

**Asperger's Syndrome**  
**Guidelines for Treatment and Intervention**  
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## **Introduction**

Asperger syndrome (AS) is a severe developmental disorder characterized by major difficulties in social interaction, and restricted and unusual patterns of interest and behavior. There are many similarities with "autism without mental retardation" (or "Higher Functioning Autism"), and the issue of whether Asperger syndrome and Higher Functioning Autism are different conditions is not yet resolved. Nevertheless, a considerable body of knowledge regarding this condition has been evolving in the past few years. A summary of issues regarding assessment and diagnosis of Asperger Syndrome are discussed in some detail in a related booklet circulated by the Learning Disabilities Association of America, and readers are advised to consult that text prior to reading the following guidelines. The present text is an attempt to summarize a series of concrete proposals for treatment and intervention, with a view to provide parents and care providers with specific suggestions that may be helpful in devising educational and treatment programs for children and adolescents affected by this severe form of social learning disability. Because of space constraints, these suggestions are by necessity brief. Parents and care providers seeking additional information are referred to the more comprehensive reviews listed in our reference page.

Every treatment and intervention program starts with a thorough assessment of the child's deficits and assets in the context of a transdisciplinary evaluation including assessments of behavioral (or psychiatric) history and current presentation, neuropsychological functioning, communication patterns (particularly the use of language for the purpose of social interaction, or pragmatics), and adaptive functioning (the individual's ability to translate potential into competence in meeting the demands of everyday life). The final formulation should include a characterization of the child's deficits and abilities in these various areas. The actual diagnostic assignment should be the final step in the evaluation. Labels are necessary in order to secure services and guarantee a level of sophistication in addressing the child's needs. The assignment of a label, however, should be done in a thoughtful way, so as to minimize stigmatization and avoid unwarranted assumptions. Every child is different. If one were to observe a group of individuals with Asperger Syndrome, one would probably be more impressed by how they differ than by how they are alike. Therefore, it is absolutely crucial that intervention programs derived from comprehensive evaluations are individualized to insure that they address the unique profile of needs and strengths exhibited by the given child. The psychiatric label should never be assumed to convey a precise preconceived set of behaviors and needs. Its main function is to convey an overall sense of the pattern of difficulties present. Professionals should never start a discussion of the child's needs by evoking the label. Rather, they should provide a detailed description of evaluation findings that resulted in the diagnosis of Asperger Syndrome. A discussion of any inconsistency with the diagnosis, as well as of the clinician's level of confidence in assigning that diagnosis, should also be provided.

The following set of guidelines reflects our clinical and research experience with Asperger Syndrome in the past few years. It should not be applied in specific cases without a thoughtful discussion of the individual child's profile. The specific guidelines should be seen as a series of

suggestions to be considered when planning for the individual's educational, treatment, and vocational program. In sum: Do not take the diagnosis of Asperger Syndrome for granted - ask for details and for the individualized profile of your child; do not accept a discussion of your child's profile that does not include strengths that may be utilized in the intervention program; and do not accept an intervention program that is based solely on the diagnosis - ask for the development of an appropriate program on the basis of your child's profile, his/her educational setting or living conditions, and realistic short-term and long-term goals.

## **Securing and Implementing Services**

The authorities who decide on entitlement to services are usually unaware of the extent and significance of the disabilities in Asperger Syndrome (AS). Proficient verbal skills, overall IQ usually within the normal or above normal range, and a solitary lifestyle often mask outstanding deficiencies observed primarily in novel or otherwise socially demanding situations, thus decreasing the perception of the very salient needs for supportive intervention. Thus, active participation on the part of the clinician, together with parents and possibly an advocate, to forcefully pursue the patient's eligibility for services is needed. It appears that, in the past, many individuals with AS were diagnosed as learning disabled with eccentric features, a nonpsychiatric diagnostic label that is much less effective in securing services. Others, who were given the diagnosis of autism or PDD-NOS, had often to contend with educational programs designed for much lower functioning children, thus failing to have their relative strengths and unique disabilities properly addressed. Yet another group of individuals with AS are sometimes characterized as exhibiting "Social-Emotional Maladjustment" (SEM), an educational label that is often associated with conduct problems and willful maladaptive behaviors. These individuals are often placed in educational settings for individuals with conduct disorders, thus allowing for possibly the worst mismatch possible, namely of individuals with a very naive understanding of social situations in a mix with those who can and do manipulate social situations to their advantage without the benefit of self-restraint. **It is very important, therefore, to stress that although individuals with AS often present with maladaptive and disruptive behaviors in social settings, these are often a result of their narrow and overly concrete understanding of social phenomena, and the resultant overwhelming puzzlement they experience when required to meet the demands of interpersonal life.** Therefore, the social problems exhibited by individuals with AS should be addressed in the context of a thoughtful and comprehensive intervention needed to address their social disability - as a curriculum need, rather than punishable, willful behaviors deserving suspensions or other reprimands that in fact mean very little to them, and only exacerbate their already poor self-esteem.

