

Asperger Syndrome Grows Up Recognizing AS Adults in Today's Challenging World

Roger N. Meyer

with

Aleta Root

Linda Newland

Copyright 2003, All Rights Reserved

Outline

This article introduces the "basic level reader" to Asperger Syndrome (AS), with primary emphasis placed upon adults. The first and longest part of the article reviews the diagnostic criteria for AS, and covers its manifestations under each of five primary characteristics. The second part of this article briefly reviews related medical conditions common to children and adults with AS. The third section takes the reader through a brief tour of AS as it is expressed at each major stage of life, with emphasis upon childhood and adolescence. Section four discusses AS and its impact on the family. Section five reviews some of the considerations involved in seeking a formal adult diagnosis, drawing the connection between self-determination and adult employment.

This article is a result of the collaborative effort of four authors. An earlier version of it may be found at two Internet web sites, listed in the references at the end of the article.

I

Introduction

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 Austrian 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. Over the years, well-conducted demographic studies indicate that the incidence may be one in five hundred. Some studies suggest a higher incidence, up to one in 250 persons.

Asperger Syndrome is considered to be at the higher end of the continuum of Autistic Spectrum Disorders (ASD). Individuals diagnosed with AS generally have normal and above-normal IQ scores. Since IQ tests were not normed to include autistic individuals, IQ scores, particularly "low ones" found in some young children are likely to be misleading. What is consistent in tests and evaluations are findings that individuals with autism have markedly 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 to different tasks.

Depending on who is using the term, and what label is considered politically correct

at the time, autism is considered a disability, a disorder, a syndrome or a difference. The multiple features aspect of a syndrome make it hard for educators, and diagnosing clinicians to arrive at commonly agreed-upon criteria for "classifying" persons with AS. Educators and varying government benefits programs do not accept a physician or psychologist's diagnosis as reason enough to find individuals eligible for benefits or services. Each benefits system requires the applicant to meet additional eligibility criteria. For this reason, readers of this article must realize how differently AS manifests itself in each person before making an uncritical determination as to "where" the individual is to be placed in any classification system.

AS has been called an epidemic by many because of the substantial increase in reported AS diagnoses for special education over the last ten years. Despite some argument, there are solid demographic arguments suggesting that autism is on the rise. Explanations of the cause vary widely.

Despite the increase in diagnosed cases, AS still remains a relatively unknown or "hidden" neurobiological condition. Numerous recent imaging studies of the brains and brain functions of autistic individuals demonstrate clearly that AS expresses itself as a different way of processing sensory experiences and problem solving.

Autistic thought is truly a different way of thinking.

Manifestations of autism are primarily related to the different way the brain functions in autistic individuals. Autism appears to be a "hard wiring" phenomenon, but the developing brain is plastic. Progress towards "normal functioning" is persuasively demonstrated when children are identified early and worked with intensively. While there is no "cure" for autism, early sensory training, behavioral, medication and dietary interventions appear to play a huge role in the child's later success as an adult.

Autism involves a different means of thinking -- a different cognitive process -- there is no surgery or medication that will "cure" it. Some of its symptoms can be controlled through the interventions identified above, but the individualized character of each person's brain and their unique response to the environment does not assure that the same drug will have the same effect on two individuals whose outward manifestations and environments appear to be the same. Individuals' responses to medication and to therapeutic interventions vary enormously. Experienced autism specialists who see a large number of AS individuals on an ongoing basis express doubt about any "one size fits all" approach. The "tragedy of treatment" is that there isn't enough of it; what there is is expensive and very often not effective.

Despite gloom and doom characterizing popular perceptions of autism, the condition does have positive traits. Some higher functioning individuals are extremely creative, and have been linked with many innovations in the arts and sciences. Reviewing the work and lives of well known historical figures, diagnosticians posit that Albert Einstein, Leonardo da Vinci, Vincent Van Gogh, Thomas Thoreau, Ansel Adams, and Thomas Jefferson all had substantial autistic traits.

Official Criteria for Asperger Syndrome

The official diagnostic criteria for Asperger Syndrome are found in the Diagnostic and Statistical Manual of Mental Disorders, Text Revised DSM-IVTR (2000) published by the American Psychiatric Association. The DSM-IVTR is the major diagnostic classification reference for psychologists and medical professionals. Prior to its first inclusion in the 1994 version, Asperger Syndrome was not included in the DSM. Readers can find the original descriptive language under classification 299.80, Pervasive Developmental Disorders.

The summary listed below was taken from Pediatric Neurology ([http://www.pediatricneurology.com/autism.htm#Asperger's Syndrome](http://www.pediatricneurology.com/autism.htm#Asperger's%20Syndrome)). It reads in a rather stilted way, but that is a common complaint about the entire 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

The characterization of Asperger Syndrome above provides the reader with an "official view" of AS characteristics. However, among many clinicians who have seen vast numbers of autistic individuals since 1994, there is strong disagreement about the accuracy of the DSM-IV criteria. The 1994 criteria were developed after study of a relatively small number of persons. Since then, much more has been discovered about AS. Experienced child and adult diagnosticians have discovered that the official criteria are factually wrong on several critical areas; they also fail to account for many individuals seen in clinical and natural settings who exhibit classical autistic symptoms but develop speech late and demonstrate substantial deficient cognitive functioning and faulty perceptual awareness of others at an early age. There is strong pressure now being exerted on the editorial board of the DSM-V -- scheduled for publication in late 2005 or early 2006 -- to revise the criteria to better suit what sensitive diagnosticians have found to be true with thousands of late-diagnosed children and adults.

Since 1994, ethically responsible diagnosticians have adopted the view that autism is a spectrum disorder. Individuals diagnosed with Autistic Spectrum Disorder (ASD) occupy positions from one extreme end of autistic functioning continuum to the other.

To reflect current professionals' thinking about ASD's, the following section is a more accurate depiction of AS. Symptoms of AS include: impaired ability to utilize social cues such as body language, understand irony, or other "subtexts" of communication; restricted eye contact and odd, failed efforts at socialization; a marked and limited range of encyclopedic interests; perseverative, odd behaviors; didactic speech, verbosity, substantial problems with prosody, with voice tone regulation (monotone, droning voice); "concrete" thought accompanied with black and white dichotomous thinking; hyper and hyposensitivity to sensory stimuli; and unusual body awareness and movement.

For ease of discussion and reading, the term "he" is used in this article to refer generically to both AS males and females. In the writing below, where there is differentiation in responses or characteristics between the sexes, it will be noted separately.

Uta Frith, the English clinician who first translated Hans Asperger's 1944 German language paper into English in 1991, suggests 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 the reader can better understand how AS is identified. In the material below, a variety of symptoms associated with AS are discussed. Not every characteristic manifests the same way in each individual. What makes AS a syndrome as opposed to a singular description of a specific disabling condition is that its symptoms appear with high frequency within the same individual, in "clusters" as opposed to individually identifiable features, and with great consistency at any given stage of the individual's development. For this reason, it is classified in the DSM-IV as a pervasive developmental disorder.

When first being diagnosed, whether as children or adults, clinicians familiar with differential diagnosis best assess individuals. Individuals diagnosed with AS often have other mental or physical health conditions, which combined with autistic traits, limit their ability to function. Individuals diagnosed as being "on" the autistic spectrum -- a continuum that ranges all the way from extremely low functioning individuals to those whose intellect is high -- are identified as autistic precisely because they are unable to function at critical levels of child or adult cognitive, social and communicative activity.

Impaired Social Relationships

As an AS child approaches school and has opportunity to be with his non-autistic peers, his social and communication challenges become noticeable. Invariably the AS child remains off by himself rather than being actively engaged with other children. Even when with a group of children, AS children operate on what appears to be a parallel track. At this stage of social development, observers note that the AS child is a "loner. Found in their remarks may be terms phrases describing the child as "in a world of his own".

AS children may desperately want to have friends, but without formal and patient training they are unaware of how to initiate contact with others in order to move on to forming the friendship bond appropriate for "normal" persons their same age. When asked about their friends at each developmental stage where friendship is described by "normal" children in increasingly sophisticated terms, AS children describe friendship in ways quite differently than their peers. While many AS adolescents state they have a number of friends, upon closer examination their "friends" are more accurately described as acquaintances, or even individuals they see casually or once. By the time AS children reach adulthood, they have learned to be either direct in their statement that they have few or no friends, or be evasive and circumspect with their answers. Without careful prodding and determining what the AS adult "means" when describing their friendships, many diagnosticians miss critical information that would otherwise inform them that the AS adult's notion of friendship is both developmentally delayed and distorted from the ordinary meaning of the term "friend".

Without deliberate, patient instruction about the meaning of relationships, friendship, and sexual bonding, many individuals with AS remain adrift on a sea of confusion 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 "first base" acquaintanceships, but lack the expertise to change those relationships into adult friendship, a social date, or a successful spousal relationship.

Most AS individuals report being victims of childhood bullying, victimization, abuse, and teasing that they continue to fear in adulthood. Individuals not accurately diagnosed as autistic in childhood and adulthood are often abused and misunderstood within their own families, the one "last, safe refuge" of children and adults. As a result of their negative social conditioning, AS children and adults avoid strangers out of fear that earlier patterns of abuse will continue. Given ideal child-rearing conditions, even if they weren't actively abused, AS children and adults still feel misunderstood, and they often are. Out of fear of making mistakes, of being misunderstood, AS adults carry socially avoidant and distancing behavior into their hesitancy to initiate social communication and activities throughout their lives.

AS individuals appear naive and gullible to others. Studies of bullying and child abuse at the hands of non-family members show that individuals who are isolated or alone are perfect victims. They are 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 AS individuals 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 non-autistic peers.

Anger, Frustration, and Dealing with Difficult Emotions

There are two common responses to thoughts and feelings of being misunderstood. One response is aggression; the other is passivity. While both responses may be present to some degree in the same AS individual, professional literature identifies at least these two phenotypes: dominant, aggressive, and controlling; passive, submissive yet controlling in more subtle ways. Throughout their lives, individuals maintain the same type of response to stress and frustration.

With both types of responses, there are common clinical conditions that accompany the AS diagnosis: depression and anxiety.

Aggression and "Behavior Problems"

In their effort to be accepted by people they do not understand, AS individuals may mimic the behavior and language of groups they hope will accept them. This tactic rarely works. They fail to understand the subtle aspects of language and non-verbal communication between members of these groups. If such groups engage in anti-social behavior, they often leave the AS individual "holding the bag". While their savvy acquaintances escape notice through denial or "acting normal", AS individuals temporarily abandoned by their cohort become "discipline" and "behavioral problems" for educators and other care providers.

