

Best Practices in Children's Mental Health:

A Series of Reports Summarizing the Empirical Research on Selected Topics

Report #6 **“Children and Adolescents with** **Asperger Syndrome”** **April, 2003**

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Children and Adolescents with Asperger Syndrome

Hans Asperger first identified Asperger Syndrome (AS) in 1944. Dr. Lorna Wing “re-introduced” AS in 1981 in the United Kingdom, but it was not accepted in the United States as a disorder until the mid 1990’s (Safran, 2001). AS was recognized internationally in 1994 by the American Psychiatric Association in the Diagnostic and Statistical Manual of Mental Disorders 4th edition (DSM- IV; American Psychiatric Association, 1994) and in 1992 by the World Health Organization in the International Classification of Diseases (ICD-10: World Health Organization, 1993). Due to the relatively recent identification of the diagnosis, the average clinician’s knowledge of the diagnosis is minimal and children have typically not been diagnosed until they attended school (Barnhill, 2001; Lord, & Volkmar, 2002).

Diagnostic Criteria (*DSM-IV*), 1994, pp. 75-77)

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

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

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

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

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

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

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

F. Criteria are not met for another specific Pervasive Developmental Disorder of Schizophrenia.

The DSM-IV also notes that Aspergers is distinguished from autism when there are “no clinically significant delays in language and cognitive development or in the development of age-appropriate self-help skills, adaptive behavior (other than in social interaction) and curiosity about the environment in childhood” (criteria E above). The DSM-IV reports that the onset is “somewhat later” than Autistic Disorder because the distinguishing characteristics such as lack of socially appropriate interactions are not recognizable until children start school (American Psychiatric Association, 1994). Another reason may be the lack of familiarity clinicians have with the diagnosis, since it is relatively new (Barnhill, 2001; Henderson, 2001; Klin, Volkmar, and Sparrow, 2001; Myles, Barnhill, Hagiwara, et al., 2001).

Prevalence

The DSM IV (1994) states that “extensive prevalence studies have not been conducted...the disorder seems to be more common in males.” One prevalence study conducted in Sweden in 1989 (Gillberg & Gillberg, 1994) suggest a minimum prevalence of 3.6 out of 1,000 children ages 7-16 years. Lord and Volkmar (2002) reported that families of children with AS had a higher rate of autism and similar Pervasive Developmental Disorders (PDD) than the general population. Fombonne (1998) stated that AS may be only second to autism in the prevalence rates for PDD (cited by Volkmar, Cook, & Pomeroy, 1999).

Screening for Aspergers

Since the signs of the disorder may appear with the development of language, clinicians should be aware of the distinguishing characteristics of “idiosyncratic or circumscribed interests” and pay attention to motor delays and clumsiness (American Psychiatric Association, 1994). Assessments need to include consultation with parents, a developmental and family history, a psychological assessment, a communication assessment, and a psychiatric assessment (Klin, & Volkmar, 1995; Volkmar, Cook, & Pomeroy, 1999). Although there are no

standardized screening tools for children with AS, the Autism Spectrum Disorder Screening Questionnaire (Ehlers, Gillberg, & Wing, 1999) and the Australian Scale for Asperger Syndrome (Attwood, 1998) may be useful as diagnostic aids (Safran, 2001). In addition experts have recently developed two new scales that professionals may use. These scales have not been standardized. The ASDS (Asperger Syndrome Diagnostic Scale) assesses “language, social, maladaptive, cognitive, sensory, motor, and key questions” (Myles, Jones-Bock, & Simpson 2003). The ASDS is to be completed by professionals. The GADS (The Gilliam Asperger’s Disorder Scale) consists of several sub-scales that can be completed by either professionals or families (Gilliam, 2003).

Highlights from the literature review

Because Asperger's Syndrome is a relatively new diagnosis, the literature research studies to date have focused on clarifying the diagnostic characteristics and describing anecdotal interventions of AS. The literature search uncovered a few references that suggested mental health interventions. These references cited "structured and focused" supportive psychotherapy to address life stressors that go along with the diagnosis (Barnhill, 2001; Lord, & Volkmar, 2002). Ozonoff, Dawson, and McPartland (2002) suggest Applied Behavior Analysis, in which general principles of behavioral therapy are used to build lacking social skills. The literature from special education contains some suggestions for community and school-based interventions, but these have not been empirically evaluated (Kiln & Volkmar, 1995).