Situations that maximize the significance of the disability include unstructured social situations (particularly with same age peers), and novel situations requiring intuitive or quick-adjusting social problem-solving skills. Therefore, it is important that any evaluation intended to ascertain the need for special services include detailed interviews with parents and professionals knowledgeable of the child in naturalistic settings (such as home and school), and, if possible, direct observations of the child in unstructured periods such as recess or otherwise unsupervised settings.

## **General Intervention Setting**

The applicable educational ideology as well as quality of available services vary enormously from school district to school district, across the country as well as within the various states, and sometimes across time for the same school district. It is very important that parents become well acquainted with the following factors involved in securing appropriate placement and programming for their child:

1. The range of services available in their school district: parents should make an attempt to visit the various suggested educational placements and service providers available in their school districts so as to obtain first-hand knowledge and feelings about them, including the physical setting, staffing, adult/student ratio, range of special/support services, and so forth;
2. Knowledge of model programs: parents should make an effort to locate programs (public or private) that are thought to provide high quality services according to local experts, parent support organizations, or other parents. Regardless of whether or not they would like for their child to be placed in that program, a visit to it may provide parents with a model and criteria with which to judge the appropriateness of the local program offered to them;
3. Knowledge of the PPT (Planning and Placement Team) process: it is crucial that parents become acquainted with the PPT process so as to become effective advocates for their children. They should be counseled by clinicians, parent advocates, or legal aides as to their rights as parents of children with disabilities, and as to the alternatives available to them. Parents should attempt to avoid a confrontational or adversarial approach in the same way that they should avoid complacency and passivity. Parents should know that the legal mandate is provision of "appropriate services" to their children. Note that this does not mean the best, nor the most expensive. If parents or their representatives approach the PPT process demanding the latter, they may be seen as preempting both the due examination of the child's needs by the school district authorities, as well as the actual decision. Experience has shown that the most efficacious approach is to secure independent evaluations (to which you should be entitled of both the child's needs and any programs offered by the school district, and to present the case for appropriate programming based on evaluation findings and recommendations. In a great number of cases, the final decision is beneficial, as most educational providers are eager to serve their clients to the best of their abilities. In fact, across the country, a number of service providers are making a special attempt to better acquaint themselves with the special needs of children with social learning disabilities, to train themselves and their staff, and to creatively establish better individualized programs. Nevertheless, if parents are met with unreasonable uncooperativeness, they should seek the advice of other parents or of parent advocates, and even, if necessary, resort to the services of lawyers experienced in the area of disabilities.

The following are positive program specifications to be kept in mind when deciding on appropriate placements and programs for individuals with AS. They may not be applicable to every individual with AS, nor are they feasible in some parts of the country. Nevertheless, they may be seen as optimal conditions to keep in mind when dealing with program specifications:

1. Relatively small setting with ample opportunity for individual attention, individualized approach, and small work groups;
2. The availability of a communication specialist with a special interest in pragmatics and social skills training, who can be available for individual and small group work, and who can also make a communication and social skills training intervention an integral part of all activities, implemented at all times, consistently, and across staff members, settings, and situations. This professional should also act as a resource to the other staff members;
3. Opportunities for social interaction and facilitation of social relationships in fairly structured and supervised activities;
4. A concern for the acquisition of real-life skills in addition to the academic goals, making use of creative initiatives and making full use of the individual's interests and talents. For example, given the fact that individuals with AS often excel in certain activities, social situations may be constructed so as to allow him or her the opportunity to take the leadership in the activity, explaining, demonstrating, or teaching others how to improve in the particular activity. Such situations are ideal to help the individual with AS:
  - a. Take the perspective of others,
  - b. Follow conversation and social interaction rules, and
  - c. Follow coherent and less one-sided goal-directed behaviors and approaches. Additionally, by taking the leadership in an activity, the individual's self-esteem is likely to be enhanced, and his/her (usually disadvantageous) position vis-a-vis peers is for once reversed;
5. A willingness to adapt the curriculum content and requirements in order to flexibly provide opportunities for success, to foster the acquisition of a more positive self-concept, and to foster an internalized investment in performance and progress. This may mean that the individual with AS is provided with individual challenges in his/her areas of strengths, and with individualized programs in his/her areas of weakness;
6. The availability of a sensitive counselor who can focus on the individual's emotional well being, and who could serve as a coordinator of services, monitoring progress, serving as a resource to other staff members, and providing effective and supportive liaison with the family.

