Asperger's Disorder

Asperger's Disorder: What It Is and What It Isn't

What's in a Name?
Working with a Child with Asperger's Syndrome

Social Skills Training for Children with Asperger's Syndrome

Asperger's Syndrome in Adolescence and Adulthood:
Considerations for Support and Intervention

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Asperger's Disorder and Autistic Disorder are pervasive developmental disorders both defined, according to the DSM-IV, by the presence of impaired social interaction and restricted range of interests and activities. Asperger's is differentiated by the lack of early cognitive and language delays, autistic disorder by the presence of both. Often misdiagnosed, children with Asperger's Disorder may also have symptoms of Obsessive Compulsive Disorder, Attention Deficit/Hyperactivity Disorder, Oppositional Defiant Disorder, Bipolar Disorder, and Schizoid Personality Disorder, any of which may be appropriate comorbid diagnoses. Adolescents and adults often develop depression. Because Asperger's children appear to have normal cognitive and language development and perform well academically, they are more often seen simply as strange or deliberately annoying and oppositional. As a result, they are teased, taunted, isolated, and rejected by their peers, while their mothers and fathers are blamed for bad parenting.

In this special section, Beth Glasberg, PhD discusses the symptoms of Asperger's Disorder with attention to differential diagnosis and common misconceptions. She provides a history of the diagnostic controversy and an understanding of the symptoms from both research and clinical perspectives. Rika Alper, PhD describes her work with an Asperger's child and his family, demonstrating the ambiguities in the diagnosis, the consequences of misdiagnosis, and the importance of individual strengths and weaknesses in the treatment process. The formation, process, and content of social skills groups for children with impairments in social functioning is presented by Jed Baker, PhD. Peter Gerhardt, EdD discusses social connections among adolescents and adults with Asperger's Disorder. He suggests that there may be an Asperger's culture, as there is a culture of the hearing impaired, that requires our recognition and our adaptation. Dr. Baker and Dr. Gerhardt's articles emphasize the importance of providing a safe social community for children and adults with Asperger's disorder.

Lorna Wing, who resurrected Hans Asperger's important work using the term Asperger Syndrome, has proposed that we do away with that term and return to Autistic Spectrum Disorder (Wing, 2000). Appropriate diagnosis and
classification have important consequences for further research into etiology, comorbidity, and treatment outcome studies. The search for clear differential diagnosis may blur the differences within groups, induce us to ignore the differences at the fringes of diagnostic categories, and cause us to lose sight of the individuality of a patient's personality, strengths, and weaknesses, but only if we choose to do so. The controversy over diagnostic issues within what Gillberg (1992) refers to as disorders of empathy, however, has engendered fruitful research that has helped to remove the blame from patients and their families and focused attention on the need for more comprehensive and effective treatment.

References


difference in performance. For example, many individuals with Asperger's Disorder have a great deal of difficulty with
the pragmatics of language (Klin & Volkmar, 1996). As a result, their expressive language abilities may not be limited,
but their ability to successfully initiate and maintain conversations may be diminished. Skills such as turn-taking, as
opposed to one-sidedness in conversation, may be challenging for some individuals with Asperger's Disorder (Klin &
Volkmar, 1997).

Nonverbal communication abilities are certainly affected within Asperger's Disorder (Klin & Volkmar, 1997). For
example, most typically developing 12 year olds not only use eye contact appropriately, but also understand that you
can tell how someone feels by looking at that person's facial expression. In contrast, I recently asked a 12 year old with
Asperger's Disorder who has a verbal IQ over 140 why it might be helpful to look at someone's face. After many
probes, he finally offered, "because it's a rule of politeness." He could not name a single piece of information that one
could gain by observing someone's face. When asked to read a variety of posed facial expressions, this extremely
bright child could not differentiate between happy, sad, and angry. Imagine the difficulties this child faces in trying to
regulate a conversation with a peer based on nonverbal cues.

Other distinctions between autism and Asperger's Disorder have been suggested by researchers. For example, Klin and
his colleagues demonstrate that the cognitive profiles of individuals with autism and Asperger's Disorder differ
(Klin, Volkmar, Sparrow, Cicchetti, & Rourke, 1995). Individuals with autism display a relative strength in performance
abilities with a relative weakness in verbal tasks, while individuals with Asperger's Disorder show the exact opposite
pattern: a strength in verbal abilities with a relative weakness in the performance arena. In fact, Asperger's Disorder
has been conceptualized as a "Non-Verbal Learning Disability" (Klin, et al., 1995). During numerous conference
presentations, Klin has asked diagnosticians to consider how much "mileage individuals get for their IQ" when
attempting to distinguish Asperger's Disorder from Autistic Disorder. Because of the keen verbal abilities present
among individuals with Asperger's Disorder, they may appear more cognitively able than a peer with autism of equal
intelligence.

Clumsiness, involving both fine and gross motor skills, may also be associated with Asperger's Disorder (M.
Ghaziuddin, Butler, Tsai, & N. Ghaziuddin, 1994). The DSM-IV specifies that these motor difficulties may be evidenced
during the preschool period. However, other researchers have noted motor problems in older individuals as well. For
example, Nass and Gutman (1997) describe five early elementary aged boys with Asperger's Disorder whose motor
difficulties interfered with both school performance and social adjustment. More serious motor issues, such as tics and
Tourette's Disorder, have also been found to be prevalent among individuals with Asperger's Disorder (Ringman &
Jankovic, 2000). Nevertheless, motor difficulties may not help to distinguish between individuals with Asperger's
Disorder and those with Autistic Disorder. Ghaziuddin and Butler (1998) found that increased intelligence, rather than
diagnostic category, was associated with decreased clumsiness.

