistic spectrum by the intensity of their efforts to gain knowledge about their special interests (even if they are calling them "hobbies"), as well as their unusual fascination with out-of-the-ordinary topics not ordinarily considered age or context-appropriate by their non-spectrum peers. Many children and adults, regardless of whether they are introverts or extroverts, become known by others as "little professors". Many AS adults actually do become teachers or professors due to their considerable knowledge on one subject.

Those with ASD will often have tremendous memories for facts or events. They will enjoy DVD players or Videos because these allow them to see their favorite movies over and over, until they actually can predict the next scene or the next line from a favorite character. But this memory will also cause them to recite things to others that may have been told to them in confidence. They are unaware of the intention of the person when they are told the information, and just share it when they are under stress in a social situation—breaking confidences and hurting feelings. The individuals who have been betrayed may choose to avoid additional contact with the AS individual not realizing that it actually may be a "teachable moment" and that the breach of confidence was not meant to be hurtful, but rather to fill in a perceived uncomfortable pause in the conversation.

Repetitive Phenomena of Rituals

All individuals diagnosed with AS demonstrate unusual responses to change. Regardless of their IQ, without being prepared for or being able to anticipate changes in their environment, all individuals with AS have substantial difficulty responding to new problems. This reaction is related to their fondness for routines and predictability, as well as dependence upon rules that they do not expect will be changed.

An adult with AS prefers to work with objects or alone, not with people and in addition he/she may have difficulty with social interaction on his/her job. Many AS individuals engage in repetitive activities or prefer "mindless" tasks at work primarily because they can master such activities and perform them with increasing ease. Fondness for doing these things has a calming effect in them, and allows them to sort out confusion in what they experience as a challenging environment. The intensity of their adverse response to change is directly related to their desire for routine and sameness in what they perceive as chaotic or disordered, unpredictable situations.

If the aspie has a set routine that must be followed before something can occur, this routine is not negotiable—it must be followed—and if interrupted, it has often been noted that an aspie must start the full routine over, from the very

beginning. They are not able to restart in the middle of the routine, and they are not able to accomplish the task without that routine.

In stressful situations it is possible for an AS individual to “flap” or vocalize in unusual manners in order to try to calm themselves similarly to those who are further along the autism spectrum. It is important to remember that the overwhelming desire for routine and control of the situation is still there in an adult with AS; you just need a little more looking to find it.

Conclusion

Persons with autism have materially different brain wiring and sensory issues not found with the same frequency or intensity in the non-autistic population. Testing with MRI and CAT-scans are still in progress, even though the preliminary research shows marked differences. This is when the parent saying that the AS child “doesn’t think like I do” is totally correct.

Those with ASD often have other conditions such as gut or immune system problems, unusual reactions to medications, sleep problems, very strong food preferences, and a high expectation of "sameness" and "no surprises". There often are problems with sensory issues like smell, touch and taste. Something as insignificant to most people as the flicker of fluorescent lights might be enough to keep the AS child from concentrating and learning in the regular classroom situation.

Because ASD's reflect neurobiological differences, while it may be possible to modify body, intellectual responses and behavioral outcomes there are many things that cannot be changed, or if they can, they exact tremendous, permanent damage on the individual. One aspie compared trying to modify her behavior to stopping vomiting when you have the flu—it just isn’t possible. Many differences are now being seen as just that -- differences, rather than something to be fixed. Rather than trying to wipe out differences, enlightened persons now see strengths in what are commonly perceived as a weakness or deficits.

It turns out that the significance of any difference is what one makes of it. As long as changing the person may have devastating consequences now and in the future, parents, educators, professionals and enlightened family members now recognize that many of these strengths can become the basis for life-long satisfaction and a high quality of adult life. In order for these differences to be perceived as strengths, they must first of all be seen as differences rather than deficits. Secondly, differences that can be supported, nurtured, strengthened and increasingly accepted by society then become "normalized" rather than the basis for continued marginalization.

Although each AS person exhibits the same traits throughout their life, with age and experience, some of the characteristics become more “hidden”. An AS adult has learned to cope with the challenges of AS, and may “mask” some of the traits even to the point of “passing for normal” when in public. This section will give you a brief overview of what identifying personality traits you might expect at each age. It is important to realize that every person is different; every person has different traits, different strengths, and different weaknesses. Not every person will exhibit all the same personality traits, and in fact there may be some characteristics listed here that are totally missing in the particular aspie you are thinking about. But it is very important that you treat your aspie with respect, love, support, as you would any person you meet. He/she is an individual, and the “label” of AS will not change that.