Without painstaking training and repetitive opportunity to practice newly learned communication and social skills, AS persons will not, on their own, develop an intuitive understanding of social etiquette. Some AS individuals may become overbearing, domineering, bullying and controlling as a means of remaining in charge of their environment. This is far more common with boys than with girls, however cruelty and aggressiveness in AS women has been recently studied and found to be even more severe than that of their aggressive male counterparts (Aston, 2003). The domineering AS adult may demonstrate no sympathy for others, and show no remorse for any pain or suffering they inflict. This person does not understand that others have different expectations or "rules" of their own. Anger, frustration, and rage that an AS individual experiences may lead him to overstep the lines of decency, and move into outright psychological abuse, violence, and illegal activity. It is essential to the child's well being as an adult to work early and intensively to thwart this side of AS before it becomes ingrained into his personality.

Because of the rigid logic and limited cognitive flexibility of autistic persons with uncorrected behavior and attitudes, once an AS child becomes an adult, it is very difficult to "turn the behavior or attitude around". This feature of rigidity, of "hard

wiring of responses" is as true for persons who are passive as those who are aggressive in their response to being misunderstood. Most AS adults who have chronic negative attitudinal or behavioral responses do not benefit from standard counseling or behavioral therapy. Only in the last several years have techniques been developed -- modifications of cognitive-behavioral therapy -- which have proven effective.

However, it is important to remember that such therapy works if and only if the AS individual accepts his Asperger Syndrome diagnosis, takes active steps to understand his own particular "flavor" of the condition and is willing to change and improve his conduct through a very painstaking and slow process inherent in such work. Even if the individual expresses a desire to change, the psychological cost may simply be too great. They and others in their lives may conclude that it is easier for others to make adjustments to their new understanding of the AS individual than to expect the AS individual to change, even though, logically, such change on their part makes perfect sense.

Most medical insurance programs will not cover the cost of such work, even if available through a small handful of trained professionals. At this time, school and public mental health programs offer no such counseling capacity.

Passivity, Non-Responsiveness and Anger

The second response to being misunderstood is social avoidance and passivity. This, too, is a life-long response.

AS children and adults can become submissive and cautious in their actions. They may show considerable empathy for others, and repeatedly apologize for their actions. In most cases, however, they continue to repeat the same conduct or behavior because they know of no other alternative, all the while knowing that at its conclusion they will engage in an inevitable round of apologies. With their aggressive counterparts, they develop a hypersensitive sense of justice and fairness. As with their their aggressive AS counterparts, they are unsure how to respond to others in order to develop friendships and normal social relationships. Their response is anger turned inward. Professionals reporting on these children find levels of self-injurious behavior that are above average. Self-injurious behavior and serious thoughts and attempts at suicide often result in these children being prescribed heavy dosages of anti-depressive and mood-regulating medications. A small but significant minority of children are "frequent flyers" in psychiatric emergency facilities, and some have long histories of hospitalization and institutionalization.

Quiet AS adults describe being overcome with rage—they feel as if something is taking over their body—they cannot control it. In deeply private moments when they are sure they aren't observed, they may let their rage go, screaming, destroying objects (often the same type of object time after time) until the rage subsides. Like their aggressive counterparts, they feel that once dissipated, they can "go on." In their case, this may be possible because no one has witnessed their volcanic explosion. Instead of stifling their emotions, these adults may express a desire to be happier by learning how to safely express their feelings in socially acceptable ways.

In the case of their "aggressive" counterparts, there is a similar feeling that once they are finished with their tantrum, nothing further should be made of their behavior. Such expectations are totally out of sync with others' expectations about

how the individual should make amends for a recent explosive outburst. Even though their outbursts and controlling nature are right at the surface, individuals prone to explosive rage rarely acknowledge their feeling state. It is equally difficult for them to perceive the effect of their conduct on others.

Both aggressive and passive AS individuals tend to blame others for things leading up to their own explosions. While in the midst of a stressful event, they do not accurately perceive their contribution to an escalating situation. With aggressive individuals disinterested in changing their responses to frustration and anger, there may be little choice for others involved with them other than to physically leave the scene or the relationship. Passive individuals may be similarly inclined to feel that they can't change, but there is a greater likelihood that because much of their response to anger and frustration has been "private" others in their lives are willing to tolerate their passivity and non-responsiveness and accept the notion that they are unlikely to change. Such individuals may rely on others to perform many executive functions for them, such as time management, financial management, or short-term and long-term activities that require complex planning. Passive AS adults can be charming and attractive, especially to others who consider themselves helpers. Once married or after settling into a relationship, the AS adult's dependence becomes obvious, often earlier to others than their own partners. With an understanding of AS by their partners and others, people who consider themselves helpers or rescuers can make more informed decisions about whether they wish to maintain such a relationships. Often, they do.

Navigating the Social Mine Field

Individuals with AS cannot quickly study situations to decide on a socially appropriate course of action. Instead of having learned communication and social skills by intuition -- the process used by non-autistic children and adults -- they rely on a different process. In their writings and self-descriptions, many AS individuals describe how they make social decisions. They draw upon an experience-based knowledge base. Adults describe this knowledge base as working exactly like a computerized data bank. Asperger Syndrome individuals use this vast storehouse of knowledge to compare their perception of a current situation with ones experienced in the past.

Users of computerized data banks understand the concept of "Garbage In/Garbage Out." Asperger Syndrome individuals are notoriously inefficient organizers of information. Asked about a present situation, their perception of a given situation and its important noteworthy issues is highly idiosyncratic. Invariably, it is "I-centered". Their associations between past perceptions and their categories of response "folders" are likely to be wrong at the time they were first formed, and even more out of sync with a current event they find themselves in. Through life-long experience, they know this to be the case. Given time and enough "similar events", they eventually identify situationally appropriate responses, but the mental energy and processing time expended in finding the right words or the right behavior is enormous. When they are in a secure or stable adult relationship, their more functional partner often acts as a social go-between or interpreter of the social world for the AS partner. AS adults' dependence on their higher functioning partner is often characterized by their partner as "childlike" or even "like having another child in the household".

In all instances where AS individuals find themselves in different or unstructured social settings, they must take extra time to cognitively process their experience

before responding. Others do not realize that this "processing time" is needed by the AS person to make sense of "new data". They tend to become aggravated at the slow or delayed pace of the AS person's reactions.

Exasperation and irritation of others "waiting" for a response, or realizing that the time it takes for an autistic person to respond at all is too long often leads to social rejection. Without being able to precisely name the cause -- but knowing that something "just isn't right" with the AS individual -- others respond as they often do when they don't understand strangers who act differently than themselves. Social rejection and other adverse reactions by others is a frequent cause for school drop out in AS child and adult students, termination of employment, or frequent physical changes in the AS individual's living arrangements. Indecision stemming from a real fear of making a mistake often leaves an AS person "spinning his wheels and getting nowhere". Equally distressing to others experiencing an AS person's inefficient problem solving is the AS person's repeated reliance on solutions or techniques they may once have found helpful but that don't work well any more.

In the case of children and adolescents, early and consistent formal training through role playing, guided instruction in social skills through the use of other socially savvy , and the sensitive use of modified™children and adults, Social Stories cognitive behavioral techniques can make a difference in an AS person's understanding of how to form and sustain lasting relationships. (Attwood 2003)

For all such formal instruction, the AS individual must have safe opportunities to practice newly learned skills with another person in a supportive and respectful one-to-one setting. From that level, they can move into supportive small group settings, testing and generalizing social and thinking skills "scripts" into structured educational, social, community and work environments. (Winner, 2001; Gutstein 2002) As they experience success, many AS individuals can generalize those skills with strangers in the world at large. With rare exceptions, public school systems are unprepared for the cost and time involved in this type of social skills coaching. Because of the intensity of intervention required to work permanent results, parents of AS children spend thousands of dollars for private social skills training for their children.

For AS adults, almost nothing is known about effective treatment to obtain a similar "turnaround". For one thing, money and research time is not focused on adults; it is focused exclusively on children. Second, even for techniques that show promise with adults, formally conducted sessions by speech/language pathologists and specially trained psychologists have seen only mixed results. Third, in all cases with adults remedial work is extremely expensive and time-consuming and not covered by insurance or health care programs. For the present, AS adults' participation in support groups skillfully facilitated by other AS adults with AS appears to be one effective way that AS adults can learn to become comfortable with themselves, and, as they report, increasingly comfortable with others not on the autistic spectrum.

Very few such skillfully led adult support groups exist.

Impaired Communication

Impaired Theory of Mind combined with Processing Delays

From research in the early 1980's has come the term "mind blindness" and "failure of

Theory of Mind" describing autistic individuals' difficulty in perceiving and understanding the intentions of others. AS is characterized by rigidity of thought, black and white thinking, and impulsive behavior (or its opposite - indecision). AS individuals tend to take everything literally, understanding everything said to them just the way they hear it spoken. Their hearing is "often wrong". When put the test, many AS children and adults demonstrate little true understanding of language pragmatics or how given words or a phrases' use changes depending upon an ever-shifting context. They do not intuitively understand hidden ideas, idioms, and double meanings. When informed about these social language short cuts, some AS individuals become sullen, angry, or withdrawn when in the presence of people using these conventions of speech. Others become "students of the hidden language", going to great lengths to catalogue this information in their data banks.

Even if an AS person masters the words, he will have difficulty understanding the meaning of non-verbal methods of communication (posture, gestures, nods, winks, or minute but detectable changes in facial expressions). Even if an AS individual gets the meaning right, additional problems with language pragmatics (proper use; proper context) and delays in processing auditory information means that he experiences difficulties keeping up with rapid receptive speech (spoken and nonverbal). The result is that the AS individual often feels left behind in ordinary conversation.

Savvy AS adults can develop sophisticated language and behavioral responses to new situations (Shore, 2003). Their mastery of listening and "sounding as if" skills is akin to mimicry. Even so, they operate within a very tight envelope. When pressed, many bright AS adults cannot further demonstrate an understanding of complex concepts or complex behaviors that have additional meanings. Many AS individuals who depend upon their verbal fluency know how to "fake it" or "pass as normal". (Willey, 1999) This coping behavior may get them by for a while. However, their oddness and slow processing eventually becomes known to others who interact with them frequently. Depending on the social context, others can adjust to their communication impediments because of the value of their contribution to a given enterprise or project.

Others don't.

Unusual Speech

Many AS children and adults develop a style of expression characterized by long, fact-filled monologues. They show an apparent disinterest about engaging other children or adults in a reciprocal exchange of conversation. They talk "to" individuals rather than "with" them. Some AS adults describe this speech process as a "data dump". They report that once started with a monologue, they find it difficult to stop. Much to the irritation of their age mates as well as adults, they also find comfort in repeating the same routine ad nauseum.

Asperger Syndrome children characteristically develop an erudite mastery of a special topic that may be of initial interest to their age mates, but just as likely not. AS individuals have a poor understanding of the visual and gestural non-verbal signs of listener boredom. Wrapped up in their monologue, when told to cut their presentation short, they may not hear an adult or another child asking them to stop or switch topics. Unless they've been repeatedly coached and have good self-monitoring skills, AS individuals don't understand polite but indirect hints to stop. Vague or non-concrete hints don't work either. Children are often direct and brutal when they

correct one another. They leave or shun their motor-mouthed age mates.

