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ASPERGER SYNDROME

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Introduction:

Asperger syndrome (also called Asperger disorder) is a relatively new category of developmental disorder, the term having only come into more general use over the past fifteen years. Although a group of children with this clinical picture was originally and very accurately described in the 1940's by a Viennese pediatrician, Hans Asperger, Asperger Syndrome (AS) was "officially" recognized in the **Diagnostic and Statistical Manual of Mental Disorders** for the first time in the fourth edition published in l994. Because there have been few comprehensive review articles in the medical literature to date and because AS is probably considerably more common than previously realized, this discussion will endeavor to describe the syndrome in some detail and to offer suggestions regarding management. Students with AS are not uncommonly seen in mainstream educational settings, although often undiagnosed or misdiagnosed, so this is a topic of some importance for educational personnel, as well as for parents.

Asperger syndrome is the term applied to the mildest and highest functioning end of what is known as the spectrum of pervasive developmental disorders (or the autism spectrum). Like all conditions along that spectrum it is felt to represent a neurologically-based disorder of development, most often of unknown cause, in which there are deviations or abnormalities in three broad aspects of development: social relatedness and social skills, the use of language for communicative purposes and certain behavioral and stylistic characteristics involving repetitive or perseverative features and a limited but intense range of interests. It is the presence of these three categories of dysfunction, which can range from relatively mild to severe, which clinically defines all of the pervasive developmental disorders, from AS through to classic autism. Although the idea of a continuum of PDD along a single dimension is helpful for understanding the clinical similiarities of conditions along the spectrum, it is not at all clear that Asperger syndrome is just a milder form of autism or that the conditions are linked by anything more than their broad clinical similarities.

Asperger syndrome represents that portion of the PDD continuum which is characterized by higher cognitive abilities (at least normal IQ by definition and sometimes ranging up into the very superior range) and by more normal language function compared to other disorders along the spectrum. In

ct, the presence of normal basic language skills is now felt to be one of the criteria for the agnosis of AS, although there are nearly always more subtle difficulties with pragmatic/social nguage. Many researchers feel it is these two areas of relative strength that distinguish AS from ner forms of autism and PDD and account for the better prognosis in AS. Developmentalists have ot reached consensus as to whether there is any difference between AS and what is termed high unctioning autism (HFA). Some researchers have suggested that the basic neuropsychological eficit is different for the two conditions, but others have been unconvinced that any meaningful istinction can be made between them. One researcher, Uta Frith, has characterized children with S as having "a dash of autism." In fact, it is likely that there may be multiple underlying subtypes nd mechanisms behind the broad clinical picture of AS. This leaves room for some confusion egarding diagnostic terms and it is likely that quite similiar children across the country have been iagnosed with AS, HFA, or PDD, depending upon by whom or where they are evaluated.

Since AS itself shows a range or spectrum of symptom severity, many less impaired children who might meet criteria for that diagnosis receive no diagnosis at all and are viewed as "unusual" or just different,"or are misdiagnosed with conditions such as Attention Deficit Disorder, emotional disturbance, etc. Many in the field believe that there is no clear boundary separating AS from children who are "normal but different." The inclusion of AS as a separate category in the new DMS-4, with fairly clear criteria for diagnosis, should promote greater consistency of labeling in the future.

Epidemiology

he best studies that have been carried out to date suggest that AS is considerably more common than "classic" autism. Whereas autism has traditionally been felt to occur in about 4 out of every 10,000 children, estimates of Asperger syndrome have ranged as high as 20-25 per 10,000. That means that for each case of more typical autism, schools can expect to encounter several children with a picture of AS (that is even more true for the mainstream setting, where most children with AS will be found). In fact, a careful, population-based epidemiological study carried out by Gillberg's group in Sweden, concluded that nearly 0.7% of the children studied had a clinical picture either diagnostic of or suggestive of AS to some degree. Particularly if one includes those children who have many of the features of AS and seem to be milder presentations along the spectrum as it shades into "normal", it seems not to be a rare condition at all.