In preschool, a child may hesitate talking well beyond the normal age of his/her peers. Or he/she may begin talking in complete sentences about complex issues well beyond what you would expect. These sentences will seem memorized, and in reality they may be, with the child actually totally oblivious of the meanings of what he/she is saying. He/she will be observed playing by himself/herself. Adults often say that the child “is in his own world”. There may be a tendency for the child to rock, “fidget”, or even “flap” when concentrating. Or the child may have unusual vocalizations (a certain word or words, hum, click, grunt or the sound of a motor) that occur frequently when the child is concentrating. The child may start screaming and “meltdown” in a situation with many people around (like the grocery store, or parades). He/she is unable to participate in “imaginary” play, but rather seems to review “scripts”—perhaps a movie seen, or a book read previously. He/she may spend hours at a time lining up object or sorting them—not really using them in the method intended. It has been noted by many parents there is difficulty in toilet training an AS child, and “accidents” will occur at a much older age than might be expected (throughout the elementary school years). Eye contact may be avoided. He/she may seem to have unusual difficulty in learning to dress himself/herself (many an aspie parent has appreciated the invention of Velcro, especially when it was added to shoes).

In regular school, the child does not seem able to have conversations with his age-peers—he/she is more inclined to carry on monologues, and prefers being with older or younger individuals (unless someone really listens to the conversation, teachers and administrators may incorrectly assume that the child is “social” because he/she talks to another child). Or the child will be a “loner”, and off to one corner of the playground all by himself/herself. The child may be uncoordinated, and has difficulty with any activity that requires cooperation between both hands simultaneously (the last one picked for team events). Fine motor skills are slower in developing. Handwriting is laborious and awkward. Papers are messy. The child seems to lack organization—if the homework is done, it is “lost” before it can be turned in. The extreme spikes of interest are beginning to appear—very knowledgeable about one subject, and absolutely no interest at all in another. Or they can study forever about one subject, and all the knowledge disappears into an

unknown “black-hole” (My son would study all week on his spelling words, writing them, orally saying them, looking at them, but come Friday it would be like he had never heard of these words ever—and week after week he would fail each spelling test). The child may find it very difficult to stay in his/her seat for an extended period of time because it is “uncomfortable”. In fact the child may even stand and walk out of the classroom in the middle of the lesson, causing the teachers, administrators, and parents considerable concern (the child is really trying to leave what they perceive as a stressful situation, and does it the only way he/she knows how—by walking out). The child may become demanding about type of clothing he/she will wear (a certain color, a certain style, or even a certain fabric content). It might even be necessary to remove all tags from clothing for it to be worn. The child may desire to wear the same thing day after day after day, causing problems in hygiene and in washing his/her clothes. The child will begin to adopt the loud, high, or monotone voice that is so identifiable with AS. Sleeping or eating problems become identifiable, and cause family stress. The stress of “holding it together” when at school may cause the child to come home and “meltdown” at home as frequently as daily. Parents who do not understand AS at this stage will begin to put additional pressure on the child to “conform” to their expectation, are in actuality cause more stress, confusion, and frustration for the child, accentuating the problems.

As a teenager, the lack of organization and spikes of interest continue. The aspie becomes the brunt of jokes and the victim of bullies. Since the individual does not learn by watching others, he/she will tend to be immature, and lack many socially required manners (e.g. Tactile sensitivities might cause them to pick at scabs or scratch their crotch in the classroom during High School). They begin to sense that they are “different” and not accepted, but they have no understanding of why and actually start spiraling into depression. Aspies rarely date in High School because even though the child may begin to see others “pairing off”; he/she may have no idea how to initiate any social conversation or contact. He/she wants to be “normal” like everyone else but has no idea how to achieve it. Homework can become a major stumbling block – the AS student has no idea how to write down the assignments, forgets textbooks necessary for the lesson, doesn’t understand what he/she is supposed to do, or if the homework is actually done, loses it or just does not turn it in. The AS student may tend to be a perfectionist because he/she has been repeatedly criticized—but this means that if there is one math problem that is not understood, the total page will not be turned in. Homework will turn into battles, as the child is so stressed from school, he/she really needs to have some time to “unwind” at home in the evening but the assignments take more and more time, leaving no time to unwind at all. In addition, he/she is unable to take specific examples from the classroom and generalize them and apply them in everyday life. Analysis types of assignments are almost impossible, as the executive functioning necessary for this type of work is missing in an aspie. Team assignments are guaranteed to drive an AS student crazy—he/she is unable to determine how to cooperate with the others, and is often ostracized when picking teams (ending up with the “goof-offs” and “losers”, and thereby unable to learn any beneficial habits

from those who really do know how to do the assignment). There have lately been several cases where an aspie teenager has committed suicide because he/she has become so distraught over life (thankfully none of these cases have been local).