Adults offer acceptance not available from their age peers. AS children seek out adults who indulge them out of true curiosity and amazement at their knowledge. Adults are socialized to be polite and subtle when dealing with people who run on. With their patience taxed to the breaking point, adult listeners often become exhausted, exasperated and bored. They can extricate themselves from uncomfortable situations because, as adults they have more power to control time and place.

Listeners wonder why AS individuals continually return the conversation to their favorite interest no matter how far the conversation has progressed into new topics. Sometimes this is because the AS person has mastered a script to tell a long story. He will turn to exactly the same choice of words and order of events as the last time the story was told. Some AS individuals react to interruptions to their monologues by starting them over again. Until they feel completed with their presentation, it is often impossible to have them move on in a conversation without their appearing irritated or even rude. The same need to start all over again when interrupted in a task impacts AS children and adults alike.

Oddly constricted special interests of AS individuals may be very difficult for listeners to deal with. 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.

Some AS individuals maintain the same interest in a given topic throughout their lives, while others move from one intense interest to another, often returning to earlier ones at later times in their lives. (Shore, 2003). If their special interest fits into the fold of general adult interests such as sports, entertainment or electronics, it is easier for them to make connections with like-minded individuals. AS individuals frequently put much effort into finding "targets" for their monologues by hanging around locations where such interests are common. While their knowledge still remains erudite, AS individuals can form intense, interest-based relationships with other adults. Adults who succeed in forming these relationships can gradually "catch the cues" of others. True adult friendship can arise from such relationships, but with a difference: the enjoyment an AS adult expresses when describing these relationships is often described in intellectual terms rather than emotional ones. Regardless of the terms they use, these relationships do have a substantial emotional component to them.

Expressive Speech Issues

Individuals with AS are often unaware of how their words and non-verbal signals "sound" to others. They may speak with loud, authoritative, monotone voices, droning on and on. Others, especially AS women, retain a small-person, child-like prosody and pitch to their voices, causing listeners to strain to hear them. Other AS individuals have normal adult speech, but they may be exceedingly quiet, limiting their contributions in conversations to a few words. They may go for hours at a stretch without saying anything. The AS person is quite unaware of the unintentional messages their style of speech sends to listeners. Many AS individuals do not know how to send the small postural, gestural, or vocal signals indicating they are still tracking what others are saying. When asked, AS individuals will say that they see no need to do that. They expect their mere presence to be enough of a signal to others

that they are listening. They are unskilled in the art of repairing communication that has run off track or has "misfired". Based on voice tone, volume and postures that send a different message, listeners may conclude that the person is disinterested, angry, or hasn't heard them.

Employment problems of adults are often traceable to their poor social and communication skills. They may have some awareness that others are confused by or displeased with them, but don't have the social skills or conversational tools to find out why and correct their conduct. When asked about repeated instances involving the same faux pas, they cannot "connect the dots" or divine patterns in their own social conduct or speech responsible for their dilemma. By the time they realize they are making mistakes -- often in the midst of a string of behavioral and language-choice errors -- it is often too late for them to repair a deteriorated relationship. If the AS adult is lucky to have other adults available to help them unravel a confusing situation, the individual may learn how to sense danger signals and self-monitor his conduct before things reach a point of no return. Many AS adults reporting success and a tolerable level of social comfort later on in life can identify others in their lives who have acted as personal coaches or patient adult-skills instructors.

Stilted Speech

Highly verbal AS individuals tend to use more advanced vocabulary and grammar when simple words and simple syntax are called for. Their speech sounds stilted and "professorish". If they are fluent writers, they tend to write in an overly complex way. How much they say and write is related to their personal interest in a topic. An AS individual has difficulty tailoring his response to the situation, which includes differentiating the information needs of listeners. He is just as likely to go on and on with a classmate as he is with the teacher or professor.

Saying too Little

If the AS person is not interested in a topic, his answer is likely to be short. To illustrate, correct but short answers to essay questions are a constant problem for AS school children. The student may have mastered the subject matter, but doesn't "see any need" to expostulate on it. AS adults are likely to treat conversations in which they have no personal interest in the same way. They may abruptly walk away or turn their back, leaving others confused or insulted.

Humor

AS individuals do have a sense of humor, but it can be creative and idiosyncratic. If an AS person is very verbal, his humor often involves making complex puns. This reflects his advanced, dictionary-like vocabulary. Some AS individuals haul out entire memorized scripts from comedy shows and put on the whole show, whether or not their audience is interested or amused. They also enjoy humor if a story includes a familiar topic or punch line.

AS individuals do not like practical jokes. Even if the joke is harmless, their response to them is way out of scale. They are likely to harbor resentment for having been "victimized" for a long time.

If a joke made by others involves something unfamiliar, an AS individual may be totally lost. (The response is a blank stare reminiscent of Data in Star Trek.) It may

take the person a while to process everything. Their reaction and laughter may be delayed or subdued. In other instances, once having been given explicit information and clarifying the meaning, they may join in the laughter.

Proving One's Point and Getting Things Right

AS individuals have problems identifying their emotions and the emotions of others, problems that can lead to outbursts of frustration, anger and rage. To convince others of their point of view, some individuals become argumentative, righteous and persistent beyond reason. Passive AS individuals might go silent or withdraw from the same stressful conditions. AS individuals are unable to learn social manners simply by watching others unaided. Behaviors and ways of doing things that come automatically to others must be taught step by step. Once the individual learns the basic steps, the other component to manners mastery is role-playing the behavior. Only through role-play may an AS individual learn to distinguish proper responses from socially inappropriate ones. For example, patient instruction can teach a 12-year-old answering the family phone with "Hello" rather than a gruff "Who's talking?"

Impaired Make-Believe Play

Parallel Play

Under unstructured conditions, AS children are often observed engaged in their own, separate play activity despite the presence of other children. This is because AS children do not understand the imaginary play of other youngsters their same age. They are unable to understand the projected emotions of others or imagine that others have emotions different than their own. For many AS children, their version of play hinges on the safety of scripts and dialogue memorized from movies, videos or favorite stories told to them.

Repetitive and/or Age-inappropriate Play Activities

If they favor play figures or dolls, AS children may act out these scripts in creative ways. Creativity with roles and ability to fashion complete and novel fantasy parts is more common in girls' play than in the play of boys. Boys are more apt to engage in endless repetition of the same memorized scripts or act out roles in more violent ways than girls. AS girls may desperately hue to the social scripts they see being acted out by their peers, or reject the expected social roles of girls by engaging in tomboy behavior or other kinds of activities not favored by their age-mates.

As they get older, many boys remain infatuated with role-playing fantasy games, a special interest that often follows them into young adulthood. Video games and role-play games involving cards and complicated scripts engage the attention of many young AS adults to the extent that moving into more adult game and leisure activities becomes a problem for them. Young AS adults with such interests often seek one another out, continuing a pattern of "group parallel play" difficult for non-autistic young adults to relate to. Friendships can develop from mutual involvement in such young adult "play groups", but just as likely, connections remain instrumental and focused on mutual enjoyment of a limited and predictable range of activities. AS individuals are at a loss when their companions lose interest in these activities and drift away. They do not know how to expand a friendship or allow it to move through stages where other's different interests provide the basis the basis for continued

involvement.

Some young AS adults continue their play activities with child-age play objects, such as small stuffed toys or action figures. While such objects offer them comfort, the later on in life they continue to choose such play objects, the more difficult it is for others to make contact with them and pull them out of their I-centered world into the social life of non-autistic adults.

For AS boys, finding acceptance with their own age-mates is a great challenge. As mentioned above, they will seek out adults, engaging them intellectually as a result of their specialized knowledge, and less often just for unstructured social interaction. In response to their not understanding the play of their peers, they may prefer the company of younger children. This way, they can demonstrate an advanced mastery and take charge of the play experience of their playmates. The danger to this type of age mismatch for boys comes when they reach puberty and are seen playing with much younger children. Although the boys' experience is commonly devoid of sexual overtones, adults in charge act unfavorably to such arrangements. When their parents or caregivers remove these younger playmates, older AS children may not understand the reason. This is because they find it difficult to understand the intentions of others, or that others have different concerns than they do.

Because of differences in socialization, AS girls are less prone to seek out differently aged playmates. Age and developmental hierarchies are more rigidly enforced between girls than boys. (Attwood, 1999; Thompson, O'Neil and Cohen, 2001). AS girls are likely to suffer more from depression as they are rejected by their age-mates, and are far more likely to internalize their anger than boys, whose aggressive responses to rejection at almost any stage of childhood is more accepted. Out of desperation to be accepted by both sexes, later adolescent and young adult AS women stand a higher risk than AS males of becoming promiscuous and engaging in risky social behavior.

Memory

AS individuals are known for their remarkable memories. There is a social disadvantage to having a capacious but unselective memory. In many settings, they use their recall of facts to "win" arguments. Details long forgotten by others have a disturbing way of resurfacing especially when an AS individual acts to "remind" others of facts which, though correct, are irrelevant or don't fit a current context. Arguments often arise when the AS person demands that a present situation match their recall of a similar event or experience from the past.

AS children and adults are great historians, especially about events that they participated in. (if you want to review what happened last Tuesday at noon, and who said what, ask your AS child or AS partner.) Their desire for sameness and adverse reactions to any current variation on an historical theme are responsible for their abrupt reactions to change.

There is another unpleasant social consequence to having total recall. AS individuals may uncritically divulge things to others that were told to them in confidence. They feel compelled to share all, thus breaking confidences and hurting feelings. They are unaware of the intention of the person who confided the information. They may disclose secrets out of anxiety to say something during a lull in conversation. Individuals who have been betrayed by this conduct may avoid additional contact

with the AS individual. They are so often taken aback by the disclosure that they can't convert the situation into a "teachable moment" for the AS individual.

Peculiar Patterns of Intellectual Abilities

As seen above, AS individuals have strong but relatively constricted interests. They may develop them as children and persevere in their pursuit of knowledge in the same topic throughout their lives. Other individuals develop strong but successive interests, moving from one intense perseveration to the next. Many AS 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. Universities and research institutes are perfect homes for persons with exquisite and arcane knowledge. Even if the AS person does not master many of the social conventions of professional, academic life, disciplines such as linguistics, mathematics, esoteric areas of science, accounting, and information technology all tend to attract individuals of both sexes who were earlier known as geeks, but now have perfectly acceptable titles and tenure.

Repetitive Phenomena of Rituals

Unanticipated change is the major stressor for AS individuals, but even when change is scheduled and known well in advance, AS individuals still experience inordinate amounts of anxiety about it. For autistic individuals, repetitive rituals and behaviors are means to gain a personal sense of self-control in constantly changing, unpredictable environments.