All studies have agreed that Asperger syndrome is much more common in boys than in girls. The reasons for this are unknown. AS is fairly commonly associated with other types of diagnoses, again for unknown reasons, including: tic disorders such as Tourette disorder, attentional problems and mood problems such as depression and anxiety. In some cases there is a clear genetic component, with one parent (most often the father) showing either the full picture of AS or at least some of the traits associated with AS; genetic factors seem to be more common in AS compared to more classic autism. Tempermental traits such as having intense and limited interests, compulsive or rigid style and social awkwardness or timidy also seem to be more common, alone or in combination, in relatives of AS children. Sometimes there will be a positive family history of autism in relatives, further strengthening the impression that AS and autism are sometimes related nditions. Other studies have demonstrated a fairly high rate of depression, both bipolar and unipolar, in relatives of children with AS, suggesting a genetic link in at least some cases. It seems

likely that for AS, as for autism, the clinical picture we see is probably influenced by many factors, including genetic ones, so that there is no single identifiable cause in most cases.

Definition

The new DSM-4 criteria for a diagnosis of AS, with much of the language carrying over from the diagnostic criteria for autism, include the presence of:

Qualitative impairment in social interaction involving some or all of the following:

- impaired use of non-verbal behaviors to regulate social interaction,
- failure to develop age-appropriate peer relationships,
- lack of spontaneous interest in sharing experiences with others,
- and lack of social or emotional reciprocity.

Restricted, repetitive, and stereotyped patterns of behavior, interests, and activities involving:

- preoccupation with one or more stereotyped and restricted pattern of interest,
- inflexible adherence to specific non-functional routines or rituals,
- stereotyped or repetitive motor mannerisms, or preoccupation with parts of objects.

These behaviors must be sufficient to interfere significantly with social or other areas of functioning. Furthermore, there must be no significant associated delay in either general cognitive function, self-help/adaptive skills, interest in the environment or overall language development.

Christopher Gillberg, a Swedish physician who has studied AS extensively, has proposed six criteria for the diagnosis, elaborating upon the a criteria set forth in DSM-4. His six criteria capture the unique style of these children and include:

*** Social impairment with extreme egocentricity, which may include:**

- inability to interact with peers
- lack of desire to interact with peers
- poor appreciation of social cues
- socially and emotionally inappropriate responses

*** Limited interests and preoccupations, including:**

- more rote than meaning
- relatively exclusive of other interests
- repetitive adherence

*** Repetitive routines or rituals, that may be:**

- imposed on self, or
- imposed on others

*** Speech and language peculiarities, such as:**

- delayed early development possible but not consistently seen
- superficially perfect expressive language
- odd prosody, peculiar voice characteristics
- impaired comprehension including misinterpretation of literal and implied meanings

*** Non-verbal communication problems, such as:**

- limited use of gesture
- clumsy body language
- limited or inappropriate facial expression
- peculiar "stiff" gaze
- difficulty adjusting physical proximity

*** Motor clumsiness**

- may not be necessary part of the picture in all cases

Clinical Features

The most obvious hallmark of Asperger syndrome and the characteristic that makes these children unique and fascinating, is their peculiar, idiosyncratic areas of "special interest". In contrast to more typical autism, where the interests are more likely to be objects or parts of objects, in AS the interests appear most often to be specific intellectual areas. Often, when they enter school, or even before, these children will show an obsessive interest in an area such as math, aspects of science, reading (some have a history of hyperlexia--rote reading at a precocious age) or some aspect of history or geography, wanting to learn everything possible about that subject and tending to dwell on it in conversations and free play. I have seen a number of children with AS who focus on maps, weather, astronomy, various types of machinery or aspects of cars, trains, planes or rockets. Interestingly, as far back as Asperger's original clinical description in 1944, the area of transport has seemed to be a particularly common fascination (he described children who memorized the tram lines in Vienna down to the last stop). Many children with AS, as young as three years old, seem to be unusually aware of things such as the route taken on car trips. Sometimes the areas of fascination represent exaggerations of interests common to children in our culture, such as Ninja Turtles, Power Rangers, dinosaurs, etc. In many children the areas of special interest will change over time, with one preoccupation replaced by another. In some children, however, the interests may persist into adulthood and there are many cases where the childhood fascinations have formed the basis for an adult career, including a good number of college professors.