As an adult, the individual has self-taught mechanisms to protect themselves. Some aspies may have learned to lie, while other aspies continue to be exceedingly truthful throughout their life. The aspie may have learned to explode in rage, scaring others into submission. They may have learned to talk in a loud, overbearing monotone, so that others believe that they really know what they are talking about and let them have their way. They may just spend all their time talking about only their “favorite subject”. When it comes to jobs, either an AS individual has learned to go into something having to do with their “special subject” (like be a teacher or a consultant), or has found a meaningless job with repetition, and with little social contact. There are other aspies that have continual difficulty with finding any sort of a job, and end up in the unemployment and disability lines most of their life. An AS adult is generally very good with objects, such as computers (a computer only does what it is programmed to do, so it is very predictable). Some AS adults have successfully gone into business for themselves, especially if there have someone to “help” with their weak areas. Some extrovert AS adults wish to be around people all the time, but with the social stress they self-medicate and become addicted to alcohol or drugs (either legal or illegal). The explosive rage of an AS adult, as well as the lack of understanding of others, may lead to doing things they shouldn't.

But not everything is negative. Those with AS can use their special interest to make a financially rewarding career. But the career must be matched to the aspies talents and interests to be successful. Aspies are unusually creative, and have become known for special talents such as writing music, painting, inventing, and yes, even writing computer programs. Yes, most AS adults have married and had families and are living independent lives. There are many books and studies being done currently on AS, resulting in increasing knowledge and understanding. With understanding, it is easier to encourage rather than criticize the AS individual. The opportunities exist; it is simply necessary to identify them.

The Truth and AS

Aspies do not have an early natural, untrained ability to lie or to detect lies when spoken by others. They may not understand the full consequences of the misbehavior of other children or adults, and often find themselves "holding the bag" while their peers' misbehavior remains unnoticed or denied by children and adults who do know how to tell convincing lies. Because the unwritten rules of social behavior and language remain mysteries to them, they become attached to enforcing rules and often gain the reputation of being little super cops or informers in situations where other children commonly ignore or break rules undetected

without consequences. Some AS individuals continue this pattern of being "enforcers" into their adulthood, insisting that others adhere to rules and inconvenient routines that are regularly broken or ignored. As an example, one AS son thought it was a mortal sin for his mother to go through the express check out line with more than the maximum number of items. She had eleven items; the sign said nine! How dare she break the rules! He would have a dramatic meltdown as others in adjacent lines stared in amazement at his behavior. It didn't matter to him that the Checker had asked her to come into that line. The rules were posted, and she had broken them.

AS individuals can also be blunt and disarmingly honest. Observing someone on the street or in a store, they may loudly say, "Look at her. She is soooo fat! She should go on a diet!" Well, that might be true but it is socially inappropriate to say this in public because it hurts the other person's feelings. AS children have difficulty understanding their own feelings, and therefore they also have trouble understanding the feelings of others. "Why would it hurt her feelings as every one can see that she is fat? I am only saying what ever one else knows to be the truth." Without careful, repetitive training, they simply do not understand "socially unacceptable" public observations. Some parents teach their children the "No's" without teaching them how to express their concerns in socially appropriate ways. Rather than saying the wrong thing, or learning how to tell socially approved white lies or to express their feelings later, in safety, many parents adopt an inappropriately rigid response to the social misbehavior of their children. At the point where it no longer becomes possible for parents or care givers to watch every word or behavior of the child, it is essential that our children understand their own particular "flavor" of AS and start to deal with the world in a comfortable way from an accurate self-understanding.

The overwhelming desire for literal meanings of words, combined with the desire for truth, can cause problems for children as they are growing up. For example, a well-intentioned teacher who asks that the class take a "nap" might find a child who refuses to sit down. That child when asked why he/she is still in the book section of the room might respond truthfully with "I'm not tired". If the teacher is willing to reword the request "Will all of you please find a place on the mat and lie down for a few minutes?" the problem is averted. If the teacher angrily demands the child "take a nap" there will be a battle of the wills, and the student will suffer the wrath of the controlling, domineering teacher. This is a very important lesson in word meaning that everyone associated with a person with AS should learn.

Disclosing AS to others needs to become a careful, well-thought-out process. Inappropriate disclosure has many uncontrollable and unexpected consequences; so children and newly diagnosed adults should be given ample opportunity to role-play, engage in guessing games about "What would you do if?" The life-long knowledge about their own traits, strengths, and weaknesses should be something

that the AS person should know how and when to hide as well as how and when to disclose.