Individuals later diagnosed with Asperger Syndrome are sometimes earlier diagnosed with Tourette's Syndrome (TS) and Obsessive Compulsive Disorder (OCD). Some TS diagnoses are written very tentatively, as though the diagnostician made the best guess but still wasn't sure. Autistic childhood vocalizations (echolalia) are often accompanied by repetitive motions (echopraxia). Both behaviors occur as the autistic child experiences stress (from any source, internal or external). Some children diagnosed with TS make regular return trips to specialists who continue to confirm the diagnosis far longer than were the child to be seen by a new diagnostician at the same time. What many TS specialists "confirm" are successive, repetitive autistic ritualistic behaviors. As those behaviors lessen in intensity and frequency as the child matures, the child is pronounced "cured" by the specialist but rarely does the patient lose the diagnostic label. General medicine providers seeing the adult continue to refer to the childhood diagnosis and continue prescribing medication for their patient's "non-condition" without conducting any evaluation of the effectiveness or of their prescriptions. By history, they are prompted to look for TS, which they don't find. If they don't look for autism, they don't find ASD either.

OCD may be present in childhood and adulthood, and is a closer behavioral description of the social distress many autistic individuals experience from their ritualistic behaviors. While both childhood diagnoses may be correct, the function that ritual and repetitive behavior and vocalizations serve for the autistic individual is quite different than either purpose or function in TS and OCD.

Comforting Issues

As higher functioning autistic individuals mature, their expressive vocabularies can expand as they move through a succession of echolalic and echopraxic activities more closely approximating "appropriate" behaviors much less disturbing and distracting to others. Under conditions of stress, their need to engage in these activities -- which they find calming and "centering" -- does not disappear. As they move into adulthood and gain greater understanding of the concept of social appropriateness, they find places and times to let themselves go without upsetting others. However, for AS adults experiencing extreme stress, their behavioral response may regress to forms of reaction that typified much cruder childhood behavior.

Most adults with AS find working with people to be a very stressful experience, mainly because people are not predictable. Many AS individuals engage in repetitive activities or prefer mindless work tasks. Fondness for doing things in a rote, mechanical manner has a calming effect allowing the AS employee the time and an officially defined job task guaranteeing them a means of dealing with confusion they experience in otherwise challenging environments. These repetitive tasks are also readily given away to them by other workers. AS individuals can master such activities and perform them with accuracy, speed and ease. Following routines by the book, they may perform far better than their non-autistic workmates.

The intensity of the AS individual's adverse response to change is directly related to his desire for routine, sameness and to be in control. In all cases where AS individuals become upset with change, it is because they haven't developed an efficient mechanism to exert socially appropriate control over themselves or the situation.

Many AS individuals develop patterns and routines that must be followed. Predictable bedtime rituals are common with children, but just as common, though less noticed in adults. Dependence upon a set, ritualistic routine is commonly found with eating habits, self-care, and approaches to common personal, household or work tasks. This routine is not negotiable—it must be followed—and if interrupted, it has often been noted that an AS individual 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 following that routine. If the AS individual is in an adult relationship or in a family setting, their rituals often have the effect of "terrorizing" other members of the family into submission to their routine. (McCabe, 2003; Stanford 2003)

Socially challenged AS adults may act impulsively, changing jobs and locations with the hope that the next change will "fix things". The fix doesn't happen. Given their dependence upon routine but their poor self-understanding of how badly they respond to change, in their new settings they re-create their favored routines in desperate efforts to surround themselves with conditions they can predict and control. Through successive moves, they rely on persons important to them to remain unperturbed by uprootings and upheaval caused by moving. They are often oblivious to the pain and discomfort their impulsive moves have on family members whose other relationships are constantly under threat with the prospect of yet another move in the future.

Other AS individuals, desperate to stave off the effects of change over which they have no control, hang on to a situation or a relationship for dear life, long after the

life has been squeezed out of the arrangement due to their reliance on their helper-type partner coming to their rescue.

Providers working with AS adolescents or adults must be sensitive to the social context in which the AS individual operates. They must understand that if the individual is a "loner", unemployed or frequently unemployed, disconnected from effective support services or not in a relationship, their client's awareness of the world is vastly different than AS individuals who have made significant social connections. Loners' social-problem-solving skills are likely to be rudimentary and very inefficient. Because of their disconnectedness, results of their poor decision-making are confined to a small circle.

If the AS adult has made significant progress in the social world of adults, the perspective of any helping professional must widen to include everyone touched by the individual. Adult problems are far more complex than the problems encountered by children. The consequences of making a bad decision can be far-reaching, affecting the lives of many persons in the AS adult's life. When AS individuals marry and have children, consequences of indecisiveness and/or impulsiveness in inefficient adult decision-making and poor parenting affects the whole family. As a result of repeated experiences of poor problem-solving by the AS parent in an intact marriage, the higher functioning partner may "close" the family to the outside community, averting future embarrassment and shame caused by the past conduct of the on-spectrum partner. When families become closed, either as a result of an autistic adult or an autistic child's behavior, the closed character of the family presents special challenges to community service providers.

(For more on AS and family life, see the separate section below.)

An Interesting Exception

All individuals diagnosed with AS demonstrate unusual responses to change. Without being prepared for anticipate change, AS individuals have difficulty responding to new problems. However, if their "data bank" is large enough, they may be the cool one in situations where everyone else is in a panic. This is because they've learned the drill to handle such emergencies. The one thing they know how to do is take control. This fact may account for the successful law enforcement, corrections, military, and first-responder careers of a few people with Asperger Syndrome. Others defer to such persons. Rules governing their roles call for them to be in charge.

II Commonly Associated Conditions

This section is short.

Professional literature on Autistic Spectrum Disorders is rife with discussion concerning other conditions commonly associated with AS children and adults. Two clinical conditions have already been identified: Depression and anxiety. They remain life-long conditions for persons diagnosed with AS. How each condition is managed in later life becomes quite an individual matter, unique to each person.

Other conditions include Attention Deficit Hyperactivity Disorder, although the

"hyperactive" character of ADD rarely continues much beyond late adolescence. The likelihood that a child is not primarily ADHD is often confirmed by the decreased effectiveness over time of the types of medication, educational and other and treatment modalities prescribed for "real" ADHD. On the other hand, ADD-Inattentive Type does appear to be a condition shared by a good number of individuals eventually diagnosed with Asperger Syndrome. Tourette's Syndrome and Obsessive Compulsive Disorder are discussed above. It is possible for AS individuals to have trace elements of both conditions continue on into adulthood, but it is more common that a late and accurate diagnosis within the family of pervasive developmental disorders or PDD's (of which AS is a member) accounts for some traits of both disorders.

Chronic sleep problems are common in many children and adults diagnosed with AS. Sleep deprivation is often not seen for what it truly is and what it does to behavior, especially in children. Ear infections as well as hearing problems are surprisingly common in autistic children. In AS children and adults, Central Auditory Processing Disorder is often responsible for the individual's incapacity to hear directions, instructions, poor auditory memory, or their difficulty following conversation or directions in noisy environments. Vision difficulties are often reported early in children later diagnosed with ASD. Even with perfect acuity, ASD children and adults may experience problems processing visual imagery or accurately recalling details so that their working visual memory is not impaired. Central Vision Processing Disorder (best diagnosed by behavioral optometrists familiar with how the eyes function in relation to the rest of cognition rather than what they only "see") is a common reason why AS children and adults develop severe problems with handwriting.

Boundary violations of all kinds are prevalent features of AS conduct. Children are prone to bump into things or be unaware of where their body parts are in relation to one another or to the external world (proprioceptive difficulties). Many AS children and adults have profound difficulty understanding the concept of physical and social "appropriate distance". They must be patiently trained to comprehend these concepts. Of course, understanding boundaries has other implications as well. If a person remains unaware of the meaning of socially appropriate distance and one's own personal physical boundaries, there follows a reduced likelihood that one can begin to understand psychological distance, differences between "yours and mine" and the very concept of other's personal needs to protect their own psychic as well as physical space.

Clumsiness, problems with balance and coordination are conditions reported with much higher incidence in persons with AS. Faced with formidable developmental challenges obvious to their age-mates as responsible for much of their social rejection by them, AS children develop other means of compensating for their delayed coordination. Already "in their heads" a lot by reason of having an idiosyncratic way of thinking, AS children and adults depend upon their intellect and memory to leverage acceptance by anyone taken in by their unique way of being. Invariably, those most impressed by their exploits are adults or younger children. By both groups their physical clumsiness isn't seen as the same kind of impediment responsible for rejection by the AS child's age mates. Unless care givers and educators know how to sensitively handle the issue of including clumsy AS children in non-competitive interactions with their peers, AS adults remain mindful throughout their lives about the doors to social acceptance slammed shut against them during their childhood and adolescence.

Through the self-report of AS children and adults comes overwhelming evidence that sensory issues of all kinds overwhelm them. Autistic individuals experience hyposensitivity as well as hypersensitivity. Their reaction to sensory stimulation of the wrong kind is sometimes abrupt and unpredictable. Textures, tastes, smells, certain visual and auditory conditions, all affect AS individuals differently and uniquely. An autistic person's reactions to sensory overload can be mild or severe and often cannot be explained unless the observer understands the stressors that have built up a person's "charge" to a breaking point. Many AS children seen by Occupational Therapists trained in sensory integration techniques benefit from a variety of "sense-making" and "sense-management" techniques that can be learned. If a child is disturbed by sensorially overwhelming experiences, or needs an "extra dose" of a vital sensory experience to function, the child remains unready to learn until the situation is corrected. The same is true for many AS adults, although by the time of adulthood, many persons aware of their sensory issues know what is necessary to maximize their learning or performance potential.

Sensory issues are so influential for many AS individuals that one AS woman described the effect of staunching a sensory reaction as trying to stop vomiting when you have the flu—it just isn't possible.

Many individuals diagnosed with AS experience dietary intolerance to certain basic food substances such as gluten or dairy. The incidence of immune system reactions associated with digestive disorders is much higher with autistic individuals than the standard population. Diverticulitis, Celiac Disease and Krohn's Disease are three such disorders. Neurological disorders such as fibromyalgia also have a higher incidence and earlier onset date in autistic individuals.

Reduction of distressed behavior of many children (and fewer adults) once certain substances are removed from their diet is widely reported but still largely ignored by traditional medical providers. This is the reason why parents of autistic children often turn to naturopaths and holistic medical practitioners whose approach to differences in human conduct is much different than their Western medical counterparts.

III Traits by Age

Under extreme stress, AS adults can exhibit very child-like manifestations. However, as individuals age, most develop a wide variety of coping skills and discover ways to mask their behavioral traits so that under many circumstances they can "pass for normal".

This section gives the reader a glimpse of telltale traits of Asperger Syndrome commonly expressed at each stage of development. Readers must remember that every AS individual is different and they may not manifest all of the traits identified for each age.