### **General Intervention Strategies**

Specific interventions, e.g. teaching practices and approaches, behavioral management techniques, strategies for emotional support, and activities intended to foster social and communication competence, should be conceived and implemented in a thoughtful, consistent (across settings, staff members, and situations), and individualized manner. More importantly, the benefit (or lack thereof) of specific recommendations should be assessed in an empirical fashion (i.e., based on an evaluation of events observed, documented or charted), with useful

strategies being maintained and unhelpful ones discarded so as to promote a constant adjustment of the program to the specific conditions of the individual child with AS. The following items can be seen as tentative suggestions to be considered when discussing optimal approaches to be adopted. It should be noted, however, that there are degrees of concreteness and rigidity, paucity of insight, social awkwardness, communicative one-sidedness, and so forth, characterizing individuals with AS. Care providers should embrace the wide range of expression and complexity of the disorder, avoiding dogmatism in favor of practical, individualized, and common-sensical clinical judgment. The following suggestions should be seen in this context:

1. Skills, concepts, appropriate procedures should be taught in an explicit and rote fashion using a parts-to-whole verbal teaching approach, where the verbal steps are in the correct sequence for the behavior to be effective;
2. Specific problem-solving strategies should be taught for handling the requirements of frequently occurring troublesome situations. Training should also be necessary for recognizing situations as troublesome and applying learned strategies in discrepant situations;
3. Social awareness should be cultivated, focusing on the relevant aspects of given situations, and pointing out the irrelevancies contained therein. Discrepancies between the individual's perceptions regarding the situation in question and the perceptions of others should be made explicit;
4. Generalization of learned strategies and social concepts should be instructed, from the therapeutic setting to everyday life (e.g., to examine some aspects of a person's physical characteristics as well as to retain full names in order to enhance knowledge of that person and facilitate interaction in the future);
5. To enhance the individual's ability to compensate for typical difficulties processing visual sequences, particularly when these involve social themes, by making use of equally typical verbal strengths;
6. The ability to interpret visual information simultaneously with auditory information should be strengthened, since it is important not only to be able to interpret other people's nonverbal behavior correctly but also to interpret what is being said in conjunction with these nonverbal cues;
7. Self-evaluation should be encouraged. Awareness should be gained into which situations are easily managed and which are potentially troublesome. This is especially important with respect to perceiving the need to use prelearned strategies in appropriate situations. Self-evaluation should also be used to strengthen self-esteem and maximize situations in which success can be achieved. Individuals with AS often have many cognitive strengths and interests that can be used to the individual's advantage in specific situations as well as in planning for the future;
8. Adaptive skills intended to increase the individual's self-sufficiency should be taught explicitly with no assumption that general explanations might suffice nor that he/she will be able to generalize from one concrete situation to similar ones. Frequently occurring problematic situations should be addressed by teaching the individual verbally the exact

sequence of appropriate actions that will result in an effective behavior. Rule sequences for e.g., shopping, using transportation, etc., should be taught verbally and repeatedly rehearsed with the help of the interventionist and other individuals involved in the individual's care. There should be constant coordination and communication between all those involved so that these routines are reinforced in the same way and with little variation between the various people. Verbal instructions, rote planning and consistency are essential. A list of specific behaviors to be taught may be derived from results obtained with the Vineland Adaptive Behavior Scales, Expanded Edition (Sparrow, Balla and Cicchetti, 1984), which assess adaptive behavior skills in the areas of Communication, Daily Living (self-help) Skills, Socialization, and Motor Skills;