The other major characteristic of AS is the socialization deficit, and this, too, tends to be somewhat different than that seen in typical autism. Although children with AS are frequently noted by teachers and parents to be somewhat "in their own world" and preoccupied with their own agenda, they are seldom as aloof as children with autism. In fact, most children with AS, at least once they get to school age, express a desire to fit in socially and have friends. They are often deeply

frustrated and disappointed by their social difficulties. Their problem is not a lack of interaction so much as lack of effectiveness in interactions. They seem to have difficulty knowing how to"make connections" socially. Gillberg has described this as a "disorder of empathy", the inability to effectively "read" others' needs and perspectives and respond appropriately. As a result, children with AS tend to misread social situations and their interactions and responses are frequently viewed by others as "odd".

Although "normal" language skills are a feature distinguishing AS from other forms of autism and PDD, there are usually some observable differences in how children with AS use language. It is the more rote skills that are strong, sometimes very strong. Their prosody--those aspects of spoken language such as volume of speech, intonation, inflection, rate, etc.--is frequently unusual. Sometimes the language sounds overly formal or pedantic, idioms and slang are often not used or are misused, and things are often taken too literally. Language comprehension tends toward the concrete, with increasing problems often arising as language becomes more abstract in the upper grades. Pragmatic, or conversational, language skills often are weak because of problems with turn-taking, a tendency to revert to areas of special interest or difficulty sustaining the "give and take" of conversations. Many children with AS have difficulties dealing with humor, tending not to "get" jokes or laughing at the wrong time; this is in spite of the fact that quite a few show an interest in humor and jokes, particularly things such as puns or word games. The common belief that children with pervasive developmental disorders are humorless is frequently mistaken. Some children with AS tend to be hyperverbal, not understanding that this interferes with their interactions with others and puts others off.

When one examines the early language history of children with AS there is no single pattern: some of them have normal or even early achievement of milestones, while others have quite clear early delays on speech with rapid catch-up to more normal language by the time of school entry. In such a child under the age of three years in whom language has not yet come up into the normal range, the differential diagnosis between AS and milder autism can be difficult to the point that only time can clarify the diagnosis. Frequently, also, particularly during the first several years, associated language features similiar to those in autism may be seen, such as perseverative or repetitive aspects to language or use of stock phrases or lines drawn from previously heard material.

Asperger Syndrome Through the Lifespan

In his original 1944 paper describing the children who later came to be described under his name, Hans Asperger recognized that although the symptoms and problems change over time, the overall problem is seldom outgrown. He wrote that "in the course of development, certain features predominate or recede, so that the problems presented change considerably. Nevertheless, the essential aspects of the problem remain unchanged. In early childhood there are the difficulties in learning simple practical skills and in social adaptation. These difficulties arise out of the same disturbance which at school age cause learning and conduct problems, in adolescence job and performance problems and in adulthood social and marital conflicts." On the other hand, there is no question that children with AS have generally milder problems at every age compared to those with other forms of autism or PDD, and their ultimate prognosis is certainly better. In fact, one of the more important reasons to distinguish AS from other forms of autism is it's considerably milder

natural history.

The preschool child:

As has been noted, there is no single, uniform presenting picture of Asperger syndrome in the first 3-4 years. The early picture may be difficult to distinguish from more typical autism, suggesting that when evaluating any young child with autism and apparently normal intelligence, the possibility should be entertained that he/she may eventually have a picture more compatible with an Asperger diagnosis. Other children may have early language delays with rapid "catch-up" between the ages of three and five years. Finally, some of these children, particularly the brightest ones, may have no evidence of early developmental delay except, perhaps, some motor clumsiness. In almost all cases, however, if one looks closely at the child between the age of about three and five years, clues to the diagnosis can be found, and in most cases a comprehensive evaluation at that age can at least point to a diagnosis along the PDD/autism spectrum. Although these children may seem to relate quite normally within the family setting, problems are often seen when they enter a preschool setting. These may include: a tendency to avoid spontaneous social interactions or to show very weak skills in interactions, problems sustaining simple conversations or a tendency to be perseverative or repetitive when conversing, odd verbal responses, preference for a set routine and difficulty with transitions, difficulty regulating social/emotional responses with anger, aggression, or excessive anxiety, hyperactivity, appearing to be "in one's own little world", and the tendency to overfocus on particular objects or subjects. Certainly, this list is much like the early symptom list in autism or PDD. Compared to those children, however, the child with AS is more likely to show some social interest in adults and other children, will have less abnormal language and conversational speech and may not be as obviously "different" from other children. Areas of particularly strong skills may be present, such as letter or number recognition, rote memorization of various facts, etc.

Elementary school:

The child with AS will frequently enter kindergarten without having been adequately diagnosed. In some cases, there will have been behavioral concerns (hyperactivity, inattention, aggression, outbursts) in the preschool years; there may be concern over "immature" social skills and peer interactions; the child may already be viewed as being somewhat unusual. If these problems are more severe, special education may be suggested, but probably most children with AS enter a more mainstream setting. Often, academic progress in the early grades is an area of relative strength; for example, rote reading is usually quite good and calculation skills may be similarly strong, although pencil skills are often considerably weaker. The teacher will probably be struck by the child's "obsessive" areas of interest, which often intrude in the classroom setting. Most AS children will show some social interest in other children, although it may be reduced, but they are likely to show weak friend-making and friend-keeping skills. They may show particular interest in one or a few children around them, but usually the depth of their interactions will be relatively superficial. On the other hand, I have known quite a number of children with AS who present as pleasant and "nice", particularly when interacting with adults. The social deficit, when less severe, may be under appreciated by many observers.

The course through elementary school can vary considerably from child to child, and overall problems can range from mild and easily managed to severe and intractable, depending upon factors such as the child's intelligence level, appropriateness of management at school and

parenting at home, temperamental style of the child, and the presence or absence of complicating factors such as hyperactivity/attentional problems, anxiety, learning problems, etc.

e upper grades:

As the child with AS moves into middle school and high school, the most difficult areas continue to be those related to socialization and behavioral adjustment. Paradoxically, because children with AS are frequently managed in mainstream educational settings, and because their specific developmental problems may be more easily overlooked (especially if they are bright and do not act too "strange"), they are often misunderstood at this age by both teachers and other students. At the secondary level, teachers often have less opportunity to get to know a child well and problems with behavior or work/study habits may be misattributed to emotional or motivational problems. In some settings, particularly less familiar or structured ones such as the cafeteria, physical education class or playground, the child may get into escalating conflicts or power struggles with teachers or students who may not be familiar with their developmental style of interacting. This can sometimes lead to more serious behavioral flare-ups. Pressure may build up in such a child with little clue until he then reacts in a dramatically inappropriate manner.

In middle school, where the pressures for conformity are greatest and tolerance for differences the least, children with AS may be left out, misunderstood or teased and persecuted. Wanting to make friends and fit in, but unable to, they may withdraw even more, or their behavior may become increasingly problematic in the form of outbursts or non-cooperation. Some degree of depression is not uncommon as a complicating feature. If there are no significant learning disabilities, academic performance can continue strong, particularly in those areas of particular interest; often, however, there will be ongoing subtle tendencies to misinterpret information, particularly abstract or figurative/idiomatic language. Learning difficulties are frequent and attentional and organizational difficulties may be present.

Fortunately, by high school peer tolerance for individual variations and eccentricity often increases again to some extent. If a child does well academically, that can bring a measure of respect from other students. Some AS students may pass socially as "nerds", a group which they actually resemble in many ways and which may overlap with AS. The AS adolescent may form friendships with other students who share his interests through avenues such as computer or math clubs, science fairs, Star Trek clubs, etc. With luck and proper management, many of these students will have developed considerable coping skills, "social graces", and general ability to "fit in" more comfortably by this age, thus easing their way.

