Issues in Children's and Families' Lives

Raymond W. DuCharme
Thomas P. Gullotta
Editors

Asperger Syndrome

A Guide for Professionals and Families

Second Edition

Springer

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Research Assistance by Jessica M. Ramos

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It's About Children

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Preface

Asperger Syndrome or Autism?

This is a book about Asperger Syndrome (AS). I happen to have a personal interest in this topic as our adopted son, Bernie, was given this diagnosis at age 14. Bern's arrival at 3 weeks of age in the Gullotta household was greeted with joy by mom, dad (me), and our golden retriever who immediately took up residence under his crib. Dickens or Nanny, if you prefer, insured that Bernie's slightest need was addressed promptly by either mom or dad and preferably both. This, she accomplished by entering our bedroom and emitting an ever-so-low soft short yelp. If we chose to ignore this signal, she would place her front paws on one of us and with copious doggie kisses disrupt any thoughts whatsoever of staying in bed. With such attention one might assume that Bern would quickly fall into a pattern, but this was not the case. He was a fussy baby who despite our every effort just seemed uncomfortable with his surroundings. By age two, we were on a search that proved fruitless at that time to explain a behavioral pattern that did not respond to a typical reenforcement schedule. Bern seemed oblivious to discipline that other children responded to when applied fairly and consistently. Bern seemed unable to learn from his mistakes – repeating the same social and behavioral errors again, again, and again.

By age five, the first of several diagnoses was attached to our son. In keeping with the medical principle of do as little (stigmatizing) harm as possible, our family journey with DSM IV-R began with ADHD. As the years went by, it grew with the addition of learning disorders, depression, and then bipolar disorder at 12 years of age. I will never forget the utter sense of hopelessness and helplessness I experienced with this last diagnosis. I can still remember, as if it were yesterday, walking the aisles of the Barnes & Noble bookstore in Washington, DC, searching for alternative medicinal treatments, so desperate had my search for help for him become. And then at age 14, after our family had been knocked off its unstable perch with my heart attack, Bern was diagnosed with Asperger Syndrome. Mind you as with so many other young people with this disorder, other issues were still alive and well in making his life difficult to live, but the overall picture moved from utter fuzziness into almost understandability.

It is amazing how labeling a pattern of behavior correctly can bring about a response that actually achieves positive change. It is amazing how understanding a behavior like Asperger Syndrome can relieve parents of the enormous guilt that their inability to parent successfully is due solely to flaws (previously unknown) in their personalities and behavioral patterns. It is amazing how such utterly bad news can be a new beginning for a young person who has experienced in the totality of his life so few moments of positive community recognition.

Perhaps because our family is walking this journey, we find discussions within the APA DSM V study group regarding Asperger Syndrome disconcerting. In an attempt to simplify the confusion surrounding autism, Pervasive Developmental Disorder (PDD), Asperger's, etc., the concept of "one size fits all" has been introduced. This is a mistake. This book is in reaction to that error. Still, many of our colleagues will react to a book title such as *Asperger Syndrome: A Guide for Professionals and Families* appearing in the second decade of the twenty-first century with a remark like, "Where have these editors been. Aren't they aware that the new DSM V will consign this category to the diagnostic waste heap?"

Yes, we are aware of the desires of many within the psychiatric community to rid themselves of this troublesome diagnosis, and we believe that they are wrong. The individual who presents the symptoms that Hans Asperger first described in 1944 is different than the individual that Leo Kanner identified in 1943.

No one can deny that Asperger's description of young people displaying a unique set of symptoms that would ultimately come to bear his name has resulted in an expansion of basic research, practice innovation, and program that has benefited the individual with this diagnosis and those, too, with the diagnosis of autism. The parents of children with an AS diagnosis have expressed appropriate concern that services and medical coverage for their children might be curtailed if this change to DSM V should go forward. They have also questioned whether this repackaging effort of "one size fits all" will relieve school systems from the present difficulties they have in designing an appropriate educational program for these young people. Parents fear justifiably that the remarks all too often expressed at Individualized Education Programs (IEP) meetings that, "We have an appropriate educational experience for children with autism," will be applied to their child no matter how inappropriate the reality of that comment might be. Frankly, those of us with children who experience this disorder are not interested in making it easier to pigeonhole these youth, these adolescents, and these adults. We have had firsthand experience with their difficult childhood, their painful adolescence, and their all too often disappointing adulthoods filled, as they often are, with unemployment and failed personal relationships. We are not interested in making it any easier for a child delivery system or any other social service system to inadequately serve their educational, mental health, and social services needs.

Neither Ray nor I will deny that the young person with an AS diagnosis may share certain characteristics with the young person with an autism diagnosis.

However, it is not the shared characteristics that matter but where these young people often differ that matters. This volume is devoted to those differences and where assistance can be offered to build their educational, vocational, and social skills to enable these individuals to experience the success that so often eludes them.

The chapters in this volume can be clustered into three general groupings, with the first two offering the reader an introduction to the subject matter. In the first chapter, Metz provides a primer to the uninitiated and draws a distinction between Asperger Syndrome and autism. In drawing that distinction, she acknowledges the occasional overlapping of behaviors that occur between the high-functioning individual with autism and the individual diagnosed with AS. Aspy and Grossman in chapter 2, "Assessment and Diagnosis of Asperger Syndrome" provide the educator and clinician with a useful approach to the identification of individuals with the AS diagnosis. They note that many mental health clinicians educated before the 1980s have little, if any, grasp of the AS diagnosis. Further they point out that while the study group working on DSM V appears ready to merge the autism and AS diagnostic classifications, the World Health Organization with its diagnostic manual, ICD-11, intends to maintain the distinction between the two disorders.

From definitions and characteristics to discerning those behaviors that suggest an individual should be diagnosed with AS, the second grouping of chapters addresses initiatives to improve the quality of life of individuals with the AS diagnosis. For example, Sharp's chapter examines those behavioral and psychopharmacological interventions that may be helpful for individuals diagnosed with AS. In her review, Sharp compares specific treatments against the current outcome literature and then provides a comprehensive overview of the use of medication and its results on treating this disorder. In chapter 4, "Early Intervention for Children/Youth with Asperger Syndrome", Baker-Ericzén continues this theme of action in examining early intervention strategies with this population. After reviewing the major theoretical explanations for AS, this chapter then focuses on encouraging cognitive flexibility and metacognition skill building in this population. The theme of building social skills continues with the chapter by Brenda Smith Myles and The Ziggurat Group. It offers the reader an extensive evidence-based overview of progress in this area since the publication of the first edition of this book.

The third grouping of chapters in this volume looks at educational efforts to appropriately and successfully equip these young people with the academic and social skills to live full and productive lives. The reader will find in chapters 6 and 7, "Evaluating Evidence-Based Instruction for Children with Asperger Syndrome" and "Comprehensive Education-Based Mental Health Services for Students Diagnosed on the Autism Spectrum", written by DuCharme and his colleagues, a systematic evidence-driven approach to addressing the needs of this population that has been tested and refined at "The Learning Clinic" for the past two decades. DuCharme's work in this area deserves replication.

The final chapter in this volume, by Jennifer Blackwell, is written by a parent. Its advice is gained from the long and often tearful journey all parents make on behalf of their children. I suspect that parents reading this chapter will identify with many of Jennifer's experiences and observations. In a sense, this chapter is confirming that we are not alone when we feel most alone. In another sense, it is a clear message to the helping and school communities offering insights into ways in which they can improve their efforts to help and educate individuals with an AS diagnosis.

I conclude this Preface having not answered the question poised in the title. Is the World Health Organization correct in maintaining the Asperger Syndrome diagnosis or is the study group working on DSM V correct? Will simplifying this diagnostic category improve services or will they provide an excuse to educators and health insurers to deny services? This volume raises questions but is admittedly short on conclusive answers. But this I do know. From that time when the medical and educational world was confronted with the words “Asperger Syndrome,” more work in basic research, education, medicine, and behavioral health has been undertaken than ever before to address this diagnosis *and* autism. As a parent of an adult with an AS diagnosis and a health professional keenly aware of the politics of health care, I am not ready to trust the system.

New London, CT, USA Thomas P. Gullotta

Contents

Contributors

Ruth Aspy, Ph.D., is a licensed psychologist in private practice with The Ziggurat Group. Dr. Aspy specializes in assessment and intervention for individuals with autism spectrum disorders. She is coauthor of *The Ziggurat Model*, winner of the 2008 Autism Society of America Literary Work of the Year. Dr. Aspy speaks internationally. She has experience in both the clinic and school settings.