In infancy and early childhood, this section will focus on additional "surprising" traits rather than those most commonly discussed in the vast literature on AS children. The reason for this emphasis is to make the reader aware of some of the features of early AS expression that prompt inexperienced professionals to conclude that the child is normal or that they see nothing wrong. Parents' primary complaint about

diagnosticians they visit in order to understand their own children is that diagnosticians, not prepared for "extraordinary phenomena" also overlook the obvious signs of autism in children. If the "A" word is not in the parent's vocabulary or isn't looked for by savvy professionals, it is often not seen. Many of the signs of AS are so subtle and mercurial in children that they are overlooked altogether, despite caregivers' insistence that the child demonstrates the "missing" behavior all the time under real life, rather than office-visit conditions.

Although the DSM criteria call for "normal" speech development, in the preschool years an AS child may hesitate talking well beyond the age at which their peers speak (delayed speech). From few words, an AS child may suddenly speak in full sentences" rather than going through some of the trial and error steps shown by other children. This development may startle observers. There is a simplistic but surprisingly accurate explanation: AS children are acutely observant of details and may rehearse things in their heads long before they express their thoughts in speech. Even at a very young age when a child is asked why he hasn't spoken before, he may say something as disarmingly simple as, "I didn't need to say anything before." Such a response may already reflect the child's undisclosed fear of making mistakes or not being perfect "the first time around".

An AS child may begin talking in complete sentences about complex issues well beyond subject matter mastered by a child of that given age. These sentences may appear to be memorized; indeed, many of them are, from sources heard or read by the child, who may be a precocious reader (hyperlexic). Listeners are often so bowled over by the length of the expression and sophisticated words being used that they rarely determine whether the child actually understands the meaning of the sentence or particular words used. Mastery of language extends to skills way beyond word recognition and memorization. It also involves understanding the pragmatics or contextually proper use of language. If there is doubt, further testing by a speech/language pathologist especially trained to test for semantic-pragmatic disorders is warranted but rarely conducted with linguistically precocious pre-school children.

Play patterns are a dead give-away and predictor of the child's current and future difficulties with social communication. The AS child does not know how to properly initiate contact with other children, or may have done so with poor results often enough in the past and been rejected by them that an early-established pattern of self-isolation may already be in place. The child will play by himself, even with "with" children. The child may be oblivious of the welcoming conduct of other children, or totally confused about how to initiate conduct in the absence of adult help in becoming included in the social world of other children.

The AS child may remain with a "mature" and serious demeanor in the midst of other children's quickly changing moods. Such "model conduct" is especially true for AS girls whose general temperament may move them to being passive. What the AS child may be doing is observing or studying the other children, trying to "get it right" before making a first step to participate with others. At this very early age, they have learned not to be risk-takers, and other children sense that about them. They are "no fun".

AS children may rock, "fidget", or even "flap" when concentrating. 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 scream and “meltdown” in a situation with many people around (like the grocery store, or parades). He is unable to participate in “imaginary” play, and on close observation seems to be acting out entire behavioral and verbal scripts from memorized or favorite games, stories or videos. He may spend hours at a time lining up object or sorting them—not using them for the play purpose intended or commonly accepted by other children.

AS children experience far more ear infections, digestive disorders, “tummy aches” migraine headaches, and undiagnosed or late-diagnosed sleep disorders. AS children often miss out on early social experiences because of illness and the effects of illness on their temperaments. If they aren't behind “before”, once they've missed a certain critical mass of days in certain settings they lose their chance to gain a place in the social pecking order of very young children's social groups. Even without health issues affecting attendance, AS children have substantial separation issues. They are often responsible for a child not attending pre-school groups. No amount of adult “repair” efforts can overcome the effects of having missed certain bonding opportunities. Parents often find themselves being asked to remove their child and to find other child-care and pre-school arrangements, whether once the child arrives he is a behavior problem or not.

Many parents of AS children report difficulties with their children's toilet training. “Accidents” continue through much older age throughout the elementary school years. The child may avoid eye contact with children and adults, or be highly selective with his eye contact. He may seem to have unusual difficulty in learning to dress himself. Problems with eye-hand coordination, time management, avoiding distractions, “getting lost in thought” and other disturbances to a smooth routine may contribute to delayed self-care of all kinds.

In regular school, the child cannot carry on reciprocal conversations and is more inclined to carry on monologues. He prefers the company of older or younger individuals. Unless they really listen in to the child's conversation, teachers and administrators incorrectly assume that a child is “social” because he is seen talking to another child. Even during structured events, and invariably during unstructured ones, the child will be a “loner off to a corner or noticeably right at the outside edge of group activities.

The child may be uncoordinated, and have difficulty with any activity that requires bilateral coordination or two-handed coordination. They may have difficulty swimming, sustaining an activity that requires good balance or coordination of their body parts. They refer to themselves as “klutzes and geeks”. So do others. AS children are among the last ones picked for team events, whether by the children themselves or by teachers. (Teachers may reinforce the marginal nature of the child by encouraging or even participating in the social exclusion conduct of their students.) They are rarely shown leisure or fitness exercises that are individualized enough to become a part of their adult life. Predictably, many adults with AS have little interest in their own personal fitness.

Many AS children have deficient fine motor skills (rarely improved in later life). Handwriting is often laborious and awkward. Papers are messy. The child lacks self-organizing skills -- even if they complete homework, they often lose it before it can be turned in. Extreme spikes of educational interest appear with the first formal in-class assignments. They are very obvious by the time homework is first assigned.

The AS child may take naturally to one or two subjects but has absolutely no interest in others. Study habits are inefficient because the student's memory or other learning abilities are deficient. An AS child can study one subject forever during the week and "lose it all at test time". One mother of an AS son writes: "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 be hyperactive for any number of reasons, some of which have nothing to do with ADHD. The child may simply be bored, or need time to decompress in the midst of a stressful subject, or become sensorially overloaded and needs to find relief. He finds it difficult to stay in his seat for an extended period of time because it is "uncomfortable". The child may stand up every now and then, or walk about the classroom, or walk out of the classroom in the middle of the lesson, causing the teachers, administrators, and parents considerable concern.

Unable to find words to describe tactile overload or tactile and other preferences, a child may refuse to wear fashionable clothing or become demanding a certain type of clothing -- a certain color, a certain style, or a certain type of fabric. Before wearing anything, the child may demand that the tags be cut out of every stitch of clothing. The child may want to wear the same "uniform" day after day revealing distressful personal hygiene and self-care issues that may remain life-long problems.

The child may adopt a loud, high, or monotone voice that is so identifiable with AS. Many girls and some boys will retain child-like "small voices" or be resistant to remediation of vocalization issues way beyond puberty. The child's sleep disorders, not as much a problem prior to the time when he is expected to manage his own time, become huge problems by contributing to family stress or squabbling for shared parental attention among siblings.

Food preferences and controlled diet, somewhat manageable at home, become major challenges once the child eats away from home and starts sharing food with classmates. Strong reactions to some foods and food odors may cause him to refuse to eat with other children. His reactions may be so severe that children avoid him because his behavior becomes obnoxious or invasive as he openly criticizes other children's food choices. The child may be so upset around food issues that he fails to eat enough -- or at all -- at school meal times. Add food deprivation to sensory stress and sleep deprivation, and you have an instant recipe for a student so stressed that he is unable to learn.

The stress of holding it together while at school may cause the child to "melt down" as he arrives home. He may disappear to his room or sit at a computer or video game for hours trying to unwind. He may sleep for hours, upsetting family life at a time it is likely to be the most active. At this stage parents who do not understand AS may begin to put additional pressure on the child to "conform" to their expectations about the child's behavior and performance at school and at home. As lessons and assignments become more complex in middle school, parents with these reactions cause more stress, confusion, and frustration for the child. If the pressure is severe enough and there is insufficient relief and understanding at home, this is a time when the child openly expresses thoughts of suicide.

From middle school into high school, the AS teenager's lack of self-organization (executive function skills) and spikes of interest (as well as troughs of disinterest)

intensify. Ever more conscious of other children (and often late in becoming so), the AS child becomes the brunt of jokes and the victim of bullying. With delayed social and communication skills, the child experiences the swirl of constantly changing expectations of teachers, fellow students, and his parents. By this time the AS child knows that he is different and not accepted by others, but rarely has insight into "why". Out of depression and anxiety, the child may start to withdraw from previous sources of support not with the idea of being more accepted by his peers, but from a desperate desire to be left alone. If the child has a special interest that gains him acceptance by even a few persons, whether peers or adults or any positive role model or mentor, he may "make it through" high school scathed but as a survivor. Many AS children are not so lucky. Parents try every thing they can to prevent their AS children from becoming drop-outs. Nevertheless, many do drop out and seriously compromise their chances for continued education, decent employment and living independently.

AS students rarely date in high school. Even though they may see others "pairing off"; they have little idea how to initiate this kind of social conversation or contact. They may approach others in very juvenile ways. That doesn't work. They want to be "normal" like everyone else but have no idea how to achieve it. By this point, AS adolescents have moved beyond the capability of most social skills specialists to bring them up to speed with such advanced skills. Social skills' training for AS teenagers rarely includes "the graduate course" of how to date.

For most AS high school students, homework is a major challenge. The student has not developed study skills that help them record assignments; they forget texts and materials needed to complete lessons, have a poor concept of priorities and little success with envisioning efficient sequences to accomplish tasks. They do not know how to ask for help. They manage their time poorly, and don't know how to initiate projects. AS students put perfectionist demands on themselves that are unrealistic, often as a result of having been repeatedly criticized. Faced with an assignment they could otherwise complete if they took it one step at a time, they engage in catastrophic and all-or-nothing thinking, a process that often leads to no work being turned in. For some "grind students", homework time at home may exceed the time the student spends at school. Other students resist a repeat of the day's struggles at school and routinely force pitched battles between themselves and their parents over the issue of how much homework -- if any -- they will do. In some cases, a parent will complete some or all of the student's assignment, resulting in passing grades but no learning by their child. Thus, what looks good to others on paper isn't what it seems. Such parent action teaches the child learned helplessness and supports the child's expectation that if they resist something long and hard enough, they can wear others down to do it for them. Such notions carry way into adulthood.

Some but not all AS students are unable to generalize from classroom or homework lessons and apply them to everyday life issues. For students with this type of specific learning disability, they fail assignments demanding that a student analyze and "extend" a problem into a general application. Complex problem solving of this kind is only partially related to the student's executive function challenges. There are other deficient cognitive processes also at play.