Another distinctive feature common among individuals with Asperger's Disorder is pedantic speech, with pedantic
being professorial, with a "bookish" quality, possibly reflecting intense interests (Ghaziuddin & Gerstein, 1996). As an
illustration, one seven-year-old with Asperger's Disorder recently regaled me with a listing and history of a variety of
fonts available on the computer. An 11-year-old boy with Asperger's Disorder with whom I work enjoys describing the
weight, length, and habits of the average Galapagos turtle as a reward for following directions during therapy sessions.

This pedantic quality is not necessarily limited to the topic of the conversation or the detail involved; instead it emerges
during even brief interactions through the use of sophisticated language to describe the most mundane of events. A
perfect illustration is provided by a nine-year-old with Asperger's Disorder who was recently asked to put his hands
down when he was caught with his finger in his nose during class. He responded, "I am in the process of removing a
pesky booger from my nostril." While the topic was less than cerebral, the language that he chose to describe the
scenario lent a scholarly air to even this situation.

Another facet of the behavior of individuals with Asperger's Disorder described by the concept of pedantic speech may
involve unusually long utterances and/or difficulty responding to listener feedback. Like the stereotype of a professor,
an individual with Asperger's Disorder may proceed with a topic after the listener's attention has expired. One
explanation for this, described above, refers to social/communicative difficulties in the ability to read listener nonverbal
cues. However, some individuals with Asperger's Disorder have reported that despite being aware that the listener is
no longer interested, they really want to complete their thought. Speaking about a topic may be enjoyed not necessarily
as a means of sharing an experience with another person, but instead as a means of reliving the experience oneself.

This point highlights a difference between individuals with autism and individuals with Asperger's Disorder noted
clinically. Individuals with autism seem to meet diagnostic criteria through actions, while individuals with Asperger's
Disorder meet diagnostic criteria through cognition and language. For example, while an individual with autism may
repeat certain behaviors over and over again, an individual with Asperger's Disorder may like to repeatedly explore
certain topics. While an individual with autism may demonstrate a restricted range of behaviors, an individual with
Asperger's Disorder may have a restricted range of interests.

**Asperger's Disorder or Something Else?**

An adult with Asperger's Disorder recently called a colleague and explained that a local clinician had told him that he
could not possibly have Asperger's Disorder because he was aware that he had difficulties with others and because he
had graduated college. These myths and others like them, typically related to social awareness and educational
Individuals with Asperger's Disorder often come to the attention of a professional as a result of difficulties associated with living with this social disability. Exclusion and rejection are common themes expressed by individuals with Asperger's Disorder, particularly around middle and high school years. On some occasions, these feelings of rejection may manifest themselves in the form of violent speech (Dewey, 1993). One boy with Asperger's Disorder described his plan to mount a very powerful laser on the moon and use it to disintegrate the earth, and then he calmly stated, “Oh yeah, I decided that I didn't want to destroy the human race. Forget that plan.” At a meeting of the Douglass Adult Group, a support and social skills group for adults with autism and Asperger's Disorder, the topic of the shootings at Columbine High School came up for discussion. Many group members described feelings of identification with the shooters in terms of the rejection and exclusion that they must have felt to bring them to the point of committing this heinous act.

Despite the violent speech that may be present among individuals with Asperger's Disorder, violent acts have rarely been documented. Although Scragg and Shah's (1994) examination of the prevalence of Asperger's Disorder in a secure hospital led them to surmise that individuals with Asperger's Disorder were over-represented in that setting, later researchers have questioned this conclusion and instead attributed the identified prevalence rate to chance (Hall & Bernal, 1995). The few case studies that describe a violent act committed by an individual with Asperger's Disorder acknowledge that such behavior is not common among individuals with Asperger's Disorder (e.g., Kohn, Fahum, Ratzoni, & Apter, 1998).

Violent images described by children with Asperger's Disorder may lead to a misdiagnosis of conduct problems. It will be important for clinicians to differentiate between violent words and violent behaviors, and to look for other aspects of the two diagnostic categories. A misdiagnosis here can lead to dire outcomes for a child with Asperger's Disorder. Because of difficulties in interpreting social nuances, individuals with Asperger's Disorder may not be able to discriminate manipulation and deceit from good intentions (Dewey, 1993). This creates a risk of victimization. In contrast, children with conduct problems are typically skilled at understanding social interactions and capitalizing on them. Almost by definition, children with conduct problems are the perfect bullies. Because misdiagnosis may lead to a placement for a child with Asperger's Disorder in the midst of a group of children with Conduct Disorder, it is crucial that this error be avoided.

Depression is also likely to co-occur with Asperger's Disorder (Klin & Volkmar, 1997). This may also result from experiences of exclusion. Children and adults with Asperger's Disorder are bright and aware. They can see if they are not being invited to parties, or if they are having difficulty getting a date. In middle school and high school, both current students and adults recalling retrospectively report intense teasing and cruelty from peers. At a recent panel of adults with autism and Asperger's Disorder (The New Jersey Center for Outreach and Services for the Autism Community, 1999), panelists urged parents to home-school their children to shelter them from these painful experiences. For many individuals with Asperger's Disorder, first contacts with mental health professionals may occur as a result of depression associated with these difficult experiences.

Individuals with Asperger's Disorder typically receive a number of inaccurate diagnoses prior to being correctly identified. This is such a common experience in the Asperger's community that a group of individuals with Asperger's Disorder created a satirical web site entitled, the Institute for the Study of NeuroTypicals or “NT's” (people without a diagnosis). I encourage professionals to explore this site (isnt.autistics.org) as a means of gaining some insight into the experience of individuals with Asperger's Disorder within the mental health system.

What's in a name?