Mary Baker-Ericzén, Ph.D., is a research scientist at the Child and Adolescent Services Research Center and clinical psychologist at the Autism Discovery Institute of Rady Children's Hospital, San Diego. She is also Director of the Intricate Mind Institute at COMPASS Family Center, a non-profit organization specializing in providing services, supports, and guidance to individuals and their families with autism spectrum disorders or learning differences. She is an adjunct faculty at the School of Leadership and Educational Sciences, University of San Diego, and clinical faculty at the Department of Psychiatry, University of California, San Diego, where she teaches and supervises graduate students. She has provided psychological assessment and treatment for children, adolescents, and adults for over 20 years, specializing in autism spectrum disorders, behavior disorders, cognitive disabilities, anxiety, and depression. She has received numerous research and service grants, published over 35 articles, and served as an editorial reviewer for various journals.

Jennifer Blackwell, B.A., earned her degree in education and taught students with severe emotional challenges. Four children and two spectrum diagnoses later, she returned to work with special needs, working in a preschool setting that included children with autism spectrum disorders. She currently is working in a middle school one-on-one with a child with autism. Jen is cofounder of AutismNotes.com. She has published articles and spoken at autism awareness events, sharing her family's challenges and experiences with life on the spectrum. Along with her family, Jen has presented regionally and nationally at autism-related conferences, as well as coauthored the "2010 Hidden Curriculum One-a-Day Calendar for Kids."

Barry G. Grossman, Ph.D., is a licensed psychologist and author. He is in private practice with The Ziggurat Group and specializes in assessment and intervention for individuals with autism spectrum disorders. Dr. Grossman, along with Dr. Aspy, wrote *The Ziggurat Model* – a book on designing interventions for students with Asperger Syndrome and high-functioning autism. He and his coauthor present on this model internationally. *The Ziggurat Model* has been adopted at the districtwide and statewide levels.

Kathleen A. McGrady, Psy. D., has been the Clinical Director of The Learning Clinic, Inc. (TLC), since 1994. She is a neuropsychologist and has been a researcher and author of numerous papers and presentations on assessment, diagnosis, and treatment of children and adolescents with autism spectrum disorders and the associated comorbid conditions.

Alexia E. Metz, Ph.D., completed her bachelor of arts in occupational therapy from Easter Michigan University in 1995. Her practice as an occupational therapist has included inpatient, outpatient, home-based, and school-based early intervention. At the onset of the increase in the rate of autism spectrum diagnoses, she felt it necessary to better her understanding of the underlying neurological bases of sensory processing. She, therefore, pursued her doctoral degree in the field of neuroscience, graduating from Northwestern University in 2006. She now teaches neuroscience and pediatric therapy in the occupational therapy doctoral program at The University of Toledo. Her research interests include occupational therapy for children and sensory processing disorders.

Brenda Smith Myles, Ph.D., a consultant with The Ziggurat Group and the Education and Treatment Services Project for Military Dependent Children with Autism, is the recipient of the Autism Society of America's Outstanding Professional Award, the Princeton Fellowship Award, and the Council for Exceptional Children Burton Blatt Humanitarian Award. Brenda has made over 500 presentations internationally and written more than 150 articles and books on ASD, including *Asperger Syndrome and Difficult Moments: Practical Solutions for Tantrums, Rage, and Meltdowns* and *The Hidden Curriculum: Practical Solutions for Understanding Unstated Rules in Social Situations*. In addition, she was the cochair of the National ASD Teacher Standards Committee and serves on the executive boards of several organizations, including the Organization for Autism Research. In addition, in the latest survey conducted by the University of Texas, she was acknowledged as the second most productive applied researcher in ASD in the world.

Jessica M. Ramos, B.A., received her B.A. in Psychology from Eastern Connecticut State University. She is a Research Assistant at Child and Family Agency of Southeastern Connecticut. Jessica has assisted in the editorial process of 19 books on the topics of primary prevention and health promotion in the last 16 years employed at Child and Family Agency. She enjoys working for the Agency and has not used a sick day in eight consecutive years, since 2005. She is involved in agency research and reviews cases for Quality Assurance.

Jayantkumar C. Patel, M.D., graduated from Baroda Medical College, India. Following his graduation, he migrated to the United States and completed his internship at Fairview General Hospital in Cleveland, Ohio, and at Norwich Hospital in Connecticut. Since 1986, he has been the Medical Director at United Services, Inc., a large community mental health center in Connecticut. During his extensive psychiatric career, he also served as the Medical Director of Natchaug Hospital in Connecticut. In recognition of his services, he was the recipient of the Natchaug Hospital Distinguished Service Award for medical leadership in the hospital and in the community in June of 1992. He is a life member of the American Psychiatric Association and presently the President of the Windham County Medical Association. His areas of expertise and interests have been individualized psychopharmacological management of Asperger Syndrome and associated comorbidities.

Gualberto Ruaño, M.D., Ph. D., is President and C.E.O. of Genomas Inc., which he founded in 2004. Dr. Ruaño has 20 years of experience in biotechnology, having founded BIOS Laboratories in 1992 and Genaissance Pharmaceuticals in 1997, which he led as C.E.O. to several pharmaceutical partnerships and to an IPO in NASDAQ. With M.D. and Ph.D. degrees from Yale and a baccalaureate from Johns Hopkins University, Dr. Ruaño is one of the leading business and medical experts in personalized medicine worldwide. Genomas is strategically located on the campus of Hartford Hospital, one of New England's largest and most respected medical centers.

Sherrie Sharp, M.D., is a board-certified child psychiatrist who works at Child and Family Agency of Southeastern Connecticut. She attended Boston University School of Medicine and went on to complete her residency in psychiatry at the Cleveland Clinic and fellowship in child and adolescent psychiatry at Brown University. She has had a long-standing interest in child development and family functioning as well as working with underserved populations. In her free time, she enjoys travel, gardening, the beach, and cooking.

The Ziggurat Group is a transdisciplinary group that provides assessment, consultation, and supports for individuals with autism spectrum disorders (ASD). The group is led by Drs. Ruth Aspy and Barry Grossman, creators of the internationally recognized comprehensive program planning and functional behavior assessment (FBA) model, the Ziggurat Model, which works for individuals with ASD from early childhood through adulthood.

What We Know About Asperger Syndrome: Epidemiology and Etiology

Alexia E. Metz

> *The identification and determination of the composition of syndromes is partly a function of the construction of the brain and partly a function of how much man knows about it at any given time.*
>
> A. Jean Ayres (1972)

As we will see in this chapter, many individuals around the world have contributed to the contemporary understanding of Asperger syndrome. The numerous studies must be evaluated both individually and collectively. Each adds value to the field despite the fact that there are few unequivocal answers to the questions this chapter sets out to discuss.

Diagnostic Criteria

Elsewhere in this text, authors discuss clinical practices related to diagnosing Asperger syndrome; however, in order to review what is known about the epidemiology (the who and how often) and the etiology (the why) of Asperger syndrome, we must begin with a brief introduction to the diagnostic criteria of the syndrome. As is commonly reported, Asperger syndrome was first described in 1944 by Dr. Hans Asperger who used the term *autistic psychopathy*. Symptoms of Dr. Asperger's initial population included social isolation; difficulty with the nonverbal aspects of communication; idiosyncratic language; self-centeredness; and intense, unusual, specific interests. Several of his cases exhibited typical to above average intelligence and notable skill in advanced fields. Through a series of case studies,

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Dr. Lorna Wing (1981) applied Dr. Asperger's name to the syndrome and provided a set of diagnostic criteria. Ten years later, Gillberg (1991) refined the characteristics. Subsequently, Ehlers, Gillberg, and Wing (1999) introduced a corresponding assessment, the Asperger Syndrome Screening Questionnaire based on these criteria. As awareness of Asperger syndrome grew, both the World Health Organization and the American Psychiatric Association included criteria for Asperger disorder in their diagnostic manuals, *The ICD-10 Classification of Mental and Behavioral Disorder* (*ICD-10*, World Health Organization [WHO], 1994) and the *Diagnostic and Statistical Manual of Mental Disorders, 4th edition* (*DSM-IV*, American Psychiatric Association [APA], 1994), respectively. See Table 1 for the diagnostic criteria of Gillberg, the *ICD-10,* and the *DSM-IV.* To describe the condition, many prefer the use of the term syndrome to disorder. The former suggests a constellation of characteristics which may or may not disrupt an individual's ability to function and achieve; furthermore, many of the characteristics may indeed augment an individual's achievements in particular fields. With deference to this stance, the term syndrome is used here, setting aside the convention of diagnostic categories of the standardized manuals.