AS individuals categorically have difficulty with team assignments. This holds true for graduate students and most adult AS employees as well as kindergartners. They do not have the social or the cognitive skills required to be sensitive to the kind of sharing, collaboration and sensing others' needs, as well as the skills to delegate

required for completion of team projects. If forced into teamwork assignments, it is likely that in elementary and secondary school they will be teamed with "goof-offs and losers" because teachers rarely have time to build teams composed of students with poor social skills to start with. Misplacement with students having similar social and communication deficits means that the AS student is robbed of the opportunity of learning essential team skills from a balanced, heterogeneous group of students.

Asperger Syndrome and Telling the Truth

Most challenges of AS adult life have already been covered in the writing above. However, one issue hasn't been addressed: the issue of AS individuals and how they handle truthfulness.

AS individuals rely heavily on rules, most of which they understand to be immutable. The one thing few of them understand and truly take to heart is that nearly all rules allow for exceptions to be made. In some cases, it may be possible to come up with clear guidelines governing when a given rule doesn't apply. With their encyclopedic data bases and given enough time to sift their view of a situation using those guidelines, AS individuals can take an almost infinite number of sub-rules and come up with the socially appropriate response.

The operative words in situations like this are "data base" and "given enough time".

AS children begin early to build their database for determining the correct course of action in difficult situations. They are taught to tell the truth, and they do so willingly and automatically. As noted above, some AS children act as "truth enforcers" uncritically applying their unsophisticated understanding of rules to anyone of any age or authority level.

The Good Side of Telling the Truth

Finding themselves in the midst of a situation that calls for fast footwork -- lying -- AS children are, at first, notoriously poor liars. If they are verbal and outgoing, they may go around acting as the "truth police", correcting others on factual details and not even hesitating to call someone -- anyone -- a liar for their not telling the truth.

It is safe to say, categorically, that the younger an AS child is, the greater the likelihood that he is telling the absolute, unvarnished and complete truth. One cannot say this for non-autistic children of the same age.

Here is one mother's description of her son's "rules super cop" reaction to a common rule being broken:

"My AS son thought it was a mortal sin for me to go through the express check out line with more than the maximum number of items posted on the sign above the cash register. I had eleven items; the sign said nine! How dare I break the rules! He would have regular, dramatic meltdowns as others in line ahead of me or behind me stared in amazement at his behavior."

An even younger child combined a number of no-nos with regard to telling the truth, without regard to the consequences. The same mother describes this "different behavior" this way:

"AS individuals can also be blunt and disarmingly honest. Observing someone on the street or in a store, an AS child might blurt out, 'Look at her. She is soooo fat! She should go on a diet!' 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 their feelings as every one can see that they are fat? I am only saying what ever one else knows to be the truth.' Without careful, repetitive training, these children simply do not understand the concept of '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 teaching the child about socially approved white lies or showing them how to express their true feelings later, many parents adopt a very 'autistic-like' 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 from an accurate self-understanding of their unique perceptual challenges."

"Good Withholding; Bad Withholding"

Many childhood games and much of childhood social life is based upon imagination, trickery, deceit, the dynamic of telling and keeping secrets, and developing an increasingly sophisticated understanding of the foibles of others while still building mutual trust with them. AS children do not understand that the telling of secrets and lies and keeping them hidden from others is the cornerstone of much early social bonding. They do not understand that sometimes hiding the truth or fudging it is what keeps a bond together.

Asperger Syndrome children generally dislike games where these skills are developed. They prefer role-plays, games whose scripts and whose characters' actions are predictable, even if they are bad actions.

They dislike being lied to directly. They dislike being told half the truth rather than the whole truth especially if they feel something is being held back from them. They are frank in their descriptions of people and events, often brutally so.

The problem with AS children and many AS adults is that they have no "escape valve" for working their way out of instant dilemmas, no way of fudging or being indirect with more words when a few, direct words do perfectly well. Those words hurt, and their words often land them into serious trouble. Such words blow away potential friends. They violate confidences. They erode trust. More than anything, they make the person uttering them an unsafe person to be around.

No one except an AS person relishes absolute and stunning honesty all the time. Almost from the time we are placed next to another child, with or without language, certain things are best not done or not said. AS individuals have to learn this idea through rough and painful lessons.

The above description applies to the very young and the very naïve. While many AS adults remain naïve and gullible, they aren't stupid. Rather than lie, they may remain silent about a situation. If they aren't particularly talkative, that's where things remain with them.

But some AS children -- an increasing number of them thanks to early social skills training -- learn the difference, and start their practice somewhat late, but practice they will, and as with most practice, the more they do something, the more comfortable they are telling good social lies. Still, doing so still involves a lot of deliberation and mental effort. They will often do so out of their perception that a lie is what a person they respect "wants to hear". They can easily be led to lying, especially by persons with ulterior motives, such as criminals, people who abuse others but upon whom the AS person depends, and by unscrupulous law enforcement professionals unaware of how naïve and vulnerable a person they have in interrogation.

There is another category of AS children who also learn how to lie, and lie convincingly: children whose upbringing is physically and psychologically traumatic and full of unrelieved chaos. For them the telling of lies isn't only good practice. In the past, it has helped them survive life-threatening situations. If they've become involved in the child welfare system for any length of time, they also learn to lie to protect themselves from their "protectors".

They get good at it. They get pathologically good at it. And, these individuals grow up and become adults.

There aren't many such inveterate liars among adults, but it would be unfair in describing individuals whose individual manifestations of AS are so unique, one from another, were this fact not known.

Self-Abuse

There is one other bit of unpleasantness common to many adults with AS. Many adults who have reached a modicum of independence and control over their own lives may have done so through periods of self-medication and substance abuse. In instances where they have been able to stabilize their support systems to include marriage and employment, the reasons for drug and alcohol abuse often fall away. Except for individuals coming from families with a genetic proclivity towards substance abuse, they are able to live their lives fairly clean and sober, sometimes to the point of becoming teetotalers and swearing off all medication as harmful and unnatural. It is important for the reader to remember that despite their past abuse of drugs or alcohol, they are Asperger Syndrome first and foremost, subject to all-or-nothing thinking.

As with the non-autistic population, there is a small core of autistic individuals who become truly addicted to drugs and alcohol. While the reasons for turning to self-medication -- to dull the pain of rejection and misunderstanding by others -- are understandable, successful treatment and rehabilitation of this small core of individuals is about as likely as it is for their non-autistic counterparts. Depending upon the length of time of their addiction, it may be more humane to consider mental health attention for "wet" addicted persons than no treatment at all. Clearly, traditional 12-step programs and non-traditional anti-abuse programs are not for everyone. Depression is a constant companion to autistic individuals. There is a good but sad chance that in a few instances, dramatic behavior associated with a severe depressive episode or deterioration of their physical health may well "end" others' efforts to help such persons

IV AS in the Family

A challenge to US National Autism Organizations

Prominent national autism organizations have pussyfooted around this topic way too long. Their focus on the large majority of lower functioning autistic children and adult children has kept their eyes glued comfortably on the ground. Majority statistics surrounding classic Kanner's Autism have kept these organizations focused away from at least one reason why many of their local and state chapters continue to remain generally unwelcoming to parents and individuals with Asperger Syndrome. The reason may be as simple as this article's modification of comic character Pogo's utterance:

"We have met the enemy, and it is us."

There is uncomfortable but undeniable truth in the assertion that children who in infancy and early childhood appear to start out as profoundly impaired as their classic Kanners majority cousins somehow manage, by the time they attain school age, to move from classic autism to Asperger Syndrome. No one has come up with an explanation "why" and for the purpose of discussion in this section, it doesn't matter.

Why many parents of classically autistic children have such a problem in turning the ASD spectrum searchlight on themselves is not for us to guess, but after ten years of formal knowledge of AS, it is safe to suggest that (1) in many cases, there is a connection; and (2) massive denial of all kinds and at all political levels continues, despite what we know, not because of what we know about autistic spectrum disorders.

This phenomenon may be the biggest elephant in the room, yet few in the "autism establishment" dare touch it.

We do.

Doing so may explain some of the squeamishness and discomfort of parents and family members of profoundly affected autistic children. Intense national organizational focus has remained on finding cures and developing effective early childhood intervention methodologies. At a national level, policy and member chapter discussion centering on the reality of autistic spectrum parents raising autistic children has met with thundering silence.

Despite an increase in presentations on Asperger Syndrome and participation of AS children and adults in national convention presentations, most major autistic organizations of the US, through inaction of their member chapters remain quite inhospitable to membership of Asperger Syndrome parents.

Discussion about autism in the family has long been underway within the Asperger Syndrome community. It is now time to bring the discussion into the broader forum precisely because autism is a spectrum disorder.

Ten years ago, this section would have been likely titled "AS and the Family". Until the last decade, even had Asperger Syndrome been officially identified earlier, it

would have been possible to discuss Asperger Syndrome as a condition that occurs rarely without considering either its origins or studying its impact within families, or whether autistic families and their members function and behave differently than their non-autistic counterparts.

This is no longer the case. Interest in the human genome gave rise to the last decade of the 20th century as a period featuring two parallel tracks of intensive scientific scrutiny. One track prompted medical and psychological experts to look carefully into the family histories of thousands of individuals just being diagnosed with Autism. The second track, one featuring equally intense imaging and brain chemistry studies of how the human brain works, uncovered differences between individuals and differences between the sexes unimaginable before the dawn of new technology. For the first time, we have been able to observe autism "at work" in the brain.

Numerous family history studies all point to a greater than fifty percent chance of AS within an individual's primary relatives. Equally surprising are findings that diminishing but high incidence figures indicate that AS or AS trait behavior can be tracked, by history, back through numerous previous generations of the same individual through second and third order relatives. Even more surprising have been an increasing number of anecdotal reports that in a number of families, Asperger Syndrome runs through both the biological mother and father's families.

An increasing number of child diagnoses have led to adults in the family being diagnosed with Asperger Syndrome. No responsible child diagnostician should fail to consider whether additional members of the child's family are on the autistic spectrum. Without first considering parents, experienced child specialists may look first for AS in biological and then in blended family siblings. One reason for taking additional side views relates to statistics: a number of individuals "somewhere" on the autistic spectrum marry other persons with Asperger Syndrome, and their marriages "work". They are likely the minority of intact marriages where there is Asperger Syndrome present on a single biological parent's side of the family. In view of the increasing number of thoughtful publications focusing on Asperger Syndrome marriages, conscientious child diagnosticians should consider the possibility of additional close family members having autistic traits or full-blown autism.

Exact figures are hard to come by, but the most challenging disabilities found in children may account for up to ninety percent marriage failure. Autism is among such disabilities. Single parents raise a large percentage of Asperger Syndrome children. It isn't always the case that Asperger children are raised by the higher functioning parent of a dissolved Asperger Syndrome marriage. The single parent -- most likely the mother -- may or may not be on the autistic spectrum herself. Further, there may have been no marriage or living together arrangements of any length. If the prime parent is AS, she is susceptible to increased stress of raising children alone in addition to whatever challenges her own autism and other health complications add to the picture.