Throughout the history of psychology, the benefits and relevance of diagnoses have been questioned. For individuals with Asperger's Disorder in particular, the benefits of diagnosis seem more apparent. Asperger's Disorder, for many, is a disorder of exclusion. It describes an intelligent person with no physical abnormalities who may understand the complexities of advanced number theory more easily than she or he can understand the rules of how NT's make friends. While social allowances might be made for someone with a more obvious disability, such as having the physical difference of being in a wheelchair or a cognitive difference such as severe retardation, expectations for these individuals with purely social disabilities are not modified by family, teachers, or peers. When expectations are not met, an individual with Asperger's Disorder may be subject to ridicule and/or isolation.

Giving someone a diagnosis of Asperger's Disorder creates access to a peer group via local or online supportive communities. The individual may no longer feel isolated, but may instead feel part of a group. For more information about supportive services available for individuals with Asperger's Syndrome, contact the Asperger Syndrome Education Network (ASPEN) at www.aspennj.org.

References

I knew Danny and his family well before I knew his “diagnosis.” Danny arrived in my office, like many other four-year-olds, because his toilet training did not follow the simple path his parents had anticipated. In pre-kindergarten, Danny stood out as the only child who refused to use the bathroom at school, went to the toilet only with his parents, and chose to wiggle and jiggle in discomfort for hours rather than to relieve himself. The snowballing effects of Danny's toilet un-training were negatively affecting his life both at school and at home with his parents and baby sister.
When I first saw Danny in my office, he was an unusual four-year-old. Emotionally volatile, he was alternately articulate, charming, and funny, and oppositional, upset, and angry. His deficits in fine and gross motor skills were striking: He walked on his toes and avoided touching the art supplies and games. His play schemes were limited to crashing and banging toys, and he preferred talking to playing.

The history Danny's parents gave of his development showed a pattern of divergent strengths and deficits. Danny was verbally precocious as an infant, spoke in full sentences by 18 months, and was reading halfway through Pre-K. At four, he spoke knowledgeably about human anatomy. At five, he could identify all the states and their capitals and locate the remotest country on the globe. While his parents initially felt that these were the preoccupations of an intellectually precocious and eccentric child, over time his quirkiness began to seem less charming and more troubling. Danny was not outgrowing his severely panicky reactions to particular sounds (the vacuum cleaner, nose-blowing), and bodily functions (toileting, nausea, coughing). Socially, Danny was very immature. He had severe problems separating from his parents and making transitions, and became so frustrated playing with peers that the few playdates he had typically ended in meltdowns. He had a tendency to become attached to ritualized sequences of behavior, memorizing and acting out entire episodes of Thomas the Tank Engine videos. At times, he seemed to have his own private script running in his head, and any deviation from this script-no matter how inconsequential-provoked wild rage and frightening statements: “If you want, you can pull my skin off,” or “Go buy a gun and shoot me.”

Because Danny's toilet training problem loomed so large on the family's horizon, my first recommendation was a referral for evaluation by a pediatric occupational therapist (OT), to address the motor dyspraxia and sensory hypersensitivity that seemed to underlie this problem. The OT diagnosed Danny with Sensory Integration Dysfunction and agreed that he could benefit from a sensory-based OT program, which lasted throughout his kindergarten year and was supplemented by weekly OT at school. Though I did not work directly with Danny during this time, I functioned as a consultant to the family by staying in touch with the school, the OT, and the parents. In addition, Danny's mother invited me to consult to an ongoing support and education group she belonged to for parents of children with learning and sensory problems. Participation in this group helped me to have regular contact with Danny's mother and to stay informed about his progress.

The Diagnostic Process - A Conundrum

As it turned out, Danny's difficulty with toileting was a mixed blessing. It pushed his parents to seek help sooner than they otherwise might have, but drew attention away from his underlying and more central problems. During Danny's kindergarten year, these deficits came into sharper focus. Danny was reading well above grade level, but had difficulty maintaining concentration on classroom tasks. He did not know how to interact socially with classmates and was not making friends.

When I observed Danny in school at the end of kindergarten, the gap between his precocious academic skills and his social ineptness was striking. He was gifted at reading and math, but had trouble completing coursework. During free play periods, he wandered around the classroom or playground talking to himself, not interacting with classmates or play equipment. His few attempts to initiate a conversation or join in a game were so socially inappropriate that his classmates were often at a loss as to how to respond to him. His teachers reported that he had episodes which seemed like panic attacks, where he became severely anxious and upset.

At this point, Danny's parents initiated an intensive evaluation process with input from a variety of clinicians including a pediatric psychiatrist, neurologists, a neuropsychologist, a psychologist, and speech/language pathologists. The outcome of this process illustrates how complex and inconclusive the differential diagnosis of Asperger's Syndrome (AS) can be, particularly with young children. The characteristics of AS, including idiosyncratic speech, poor social communication skills, and motor awkwardness, can all be caused by developmental delays. Danny's anxiety and panic attacks were characteristic of an anxiety or panic disorder; his intense and unregulated mood changes could suggest bipolar disorder; his episodes of inattention and physical awkwardness might be symptomatic of a seizure disorder; and his insistence on scripted behavior sequences suggested OCD.

Of the bevy of professionals involved in evaluating Danny, one (the most senior) ascribed Danny's behavior to poor parenting, two identified it as ADD, and several diagnosed Danny as having Asperger's Syndrome. Ultimately, Danny's parents selected Asperger's as the diagnosis that provided the best fit and began to put a treatment program in place for him.

With a diagnosis of AS, Danny was identified by his school as eligible for special education services at the beginning of first grade. He had an aide for half of each school day and received two weekly sessions of OT and speech therapy. Speech therapy was intended to address the wide disparity between Danny's rich vocabulary and his poor pragmatic language skills. He also began taking medication for anxiety and depression (an SSRI) at this time. The medication made an obvious and powerful improvement in Danny's mood, seemed to diminish the frequency of his panic attacks, and shortened his outbursts of rage and anguish. As his mom describes it, the medication partially alleviated his "loose wire syndrome" where Danny seems to be acting out the message "All circuits are busy; please try your call again later."