There has been difficulty in consistent discrimination between Asperger syndrome and autism, particularly so-called high-functioning autism (Gillberg, 1998). High-functioning autism (HFA) is not a diagnostic category listed in either the *ICD-10* or the *DSM-IV*. Individuals with HFA are described as meeting the criteria for autism but having minimal intellectual disability (Gillberg, 1998; Ozonoff, Strayer, McMahon, & Filloux, 1994; Szatmari, Bartolucci, & Bremmer, 1989). Indeed, the difficulty in differentiating between these conditions appears to have led to the suggestion to eliminate Asperger syndrome as a stand-alone condition in the upcoming edition of the *DSM-5,* APA (2011). In the proposed revision, due out in 2013, autism spectrum disorder will represent a single diagnostic category with two domains of symptoms: (1) deficits in social communication and (2) restricted interests and repetitive behaviors. For each domain, the severity of symptoms will be described by three levels ranging from "requiring support" to "requiring very substantial support." There remain no specific criteria for impairment in verbal abilities or intelligence.

In their writings, Dr. Wing and her colleagues (Wing, 1981, 2005; Wing, Gould, & Gillberg, 2011) give their opinion that Asperger syndrome is properly part of the autism spectrum. Yet, Dr. Wing (1981) has related that Dr. Asperger himself felt that the condition he described was distinct from the condition then referred to as infantile autism, as described by Dr. Kanner. She explains that Dr. Asperger felt he had described a personality trait, whereas Dr. Kanner had described a psychosis. However, as both conditions are exhibited as a range of behaviors in similar domains, clinicians are hard pressed to distinguish between them in many cases (Wing, 1981, 2005). Dr. Wing explored the similarities and differences of autism and Asperger syndrome in her seminal paper (1981); see Table 2 for a summary. She elaborates that many developmental delays present with varying patterns of impairment in each of the iconic domains of social interaction, language, and behavioral repertoires in conjunction with any level of intellectual abilities. She argues that without known etiology, any of these can be considered part of the autism spectrum (Wing,

Table 1 Diagnostic criteria for Asperger syndrome

Gillberg (1991)	1. Social impairments
	2. Narrow interests
	3. Repetitive routines
	4. Speech and language peculiarities
	5. Nonverbal communication problems
	6. Motor clumsiness
DSM-IV (1994)	This disturbance must be clinically significant but without clinically significant language delay or delay in cognitive development or other skills. A total of six items from the social, communication, and behavioral criteria are required. Delay in at least one of these domains must occur before age 3
	A. Qualitative impairment in social interaction, as manifested by at least two of the following:
	(1) Marked impairment in the use of multiple nonverbal behaviors such as eye-to-eye gaze, facial expression, body postures, and gestures to regulate social interaction
	(2) Failure to develop peer relationships appropriate to developmental level
	(3) A lack of spontaneous seeking to share enjoyment, interests, or achievements with other people (e.g., by a lack of showing, bringing, or pointing out objects of interest to other people)
	(4) Lack of social or emotional reciprocity
	B. Restricted repetitive and stereotyped patterns of behavior, interests, and activities, as manifested by at least one of the following:
	(1) An 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. Qualitative impairments in communication as manifested by at least one of the following:
	(1) Delay in, or total lack of, the development of spoken language (not accompanied by an attempt to compensate through alternative modes of communication such as gesture or mime)
	(2) In individuals with adequate speech, marked impairment in the ability to initiate or sustain a conversation with others
	(3) Stereotyped and repetitive use of language or idiosyncratic language
	(4) Lack of varied, spontaneous make-believe play or social imitative play appropriate to developmental level

(continued)

Table 1 (continued)

ICD-10 (1994)	A. A lack of any clinically significant general delay in spoken or receptive language or cognitive development. Diagnosis requires that single words should have developed by 2 years of age or earlier and that communicative phrases be used by 3 years of age or earlier. Self-help skills, adaptive behavior, and curiosity about the environment during the first 3 years should be at a level consistent with normal intellectual development. However, motor milestones may be somewhat delayed, and motor clumsiness is usual (although not a necessary diagnostic feature). Isolated special skills, often related to abnormal preoccupations, are common, but are not required for diagnosis B. Qualitative abnormalities in reciprocal social interaction (criteria as for autism) (1) Failure adequately to use eye-to-eye gaze, facial expression, body posture, and gesture to regulate social interaction (2) Failure to develop (in a manner appropriate to mental age and despite ample opportunities) peer relationships that involve a mutual sharing of interests, activities, and emotions (3) A lack of socio-emotional reciprocity as shown by an impaired or deviant response to other people's emotions, or lack of modulation of behavior according to social context, or a weak integration of social, emotional, and communicative behaviors C. An unusually intense circumscribed interest or restricted, repetitive, and stereotyped patterns of behavior, interests, and activities (criteria as for autism; however, it would be less usual for these to include either motor mannerisms or preoccupations with part objects or nonfunctional elements of play materials) D. The disorder is not attributable to the other varieties of pervasive developmental disorder, schizotypal disorder, simple schizophrenia, reactive and disinhibited attachment disorder of childhood, obsessional personality disorder, obsessive-compulsive disorder

Gillberg (1991)
APA (1994)
WHO (1994)

Table 2 Differences and similarities in autism and Asperger syndrome (Adapted from Wing, 1981)

Domain	Autism	Asperger syndrome
Social interactions	Aloof and indifferent	Passive or one sided
Language	Absent, delayed, abnormal	Mostly intact grammar and vocabulary, trouble with use of pronouns, some odd word use
Conversation		Inappropriate for context, struggles with complex content
Nonverbal communication	Severely impaired, limited use of gestures	Severely impaired, inappropriate use of gestures
Tone of voice	Monotonous or peculiar	Monotonous or peculiar
Routines and interests	Repetitive routines	Immersion in special interests
Abnormal responses to sensory input	Prominent in young children and older individuals with intellectual disability	Not typical
Motor development	Reported to be typical early but reduced coordination with age	Poor coordination of posture, gait, and gestures

1981, 2005). She acknowledges, however, that maintenance of Asperger syndrome as a diagnostic label has considerable value. The benefits she cites include providing insight for those who cannot relate behaviors of their own or their loved ones to the classical picture of autism, acknowledging the contributions of many talented albeit eccentric individuals to advances in society, and the continuing of organizations for sharing support and information (Wing, 2005; Wing et al., 2011). As a result, she and her colleagues suggest that the Asperger syndrome be maintained as an allowable label for individuals on the autism spectrum "who have impairment of social interaction, social communication and social imagination but who have an average or high IQ, a wide vocabulary and good grammar but who use speech in non-social ways, e.g. to talk only about their special interests" (p. 771).

Several studies have empirically examined the validity of separate diagnoses of Asperger syndrome and autism. Kamp-Becker and colleagues (2010) conducted a study in which individuals with a variety of diagnoses but no intellectual disability were assessed with a battery of standardized tests, some specific to autism and others to test life skills and neuropsychological functioning. Within the sample, the researchers observed a range of scores on the autism assessments. Severity of scores correlated negatively with scores for functional behaviors and neuropsychological functioning. In other words, the more severe the autism symptoms, the more severe the functional impairment. However, no diagnostic groups (phenotypes) emerged to suggest differential diagnoses. One previous study (Ozonoff, Rogers, & Pennington, 1991) found evidence for differentiation between the diagnoses; however, the study did not control for differences in intellectual functioning. In a subsequent study, the same group (Ozonoff & Miller, 2000) found that when intelligence was accounted for, there were no differences in motor, visual spatial, and executive functioning. Nonetheless, studies have sought to distinguish Asperger syndrome from high-functioning autism on the basis of neuroanatomy (Lotspeich et al., 2004; Yu, Cheung, Chua, & McAlonan, 2011), personality and anxiety traits (Thede & Coolidge, 2007), brain activity related to movement (Rinehart et al., 2006), and neuromotor behavior (Nayate et al., 2007). The results have been mixed, finding subtle differences in some studies that warrant continued investigation.

Epidemiology

The rate of a diagnosis can be quantified by incidence and prevalence. Incidence reports the number of newly diagnosed cases in a given period of time, usually the number of new cases in a year. Prevalence reports the number of individuals diagnosed within a population, usually per 10,000 people. Many, however, relate to prevalence better when it is presented in terms of percent of a population. At the risk of redundancy, both numbers are utilized here.