- Individuals with AS have IQs similar to the general population and may be overly represented in the gifted population (2,4,5,6).
- Though the individual with AS may be able to function better in social situations than individuals with more autistic symptoms, individuals with AS still struggle with reciprocal social interactions and may benefit from a variety of targeted social skills interventions (3,5,7,8,9).
- Characteristics of AS such as intensity of focus on certain topics and rote memorization of facts and figures may be capitalized on as strengths in settings where these traits are needed and desired (1,2,4,5,6).
- The field of special education has generated a variety of school-based interventions for children and adolescents with AS. These interventions focus on social skills but have not been empirically tested. (2,3,6,7).
- Children, and especially adolescents with AS, are likely to be emotionally vulnerable especially in social situations that demand flexibility (1,2,5,7,8,10).
- Descriptive interventions of programs within the schools focused on the use of multi-disciplinary teams (1,3,7,10).

- Diagnosis of AS may not occur until school age because this is when children are regularly exposed to social situations (4,5).
- Individuals with AS may have symptoms of depression and anxiety. Case studies point to symptoms of inattention and hyperactivity in childhood and depression and anxiety in later adolescents (5,7,8,9,10).
- Several studies have documented a co-occurrence of tics, Tourettes Syndrome (Kerbeshian & Burd, 1996), and depressive disorders (Gillberg et al., 2000).
- Although AS is often viewed as “high-functioning autism,” children with AS may share only one symptom or diagnostic criteria such as qualitative social impairment, and otherwise differ greatly in cognitive, language, and self-care abilities (2,5,8,9).

Future Research

Researchers are currently focused on distinguishing AS from the other Pervasive Developmental Spectrum Disorders. Most of the literature points to the different “developmental trajectories or pathways.... Generally children with AS develop some useful speech by 3 years of age...children with autism develop speech after 3 years” (Szatmari, 2001 p 120).

Asperger's Syndrome has one criterion in common with the PDD spectrum disorders, and that is qualitative social impairment. When planning for treatment, it is important to note the individual capabilities (such as normal language development, speech and competency with self-care) that will allow for substantially different interventions with individuals with AS. As well as fine-tuning assessment tools, several theorists have pointed to the need for studies that establish the efficacy of social skills interventions for children and adolescents with AS.

Asperger's, Developmental Disability or Serious Emotional Disturbance (SED)?

Children with AS may fit into both target populations. The literature indicates that a high proportion of individuals with AS may have an additional psychiatric diagnosis. These disorders present as disruptive behaviors and hyperactivity in younger children and depressive symptoms in adolescents and adults (Ghziddin, 2002). Aggression and self-injury are the most common reasons for referral to a mental health clinician (Frazier, Doyle, Chiu, & Coyle, 2002). The social and environmental consequences

of AS may cause a personal reaction that justifies an additional psychological disorder (Tantam, 2000). Individuals with AS tend to have average to superior speech capabilities, which would enable them to participate in mental health treatment modalities. Due to the chronicity of AS, long-term planning for remediation of the social deficits is a necessary component of treatment.

Collaboration

Due to the high incidence of behavioral or emotional vulnerability in children with AS, it is important that regular and special education staff make appropriate and timely referrals to mental health centers. As stated in the highlights section, the literature review revealed a body of knowledge generated from the special education field for children and adolescents with AS. The variety of social skills interventions and accommodations for children and adolescents with AS may be useful to Community Mental Health Centers (CMHCs) especially in the provision of more intensive community based services to children who experience SED.

The Community Developmental Disability organizations in the local communities are another resource that may provide the long-term planning necessary to address the social disabilities associated with AS.

Independent Living centers in the local communities may also provide some needed resources as adolescents with AS transition to adulthood.