The Components of Treatment

I met with Danny for weekly therapy sessions throughout his first grade year, with the goal of increasing his play and
social skills. The theory behind this effort rests in part on Stanley Greenspan's "floortime" model of play intervention for children with communication disorders: the idea that communication skills are central to social/emotional development and develop best in the context of pleasurable interaction within relationships (Greenspan, 1992). The task for me as a therapist has been to challenge Danny to, in Greenspan's terms, open and close as many "circles of communication" as possible. The hope is that he will experience social interaction as enjoyable and worth pursuing, and will learn to explore and share his feelings and experiences in the context of a relationship of growing familiarity and affection.

Danny presents many challenges even to a practitioner accustomed to the play therapy medium. His discomfort with all things social extends to gamesmanship, so that the usual tools of the play therapist's trade-toys, games, drawing materials, etc.-are largely uninteresting to him. He may set up a game, such as Checkers or Jenga, only to sabotage and end it with his first move. He is so cognitively smart that it is tricky to keep him intellectually challenged while playing at a level he can emotionally handle. If it were up to him, Danny would spend whole sessions playing computer games, which are delightful for him since they are intellectually stimulating and require no sociale interaction. When pushed beyond what he can handle emotionally, Danny gets angry and withdraws or resorts to early childhood play schemes-crashing and throwing toys, or acting out being sick and helpless.

One of the recommendations that came out of Danny's assessment had been participation in a social skills group. However, the first social skills group leader who interviewed him for admission to a group told Danny's parents that he was not an appropriate candidate because he became so upset and oppositional during the interview. At times I thought it would be useful to add another child to Danny's sessions; we started by including his three year-old sister. When she joins our sessions, Danny can be a fully engaged play partner with her, writing scripts for puppet plays, sharing toys, and enjoying three-way turn-taking. In the future it may be possible to expand this circle by adding a friend or two. Or perhaps Danny will become more able to make use of a social skills group as he grows older. At Danny's recent IEP meeting, which I attended, the child study team agreed that next year his aide will assist not only with academics in the classroom, but also at lunch and recess, when Danny most needs help participating.

When Danny's therapy sessions work, they yield collaborative interchanges that are wonderfully rich. At his most engaged, Danny is able to mobilize his articulateness and wisdom to infuse play with humor, irony, empathy, and responsiveness. One of our best sequences combined two of his favorite themes - being an alien and wanting to be famous. Using markers and a white board, we jointly created an illustrated story about an alien who landed on earth, metamorphosed into a reservoir, and ultimately became famous for its generosity by sharing its water with the community. The story of the "The Famous Generous Alien Reservoir" was a metaphor for Danny's own journey-to become comfortable enough in the human world to be able to leave behind his "alien" persona and become a plentiful source of life for himself and other people.

Having worked with Danny on and off for two years, I am still almost as perplexed by his bundle of strengths and problems as I was on first meeting him. The AS diagnosis encompasses and describes his diverse characteristics more accurately than any other label we now have, but it also conflicts with or omits vital parts of his being. For example, watching this six year-old spoof my work by becoming the "Un-doctor" -agleeful character he invented who attacks with a beanbag chair - I wonder if he really fits anywhere on the autistic spectrum. Most likely the diagnosis, like the treatment, is a work in progress.

Note: The author wishes to thank "Danny's" family for the support and consultation they provided in writing this article.

References


Suggested Reading


My co-therapist and I sat waiting to begin the first session of a new social skills group for children with Asperger's Syndrome (AS). Three 12-year-old boys quietly entered the room, avoided all eye contact, and sat down without a word. The silence was broken as our youngest member, an 11-year-old, burst in and began (in a phony British accent), "It was 1944, the troops stormed Normandy ..." My young friend's monologue continued as the other boys sat giggling, looking annoyed, and at times oblivious to the World War II lesson that was taking place. Our youngest member, fully aware of his AS diagnosis, framed the scene for our first group: social skills as a "battleground" set in 1944 (perhaps not coincidentally the same year Hans Asperger wrote about the syndrome later to bear his name).

My original goals for the group were modest: create a safe environment in which the members developed a sense of belonging to help combat the social isolation they felt outside the group. My co-therapist's goals were more ambitious: to create a class in which the boys could learn, step by step, how to relate to others outside the group. The adoption of both goals proved to be fruitful. The skill lessons were crucial to helping the boys develop the building blocks to connect with each other, in addition to developing relationships outside the group. Without very specific lessons in "Talking Briefly" and "Initiating a Conversation," our young World War II aficionado may have continued to alienate himself from the other group members.

Allowing time for both structured skill lessons and more "natural" interactions continues to be my preferred format. Groups usually involve a conversation time, a skill lesson, and a game-playing time. Games might include typical board or card games for their age group, as well as activities geared to teaching verbal and non-verbal communication skills (e.g., charades, twenty questions, and other guessing games). It is important for individuals to first learn a skill, then have a chance to practice it in "real" conversations or play situations with each other. The group, as such, is a microcosm of the outside world allowing members to experiment with new skills within an accepting atmosphere.

Since that first session, I have run and supervised over 30 groups for individuals with AS from four year-olds to young adults. With each session and each group, new skill steps were created or borrowed from other resources (e.g., Gajewski, Hirn, & Mayo, 1998; McGinnis & Goldstein, 1997). These skills have now been compiled into a skill menu, which I use both to assess a prospective group member's social skills and to design an individualized curriculum. The following describes assessment issues in screening members for groups, the types of skills taught, techniques to teach social skills, and the activities of a typical group session.