9. The individual with AS should be instructed on how to identify a novel situation and to resort to a pre-planned, well rehearsed list of steps to be taken. This list should involve a description of the situation, retrieval of pertinent knowledge and step-by-step decision making. When the situation permits (another item to be explicitly defined), one of these steps might be reliance on a friend's or adult's advice, including a telephone consultation;
10. The link between specific frustrating or anxiety-provoking experiences and negative feelings should be taught to the individual with AS in a concrete, cause-effect fashion, so that he/she is able to gradually gain some measure of insight into his/her feelings. Also, the awareness of the impact of his/her actions on other people's feelings should be fostered in the same fashion;
11. Additional teaching guidelines should be derived from the individual's neuropsychological profile of assets and deficits; specific intervention techniques should be similar to those usually employed for many subtypes of learning disabilities, with an effort to circumvent the identified difficulties by means of compensatory strategies, usually of a verbal nature. For example, if significant motor, sensory-integration or visual-motor deficits are corroborated during the evaluation, the individual with AS should receive physical and occupational therapies. These latter should not only focus on traditional techniques designed to remediate motor deficits, sensory integration or visual-motor deficits, but should also reflect an effort to integrate these activities with learning of visual-spatial concepts, visual-spatial orientation and causation, time concepts, and body awareness, making use of narratives and verbal self-guidance.

### **General Strategies for Communication Intervention and Social Skills Training**

For most individuals with AS, the most important item of the educational curriculum and treatment strategy involves the need to enhance communication and social competence. This emphasis does not reflect a societal pressure for conformity or an attempt to stifle individuality and uniqueness. Rather, this emphasis reflects the clinical fact that most individuals with AS are not loners by choice, and that there is a tendency, as children develop towards adolescence, for despondency, negativism, and sometimes, clinical depression, as a result of the individual's increasing awareness of personal inadequacy in social situations, and repeated experiences of failure to make and/or maintain relationships. The typical limitations of insight and self-reflection vis--vis others often preclude spontaneous self-adjustment to social and interpersonal demands. The practice of communication and social skills do not imply the eventual acquisition of communicative or social spontaneity and naturalness. It does, however, better prepare the

individual with AS to cope with social and interpersonal expectations, thus enhancing their attractiveness as conversational partners or as potential friends or companions. The following are suggestions intended to foster relevant skills in this important area:

1. Explicit verbal instructions on how to interpret other people's social behavior should be taught and exercised in a rote fashion. The meaning of eye contact, gaze, various inflections as well as tone of voice, facial and hand gestures, non-literal communications such as humor, figurative language, irony, sarcasm and metaphor, should all be taught in a fashion not unlike the teaching of a foreign language, i.e., all elements should be made verbally explicit and appropriately and repeatedly drilled. The same principles should guide the training of the individual's expressive skills. Concrete situations should be exercised in the therapeutic setting and gradually tried out in naturally occurring situations. All those in close contact with the individuals with AS should be made aware of the program so that consistency, monitoring and contingent reinforcement are maximized. Of particular importance, encounters with unfamiliar people (e.g., making acquaintances) should be rehearsed until the individual is made aware of the impact of his/her behavior on other people's reactions to him/her. Techniques such as practicing in front of a mirror, listening to the recorded speech, watching a video recorded behavior, and so forth, should all be incorporated in this program. Social situations contrived in the therapeutic setting that usually require reliance on visual-receptive and other nonverbal skills for interpretation should be used and strategies for deciphering the most salient nonverbal dimensions inherent in these situations should be offered;
2. The individual with AS should be taught to monitor his/her own speech style in terms of volume, rhythm, naturalness, adjusting depending on proximity to the speaker, context and social situation, and number of people and background noise;
3. The effort to develop the individual's skills with peers in terms of managing social situations should be a priority. This should include topic management, the ability to expand and elaborate on a range of different topics initiated by others, shifting topics, ending topics appropriately and feeling comfortable with a range of topics that are typically discussed by same-age peers;
4. The individual with AS should be helped to recognize and use a range of different means to interact, mediate, negotiate, persuade, discuss, and disagree through verbal means. In terms of formal properties of language, the individual may benefit from help in thinking about idiomatic language that can only be understood in its own right, and practice in identifying them in both text and conversation. It is be important to help the individual to develop the ability to make inferences, to predict, to explain motivation, and to anticipate multiple outcomes so as to increase the flexibility with which the person both thinks about and uses language with other people.

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### **General Guidelines for Behavior Management**

Individuals with AS often exhibit different forms of challenging behavior. It is crucial that these behaviors are not seen as willful or malicious; rather, they should be viewed as connected to the individual's disability and treated as such by means of thoughtful, therapeutic, and educational

strategies, rather than by simplistic and inconsistent punishment or other disciplinary measures that imply the assumption of deliberate misconduct. Specific problem-solving strategies, usually following a verbal rule, may be taught for handling the requirements of frequently occurring, troublesome situations (e.g., involving novelty, intense social demands, or frustration). Training is usually necessary for recognizing situations as troublesome and for selecting the best available learned strategy to use in such situations. The following are some suggestions on how to approach behavioral management in the case of individuals with AS:

1. Setting limits: a list of frequent problematic behaviors such as perseverations, obsessions, interrupting, or any other disruptive behaviors should be made and specific guidelines devised to deal with them whenever the behaviors arise. It is often helpful that these guidelines are discussed with the individual with AS in an explicit, rule-governed fashion, so that clear expectations are set and consistency across adults, settings and situations is maintained. These explicit rules should be not unlike curriculum guidelines. The explicit approach should be devised based on the staff's ongoing experiences, determined empirically, and discussed in team meetings. An effort should be made to establish as much as possible all possible (though few) contingencies and guidelines for limit setting so that each staff member does not need to improvise and thus possibly trigger the individual's oppositionality or a temper tantrum. When listing the problematic behaviors, it is important that these are specified in a hierarchy of priorities, so that staff and the individual himself/herself concentrate on a small number of truly disruptive behaviors (to others or to self);
2. Helping the individual with AS make choices: There should not be an assumption that the individual with AS makes informed decisions based on his/her own set of elaborate likes and dislikes. Rather he/she should be helped to consider alternatives of action or choices, as well as their consequences (e.g., rewards and displeasure) and associated feelings. The need for such an artificial set of guidelines is a result of the individuals' typical poor intuition and knowledge of self.

## **Academic Curriculum**

The curriculum content should be decided based on long-term goals, so that the utility of each item is evaluated in terms of its long-term benefits for the individual's socialization skills, vocational potential, and quality of life. Emphasis should be placed on skills that correspond to relative strengths for the individual as well as skills that may be viewed as central for the person's future vocational life (e.g., writing skills, computer skills, science). If the individual has an area of special interest that is not as circumscribed and unusual so as to prevent utilization in prospective employment, such an interest or talent should be cultivated in a systematic fashion, helping the individual learn strategies of learning (e.g., library, computerized data bases, Internet, etc.). Specific projects can be set as part of the person's credit gathering, and specific mentorships (topic-related) can be established with staff members or individuals in the community. It is often useful to emphasize the utilization of computer resources, with a view to:

- a. Compensate for typical difficulties in grapho-motor skills,
- b. To foster motivation in self-taught strategies of learning, including the use of "on-line" resources, and

- c. To establish contact via electronic mail with other people who share some interests, a more non-threatening form of social contact that may evolve into relationships, including personal contact.

### **Vocational Training**

Often, adults with AS may fail to meet entry requirements (e.g., a college degree) for jobs in their area of training, or fail to attain a job because of their poor interview skills, social disabilities, eccentricities, or anxiety attacks. Having failed to secure skilled employment (commensurate with their level of instruction and training), sometimes these individuals may be helped by well-meaning friends or relatives to find a manual job. As a result of their typically very poor visual-motor skills they may once again fail, leading to devastating emotional implications. It is important, therefore, that individuals with AS are trained for and placed in jobs for which they are not neuropsychologically impaired, and in which they will enjoy a certain degree of support and shelter. It is also preferable that the job does not involve intensive social demands. As originally emphasized by Hans Asperger, there is a need to foster the development of existent talents and special interests in a way as to transform them into marketable skills. However, this is only part of the task to secure (and maintain) a work placement. Equal attention should be paid to the social demands defined by the nature of the job, including what to do during meal breaks, contact with the public or co-workers, or any other unstructured activity requiring social adjustment or improvisation.

### **Self-Support**

As individuals with AS are usually self-described loners despite an often intense wish to make friends and have a more active social life, there is a need to facilitate social contact within the context of an activity-oriented group (e.g., church communities, hobby clubs, and self-support groups). The little experience available with the latter suggests that individuals with AS enjoy the opportunity to meet others with similar problems and may develop relationships around an activity or subject of shared interest.

### **Pharmacotherapy**

Although little information about pharmacological interventions with individuals with AS is available, a conservative approach based on the evidence from autism should probably be adopted (McDougle, Price, and Volkmar, 1994). In general, pharmacological interventions with young children are probably best avoided. Specific medication might be indicated if AS is accompanied by debilitating depressive symptoms, severe obsessions and compulsions, or a thought disorder. It is important for parents to know that medications are prescribed for the treatment of specific symptoms, and not to treat the disorder as a whole.

### **Psychotherapy**

Although insight-oriented psychotherapy has not been shown to be very helpful, it does appear that fairly focused and structured counseling can be very useful for individuals with AS, particularly in the context of overwhelming experiences of sadness or negativism, anxiety, family functioning, frustration in regard to vocational goals and placement, and ongoing social adjustment.