Describing the incidence and prevalence of Asperger syndrome is somewhat problematic. In part, this is because of inconsistent use of criteria for diagnosis (e.g., Fombonne, 2001; Wing & Potter, 2002). A second factor is that many studies include Asperger syndrome under the autism spectrum disorder (ASD) category without specific reporting on Asperger syndrome separately. Nonetheless, reports of the rate of ASDs which include Asperger syndrome may provide the upper limit for the estimate of the rate of Asperger syndrome. Even so, estimates of ASDs range widely from study to study.

On the low end, incidence of ASDs could be 0.3 % of children born each year. In 2005, Honda and colleagues reported the cumulative incidence of autism spectrum disorders in four birth cohorts in Yokohama, Japan. Children born in the years 1988–1991 were followed by a comprehensive public health initiative from birth to age 5. Within the total sample, the incidence of autism diagnoses during the first 5 years of life was 27.2 per 10,000 children, with a ratio of 2.5 males to each female. Of the individuals with autism diagnoses, 13.7 % had average to high intelligence. The researchers noted that prevalence (the number of cases in the region) of autism diagnoses in the research area was higher than incidence (the rate of diagnoses in the population born in the region) because families of children with autism diagnoses had moved into the research area because of its reputation for providing comprehensive services. They therefore caution that incidence is a more reliable estimate of the rate of ASDs in the population.

Because the study by Honda and colleagues was conducted in Japan, the low estimate of incidence may be specific to that region of the world. However, the rate found in England was only slightly higher, a prevalence of 0.4 %. In 2006, Baird and colleagues conducted a prevalence study of autism and other autism spectrum diagnoses, according to ICD-10 criteria, in a population of 9–10-year-old children in South Thames, England. The researchers reviewed education documents for children already identified as having ASDs and those felt to be at risk for ASDs. They further directly evaluated a randomized sample of these children to confirm or refine diagnoses. From positive cases, they estimated prevalence of autism at 38.9 per 10,000. The authors reported that children who met ICD-10 criteria for Asperger syndrome were included in this estimate, but they did not provide separate statistics for the diagnosis.

One of the most recent estimates of prevalence in the United States is notably higher than the estimates documented elsewhere, approaching nearly 1 % of children. In 2009, the Center for Disease Control released their Autism and Developmental Disabilities Monitoring Network report summarizing the 2006 prevalence of ASDs in children 8 years of age, authored by Catherine Rice (2009). The age of 8 was selected to include children whose symptoms were apparent at or before school age. Data were collected within ten states from varying regions of the continental United States. Cases of ASDs were quantified in two stage approach. In the first phase, researchers from state health departments conducted chart reviews of health and education records in their region. Information collected from charts included diagnostic and educational classification, behavioral test results, and descriptions of behaviors. In the second phase, trained community professionals scored the cases for the *Diagnostic and Statistic Manual of Mental Disorders, 4th edition (DSM-IV), text revision* (APA, 2000) criteria for ASDs including autistic disorder, pervasive developmental disorder-not otherwise specified, or Asperger syndrome. Using census estimates of the number of 8-year-olds in each study region, the study calculated the prevalence of ASDs.

Although those meeting the criteria for Asperger syndrome were included, the report did not specify prevalence of this diagnosis separately. At nine per 1,000 children, the average prevalence of ASDs in 8-year-old children approached 1 %. Rates were consistently higher in males than females with 4.5 males categorized as having an ASD for every one female. Where complete data sets included IQ results, 41 % of ASDs cases were associated with cognitive impairment, indicating that over half of the children with ASDs did not have global cognitive impairment. Several factors, acknowledged by the researchers, may reduce the accuracy of the estimate of prevalence of ASDs. Cases that included more diagnostic assessments had a higher rate of categorization for ASDs. In these cases, there may have been fewer assessments because early results may have suggested the absence of a diagnosis, and therefore, no further testing was needed. On the other hand, continued assessments may have revealed a diagnosis. As a result, there is a risk of underidentification in cases with fewer assessments. In the cases with more assessments, there is a risk of overidentification. There is some amount of error associated with each test conducted, so the higher number of tests, the more likely a diagnosis will be made. Another limiting fact was that the research sites were not to be representative of the national population. They were, however, selected through a competitive process to ensure the capability to collect data in a rigorous manner. Finally, not all charts were located for review. Since this study was conducted with a point-in-time approach, only prevalence was reported. The researchers noted that most regions included in the study had had very little migration, suggesting that prevalence should be similar to incidence.

This high rate of ASDs in the United States found by case identification was reflected in a national study which employed a survey approach. Kogan and colleagues (2009) randomly interviewed households of children aged 3–17, asking the parents whether they had ever been told that their child has “autism, Asperger disorder, or other autism spectrum disorder” (p. 1,396) by a doctor or health care provider and whether their child had the condition at the time of the interview. This yielded a point prevalence estimate of 110 per 10,000 children. Half (49.6 %) reported that their child’s ASD was mild, while 33.9 % and 16.5 % reported their child’s ASD as moderate and severe, respectively. The authors suggest that one contributing factor to the high prevalence of ASDs was the increased awareness of and inclusion of Asperger syndrome.

An estimate of specific prevalence of Asperger syndrome is available in Kadesjö, Gillberg, and Hagberg’s 1999 report from a longitudinal study of the 1985 birth cohort in the Swedish town of Karlstad that were assessed for ASDs. Researchers employed interview and standardized assessments to assess ASDs in this cohort in 1992 and again in 1996. The prevalence was stable from the first time point to the second. Asperger syndrome was ascertained through use of the ICD-10 (WHO, 1994), the DSM-IV (APA, 1994), and the Asperger Syndrome Screening Questionnaire criteria (Ehlers et al., 1999). The authors estimated the prevalence of Asperger syndrome at 48 per 10,000. All of the children identified with Asperger syndrome were male such that 0.94 % of males in the cohort had the diagnosis. The total estimate of prevalence of ASDs was 121 per 10,000. The major limitations of this study were the small sample size (n = 826) and the limited geographic region; however, these were offset by the use of a total population.

The high rate reported in Sweden is certainly alarming. Studies in the western hemisphere have not replicated this high rate. In 2001, Bertrand and colleagues reported on the prevalence of ASDs in Brick Township, New Jersey, for the population of children aged 3–10 in residence during 1998. Cases were identified through record review from a variety of sources. Diagnosis was confirmed and refined by direct evaluation by the authors. In this town, the prevalence of ASDs in this age group was 0.67 per 10,000. The diagnoses of pervasive developmental disorder-not otherwise specified and Asperger syndrome were combined and occurred at a rate of 0.27 per 10,000. This group of children had higher intelligence rating than the children with autistic disorder.

Similarly, the estimate of prevalence of Asperger syndrome was notably low in a more recent study. Nassar and colleagues (2009) studied the effect of increased awareness of diagnostic criteria and availability of treatment on the rate of diagnoses of ASDs in Australia. Their findings suggested that as awareness and services increased, so did the rate of diagnosis, particularly at younger ages. This was established by analyzing the number of diagnoses reported in several national data bases for birth cohorts from 1983 to 1989. During this period, prevalence increased 16.6 %, beginning at 1.7 and increasing to 53.4 children per 10,000. Of the total cases identified over this period of time, 4 % met criteria for Asperger syndrome (prevalence of 1 per 10,000). The authors note that Asperger syndrome is often diagnosed at age 7 or later. Therefore, children in the later birth cohorts may not yet have been identified, thereby lowering the estimate of total prevalence. Another interpretation is that children with Asperger syndrome were diagnosed with other forms of ASDs.

In summary, the rate of Asperger syndrome, individually or as a component of the autism spectrum, is not definitively known. Estimates from a variety of sources range from 0.67 to 48 to 10,000 children. For reasons such as policy and planning, many might desire a more definitive number regarding how many children have Asperger syndrome. As well, factors contributing to the observed range may illuminate the nature of the syndrome, e.g., regional influences, diagnostic practices, and time course. More research will be needed on both fronts.

Etiology

Certainly, we are far from a definitive known cause of Asperger syndrome, but research efforts of a variety of methodologies have provided contributions toward an answer.