Assessment Issues

My assessment goal is rarely to arrive at a diagnosis, which, by itself, gives me little information. Instead, my assessment objectives are to: (a) determine what social skills the youngster needs to work on, (b) what strategy would be best to teach the social skills, and (c) what therapy modality would be best to teach the social skills. There are essentially two pieces of information that I want to distill from my assessment in order to make these decisions: receptive language ability and level of attentiveness.

Receptive Language Ability Determines the Strategy to Use

A Verbal IQ score along with an interview with the child is often adequate for my purposes in determining receptive language ability. The child's ability to understand language concepts helps me to determine what strategies will be helpful to teach social skills. Youngsters with good receptive language ability (e.g., Verbal IQ in the average range) can benefit from a "top-down" or conceptual approach in which we verbally explain why and how to perform a skill. Other youngsters may benefit more from an approach that relies on visual aides or a bottom-up approach in which we model and prompt the skill in specific situations hoping to build a more general concept over time.

Level of Inattention Determines the Therapy Modality

Many AS children present with inattention, impulsivity, and hyperactivity although they may not have a true Attention Deficit/Hyperactivity Disorder (e.g., the "inattention" may actually be due to perseveration on an irrelevant aspect of a situation). As a result of their inattention, some youngsters may not be ready to maintain their focus in a group. They may instead benefit from individual therapy, or to pair off with another youngster until they can build the attending skills necessary to be in a group. My rule of thumb regarding readiness for group relies heavily on the child's response to efforts to be redirected to task. If the youngster can be redirected by my verbal prompts or with the help of a token economy in which tokens are dispensed for returning to task, then I will consider the youngster for group. On the other hand, if during typical one on one situations, neither I nor the parent can redirect the youngster back to task through verbal means, gentle physical prompts, or a token system, then I will not consider that youngster ready for group.

Grouping Members

In private practice, my groups are usually quite homogenous with respect to diagnostic issues because few "typically functioning" children are referred for social skills training. Most children I see have AS, a related pervasive
developmental disorder, or ADHD with social skill difficulties.

What we miss in not having typical peers is more than made up for in the advantages of a homogenous group. I continue to be amazed how youngsters with related disabilities quickly accept each other. They share many experiences of being teased or rejected, as well as sharing similar “obsessive” interests. For many it is the first time they have felt part of a peer group.

An important consideration is to keep the level of receptive language ability relatively consistent in the group. Otherwise, the required teaching strategies become too disparate, and one member becomes frustrated, or another becomes bored when the strategy is too simplistic. I have found that this is far more important than grouping by age. Thus, I might have children up to two years apart, as long as their conceptual understanding of language is similar.

Almost all the members are boys, which is not surprising given the much higher prevalence of AS in boys (Ehlers & Gillberg, 1993). Thus when I do have a girl with AS, she remains a minority in the group. In adolescent groups where dating is a common concern, this becomes a complicated issue as many of the boys may vie for that one girl’s attention. Special care must be taken to teach group members about personal boundaries and interpersonal assertiveness to prevent potential conflicts.

Determining What Skills to Target and For What Length of Time

As part of the assessment, I ask parents and teachers to fill out a social skill menu I have compiled, which lists about 50 different skills relating to: language pragmatics (conversational skills), cooperative play, dealing with your own feelings, dealing with other’s feelings, dealing with conflicts and teasing, and friendship management (e.g., pacing offers to get together, reciprocating). Parents and teachers circle the items with which the youngster may need help. Typical problems identified for youngsters with AS often fall into two categories: behavioral excesses and behavioral deficits. Excess behaviors might include interrupting, perseverating on a topic despite the listener’s disinterest, off-topic comments, violating others’ personal space, excessively loud tone of voice, refusing to compromise, and imposing rules on others. Behavioral deficits might include failing to greet or respond to others’ questions, an absence of initiating or maintaining conversation or play with others, and ignoring others’ feelings.

I will put together an initial curriculum for a group based on the most frequently circled items on the social skill menus of those group members. I typically choose no more than ten skills to try to cover in a 12-week period. I run my groups for 12 weekly sessions, after which individuals can leave, new members can come in, or members can continue for the next 12-week cycle. The average youngster attends for close to one year, with progress (based on parent and teacher ratings for each skill taught) typically shown after 12-24 weeks.

In general, the better the youngster’s conceptual ability and the more home practice he or she receives, the quicker one will see results as the individual is better able to generalize skills outside of the group. It is the constant repetition of a skill in actual situations that allows for learning the skill in a meaningful way. As autism expert Diane Twachtman-Cullen (1998) says, “Cells that fire together, eventually wire together.”

It is important to keep in mind that not all problems can be addressed through social skill training. Teaching youngsters what to do and why does not guarantee that they will be able to perform the skills. Individuals with extreme impulsivity may need a good behavioral management program and/or medication to allow them to implement the skills they have learned.

Strategies to Teach Social Skills

Most children before the age of eight and any youngsters whose receptive language ability is low will benefit from strategies that rely more on pictures, physical prompts, and direct modeling than strategies that rely on verbal explanation. For adolescents and those with good receptive language ability, it is useful to teach social skills conceptually by discussing why to act in certain ways along with direct modeling. The following describes various strategies from the most concrete to the most conceptual.

Discrete-Trial

Although a full description of discrete-trial training is beyond the scope of this article, I will offer a brief overview. A discrete-trial has at least four components: a cue, a prompt, behavior, and reinforcement. As an example, consider teaching a youngster to make eye contact. A cue might be the word “look here” as I point to my eyes. The prompt might be to physically move his head so that he is looking at me. His behavior would be to either look at me or look away, and the reinforcement would come only when he looks at me. This approach does not rely heavily on language. Since most youngsters with AS have good language ability, they generally do not need such a structured approach.