Asperger children grown up:

It is important to note that we have limited solid information regarding the eventual outcome for most children with AS. It has only been recently that AS itself has been distinguished from more typical autism in looking at outcomes and milder cases were generally not recognized. Nonetheless, the available data does suggest that, compared to other forms of autism/PDD, children with AS are much more likely to grow up to be independently functioning adults in terms of employment, marriage and family, etc.

Some of the most interesting and useful sources of data on outcome comes indirectly from observing those parents or other relatives of AS children, who themselves appear to have AS. From these

observations it is clear that AS does not preclude the potential for a more "normal" adult life. Commonly, these adults will gravitate to a job or profession that relates to their own areas of special interest, sometimes becoming very proficient. A number of the brightest students with AS are able to successfully complete college and even graduate school. Nonetheless, in most cases they will continue to demonstrate, at least to some extent, subtle differences in social interactions. They can be challenged by the social and emotional demands of marriage, although we know that many do marry. Their rigidity of style and idiosyncratic perspective on the world can make interactions difficult, both in and out of the family. There is also the risk of mood problems such as depression and anxiety, and it is likely that many find their way to psychiatrists and other mental health providers where, Gillberg suggests, the true, developmental nature of their problems may go unrecognized or misdiagnosed.

In fact, Gillberg has estimated that perhaps 30-50% of all adults with AS are never evaluated or correctly diagnosed. These "normal Aspergers" are viewed by others as "just different" or eccentric, or perhaps they receive other psychiatric diagnoses. I have met a number of individuals whom I believe fall into that category, and I am struck by how many of them have been able to utilize their other skills, often with support from loved ones, to achieve what I consider to be a high level of function, personally and professionally. It has been suggested that some of these highest functioning and brightest individuals with AS represent a unique resource for society, having the single mindedness and consuming interest to advance our knowledge in various areas of science, math, etc.

Thoughts for Management in the School

The most important starting point in helping a student with Asperger syndrome function effectively in school is for the staff (all who will come into contact with the child) to realize that the child has an inherent developmental disorder which causes him or her to behave and respond in a different way from other students. Too often, behaviors in these children are interpreted as "emotional", or "manipulative", or some other term that misses the point that they respond differently to the world and its stimuli. It follows from that realization that school staff must carefully individualize their approach for each of these children; it will not work out to treat them just the same as other students. Asperger himself realized the central importance of teacher attitude from his own work with these children. In 1944 he wrote, "These children often show a surprising sensitivity to the personality of the teacher...They can be taught, but only by those who give them true understanding and affection, people who show kindness towards them and, yes, humour...The teacher's underlying emotional attitude influences, involuntarily and unconsciously, the mood and behaviour of the child."

Although it is likely that many children with AS can be managed primarily in the regular classroom setting, they often need some educational support services. If learning problems are present, resource room or tutoring can be helpful, to provide individualized explanation and review. Direct speech services may not be needed, but the speech and language clinician at school can be useful as a consultant to the other staff regarding ways to address problems in areas such as pragmatic language. If motor clumsiness is significant, as it sometimes is, the school Occupational Therapist can provide helpful input. The school counselor or social worker can provide direct social skills training, as well as general emotional support. Finally, a few children with very high management

needs may benefit from assistance from a classroom aide assigned to them. On the other hand, some of the higher functioning children and those with milder AS, are able to adapt and function with little in the way of formal support services at school, if staff are understanding, supportive and flexible.