This section cannot do justice to the topic of Asperger Syndrome marriages or relationships found in recently published books, but it can raise two issues that hover just beyond the focal point of this growing body of literature.

The first is family violence and spousal abuse. The second is the probability that children on the autistic spectrum raised by an autistic parent or parents may experience the effects of problems in parenting caused by the kinds of cognitive

challenges common to adults on the spectrum.

Domestic Violence and Abuse

Just as with regular marriages and relationships, domestic violence of all kinds, and spousal and child abuse are very real phenomena in Asperger Syndrome relationships. Understanding abuse makes it no less tolerable. Just because inexcusable acts are committed by autistic adults does not make them any less despicable, nor does autism soften the effect of its visitation on spouses, an Asperger child or children in the marriage, non-autistic children in the family, close or extended family members, or professionals providing service and support to the family and its members.

Earlier in this article, reference was made as to why some Asperger Syndrome families become "closed families". They become closed for much the same reasons that families experiencing domestic violence and abuse become closed and secretive, inaccessible to community support providers, mysteries to neighbors, but not very well hidden secrets to community justice and public school authorities. Victimizers as well as those victimized withdraw from the community at large out of a zealous need to control the chaos in which they live and which they exact in turn upon their victims -- all of the children in the marriage. In this picture, not holding the victimized adult accountable for the effects of domestic violence on the rest of the family is both unrealistic and unhealthy.

When the family withdraws from involvement in the community, what victimizers and their adult victims unleash are repeated acts of chaotic violence and abuse, each instance standing a chance of being less likely to be reported by its all of its victims as well as those in the community well aware of problems in the closed family but reluctant to report it. It is fashionable and a least expensive policy for first responders to refer for treatment the obvious victims of domestic violence. With human services support resources in our states stretched thin or bankrupt, unless things turn around immediately, the next decade will see more throwaway children and irreparable relationships hobbling on without meaningful, long term help.

Dysfunction in AS Families in the Absence of Outright Violence

All of the illustrations below depict worst-case scenarios.

Worst cases are presented for this reason:

It is important for social and policy planners to have a good understanding of the complexity of problems that can and do arise in AS families so they can design support systems to accommodate the toughest cases. For other easier to understand and more traditional mental health conditions, some of this has been done. Specialized mental health disorders organizations long ago began the work that should now commence within the autistic spectrum community.

Dysfunctional AS family life can dip to such extremes. The purpose of presenting these examples is not to encourage readers to expect this level of dysfunction where one or both parents are on the autistic spectrum. However, these examples are not fictional. As a result of his work as a Social Security claimant representative, the principal author of this article has seen the dysfunction depicted here in numerous families of late-diagnosed adults where there is Asperger Syndrome present in at

least one member, and likely undiagnosed AS present in multiple family members.

A Note about "Successful AS Families"

Myriads of books have been published over the past 15 years trumpeting individual family success stories. There is no need to repeat them here. To a very large extent, we do not hear of typical AS families until and unless things start to break down with them.

As a result of benefiting from their own self-determination, disabled parents can be good or better parents than non-disabled parents. Their decision to marry and have children may involve much anticipatory discussion and problem solving in advance of the marriage.

That's the good and hopeful side.

However, whenever there is disability in the family, whether with a child, or with several children, or present in the parent(s), special strains and stresses may be present that are harder to compensate for, even though resources outside of the family often do make a difference, especially to the children. Ultimately, a family could spiral into dysfunction and dissolution unless such external resources remain in place as "fail safe protections".

They rarely do.

Control

Money and finances are often the most insidious means of exerting control by an AS spouse when everything else fails. Asperger Syndrome spouses may be good or bad financial managers but are, in fact, the principal breadwinners in the house. To the outside world, they maintain the veneer of respectability and normalcy. Within their family settings, their behavior changes from one unpredictable extreme to the other, from kindness to unspeakable cruelty.

They may hide their money from their partners, or dole out demeaning amounts, demanding exact accounting for each penny spent. Critical household bills may remain unpaid as the AS spouse indulges himself with expensive special interests or hobbies. Joining him in those activities may be the only way the children share time with him. Even then, he may suffer their attention or interest or easily become upset because their interest is not as intense as his.

AS parents can and do go on the attack against a same-sex child with their same condition, scapegoating the child, demanding performance of the child they once demanded of themselves or out of memories of what their own autistic parent may have done to them "at the same age". Allowance is rarely made for their child's age or recognition of the child's accomplishments. A higher functioning parent may do all she can to shield the child from her partner's attacks, but as long as the partnership lasts, the child holds both of them responsible for what is happening. For the AS child, memories and the effects of such treatment remain life-long, and may remain every bit as influential years later as they are at the time they are first recorded.

Tyrannical, volcanic temper tantrums can erupt at any time, or with frightening predictability. No one is spared as a target or onlooker.

Control can extend to far more than finances. Family members may be conditioned to "walk on eggshells" due to an AS parent's eccentricities or unpredictability. The entire family's schedule and routines can be dominated by one parent's absolute need for routine, order, and having things done "my way". Vacations and family outings may be totally determined by the singular interests of a dominant AS parent. Often the effect is so far-reaching and may have gone on so long that other family members and family friends and acquaintances also accede to the AS spouse's "special needs" in ways that unknowing outside observers find quite unbelievable. (McCabe, 2003)

A financially dependent but higher functioning partner may see no way out of the relationship until the children reach a certain age. She may stay in the relationship "for the sake of the children" without considering the toll such a forced commitment may have upon the children's singular experience of "this kind" of marital dynamic. If the family isn't completely closed, it may be possible for the children to experience alternative family lifestyles with relatives or friends. With one or both parents' approval or acquiescence, some AS children actively seek out proxy families or proxy parents in an effort to experience things missing in their own families.

The AS spouse can be a packrat, with personal and special interest items spilling into common family areas or overtaking the entire house, crowding into the other spouse's identity and everyone's personal space. With an absolute need to control things, the AS partner continually violates boundaries unaware of the ruinous effects of his conduct. Housekeeping chores such as vacuuming or laundry may remain on hold due to sensory hypersensitivities or a demand for complete silence from individuals or activities carried on anywhere near the AS parent. Household maintenance and repairs may remain undone due to the AS partner's clumsiness or scattered ability to stay on task and complete one project before half-starting another.

The AS partner may be totally unable to multi-task, so patient parsing out of tasks or parenting responsibilities one by one, or one step at a time, may be all that can be managed. The AS spouse may have no interest in a disabled child's education or that of the other children. The AS parent may be unable to care for a sick child or even be aware of a well child's basic emotional needs. Important dates such as birthdays, holidays, and other special occasions are "kept" by the higher functioning partner with the AS partner often in complete oblivion about the importance of remembrances or special acknowledgments to family members. If the partners have struck an arrangement regarding "appearances", for a given occasion the AS spouse may put in an appearance or utter rehearsed but obviously forced words. While minimal, such "sharing" evidences some kind of acknowledgment of considerate behavior.

Housekeeping standards of cleanliness and orderliness may be set to unusually high or very low standards. Strangers visiting the household are often surprised at what they find. These may be conditions of almost unbelievable order despite the presence of young children, or equally unbelievable squalor and litter. In marriages where there is a healthy degree of give and take through negotiation between the partners, some middle ground may be struck. On the other hand, standards may be set or left at such extremes that the tension standing between the partners on this one issue is almost palpable.

The AS parent may ignore all or some of the children, obviously favor one child over

others or be so unaware of the children's needs as to be an unsafe or neglectful caregiver. Chore division and sharing of responsibilities may be so one-sidedly piled upon the higher functioning partner that the AS spouse acts like and demands as much or more attention than the children. The AS partner may have a number of serious health problems and medical care needs, some of which are more frequently seen in autistic adults than in the non-autistic population.

Tactile defensiveness or other sensory issues of the AS partner may be so extreme that shared adult sleeping arrangements are not possible. Except for procreation, sex may be a non-starter for the AS spouse. On the other hand, sexual demands may be so high as to drive the other partner to distraction, leaving him or her little time for rest or respite.

The marriage and family may retain a name-only character, with the AS partner physically or psychologically absent most of the time. The AS partner may be a workaholic, rarely present, or if present, always tired and charging his batteries for the next day or next project.

Both Parents on Spectrum

In dual AS partnerships, both parents may be workaholics, leaving it to others to take on basic care giving and attending to the emotional and other needs of the children. As an example of extreme neglect and total self-involvement, this true anecdote is offered:

When inquiry was made by one such parent to an AS parent support listserv for after-school care for a single, high-demand AS son, follow-up revealed that the previous summer they abandoned their eight year old child on another continent in a boarding school during the high activity period of their seasonal business. The child returned a washout after four or six weeks from a very posh alternative educational setting. They had the means to pay others to parent their child. They thought that such an arrangement was a sufficient replacement for themselves. It was clear they were looking for someone to be a total proxy parent to their child.

Single Parenthood

Single parenting of a disabled child or disabled children may offer relief from an impossible marriage. It is rarely a first choice. Women with problem children make less than ideal first marriage or re-marriage choices. However a good number of women are able to enter second or later marriages and do well. Prior to recent social acceptance of single parenthood, not having a partner moved many women in to remarriage or a succession of live-in arrangements to preserve appearances. Some proved to be successful partnerships.

Separation from a difficult spouse often frees the custodial parent to attend to her health and the previously underserved needs of her children. However, divorce or separation isn't cheap. Following separation, family finances can be rocky for some time. Previously affordable special help may not be affordable once household bills are paid. While divorce or separation has its generic problems, if a single parent is disabled, stress levels can mount rapidly. If there is more than one child in the family, multi-tasking is a given. Asperger Syndrome adults do not multi-task very well.

One contributing author to this article has encountered several instances of very high levels of risk to Asperger children where an undiagnosed autistic parent has tried and failed to overcome personal health, mental health and other cognitive challenges. The main areas of parenting deficiency seem to be with planning, time management, wise setting of priorities, and difficulties with multi-tasking. In two instances, the children were late diagnosed, way into their advanced adolescence. In one instance, all four adult children were in their forties before the first diagnosis of AS was made for one dependent adult following the death of the mother, who was an undiagnosed but "flaming Aspie". Other family member diagnoses followed.

Diagnosis at a late age presents its own problems for the child. Being undiagnosed as an adult, and being hit with a life-changing diagnosis for one or more of one's nearly-adult children can be profoundly unsettling to a single parent.

Without being fully aware of the consequences of her behavior or attitudes, an undiagnosed parent can pose several risks to her children. For one thing, she may have no parenting skills and knows that she doesn't even like children. Still, she heeds the call to motherhood as a social duty. In the case of older women, because of social pressures at the time they attained adulthood they had little choice about remaining childless. Having someone's child also offered the prospect of a meal ticket and some welfare money. In one sixty-year-old mother of four children's case, that's exactly how she handled her life. While they were small, she abandoned all of her children at various times to the care of relatives of the men who fathered them. Her children were all throwaways, yet two of them make efforts to care for her in her old age, efforts she regularly rejects.