Incidental Teaching

The term “incidental” refers to teaching a youngster about a social situation as it is occurring rather than in a structured lesson. The goal is to amplify the social environment for youngsters as it is unfolding so they pick up on the social cues and rules. This strategy represents the basis for facilitating the groups during unstructured conversation and playtime.

Incidental teaching can be done very concretely for some children. One might use visual aides (e.g., using a turn card
to denote whose turn it is during a game), or physical prompts (e.g., a tap on the shoulder to indicate a child's turn). Alternatively, incidental teaching can be more conceptual. For example, if a boy is talking non-stop about his obsession with light fixtures during the group and his peers are starting to get restless, we might say to the boy, “Look how the other children are yawning and squirming in their seats. What do you think they are feeling? Why? Can you ask them if they want to hear more?” In contrast to this incidental lesson, we might later do a formal class lesson on “Talking Briefly So Others Will Listen.”

Social Picture Books

These are mini-books depicting, step by step, children demonstrating various social skills (Baker, 2000). The books are like cartoon strips, yet they are composed of digital pictures of actual children combined with text and cartoon bubbles to denote what the children are saying as they engage in the skills. The pictures show, for each step of a skill, the right and wrong way to act with accompanying text that explains what to do. The books have two important uses and functions. First, by reading the book, children can learn the steps of the skills before they role-play or enact skills. It serves as an excellent tool for practice at home or in school. Secondly, children can actively participate in the creation of these books either by having their pictures taken or by assembling the books on a computer. The benefits are doubled for youngsters who create their own books. They have the opportunity to role-play the skills during the picture taking, then have their attention drawn to a permanent, highly appealing record of themselves engaged in the skill.

Cognitive Picture Rehearsal

This strategy utilizes cartoon-like drawings combined with positive reinforcement principles (Groden & LaVasseur, 1995). Cognitive picture rehearsal always includes drawings or pictures of three components: the antecedents to a problem situation, the targeted desired behavior, and a positive reinforcer. The pictures are displayed on index cards. On the back of each card is a script describing the sequence of events. Children are shown the sequence of cards until they can repeat what is happening in each picture. Then the sequence is reviewed just prior to the child entering the potentially problematic situation.

Unlike social skill picture books, which were designed to model general social skills, cognitive picture rehearsal is used for a specific problem situation. As an example, I had a seven-year-old group member who would run out of the office into the street whenever another member began to cry. We drew pictures of him watching another member crying (antecedent), then putting his fingers in his ears and going to a quiet area of the room (the desired behavior), then playing and getting his snack at the end of group (reinforcers). His mother would read the cards to him as a bedtime story and then always just before group. Remarkably, we had no more incidents of running out of the group.

Social Stories

Developed by Carol Gray and colleagues (Gray, Dutkiewicz, Fleck, Moore, Cain, Lindrup, Broek, Gray, & Gray, 1993), this strategy uses stories written in the first person to increase youngsters understanding of problematic situations. Beginning with the child's understanding of a situation, a story is developed describing what is happening, why, and how people feel and think in the situation. The story contains some directive statements (i.e., what to do in the situation), but the focus is on what is happening in the situation.

Like cognitive picture rehearsal, social stories are read repeatedly to children until they have over-learned them, then read again just prior to the problematic situation. I have often used this strategy for youngsters with AS who believe they are being teased in a situation where they are not actually being teased. The story describes, for each behavior the child observed, what else the accused teaser may be doing or thinking. It may also contain ways to tell if the person really is teasing (e.g., the person is looking right at you and makes a critical remark). The more specific one can spell out how and why people are behaving in certain ways, the better the story.

Structured Learning and Promoting Generalization

This approach forms the core teaching model for skills lessons used in my groups. The term refers to the strategies of Goldstein and colleagues in their “skills streaming” series (McGinnis & Goldstein, 1997). Structured learning contains four components: didactic instruction (explanation of the skill steps), modeling, role-playing with feedback, and practice in and outside the group.

The skills streaming series is an excellent resource that articulates skill steps for numerous skills. In addition, the format for teaching and promoting generalization is quite helpful. However, it does not contain many of the language pragmatic skills that are relevant for youngsters with AS and it does not always spell out specifically enough the steps or scripts that might be useful for individuals with AS. As such, I have adopted their model for teaching, but rewritten most of the skill steps and added more language pragmatic skills.

The key to this approach, or any that relies partially on verbal instruction, is to engage the member's attention. Explanation of a skill is inherently dry and needs to be spiced up with game formats and lively presentations. For example, many of the children I have worked with are game show fans (undoubtedly because they excel in memorizing factual information). Thus, discussing the steps in the form of shows like Jeopardy, Wheel of Fortune, or Who Wants To Be a Millionaire? is usually well received. Also interspersing didactic presentation with live modeling or video modeling breaks up the verbal instruction.
Another key to this or any of the other approaches is how to promote generalization. Each skill has a written practice sheet in which members are asked to consider with whom and when they will practice the skill. Parents and teachers are informed about the skill steps after or during the group and given instructions on how to practice with their youngster. Parents and teachers can engage in four activities to encourage generalization: (a) quiz the youngster about the skill steps, (b) model and role-play the steps, (c) prompt the youngster to enact the skill when needed (i.e., incidental teaching), or (d) provide a reward for enacting the skill. I will typically offer rewards to children who return their practice sheets to me the next week indicating they have practiced the skills. Teachers can set up school/home behavior charts in which some of these skills are targeted to promote skill generalization.

As a rule, I usually have parents in the groups with me for children eight and younger. This allows me to model for parents how they can prompt their youngsters at home, and it also provides more support during the group to handle challenging behaviors. For older children, I will tell the parents after the group what the skill was and how to practice it. Moreover, parents are encouraged to set up play-dates with other group members to continue the practice, and to foster growing friendships.