Familial Factors

Gillberg and Cederlund (2005) examined the birth records of 100 males with Asperger syndrome from a well-established clinic. Of them, 71 had a first- or second-degree relative with at least some suspicion of ASDs, 50 with the concern on the father's side of the family. The Interactive Autism Network (IAN) is an online database which contains demographic information and scores for a battery of diagnostic tests for individuals diagnosed with ASDs. Rosenberg and colleagues (2009) examined the records of any twin pair in the database in which at least one sibling had an ASD. In total, 277 twin pairs were included in which 210 were dizygotic (fraternal) and 67 were monozygotic (identical). Concordance refers to the rate of diagnoses in both individuals in a twin pair. At 96.1 %, monozygotic twins had a higher concordance for Asperger syndrome than did dizygotic twins (80.8 %). Among dizygotic twin pairs, concordance was higher in male-male pairs than when there was at least one female twin. The authors concluded that heritability is influenced by zygosity and gender. This suggests that Asperger syndrome has a heritable aspect to which males tend to be more vulnerable.

Birth History

Events that surround birth have been investigated for their association with later appearing symptoms of Asperger syndrome. In Gillberg and Cederlund's 2005 record review, 58 of the 100 cases of individuals with Asperger syndrome had had pre- and/or perinatal problems including alcohol use during pregnancy, birth asphyxia, seizures, and prematurity. Glasson and colleagues (2004) examined the records of 1,313 children with autism spectrum disorders, 67 of whom had Asperger syndrome. These were compared to the 481 unaffected siblings and case controls. Maternal age was found to be the strongest factor, though paternal age also played a factor. Among the cases of ASD, there were more threatened miscarriages, higher incidence of Cesarean section deliveries, and lower APGAR scores.

Gender-Based Differences

Dr. Asperger noted that some of the behaviors in the cases he described could be considered exaggerations of typical male behaviors. Baron-Cohen and colleagues have followed up on this, hypothesizing that autism represents the phenotype of an *extreme male brain*. In their 2005 paper in the journal *Science*, they describe gender-based differences observable beginning in early infancy. Girls, they suggest, begin to understand their world through empathizing with others, searching their faces "attempting to identify another's mental states and respond to these with an appropriate emotion, in order to predict and respond to the behavior of another person" (p. 820). Boys, on the other hand, are described as using a more mechanistic approach to understand their surroundings, "attempting to analyze a system in terms of the rules that govern the system in order to predict the behavior of the system" (p. 820). They suggest that the female approach to creating an understanding of the world through empathy is supported by a greater degree of coordinated activity between the frontal and parietal regions of the cortex, regions that are separated by a relative great distance and connected by long tracts of white matter (myelinated pathways). On the other hand, male brains tend to have a higher degree of local connectivity, as evidenced by smaller volume of long white matter pathways, particularly between the two hemispheres (the corpus callosum) yet larger brain volumes. They point out that within ASDs, there is a greater tendency to approach the world through systemizing versus empathizing, a tendency toward larger head size and brain size, and a tendency toward more white matter. They propose that the "extreme male brain" results from increased prenatal exposure to androgens, the hormones that trigger male development.

Brain Connectivity

The theory that differences in connectivity of brain regions was explored in review articles by several authors (Belmonte, Allen et al., 2004a; Belmonte, Cook et al., 2004b; Brock, Brown, Boucher, & Rippon, 2002; Rubenstein & Merzenich, 2003). Belmonte, Allen, and colleagues (2004a) explain how long-range interconnectedness of brain regions provides greater computational power than over-proliferation of local connectivity, as depicted Fig. 1. Coordinated activity in distant, interconnected regions appears to assist the brain in discriminating functional units of information in the environment against the contrast of so-called *noise*, or the background stimuli that do not relate relevant information. The pattern of high local connectivity but limited long-range connectivity creates many disconnected "computational units" that work separately rather than in a coordinated fashion to produce a gestalt impression of the world.

This pattern of white matter connections within the brain of individuals with autism spectrum diagnoses was observed by Herbert and colleagues (2004). In a sample of 8-year-old children with ASDs and average intelligence, magnetic resonance imaging (MRI) was used to examine white matter distribution. Compared to a control sample, the children with ASD had larger brain volume due to intraregion white matter in all lobes of the brain. The authors concluded that one specific process underlying autism may be the development of connection patterns within regions of the brain.

During a language task, two regions of the brain must work closely together: Wernicke's which helps in perceiving speech and its meaning and Broca's which helps with the production of speech. As reported by Just, Cherkassky, Keller, and Minshew (2004), individuals with autism appear to have more activation in the former – where more activity may not represent a strength but rather inefficient processing. They also have less activation in Broca's. More significantly, however, the degree of synchronous activity between the two regions is less than in neurotypical controls. During a task that involves processing emotional facial expressions, the brain activation pattern in a sample of individuals with autism and Asperger syndrome showed disconnectivity in the medial temporal lobe, including the amygdala and the cortex surrounding the hippocampus (Welchew et al., 2005), areas important for emotional processing, learning, and memory.

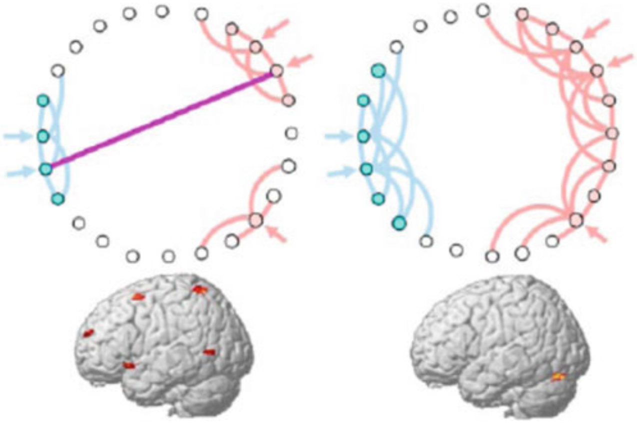

Fig. 1 Potential effects of network connectivity patterns on brain activation. In the network on the left, a combination of strong local connectivity within delimited groups of neural units and selective long-range connectivity between local groups constitutes a computational structure within which information can be efficiently represented and efficiently propagated. Inputs (*double arrows*) evoke representations that are easily differentiable from noise (*single arrow*) and can be linked across regions, yielding high computational connectivity. In the network on the right, strongly connected subregions are not appropriately delimited and differentiated, and computationally meaningful long-range connections fail to develop. The brain images at the bottom, from a visual attention task, display distributed patterns of functional activation in the normal brain (*left*) and abnormally intense and regionally localized activation in the autistic brain (*right*), a pattern that may stem from such differences at the network level (From Belmonte et al. 2004a)

The cerebellum has a role in detecting and correcting errors. It has reciprocal connections with many parts of the brain and provides feedback to each one to aid in learning and adjusting to changes in the environment. In individuals with Asperger syndrome, the inputs to the cerebellum appear to be similar to neurotypical counterparts; however, there may be less feedback from the cerebellum to the back to the brain, as seen in an MRI study by Catani and colleagues (2008).

Social Responsivity

Recognizing faces and processing facial emotions is an area of notable difficulty for individuals with Asperger syndrome. Brain imaging studies (Baron-Cohen, O'Riordan, Stone, Jones, & Plaisted, 1999; Castelli, Frith, Happé, & Frith, 2002; Happé et al., 1996; Nieminen-von Wendt et al., 2003) have demonstrated decreased brain activation in the temporal and medial prefrontal cortices when individuals with Asperger syndrome and HFA were engaged in identifying facial expressions. Schultz et al. (2000) showed that the fusiform gyrus, a region important for recognizing faces, was less active in individuals with Asperger syndrome when they were studying faces. Dawson and colleagues (2002) studied the brain activity in children with ASDs as they studied visual stimuli including faces and toys. The pictures of faces were those of their own mothers and those of strangers with similar features. The pictures of toys were those of their favorites or those of a novel toy. The subjects' brain activity did not show differences in activity between studying the faces of their mothers and the faces of strangers; however, it was different between studying their favorite toys and novel toys, indicating a greater ability to discriminate between toys (i.e., objects) than faces. Another brain region that contributes to our ability to interact socially is the inferior frontal gyrus. As part of the human mirror neuron system, this area is active in modeling behavior of others. In a study using MRI of the brain, Yamasaki and colleagues (2010) showed that this region was significantly smaller in a population of adults with Asperger syndrome than in a well-matched control sample. Within the individuals with Asperger syndrome, those with more impairment in social interaction had the smallest volume in this brain region on the right side of the brain. In an earlier study (Dapretto et al., 2006), this area showed lower levels of activity in children with ASDs, compared to controls matched for age and intelligence, as they studied pictures of a variety of emotional facial expressions: anger, fear, happiness, and sadness. The level of activity was lower in subjects with more severe symptoms. However, the involvement of the mirror neuron system in autism has not been unequivocally established. Participants with ASDs showed similar brain activity, measured by electroencephalogram, both when observing and performing hand motions as did typically developed subjects, in a study conducted by Fan, Decety, Yang, Liu, and Cheng (2010). The researchers commented that the individuals with ASDs had difficulty in copying the targeted motion even though their mirror neuron system showed similar activity to controls. Therefore, they caution that further research needs to be done before the mirror neuron system can be confidently implicated as a contributing factor in autism.