A single AS parent may be unable to manage the household finances to the point that month-long food planning is impossible since the food runs out by the third week of the month. Depending on the age of the children, the parent may be able to work a little to supplement the family income, especially if one or more of the children qualify for SSI. However, for each dollar earned and taxed, she loses a dollar in combined SSI benefits for the family.

With divorce or separation may come the loss of an automobile or other independent, non-public means of transportation essential for shopping, transportation to school and appointments. Medical care of the children may suffer as a consequence of loss of insurance or failure to take advantage of free or low-cost care. Time delays take on a new meaning with the loss of a car. Loss of a family home invariably means high cost for rent under far less desirable living conditions. With losses experienced through separation or divorce, long-range planning may become impossible under the pressure of making do from day to day.

Dire economic straits can prompt an autistic parent into making foolhardy decisions. A parent may encourage her disabled children to apply for SSI benefits as they become adults, thinking more of immediate added income to the household than the long-term future cost of placing them into a permanent sub-poverty income status that few beneficiaries escape. A stressed-out autistic parent may push a dependent child out of the house before the child is ready for independent living. On the other hand, the parent may not have the skill to prepare her children for independence and stifle their interest in living independently. The parent may rely upon her children as caregivers for herself although they cannot care for their own needs. A financially desperate parent may induce her children into taking any job rather than completing high school, getting a GED, or going on to college. They know their children could do

better, but they don't know how to help them. Parents in such need rarely help their children make plans for their own future after the parent is no longer able to care for them. Many such children "fall through the cracks" and become lost souls -- or the next generation's parents.

Even if a parent is AS diagnosed, the way the current social support system operates has been to provide minimal cash assistance to impoverished children but little to no help to their developmentally disabled parent. The social toll and cost for such shortsighted assistance is enormous and growing.

V

Adult Diagnosis and the Aftermath

A number of recently published books cover the issue of child and adult diagnosis and disclosure issues comprehensively. Several of them are listed as references at the end of this article. Obtaining a competent, thorough evaluation and diagnosis for an Asperger Syndrome child is still very problematic. However, the number of professionals doing a competent job is growing, funded largely by the availability of research and insurance coverage for medical and psychological diagnoses. Obtaining intervention and treatment for Asperger Syndrome "as AS" is still very difficult. Intelligent providers know how to play the billing-codes game with insurance companies and other funding sources to obtain third party payment for vital services to children.

By the time they are diagnosed and given the Asperger Syndrome label, adults have differing opinions about its value. If an AS parent is open to his child's diagnosis and the child's diagnosis is made early, the AS parent can take advantage of all the excellent information and support available to AS children to understand more about himself and start to review his various role relationships to his partner, the rest of his children, and others. This would be the ideal scenario, but things rarely happen like this. However, an increasing number of AS parents do perform very public, "up-front me-to's". Such early disclosure to strangers can impart a degree of authenticity and depth of understanding to parent observations about their children.

Many professionally or self-diagnosed AS adults experience relief at finding a "label that fits". The label is more than just a tag. 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 involve many others at different levels compared to the lives of their children.

Adult diagnosis may suddenly bring interpersonal problems to the fore in AS/non-spectrum partner relationships that have bubbled just beneath the surface and now have a name.

Since autism is a spectrum condition, some AS individuals exhibit more of the traits identified in this article than others who are also "on the spectrum". Looking at the family, one might be able to observe trait behaviors ranging from slightest to the most impaired signs of ASD. Family members only slightly touched by autism may not exhibit enough traits or with severity qualifying them for a diagnosis, but they clearly belong to what is called "the autism phenotype".

Suddenly more sensitive to autistic spectrum disorder, parents, educators and professionals may look in vain for the elusive "line drawn in the sand" distinguishing

between those who "are" and those who "aren't" autistic. There are scales and other instruments that track professional diagnosis of ASD with increasing reliability, but scales and questionnaires are not diagnostic instruments. In the hands of amateurs and others out to prove a point, they may wreak more damage than bring light into complicated evaluations. Despite many years of research, there remains no single diagnostic tool for Asperger Syndrome that is universally accepted by medical and psychological professionals with doctoral degrees authorized to clinically diagnose individuals.

One thing is certain, however. With more sophisticated knowledge about ASD's persons "just barely on the spectrum" are the ones 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.

Whether one should seek a diagnosis is an entirely personal decision, but it must be truly voluntary. When individuals are forced by circumstances or "ordered by a partner" or a person in authority to "seek a label or else...", the outcome is rarely positive. One should never arrive at the professional diagnostician's office angry and belligerent. No responsible professional should consider evaluating a person in such a state of mind. Coming into a diagnostician's office riding another person's agenda may guarantee that the diagnosed individual may resist or deny the diagnosis. Even if correctly labeled, the individual may tote this most recent experience up with the many he has experienced in the past: a sense that someone, not themselves, is calling the shots, is again continuing to control their life.

Asperger Syndrome is a "label" not lightly given, nor lightly viewed. Receiving the label has life-changing consequences. Individuals who seek the label are generally relieved at being given an officially sanctioned description of something many of them have known for a long time, but that didn't previously have a name they could relate to.

The Non-Curious and the Deniers

The later the diagnosis, the greater the likelihood of an individual denying the diagnosis, remaining uncurious or being actively resistant to information about AS.

The reasons for this phenomenon are many, but the dynamic is similar to those who receive any kind of life-changing diagnosis and remain in denial about it. For some individuals, advanced age allows them to take the stance of, "What good does knowing about it do, anyway? Leave me alone!" For younger individuals expressing the same sentiment, the psychological cost to them of undoing the way they've always thought of themselves is just too high. Holding on to such an attitude forces others in their lives into increasingly disjointed relationships with them, as their knowledge and understanding grows and the "denier's" doesn't.

One thing is known for certain. If the AS individual in a committed relationship continues to deny his diagnosis, the relationship has virtually no chance of surviving. (Aston 2002; Aston 2003)

Connection between Self-Determination and Adult Employment

Late adolescent and young adults can remain highly resistant to changing self-

concepts that they've recently struggled so hard to carve out for themselves. If any forward progress is to be made in their lives including any reasonable prospect of becoming independent of others and being capable of managing complex adult relationships and responsibilities, they must either undergo a very painful process of "unlearning recent lessons" or remain infantile and dependent on their aging parents and caregivers for the rest of their lives. Unfortunately, many of them do just that. These young adults are already heavily dependent upon their parents. Their parent(s) are also invested in the idea of having to care for their adult children as long as they can. Any professional unaware of their Asperger Syndrome would conclude that they and their parents have serious unresolved separation issues.

Parents of these adult children often have unrealistic expectations and fears about their children and the world of work. Their distorted attitudes don't just start when their child reaches the age of 18. Vocational research has shown that by the time children reach the mental age of six, they have well-defined concepts about work. If the parent has defective or distorted attitudes about disability and employment, the child's outlook towards work reflects those ideas. Regardless of the person's later age, these ideas "stick". They make the adolescent resistant to the idea of hard work (starting with doing household chores and doing homework) because there is a defective connection in their mind between the idea of work, desert, and complex values involved in becoming an independent adult.

If the late adolescent or young adult is lucky enough to make the connection between his special interests and a paying future or a career, he may be able to live out his life in a highly varied and individualistic relationship to the world of work. These individuals often finish high school or complete their GED's. Many of them continue on into post-secondary education, often with very specific career targets in mind. The pulling power -- the hook between a developable narrow interest and the prospect of substantial competitive market employment and independence -- must be very strong for such individuals to succeed.

Some do. Many do not. Dreams about extending one's life interest into a way of supporting oneself in adulthood are tenuous threads often not strong enough to withstand the weight of real adult responsibilities. For the most part, AS individuals stuck in the type of mind-warp described above, do not succeed in becoming productive, competitive employment market employees.

Even for successful individuals, it is safe to say that there is no set of "ideal jobs" for persons with Asperger Syndrome. AS is one of the few cognitive disabilities where an essential fit must exist between the individual's unique and narrowly expressed interests and strengths and "a" particular job. Most AS individuals and their families cannot afford the kind of careful functional vocational evaluation needed to provide a given individual with even a limited range of career choices from which to choose.

Opinions offered by vocational experts tying their limited understanding of Asperger Syndrome and the number of "available jobs" in the economy often reflect their failure to understand the individualized character of the job-matching process and the amount of work it takes rehabilitation specialists and job developers to arrange for successful outcomes for persons with cognitive and developmental disorders.

Asperger Syndrome is a particularly difficult disorder to understand because little is known about "success" in placing individuals with this disorder into competitive employment. The few pilot programs that concentrated on employment services just

for individuals with Asperger Syndrome have closed after running only several years at very high cost. The conclusion program evaluators have come to repeatedly is that even ideal candidates for these programs experience nearly one hundred percent long time retention failure due to the withdrawal of intense post-placement training and support services.

For families with the means to support them or for individuals been found eligible for categorical assistance as disabled adults, customized job development or uniquely dogged determination by care givers or community support professionals can help them find some type of personally meaningful employment in the workplace. Because they are autistic, succesful placement and retention -- way beyond Vocational Rehabilitation's statistical determination of sixty or ninety days -- must appeal to their self-interest, their circumscribed special interests, or it will fail. For individuals whose interests are singular, narrow or immature, having others "find a match" is possible only in a tiny number of cases.

For individuals without independent family means to support their interest in employment, Vocational Rehabilitation offers a possibility. However, individuals with mental illness and developmental disabilities consistently rank at the bottom of all successful public VR case closures and have done so for decades. Despite all of the information about Asperger Syndrome available over the past ten years, few VR professionals know anything about it. Even when they do, their success rate has been miserable. AS clients often end up being passed around to successive workers VR branch offices with managers' hopes that maybe the next counselor assignment "will stick." It doesn't. The outcome is the same: short-term, inappropriate placement based upon little understanding of the client's individual needs, then return of the client through the revolving door, this time to be assigned to the next worker. Eventually, the AS client gives up.

In the future, even when his mental attitude is more positive, the average AS adult who has been through such past "treatment" by the system will rarely give VR a second -- or more likely a fifth or sixth -- chance. The reason for his disinclination relates only partially to his past failed experiences. Even if he has a more positive mental outlook, the extent of his autistic cognitive impairment hasn't changed. It isn't only a positive outlook that would make the real difference. The only thing that will kick that difference over the top is patient professional cognitive-behavioral counseling that begins to unhook the hard-wired connections between attitudes and behavior that characterize Asperger Syndrome. Few individuals can afford such counselling on their own, and up to this point, no publicly funded Vocational Rehabilitation program has ever supported this type of personal work. Without a support system that does so, the AS individual is likely to remain stuck, mired in good intentions but without the cognitive tools to turn those good intentions into success on the job.

References [under construction]