Typical Group Sessions

The first session generally begins with a review of the purpose of the group: to make friends with each other or learn ways to make and maintain friendships outside the group. The members then develop group rules with varying degrees of guidance from me, and I describe any behavioral management system we may use. I have rarely needed a behavioral management system with teens, yet with younger groups I use a token system with play money earned towards snack (or any other discovered incentive). I find the play money to be a good, concrete, visual incentive, quieter than tokens, and somewhat reinforcing by association.

Since most members are quite nervous entering the first session, we will usually begin with familiar territory. Each member has the opportunity to talk about his current interest (or obsession) during a “show and tell” period. This usually “breaks the ice,” allows members to identify with each other, and sets the stage for conversation skills we will be working on.

Subsequent sessions follow the format described earlier: conversation, skill, then playtime and snack. Conversation time resembles any typical therapy group in which members discuss their week, problematic situations, and gain support and advice from other members. The difference, however, is that I am equally concerned about how they are conversing as I am about what they are saying. My main job as facilitator is to coach, prompt, and highlight the social environment as it unfolds during group. I will prompt youngsters to begin conversation, ask questions, make on-topic comments, edit sensitive remarks, show understanding when someone is upset, talk briefly and check if others want to hear more, take turns, shift topics appropriately, wait for a pause, make eye contact, keep an appropriate distance from each other, and modulate their tone of voice as necessary.

My role during playtime is similar. I prompt and highlight for members how others are feeling. If members are arguing about who goes first or a similar conflict, I will not let the hostility escalate too far. If emotions are high, I will try to calm others using some kind of distraction. Later, I will return to the problem and use it as a learning opportunity, by imbedding it in a social skill lesson or problem-solving discussion to prepare them for future similar situations. In general, my rule of thumb for situations that can prompt temper outbursts is: (a) during moments of intense anger, use distraction as a calming technique, and (b) try to prevent the temper outburst by teaching a skill that prepares the individual for how to handle the problematic situation.

Conclusion

Although it is not 1944 and the troops are not storming Normandy, the social world continues to be a battleground for many youngsters with AS. Social isolation, neglect, harassment, and direct rejection are frequent daily experiences for some in mainstream settings. As a result, having a safe place to connect with other students and to not be taunted become very valuable experiences.

From a parent's or educator's perspective, a crucial goal of the group is that children will learn social skills that will help them gain greater acceptance. However, from the group members' points of view, having and being with friends while in the group may be the most important issue, regardless of any skills learned. With this in mind, an effective group cannot just be a class, but a place where members feel safe and enjoy themselves.

References


Asperger's Syndrome in Adolescence and Adulthood: Considerations for Support and Intervention

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Asperger’s Syndrome (AS) is a developmental disability associated with significant deficits in the areas of social and communication skills (Attwood, 1997). On the surface this may appear to some as being a relatively minor disability; after all, there are little if any physical challenges with AS and academic skills are generally strong. However, within the context of a society that values social competence, such deficits often present individuals with AS significant, life-long challenges to their ability to live, work, and recreate as independently as possible (Harris & Handleman, 1997; Landa, 2000; McConaughy, Stowitschek, Salzberg, & Peatross, 1989).

Specific social and communication difficulties often are first recognized as truly problematic in early adolescence when social cliques and peer social status become important components of one’s life (Attwood, 1998) and the day-to-day challenges of school life may become overwhelming. As such, appropriate educational programming for these individuals needs to include an explicit social/communication component of instruction in addition to instruction in grade level academics (Klin & Volkmar, 2000). Unfortunately, school personnel are often limited in their knowledge of, and therefore their ability to best address the social and communication needs of individuals who are not failing academically.

To help remedy this, Klin and Volkmar (2000) propose six components necessary for the appropriate education of learners with AS. These include: 1) a high level of individualized instructional methods and attention; 2) the availability of a communications specialist with training in pragmatics and social skill instruction and support; 3) ample opportunities for social interaction in both structured and nonstructured settings; 4) attention to life-skills in addition to specific social and academic goals; 5) a willingness on the part of the school personnel to be flexible in how curriculum content may be addressed; and 6) the availability of in-school case management and, when necessary, specific counseling services.

Absent attention to the above noted components, the use of the term “appropriate” to describe the education of many learners with AS would appear to be inaccurate at best. Although long-term follow-up studies are generally absent (Attwood, 1997; Gerhardt & Holmes, 1997) continued failure on the part of the educational system to provide an appropriate, effective education can only be associated with continued post-graduation difficulties such as high rates of unemployment among adults with AS, limited access to relevant services, and continued social isolation. In light of these existing challenges, the critical need for individually determined interventions and supports for post-graduation learners with AS becomes apparent.

The AS Adult in the NT World

During initial meetings, consultations, or job interviews, many adults with AS may present as socially competent if a bit “quirky.” Obviously this is not the case. Such misperceptions are often based on either relatively small samples of behavior (for example, a 20 minute doctor visit) or a misunderstanding regarding the nature of AS (“He can do it if only he would try harder.”). Anecdotal reports (Vickers; Shery, 2000) suggest that many individuals with AS experience significant levels of frustration with the inability of the “neurotypical world” (NT) to better understand and recognize how difficult life may be for them.

A sentiment often expressed at The Douglass Group, a support group for adults with AS with which I am associated, is
“If you NTs have all the skills, why don't you adapt for a while?” The perceived professional proclivity to focus on somehow “changing” the person with AS is often discussed at the group in contrast to how no one, generally, expects a blind person to see. Instead, the focus of such intervention is on the provision of skills coupled with environmental modifications and community education.