The limbic system of the brain consists of the hippocampus, the amygdala, the orbitofrontal cortex, and the cingulated gyrus. These structures and cortical regions are important for emotion, social behavior, motivation, learning, and memory. The orbitofrontal cortex, the region of the brain found just above the eyes on the underside of the frontal cortex, has a role in socially appropriate behavior and emotional regulation. This same region has a role in olfaction; therefore, a probe for the function of this region is the ability to discriminate between odors. In an experimental study by Suzuki, Critchley, Rowe, Howlin, and Murphy (2003), 12 individuals with Asperger syndrome were able to detect but not discriminate between odors suggesting depressed function of the orbitofrontal cortex. In an anatomy study by Pugliese and colleagues (2009), white matter pathways of the limbic system were studied in a sample of young adults with Asperger syndrome. The researchers report different volumes in all of the limbic pathways they examined, with higher volume in some and lower volume in others, compared to healthy controls.

Genetic Contributions

Studies have sought to identify the heritable contributions to Asperger syndrome. Several candidate genes have been studied by researchers in Finland. In 2004, they conducted a genealogical study and genome-wide scan (Ylisaukko-oja et al., 2004).

In the genealogical study, 17 families in which Asperger syndrome was observed in a unilinear dominant inheritance pattern in males were traced back to the 1700s to ensure that there was no shared ancestry within the research sample. In the entire genome scan, the gene region D1S484, including 1q21-22, showed the greatest evidence for linkage, suggesting that it is correlated with the heritability of Asperger syndrome through generations. A dozen other markers also demonstrated linkage, including 3q21-24. In a replication study (Rhenström et al., 2006), this same group verified the involvement of 3q21-24 as a candidate for Asperger syndrome. The DISC1 gene at locus 1q42 was studied by these researchers as well (Kilpinen et al., 2008). This gene is thought to be involved in brain development and was observed to have an inheritance pattern similar to Asperger syndrome.

In a novel approach, Chakrabarti and colleagues (2009) examined candidate gene segments with already identified roles in the processes hypothesized to contribute to the autism phenotype. These gene segments, single nucleotide polymorphisms (SNPs), were analyzed for the frequency of the occurrence of variants (alleles). The working assumption was that the possible alleles of SNPs that contribute to the phenotype would be normally distributed in a population in correlation to the distribution of autistic traits. A sample consisting of both typical adults and those with identified Asperger syndrome completed a battery of tests to identify the presence and severity of autistic traits. Comparison of the rate of expression of SNP alleles across these two populations suggested several strong SNP candidates that co-occurred with autistic traits.

SNPs that were tested following from the extreme male brain theory:

- CYP17A1 which contributes to organization of the brain’s cortex,
- CYP11B1 which contributes to the production of the stress hormone cortisol, and
- ESR2 which contributes to the production for the receptor for estrogen which plays a role in the defeminization of the male brain during fetal development, as established in animal models.

SNPs that were tested following from the neural connectivity theory:

- HOXA1 is associated with head growth,
- NLGN4X is associated with formation and remodeling of connections between brain cells,
- NTRK1 is part of the nerve growth signaling pathway, and
- ARNT2 has a role in chemical communication between the brain and the body for regulating growth, maturation, and homeostasis (neuroendocrine activity).

SNPs that were tested following from the social-emotional responsivity category emerged:

- MAOB is thought to have a role in response to novelty and habituation,
- GABRB3 is similarly thought to have a role in social and exploratory behaviors,
- WFS1 is expressed in the amygdala, a brain region that has a role in responses to fear-inducing stimuli, and
- OXT which gives rise to the hormone oxytocin which has a role in social bonding.

In 100 individuals with autism spectrum disorder, of whom 51 had Asperger syndrome, a particular allele of a SNP of the OXTR gene was examined (Wermter et al., 2009). One particular allele of the gene (T-G-T-T) was expressed in individuals with poor social bonding.

Salyakina and colleagues (2010) repeated a genome-wide association study in two separate populations. In the first stage, participants were 124 families with a child aged 3–21 with a confirmed diagnosis of Asperger syndrome from a clinical database. In the second step, participants were 110 families from a research database who met the same criteria. Both sets of participants underwent complete genome testing. Then the researchers compared the gene regions that associated with Asperger syndrome for similarities between the two groups of participants. They identified two novel regions (5q21.1, 15q22.1-q22.2) and three regions that had been previously reported to be associated with Asperger syndrome (3p14.2, 3q25-26, and 3p23). Similar to studies cited above, gene region 15q22.1 is part of the estrogen transcription pathway. Further eight regions had been seen in the past studies of autism spectrum disorders. This suggested that there are unique genetic risk factors for Asperger syndrome, as well as some that are shared in common with other autism diagnoses.

The findings of these studies, on the one hand, provide many genes and gene products for future investigations and, on the other hand, suggest that Asperger syndrome has a complex (and perhaps not singular) genotype.

Comorbidity

Comorbidity is a term that describes the situation in which the same individual has two, or more, distinguishable diagnoses. Unfortunately for individuals with Asperger syndrome and other ASDs, a number of mental health diagnoses which have dire implications for functional outcomes have high comorbidity with ASDs. Accurate identification of comorbid diagnoses can assist in treatment planning. Because of the features of ASDs, particularly communication difficulties, diagnosis of comorbid disorders can be very difficult. An initial report suggested that attention deficit hyperactivity disorder and depression are present at higher rates in individuals with Asperger syndrome (Ghaziuddin, Weidmer-Mikhail, & Ghaziuddin, 1998). Later studies have confirmed this pattern and revealed that other mental health diagnoses should be screened for as well. Leyfer and colleagues (2006) modified previously available assessments of psychiatric disorders in children for use with individuals with ASDs, entitled the Autism Comorbidity Interview – Present and Lifetime Version. In their work to establish the instrument as valid and reliable, the research group described comorbidities in a pilot sample of children aged 5–17 years with a range of verbal and intellectual abilities. The individuals in this study had not been referred for clinical services targeting psychiatric disorders but did have a confirmed ASDs and were described as “relatively high functioning” (p. 855). The most common comorbid diagnosis was specific phobia (44 % of the sample had one or more specific phobias, including “fear of needles and/or shots and crowds" (p. 853) and loud noises). Obsessive-compulsive disorder was the second most common comorbid disorder, at 37 % of the sample. The researchers noted several common compulsive behaviors in this population: rigid routines for greeting and separation, rigid daily schedules, and repetitive statements and questions. Thirty-one percent of the sample met criteria for attention deficit hyperactivity disorder, with an additional 24 % displaying some symptoms. Ten percent of the sample had had a major depressive episode and an additional 14 % had symptoms of depression. Approximately 5 % of the sample had both obsessive-compulsive disorder and major depressive disorder, in addition to their ASDs. Other diagnoses detected included oppositional defiant disorder, separation anxiety, social phobias, and bipolar disorders. In total, 72 % of the sample had at least one comorbid psychiatric disorder. It is interesting that despite early confusion in separating autism diagnoses from schizophrenia (as discussed by Volkmar & Cohen, 1991), none of the children in this sample had schizophrenia (much like Volkmar and Cohen's findings). In total, one third of the sample had two or more comorbid diagnoses. In a follow-up study, Mukaddes, Hergüner, and Tanidir (2010) utilized the same assessment with age- and gender-matched samples of children who carried specific confirmed diagnoses of high-functioning autism (HFA) or Asperger syndrome, using DSM-IV criteria to distinguish between cases of autism and Asperger syndrome. Individuals were deemed to have HFA if they had no intellectual disability. Similar to the results of Leyfer and colleagues (2006), the most common comorbid diagnoses within the combined sample were specific phobias (60 % of individuals with HFA, 47 % of individuals with Asperger syndrome) and attention deficit hyperactivity disorder (ADHD, 63 % of individuals with HFA, 67 % of individuals with Asperger syndrome). In comparing the two groups, children with Asperger syndrome had a higher rate of combined type ADHD (inattentive and hyperactive). Also under the category of disruptive behavior disorders, 30 % of individuals with Asperger syndrome also had oppositional defiant disorder, a rate which was similar to the group with HFA. The two groups also had similar rates of obsessive-compulsive disorder (38 % in HFA, 37 % of Asperger syndrome) and tic disorders (30 % HFA, 27 % Asperger syndrome). The group with Asperger syndrome had higher rates of major depressive disorder (40 % of individuals compared to 10 % of the HFA group). Also similar to Leyfer and colleagues (2006), none of the individuals with Asperger syndrome had comorbid schizophrenia. In total, 93 % of the individuals with HFA and 100 % of the individuals with Asperger syndrome had comorbid psychiatric disorders. The authors suggest that one contributing factor to the observed high rate may have been that the source of participants was the researchers clinic which provides mental health services, resulting in a bias toward participants with psychiatric diagnoses. Nonetheless, the consensus in the literature appears to support a vulnerability to comorbid diagnoses among individuals with Asperger syndrome, with specific phobias, attention deficit hyperactivity, and major depressive disorders chief among them. It may be the case that Asperger syndrome and the comorbid diagnoses share underlying causes. On the other hand, the latter may be a reaction to the former, particularly in the case of depression. With limited intellectual disability and a presumed desire to interact with others, individuals with Asperger syndrome may have greater insight into their social disability, and their depression may be a reaction to this (Mukaddes et al., 2010).