There are a number of general principles of managing most children with PDD of any degree in school, and they apply to AS, as well:

- The classroom routines should be kept as consistent, structured and predictable as possible. Children with AS often don't like surprises. They should be prepared in advance, when possible, for changes and transitions, including things such as schedule breaks, vacation days, etc.
- Rules should be applied carefully. Many of these children can be fairly rigid about following "rules" quite literally. While clearly expressed rules and guidelines, preferably written down for the student, are helpful, they should be applied with some flexibility. The rules do not automatically have to be exactly the same for the child with AS as for the rest of the students--their needs and abilities are different.
- Staff should take full advantage of a child's areas of special interest when teaching. The child will learn best when an area of high personal interest is on the agenda. Teachers can creatively connect the child's interests to the teaching process. One can also use access to the special interests as a reward to the child for successful completion of other tasks or adherence to rules or behavioral expectations.
- Most students with AS respond well to the use of visuals: schedules, charts, lists, pictures , etc. In this way they are much like other children with PDD and autism.
- In general, try to keep teaching fairly concrete. Avoid language that may be misunderstood by the child with AS, such as sarcasm, confusing figurative speech, idioms, etc. Work to break down and simplify more abstract language and concepts
- Explicit, didactic teaching of strategies can be very helpful, to assist the child gain proficiency in "executive function" areas such as organization and study skills.
- Insure that school staff outside of the classroom, such as physical education teachers, bus drivers, cafeteria monitors, librarians, etc., are familiar with the child's style and needs and have been given adequate training in management approaches. Those less structured settings where the routines and expectations are less clear ten to be difficult for the child with AS.
- Try to avoid escalating power struggles. These children often do not understand rigid displays of authority or anger and will themselves become more rigid and stubborn if forcefully confronted. Their behavior can then get rapidly out of control, and at that point it is often better for the staff person to back off and let things cool down. It is always preferable, when possible, to anticipate such situations and take preventative action to avoid the confrontation through calmness, negotiation, presentation of choices or diversion of attention elsewhere.

A major area of concern as the child moves through school is promotion of more appropriate social interactions and helping the child fit in better socially. Formal, didactic social skills training can take place both in the classroom and in more individualized settings. Approaches that have been most successful utilize direct modeling and role playing at a concrete level (such as in the Skillstreaming curriculum). By rehearsing and practicing how to handle various social situations, the child can

hopefully learn to generalize the skills to naturalistic settings. It is often useful to use a dyad approach where the child is paired with another to carry out such structured encounters. The use of a "buddy system" can be very useful, since these children relate best 1-1 . Careful selection of a non-Asperger peer buddy for the child can be a tool to help build social skills, encourage friendships and reduce stigmatization. Care should be taken, particularly in the upper grades, to protect the child from teasing both in and out of the classroom, since it is one of the greatest sources of anxiety for older children with AS. Efforts should be made to help other students arrive at a better understanding of the child with AS, in a way that will promote tolerance and acceptance. Teachers can take advantage of the strong academic skills that many AS children have, in order to help them gain acceptance with peers. It is very helpful if the AS child can be given opportunities to help other children at times.

Although most children with AS are managed without medication and medication does not "cure" any of the core symptoms, there are specific situations where medication can occasionally be useful. Teachers should be alert to the potential for mood problems such as anxiety or depression, particularly in the older child with AS. Medication with an antidepressant (eg. imipriamine or one of the newer serotonergic drugs such as fluoxetine) may be indicated if mood problems are significantly interfering with the child's functioning. Some children with significant compulsive symptoms or ritualistic behaviors can be helped with the same serotonergic drugs or clomipramine. Problems with inattention at school that are seen in certain children can sometimes be helped by stimulant medications such as methylphenidate or dextroamphetamine, much in the same way they are used to treat Attention Deficit Disorder. Occasionally, medication may be needed to address more severe behavior problems that have not responded to non-medical, behavioral interventions. Clonidine is one medication that has proven helpful in such situations and there are other options if necessary.

In attempting to put a comprehensive teaching and management plan into place at school, it is often helpful for staff and parents to work closely together, since parents often are most familiar with what has worked in the past for a given child. It is also wise to put as many details of the plan as possible into an Individual Educational Plan so that progress can be monitored and carried over from year to year. Finally, in devising such plans, it can sometimes be helpful to enlist the aid of outside consultants familiar with the management of children with Asperger syndrome and other forms of PDD, such as Boces consultants, psychologists, or physicians. In complex cases a team orientation is always advisable.

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