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Citation	Description	Pertinent Findings
<p>1) Adreon, D. & Stella, J. (2001). Transition to middle and high school: Increasing the success of students with Asperger Syndrome. <i>Intervention in School and Clinic</i>, 36(5), 266-276.</p>	<p>The authors discuss stressors all children face in the transitions from middle school to high school with particular attention to students with Aspergers Syndrome. The article suggests strategies to manage the transition.</p>	<ul style="list-style-type: none"> • Children with AS are likely to experience clinically significant levels of behavioral or emotional disturbance 85% of the time (Tonge, Brereton, Gray, & Einfield, 1999). The rates in the normative population in this study were approximately 10% to 15%. • Depression and generalized anxiety were the most prevalent internalizing symptoms for children and youth with AS. • Strategies to manage the transitions include transition planning meetings, teacher training, and student training. The more the child or adolescent with AS is oriented to his or her surroundings and knows what to expect, the better the transitional outcome will be.
<p>2) Barnhill, G. (2001). What's new in AS research: A synthesis of research conducted by the Asperger Syndrome project. <i>Intervention in School and Clinic</i>, 36(5), 300-306.</p>	<p>Comprehensive summary of empirical evidence designed to provide a valid profile of individuals with AS.</p>	<p>Individuals with AS present a variety of strengths and concerns that occur with variable degrees of severity. Children and adolescents with AS were found to generally have the following characteristics:</p> <ul style="list-style-type: none"> • IQs similar to the general population, ranging from intellectually deficient to very superior. • A significant difference between written and oral language scores. • Limited ability to problem solve, which is in marked contrast to their verbalizations. • Grade-appropriate word calling with problems in inferential comprehension. • Pronounced emotional difficulties recognized by parents and teachers but not acknowledged by the students themselves. • Attributes that resemble a learned helplessness approach. • Sensory problems similar to persons who function cognitively at a much lower level.