As this chapter has reflected, there has been a global effort to develop an understanding of Asperger syndrome. Not only the researchers but also the multitude of participants must be thanked for their contributions to our contemporary understanding which reveals that there is a unique identity to Asperger syndrome though it may properly belong to the autism spectrum. Continued research efforts should focus on illuminating factors that will enhance the quality of life and outcomes for individuals with Asperger syndrome while respecting both their collective identity and their individual needs.

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Assessment and Diagnosis of Asperger Syndrome

Ruth Aspy and Barry G. Grossman

Introduction

Since the release of the first edition of this book, much has changed in the field. The title of this chapter, while seemingly unremarkable, is wrapped in controversy. The title implies that Asperger syndrome is so different from autism that assessment of Asperger's would require a completely unique process. While evaluation of Asperger's requires some specific skills and training, there are commonalities to providing quality evaluation regardless of where the individual may be on the spectrum.

The mere notion that there are meaningful differences between autism and Asperger's has been hotly debated since it was first included in the two prominent diagnostic systems – the International Classification of Diseases, 10th edition (ICD-10; World Health Organization [WHO], 1993), and the Diagnostic and Statistical Manual, Fourth Edition (DSM-IV; American Psychiatric Association [APA], 1994). These resources provide criteria for making diagnoses and give professionals a common language. Since the introduction of Asperger's as a diagnosis, clinicians have found the criteria to be confusing. As a result of confusion in using the diagnostic criteria, many clinicians have ignored the DSM (Klin, McPartland, & Volkmar, 2005). Some have avoided the use of any diagnostic term altogether – preferring to use an alternative, unofficial term "autism spectrum disorder" (ASD) for Asperger's and similar disorders – known as pervasive developmental disorders. Another common approach has been to reserve the diagnostic term "autism" for cases

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that clearly meet the criteria for autistic disorder and to use the term “ASD” for all other presentations (combining all other subtypes such as Asperger’s). Other clinicians who have used the term Asperger’s have based the decision on factors other than the DSM criteria. For example, they have assigned the diagnosis based on intellectual ability (i.e., average to above average), age (e.g., adults), level of functioning (e.g., work, communication, and social), and “mild” impact (Klin et al., 2005).

Difficulties with consistent utilization of the DSM are further complicated by the diagnostic tools themselves. Few instruments that are linked to DSM criteria for Asperger syndrome exist. Klin (2009) points out that several of the prominent ASD diagnostic tools that are based on the DSM-IV, the ADI-R (Rutter, Le Couteur, & Lord, 2003), and the Autism Diagnostic Observation Schedule (ADOS; Lord, Rutter, DiLavore, & Risi, 2003) provide diagnostic outcomes only for autism or ASD and avoid Asperger’s entirely.

Due to confusion regarding the definition of Asperger syndrome (AS), clinicians have not used the diagnostic term consistently. Because one of the main benefits of using diagnoses is enhanced communication for the purpose of research and treatment, failure to consistently apply the term has resulted in a communication breakdown. Simply put, despite the existence of the DSM and ICD, professionals continue to disagree about the definition of Asperger’s. This has real consequences for researchers and clinicians alike. For example, in research, it is often important to build on the work of others. It may not be possible to generalize results from one researcher to another because the diagnosis of AS was defined differently. Clinicians who use research in their practice struggle to draw meaningful conclusions from the literature for the same reason. Moreover, one professional cannot rely on the diagnostic conclusions of another because he or she may be working from a different “playbook.” Using the same language is essential. In order to be useful, diagnostic terms must carry the same meaning across settings.

The diagnosis of AS has failed to prove meaningful in studies on its validity. Researchers have been unsuccessful in identifying factors that readily differentiate high-functioning autism from AS based on factors such as patterns of intellectual skills and language abilities (Bennett et al., 2008; Kamp-Becker et al., 2010; Macintosh & Dissanayake, 2004; Ozonoff & Griffith, 2000; Volkmar & Klin, 2000). These findings lend support for viewing autism as a spectrum (Wing, 1986, 2000) rather than as a disorder with distinct subtypes.

Due to factors such as confusion with current diagnostic criteria and questions regarding the validity of AS, the DSM (DSM-5) has merged the subtypes (autistic disorder, pervasive developmental disorder not otherwise specified, Asperger syndrome, and childhood disintegrative disorder) into a single category called “autism spectrum disorder” (APA, 2013). It is important to note that the diagnosis of Asperger syndrome may continue to be part of the upcoming ICD-11 (WHO, n.d.). Regardless of the diagnostic term used (autism spectrum disorder or Asperger syndrome), clinicians who conduct evaluations must have expertise in identifying higher-functioning individuals with autism spectrum disorder because the impact of the disorder is significant, and the need for appropriate intervention and services is great.

Knowledge and Experience

Evaluation of ASD requires knowledge and experience. Quality assessment requires skilled evaluators who have a deep knowledge of ASD. Professionals who are not competent are more likely to misdiagnosis their clients and to create unnecessary delays in identification and treatment. “The consequences of a missed or late diagnosis include social isolation, peer rejection, lowered grades, and a greater risk for mental health and behavioral distress such as anxiety and depression during adolescence and adulthood” (Wilkinson, 2008, p.3). The challenges of those with ASD are heightened when they remain unidentified and therefore unaddressed. This occurs all too often – especially for individuals who are high in functioning, such as those with AS. In particular, girls are most at risk of being under-identified (Attwood, 2006). Professionals seeking to gain the necessary skills must work closely with experienced and knowledgeable colleagues until they develop competence. Professionals with expertise in ASD help to avoid delays and misdiagnosis.

Assessment of AS may be completed by a number of professions; however, the field of training does not indicate the knowledge base of the professional as it pertains to ASD. One cannot say that because a practitioner is a neurologist, psychologist, or psychiatrist that he or she is an expert in ASD. There are professionals in many fields who are knowledgeable in ASD and able to conduct a valid assessment and those for whom this is not a strength. *The field of the professional is less important than the expertise—that can only be acquired through training and experience.* Extensive literature exists regarding the best instruments and techniques for identifying ASD; however, even the best instruments are meaningless when those who use them do not have the training and experience to make accurate judgments.

Because the two diagnostic systems, the DSM and ICD, included descriptions of classic forms of autism well before the inclusion of Asperger’s, many professionals gained expertise in recognizing classic autism yet did not develop expertise in identifying higher-functioning ASD. As a matter of fact, a strong background in classic forms of ASD sometimes may interfere with the ability to recognize other manifestations of autism. With training and experience, one can learn to see the whole spectrum. While there are commonalities of individuals across the spectrum, a broad range of presentations exists. Indeed, Dr. Stephen Shore, an adult and author with ASD, says, “If you’ve met one person with autism, you’ve met *one* person with autism” (September 29, 2011, personal communication). Moreover, the range becomes wider as the level of functioning increases (see Fig. 1). It is important for professionals involved in the assessment of ASD to have training and experience, not just with ASD but with the specific level of functioning of the individuals they evaluate.