As the AS individual has matured, it is possible that they have learned how to lie as a coping mechanism with social problems. They do not see the difficulty with not telling the truth, because it accomplishes whatever their short-term goal is. They do not see the consequences to others for they are unable to understand any impact their actions might have on others. Remember that all comments made by the AS individual will be likely in a monotone with little facial expression, and perhaps little eye contact—this will make it very difficult to identify a lie versus the truth in an AS adult. Not all AS individuals will “learn” this ability to lie, but those that do may use it without remorse. It is therefore important that AS children be properly taught the reasons for being truthful, and the acceptable reasons for not disclosing something at a given time.

The Family and AS

More informed diagnostic practices leading to an Asperger Syndrome diagnosis in children and adults often leads to individuals looking around and discovering other members of the family "most likely" somewhere on the autistic spectrum. With AS, there is a strong genetic component with a greater than even likelihood that other members of the family may be autistic. For this reason, and with our greater understanding of the "family connection", diagnosis of adult members of the family, siblings, cousins, and grandparents often follows the AS diagnosis of children.

The process may or may not be equally difficult with mature adults. Many professionally or self-diagnosed AS adults experience relief at finding a "label that fits". The label is more than just a tag. It provides the key to understanding past experiences as well as a means to examine current relationships and roles. It may take an adult a longer time to "remake" his or her understanding of their past as well as their present, primarily because their lives are more complicated and “set” than the lives of younger persons.

Recent research has distinguished at least two phenotypes of AS in adults: an active, often aggressive and outspoken extroverted character characterizes the first, while the second is passive, quiet or quiet-spoken, and introverted. It is possible to have both types of individuals within the same family. One may be directly responsible for the other.

Of course the problems of interpersonal relationships between two AS member of the family, and AS/NS (non-spectrum) members of the family can be considerable. There are many web sites that have started to try to help these family members understand and solve their difficulties.

To researchers, women -- diagnosed with AS much less frequently than men, remain more of a mystery than men (currently there are 4 times more males identified than females. This difference is partially due to the difference in the way AS manifests itself in individuals. Presently most of the identification tests for AS are aimed at males). It has been noted the women are more social than men, so girls are more accepting and nurturing to female aspies than boys are to male aspies.

However, there is a developing body of research that identifies different behavioral and cognitive properties in AS girls and women from those of boys and men. Although the AS individual may have a special interest in any subject, it has been noted that males tend to be primarily interested subjects such as sciences, mathematics, space and machines (including cars, trucks, trains, planes, and rockets) whereas females tend to be more interested in subjects such as languages, environment, people, plants and animals. In addition, there is ongoing research to tell the differences in AS depending upon the age of the individual.

It must be remembered that autism is a spectrum, with some individuals exhibiting more traits than others. It is also possible to look at the surrounding family and see the lightest end of ASD. These individuals may be labeled as the "autism phenotype." These individuals exhibit some of the traits, but not enough to actually obtain a diagnosis. As parents and educators and professionals look for the magical "line in the sand" that will identify the individual with ASD, it becomes obvious that the person who is "just barely on the spectrum" is the one who can most easily be forgotten, or be pressured into trying to be something they are not. When forced to be "normal", the result is depression, anger, moodiness, rage, and other psychological problems.

At this time, "the jury is out" as to the most appropriate way to describe persons with Asperger Syndrome as a group. There are several questionnaires that have been developed trying to identify AS. Tony Attwood's Australian Scale is probably the best known at the present time. There are individuals attempting to create questionnaires that will be better suited for adults and females. Despite many years of research, there remains no single diagnostic tool for Asperger Syndrome that is universally accepted by physicians and mental health professionals.

The best way of treating AS individuals was the way everyone was treated about 100 years ago—strictly as individuals. By encouraging the strengths and teaching individuals how to react in social situations, each person, whether or not he/she is on the ASD spectrum, can achieve their best. The self-esteem must be intact for the individual to become an active, participating member of the community. Too often today's society manages to squash the self-esteem of the AS individual, regardless of age. As a direct result of the rules and regulations of the education system, it has become frequently common for parents to be homeschooling their AS children.

Should You Seek Diagnosis?

When an individual begins to understand AS, and consider it possibly affecting either himself/herself or someone he/she loves, the question becomes whether or not to seek diagnosis. There is no easy answer to that question. Remember that this analysis will be based on the situation in Central Oregon in the United States in 2003. If these criteria does not equate to your situation, your analysis and decision might be very different.