Another way of understanding this is to consider the difference between a disability and a handicap. A disability can be defined as permanent reduction in the function of a particular body part or structure. A handicap, on the other hand, is defined by the challenges that the disability presents to the individual's participation in desired, life-relevant activities. As such, the dark black in Figure One can be seen as representing the area where the disability that is AS no longer presents a significant handicap. Using this perspective, the adult with AS becomes simply one target of potential intervention among a variety of targets (e.g., co-workers, job requirements, physical environment, community knowledge) designed to lessen the extent to which AS, as a disability, results in a significant handicap. In this manner, more individualized and therefore potentially more effective systems of support and intervention may be developed and implemented across a number of domains including employment, emotional awareness and self advocacy, and life skills such as dating.

**Employment Support Inclusive of Co-Worker Training**

Because social competence is generally regarded as so integral to job success that it cannot be divorced from production competence (Hill, Wehman, Hill, & Goodall, 1986; McConaughy, Stolztschek, Salzberg, & Peatross, 1989) many, if not most, of the difficulties experienced by adults with AS in the employment arena stem not from production-related challenges but rather social-related challenges. Given that, instruction and support for the adult with AS may include such components as the identification of potentially difficult social situations on the job, direct social instruction relevant to these situations, role play, and possibly some self-monitoring or related metacognitive strategy (e.g., Dixon, Moore, Hartnett, Howard, & Petrie, 1995).

In addition, as the myriad social skills necessary to succeed at a particular job may not be immediately identifiable, the availability of long-term (if intermittent) social support and social coaching may be necessary if employment tenure is to be a viable goal. Relevant to NT co-workers, training in the areas of: 1) the social and communicative needs of persons with AS; 2) promoting a socially inclusive environment, and 3) issues related to long-term employment support should be considered essential.

**Emotional Awareness and Self Advocacy**

As social isolation accompanied by self esteem concerns are often reported by individuals with AS (Howlin, 1997; Myles & Southwick, 1999), particular attention should be paid to addressing these needs in adulthood. Although, as noted by Klin and Volkman (2000), “insight oriented psychotherapy is not usually helpful” (p. 361) for persons with AS, problem specific and generally structured counseling can be of some value. The therapeutic process, the authors note, can be helpful in alleviating individual concerns ranging from the challenges of day to day living to the complexities of interpersonal relationships.

Directly related to the concept of self esteem may be one’s ability to effectively advocate on behalf of one’s self for one’s needs. In fact, it can be argued that self advocacy skills are perhaps the most important skills that can be provided to the special needs learner as part of the process of the transition to adulthood. Specific skills relative to the self advocacy process may include, but are not limited to: 1) awareness of individual needs, strengths, rights, responsibilities and accommodations; 2) awareness of individual acts of discrimination; 3) awareness of possible solutions to problems; 4) significant planning and coordination; 5) the desire to work hard on one’s behalf; and 6) perseverance (Gerhardt, 1999).

The ability to effectively self advocate can directly impact multiple aspects of one's life and is directly relevant to supporting an individually determined, positive quality-of-life (QOL). QOL, according to Schalock and Jensen (1986) constitutes the goodness-of-fit between persons and their environment; and this goodness-of-fit can be understood as occurring along the complimentary paradigms of competence, choice, and control (Heal, Borthwick-Duffy, & Saunders, 1996). Psychologists and other support personnel, therefore, in providing services to individuals with AS need to assess individual concerns not only from the point of view of normative society (i.e., the expected demands of the environment), but also from the goodness-of-fit between the person, his or her environment, and the desired QOL outcome.

**Life Skills Including Dating and Leisure/Recreation**

Adults with AS will generally require some degree of support and instruction in order to effectively navigate the world of independent, or interdependent, living. Many of the activities that constitute life are straightforward and, more or less, concrete. For example, there is little room for interpretation regarding how and when to pay bills, balance one’s checkbook, or which bus to ride to work. However, many other activities of daily living, such as interpersonal relationships and the dating process, are considerably more variable and complex.

Not all persons with AS are necessarily interested in dating or in the development of a physically intimate relationship. However, professional avoidance of the topic may have more to do with prevailing social norms than with the actual needs of the person in question (Tantum, 2000). Space limits a comprehensive discussion of the topic, but minimally, adults with AS need to be provided with sufficient information and instruction to: 1) identify and avoid potentially
dangerous or compromising situations that may occur as the result of social deficits (Volkmar & Klin, 2000); 2) understand the responsibilities of dating and physical intimacy; and 3) how to access help or additional information when needed.

Is There a “Culture of AS”?

Those in the disability community are quite aware of the term “the culture of the deaf” wherein members view their deafness as a difference and not as disability. Members of the deaf community may often prefer to socialize with others of the same culture rather than with members of the hearing culture. Does such a culture exist within the AS community?

The answer, while far beyond the scope of this paper, may have far reaching implications as to how services might best be delivered to individuals with AS in a truly “consumer driven” manner. For example, if the answer is “yes,” that there is indeed a culture of AS, does a more congregate living arrangement (a number of persons with AS living in the same condominium complex for example) become a consumer-directed service where previously it might be considered “institutional?” If, on the other hand, the answer is “no,” do support groups where individuals come together to share common experiences (e.g., Gerhardt, Labay, Carter, & Domanski, 1999; Klin & Volkmar, 2000) become another well intentioned artifact of the history of ineffective services. With as yet no empirical data one way or the other, and until such data exist, it becomes even more critical for the consulting psychologist and other support personnel to listen carefully to individual consumers when they tell us what it is, in fact, that they need and want by way of services and supports.

Summary

Children with Asperger’s Syndrome grow up and become adults with Asperger’s Syndrome. With this transition to the world of adult interactions, demands, activities and privileges come multiple challenges. By understanding the needs, desires, abilities, and deficits of the individual with AS, and their relationship to the demands of existing and desired environments, individualized and potentially effective systems of instruction and support can be developed. In that way, the once mainly academically competent student can begin the transition to become a more broadly competent adult.

References


Return to top of page