<p>3) Bock, M. (2001). SODA Strategy: Enhancing the social interaction skills of youngsters with Asperger Syndrome. <i>Intervention in School and Clinic</i>, 36, 272-283.</p>	<p>The article describes a social behavioral learning strategy used to teach children with Asperger Syndrome a set of rules that will guide their information acquisition, manipulation, integration, storage and retrieval. The acronym, SODA (Stop, Observe, Deliberate, Act) incorporates a set of components that are utilized to guide a child through a social interaction.</p>	<p>Since children with AS have strengths in the area of memory and recall, acronyms are a useful tool in developing lessons on social skills. The author supports the use of visual recognition for each of the 4 components to queue the student while learning and practicing the strategy. Each component contains 3 to 5 questions that should be individualized to meet the specific needs and level of each child.</p> <ul style="list-style-type: none"> • The first component (Stop) assists children in developing an understanding for the setting in which the interaction will occur, the activity that is occurring, and how to prepare them for the rest of SODA. • The second component (Observe) helps children note social cues and conversations. • The third component (Deliberate) considers what children may say or do and how others would perceive them. • The fourth component (Act) guides children’s interactions with a group incorporating initiating a conversation, active listening, responding to shared interests, and ending the conversation.
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<p>4) Henderson, L. (2001). Asperger Syndrome in gifted individuals. <i>Gifted Child Today</i>, 24(3), 28.</p>	<p>The descriptive summary characterizes children with AS and gifted children with AS along with appropriate strategies for identification and intervention.</p>	<ul style="list-style-type: none"> • 72 out of 1000 children may be gifted individuals with Asperger's Syndrome. • The data indicates that the AS diagnosis is made later in life than an Autism diagnosis which may be attributed to relatively normal early development in AS and a recent recognition among practitioners of how to make an accurate diagnosis of AS. • An accurate assessment should cover "intellectual ability, academic achievement, developmental history, behavioral patterns, adaptive behavior and motor skills." • There are three AS specific screening tools that are used to assess behavioral patterns; The Australian Scale for Asperger's Syndrome (Garrett & Attwood, 1998); The Asperger's Syndrome Diagnostic Scale (Myles, Jones-Bock, & Simpson, 2000); The Gilliam Asperger Disorder Scale (Gilliam Asperger Disorder Scale (Gilliam, 2001,). The Gifted and Talented Evaluation Scale (GATES; Gililam, Carpenter, & Christensen, 1996) is used to assess specific intellectual, creative, and artistic abilities. The author did not discuss the validity and reliability of these instruments.
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<p>5) Klin, A., Volkmar, F., & Sparrow, S. (Eds.) (2000). Asperger Syndrome. New York: The Guilford Press. * Resource Recommended by NAMI (National Alliance for the Mentally Ill)</p>	<p>This book divides the current information about AS into the following topics: behavioral aspects; family genetics and neurobiology; related diagnostic constructs; assessment, treatment, and intervention in children and adults; and perspectives on research, clinical practice, and parent essays.</p>	<ul style="list-style-type: none"> • The authors suggest that neither the treatment for autism or the treatment for learning disabilities suit the social and adaptation needs of children with AS. • Assessments conducted by a multi-disciplinary team (child psychologist, speech and language pathologist, and child psychiatrist) give a clearer picture of individual strengths and needs. • “Individuals with AS often excessively verbalize and have poor judgment.” • Failure in social interactions may lead to clinical depression (Volkmar & Klin, 2000). • Higher functions of PDD such as AS “have routinely been excluded from pharmacological studies” (Martin, Patzer, & Volkmar, 2000). • AS may be associated with other diagnosis such as bipolar disorder and major depression (Martin, Patzer, & Volkmar, 2000). • There may be an association with AS and Tourette Syndrome, obsessive compulsive disorder, depression, ADHD, and anxiety disorders. “The co-occurrence of some disorders appear to be developmentally dependent.” Younger children tend to have ADHD while older children tend to have depression. • Preliminary findings of a study on the prevalence and patterns of psychotropic medications among individuals with “High Functioning Pervasive Developmental Disorders found that nearly 70% had received some form of psycho-tropic medications at some point in their lives.” (Klin & Volkmar, 1997, cited by Martin, Patzer, & Volkmar, 2000) The “extent” of the disorder of a child with AS may not be initially recognized because of language skills and an IQ with in the normal range (Klin & Volkmar, 2000). • Klin & Volkmar (2000) suggest the following characteristics be present in any “social and communication skills training program:” “topic management, flexibility in social interaction, perception of nonverbal cues, appreciation of social expectations associated with a given setting, and operational knowledge of the language of mental states and related phenomena.” • Tantam (2000) stated “the emotional consequences of the disorder have a much greater affect on outcome than is commonly recognized.” • Emotional disorders such as depression and anxiety are “over represented” in AS (Tantam, 2000).
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<p>6) Little, C. (2002). Which is it? Aspergers Syndrome or giftedness? Defining the differences. <i>Gifted Child Today</i>, 25, 58-66.</p>	<p>The citation makes descriptive distinctions between three targeted populations: children who are gifted, children with Asperger's Syndrome, and children who are gifted with Aspergers Syndrome or twice exceptional. No single treatment approaches were discussed. The article was an observatory analysis of characteristics in the three target populations with suggestions for brief educational intervention strategies.</p>	<ul style="list-style-type: none"> • The key in determining the differences in the populations lies in understanding the motivation for the behavior. • The twice exceptional children and children with Asperger syndrome, while they may be very motivated by intense interests or fixations on a specific topic and have excellent memories for facts and figures, may not understand what the information means or how it may be applied to other situations. • Language acquisition and development occur as early as age four in these target populations. • Children with Asperger's syndrome have difficulty comprehending another's perspective regarding social interactions and emotional states. Their conversations may run on and on, blending content and personal reflections, without distinction between the two. • The author suggests a serious of simple interventions. Social Stories can be used to illustrate social interactions. Limiting fixations on one topic can be accomplished by designating a certain time each day when the child can talk about his or her interests. Exposing the child to another topic in the discussion of their intense interest may motivate the child to learn about something else. Working on language comprehension could capitalize on the strengths in memory and provide rote tasks. Allowing earplugs, letting a child opt out of activities that require touch, or providing a safe place where they may go to get away from excessive stimulation may limit sensory stimulation.