There are very few professionals anywhere who really know and understand AS and the full ASD spectrum. It is a new field, and the education process has not incorporated it into the training necessary for degrees. It is too new to be other than a cursory mention in textbooks—and there are just too few knowledgeable professionals to instruct classes in it (especially if the training was obtained here in Oregon). So your first question might be “how much am I willing to spend to find out if it is AS?” If you have a limited budget, that might be your answer. At this time it is very difficult to get any insurance company to help pay for identifications of ASD or AS. In addition, very few insurance companies will pay for the therapies that AS or ASD might find helpful. It is best to start with the public programs that are available to help all citizens rather than just starting out on your own. Remember that the education department, and all the individual governmental agencies (e.g. SSI, DD, Mental Health, etc) will want to run their own tests, and none of them will accept the medical diagnosis carte-blanche.

No matter what your age your first call should be on the Central Oregon Family Resource Center (<http://www.frconline.org/>). This agency has a wonderful directory and willing staff to help you find whom you should contact, and how to reach them.

If you have a preschooler and are concerned about AS, please be aware that early diagnosis, and intervention programs have proved highly successful. There are many different programs available for children from birth to 5 years old, as well as programs to aid parents of that age group. Not all of them are designed for a child with developmental problems, so you will need to really find out about the programs before committing your time and effort to them.

For a school-aged child, contact your local school even if you are homeschooling your student. You as parent can request evaluation for your child. Be very clear in stating what you want. By the rules of the Oregon Department of Education (ODE), there are 4 criteria that must ALL be met before a child can be recommended for further testing. From the ODE website, this criteria is:

Autism - A developmental disability typically affecting the processing, integrating, and organizing of information that significantly impacts communication, social interaction, functional skills, and educational performance. Essential features, generally appearing during the first three years, may include:

- (A) Inconsistencies or discrepancies in the development of physical, language, social, or cognitive skills;
- (B) Unusual responses to sensory information;

(C) Impaired verbal/nonverbal language or social communication; and
(D) Impaired ability to relate to people or the environment. The term does not apply if a child's educational performance is adversely affected primarily because the child has a serious emotional disturbance. However, a child who qualifies for special education under the category of autism may also have a serious emotional disturbance as a secondary disability if the child meets the criteria under serious emotional disturbance

If you are an adult, or concerned about an adult, there are many different agencies that might be able to help you. At the present time, your most assistance might come from contacting the Vocational Rehabilitation Division of the State of Oregon. But, this is a rapidly expanding and changing field. It would be best for you to contact us, or come to one of our meetings so that you may obtain the most current information.

No matter what the age of the aspie in your life, you will find that attending a local support group will give you additional insight and information that you will be unable to obtain simply from books. The Special Needs Resource Center at the Alyce Hatch Center is available for anyone to access books, printed material, and computer information on any disabilities, developmental delays, and educational needs of anyone with special needs, and AS is definitely included. The Special Needs Resource Center is free to all who want to use it. . In addition, there are many chat groups and information sites on the Internet that might help you.

Reason for Support and CO-BRASS

No matter what one's age of discovery, awareness brings answers. Support and coming to terms with one self allows children and adults to say, "I am who I am, and I like ME! I am more than a label and I am ok and do not need to be fixed. I LIKE me just the way I am." In addition, it will allow other around the aspie to suddenly say, "There is a reason he/she behaves this way! He/she is not doing it just to drive me crazy!"

It is important that children and adults understand that they have AS and how their own individual AS affects their outlook on life and others, starting their journey to self-discovery. Proper diagnosis and early intervention have proven very helpful to young children. While adolescents and adults diagnosed with Asperger Syndrome relatively late in their development may have a more difficult time replacing a previously-developed concept of themselves with what they now know to be a more accurate description, discovery that one has Asperger Syndrome doesn't lead to a permanent doom-and-gloom outcome. There are many positives with AS, and many well known individuals who have had AS—it is time to focus on the positives instead of the negative.

It is interesting to note that often those who know and accept their diagnosis of AS will often start counting their birthdays from the time of understanding the

situation. This is similar to the Alcoholics Anonymous counting birthdays from the day the individual pledges to go “dry”. It show that even though the official label is assigned to a person, that individual and the family around him/her will need to continue to read, learn, and grow together. Contact with a support group like CO-BRASS will allow you to continue to access all the newest information and further your own understanding along the way.

This website is designed for Central Oregon Community and we hope to network with others in our community and State of Oregon to make your journey a little bit easier and to offer support as we climb the mountain of AS together. It is a tough world out there and we need to do a better job or organizing, communicating, sharing resources and working together. We will all benefit from this cooperation.

Welcome to C.O.-B.R.A.S.S. (Central Oregon--Bend Redmond Asperger Syndrome Support). We are looking forward to getting to know you.

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