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<p>7) Myles, B. & Simpson, R. (2001). Understanding the hidden curriculum: An essential social skill for children and youth with Asperger Syndrome. <i>Intervention in School and Clinic</i>, 36(5), 279-283.</p>	<p>The “hidden curriculum includes the skills that are not taught directly but are assumed to be known.” Practical suggestions are given to help children and youth with Asperger syndrome learn the hidden curriculum.</p>	<p>Specific techniques of instruction and interpretation systematically teach children and youth with Asperger syndrome skills to manage social situations.</p> <ul style="list-style-type: none"> • Scope and Sequence techniques focus on understanding the sequence in which social, behavioral, and communication skills develop, and using that information for direct instruction. • Direct Instruction is as follows: developing a rationale for using information, presenting information using visual and auditory cues in small segments, “modeling” how to complete the task, “verifying” that the child is not stressed and comprehending content, “evaluating” the learning process and the ability to replicate the skill, and “generalizing” the new skills to other settings in the child’s life. • Social stories “describe social situations specific to individuals’ circumstances.” • Self-esteem building is important to children with AS because of the high risk of mental health disorders (Williams, 1995). • “Acting Lessons” or role-playing exercises may be utilized to teach children how others’ feel in certain situations. • Interpretive activities such as cartooning and social autopsies lend a non-threatening perspective to situations that had little meaning or were misunderstood.
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<p>8) Ozonoff, S., Dawson, G., & McPartland, J. (2002). <i>A Parent's Guide to Asperger Syndrome and High-Functioning Autism</i>. New York: The Guilford Press.</p>	<p>The book acts as a guide for parents who have a child with AS or High Functioning Autism (HFA) by defining the disabilities and developing interventions for problem solving life situations.</p>	<ul style="list-style-type: none"> • “Very little research has been done on the effectiveness of the treatment approaches” for AS and HFA. • Age appropriate interventions are reviewed such as applied behavior analysis in a preschool setting. ABA uses behavioral therapy to build skills the child lacks such as language and play and minimize unusual behavior. • Behavioral interventions in which the behavior is modified by changing what “precedes” the behavior or changing the “consequence” of the behavior. • Group therapy focusing on social skills training may be more beneficial than individual psychotherapy. • If appropriate, “counseling should still be highly structured and rather more directive and concrete than typical psychotherapy with non-autistic individuals.”
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<p>9) Szatmari, P., Bryson, S., & Steiner D. (2001). Children with Asperger's Syndrome have different socialization scores and fewer autistic symptoms than children with autism. <i>Evidenced Based Mental Health</i>, 4, 120-121.</p>	<p>The purpose of this study was to identify differences in outcome of preschool age children with a diagnosis of autism (n=46) compared with children with Asperger's Syndrome (n=20). The research question was as follows: do children with Asperger's Syndrome have different socialization and autistic characteristics at 2 years than children with Autism? Two participants were lost to follow-up at 26 months. The original sample was 68. The settings were 4 community clinics and 2 university clinics in Southern Ontario that provided services to children with a pervasive developmental disorder. The study did not include the evaluation of interventions.</p>	<ul style="list-style-type: none"> • Children with Asperger's Syndrome had higher socialization scores than those with autism. • Covariate analysis showed that differences in socialization at follow up were explained by differences at the initial assessment (p<0.001). • Socialization was the predictor of a differential diagnosis of AS or Autism when baseline differences in language and non-verbal IQ were controlled. • Children with Aspergers Syndrome had fewer total autistic symptoms at follow up than children with autism. • A critique of the study suggest that diagnostic criteria were based on the Autistic Diagnostic Interview, which has no specificity for Asperger's Syndrome. A classification system familiar to most clinicians (ICD-10 or DSM IV) may have been more useful.
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<p>10) Williams, K. (2001) Understanding the student with Asperger Syndrome: Guidelines for teachers. <i>Intervention in School and Clinic</i>, 36, 287-297.</p>	<p>The authors identify some core characteristics of Aspergers Syndrome and suggest educational strategies for addressing these symptoms in the classroom based on her classroom experience.</p>	<p>The core characteristics identified in children with AS and suggestions for intervention are as follows:</p> <ul style="list-style-type: none"> • “Insistence of sameness.” Some accommodations include creating a predictable and safe environment that minimizes transitions and offers consistency. • “Impairment in social interactions.” Adults in the children’s life can assist by protecting the child from bullying and teasing, educating peers about the child’s limitations, emphasizing their child’s strengths, teaching certain responses to social situations, and using non-disabled classmates as mentors. • “Poor motor coordination.” Children with AS may benefit from a special physical education program and may have difficulty with team sports • “Emotional vulnerability.” Some accommodations include offering a high level of consistency, teaching concrete stress coping techniques, engaging children in a calm, predictable, patient manner and being alert to changes in behavior that denote depression such as greater levels of disorganization, inattentiveness, isolation, decreased stress threshold, chronic fatigue, and crying. Adolescents with AS are susceptible to depression due to the increase in the importance of socialization so behavioral changes must be watched closely. • Academic difficulties. Children may have difficulty with higher-level thinking and comprehension skills. Although a child may regurgitate information, he may not understand it, which suggest expectations should be clear and concrete.
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