The term “medical diagnosis” is sometimes mistakenly used in reference to ASD. The term is inappropriate because *medical diagnosis of autism is in an experimental phase and does not exist in practice.* There are no medical tests that can be used to determine if an individual has an ASD (Autism Society, n.d.). Because the term “medical diagnosis” has been used so widely, many have mistakenly

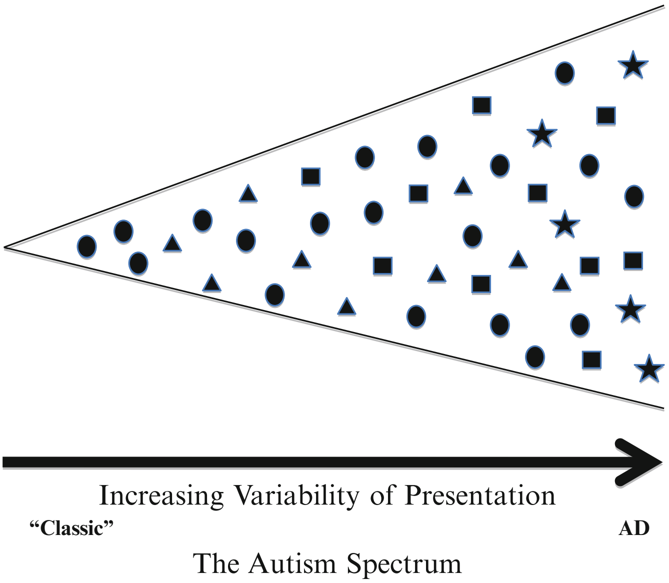

Fig. 1 Variability of ASD (Adapted from Rosenn, 1997)

concluded that a medical professional is required in order to make the diagnosis. In fact, in the absence of significant medical concerns, many specialized teams do not require staff with medical training (Aspy & Grossman, 2007).

Gender is also a factor in the identification of those with Asperger's. The gender ratios across the spectrum indicate that all forms of ASD are more prevalent among males than among females (Anello et al., 2009; Fombonne, 2003). This discrepancy, which becomes more pronounced as the level of functioning increases (i.e., fewer females in the higher-functioning population), may reflect actual gender differences in prevalence. Alternatively, it may reflect diagnostic challenges in identifying ASD in higher-functioning females. These challenges may have resulted, in part, from the fact that early descriptions of autism and AS and the diagnostic criteria were both based primarily on male clients. AS in higher-functioning females is often not recognized until much later than is typical of males with a similar level of functioning (Wilkinson, 2008). Professionals who participate in the assessment of ASD must have the training and experience necessary for recognizing the manifestations of AS in females.

Assessment of AS, like all pervasive developmental disorders, requires evaluation across a number of areas of functioning necessitating the use of an experienced team (Klin et al., 2005; Klin, Sparrow, Marans, Carter, & Volkmar, 2000; National Research Council [NRC], 2001). Areas required for a quality assessment of AS are listed in Table 1. It is clear from the scope of the assessment that a number of professionals must be involved to address all areas.

Professionals in fields including psychology, speech language pathology, psychiatry, education, pediatrics, occupational therapy, neurology, vocational

Table 1 Areas required for assessment of AS (Grossman et al., in press)

Psychological and behavioral
Developmental history (e.g., birth history, family history, developmental milestones, significant life events)
Health history
Adaptive functioning (e.g., socialization, communication, motor skills, daily living skills, community living skills)
Psychosocial factors (e.g., coexisting psychological disorders, social skills, emotion regulation)
Cognitive and academic
Intellectual functioning
Academic achievement
Language and communication
Articulation
Expressive language (e.g., syntax, MLU, pronouns, requesting, echolalia, function of language, appropriateness to situation, vocabulary use, use of nonverbal language)
Fluency
Pragmatic language (e.g., conversation, reciprocity, initiation, commenting, closing a conversation, greeting and salutation, social/conversational perspective taking)
Receptive language (e.g., answering questions, following directions, understanding word meaning, understanding nonverbal language)
Sensory and motor
Sensory processing (e.g., visual, tactile, auditory)
Motor performance (e.g., muscle tone, gross and fine motor skills, handwriting, gait, repetitive or stereotyped movements)

rehabilitation, and social work may be valuable team members (Johnson, Myers, & The Council on Children With Disabilities, 2007; Klin & Volkmar, 2003). As emphasized above, along with the expertise in his or her own field, at least some of the team members must also have expertise in ASD. Freeman and Cronin describe this high level of training and experience for assessment team members as "mandatory" (Freeman & Cronin, 2002, p. 4). This standard is echoed by the American Academy of Pediatrics in the best practice guidelines that state, "Ideally, the definitive diagnosis of an ASD should be made by a team … of specialists with expertise in ASDs" (Johnson et al., 2007, p. 1202).

While the title of this chapter is *Assessment and Diagnosis of Asperger Syndrome*, public schools do not use the term "diagnosis." Rather, evaluation in the public schools results in identification of a "disability" and determination of "eligibility" based on categories outlined by federal law, not the Diagnostic and Statistical Manual (American Psychiatric Association [APA], 2000). Table 2 summarizes the main differences between eligibility and diagnosis.

> While the education system and the private arena have different procedures, terminology, and goals, the necessity for trained and experienced evaluation team members remains the same. Whether evaluating to determine diagnosis, or to determine eligibility for special education services, the process involves considering the same characteristics of ASD outlined in different formats. Regardless of the setting, the ability to recognize the presence and impact of these characteristics requires advanced knowledge and skills that

Table 2 Eligibility versus diagnosis (Grossman et al., in press)

Eligibility	Diagnosis
Based on federal law (IDEA)	Based on a set of criteria (e.g., DSM-IV-TR, ICD-10)
Refers to a broad disability category	Refers to a specific disorder (e.g., autistic disorder, Asperger disorder)
Used only in public school system	Used in private settings
Must be determined by a team	May be determined by an individual or a team

> develop through training and experience. The difference in terminology—diagnosis vs. disability—does not reflect a difference in the necessary level of expertise. (Grossman, Aspy, & Myles, in press)

In summary, evaluation of AS is complex and requires a comprehensive evaluation by a team of trained and experienced professionals.

Challenges in Identifying Asperger Syndrome

What makes evaluation of AS different from evaluation of classic autism? The average age of diagnosis is 4.5 years for those with classic autism (Centers for Disease Control and Prevention, 2009) and 11 years for those with AS (Howlin & Asgharian, 1999). This is true because, most often, classic autism is relatively easy to recognize in both males and females. Those with classic forms of autism often experience delays in meeting developmental milestones, such as emergence of first words or playing social baby games (peekaboo), and frequently display significant cognitive delays. In contrast, individuals with AS may be harder to detect and have greater variation in their early development. While the development of speech may not be delayed, for example, the *use* of language is impaired (e.g., individual does not know how to start a conversation or dominates a conversation). It is not uncommon to hear that an initial conversation with an individual with AS was “delightful and interesting.” Indeed, the conversation was delightful and interesting; however, the perspective changes after the same “conversation” is held each day for 2 weeks. As often occurs in AS, conversations, especially those on topics of special interest, may be repeated. In fact, the language used when discussing special interests will often appear more “typical” than language on other topics. A trained eye is necessary in order to detect these more subtle yet meaningful differences.

Individuals with AS may or may not display significant developmental delays. Some display both significant delays and advanced skills. For example, it is not uncommon for children, who are later diagnosed with AS, to learn to read earlier than do most of their same-aged peers or to develop an impressive vocabulary for their young age. Because symptoms are more difficult to detect, there is more room for error – especially when clinicians lack the training and experience with this unique group. Loveland (n.d.) discusses common errors that prevent accurate diagnosis of AS. The errors and potential solutions are summarized in Table 3.

Table 3 Common errors in judgment in the diagnosis of AS and associated solutions (Adapted from Loveland, (n.d.)

Errors	Solution(s)
Diagnostic overshadowing: characteristics of another disorder are evident and mistakenly used to explain the complete diagnostic picture	Trained and experienced teams are able to readily differentiate between ASD and other conditions. They are also able to recognize when ASD occurs along with another disorder
Unremarkable developmental milestones: when developmental milestones are met in a typical time frame, other significant differences (e.g., tantrums, repetitive behaviors) may mistakenly be dismissed	Trained and experienced teams recognize that not all differences associated with ASD are developmental in nature. Experienced teams are also aware that individuals with AS often present with a typical pattern of development in a number of areas
Strong cognitive ability: those with average to above average intelligence often learn to compensate for their differences – especially in familiar situations. The characteristics of ASD often are not apparent until the individual is no longer able to compensate	Trained and experienced teams are able to recognize compensating strategies such as use of scripts, humor, and imitation. They adapt the testing to identify masked limitations
Strong interest in social interaction: an individual with AS may have friends or desire social interaction yet not have the social understanding or social competence that would be expected at his or her age "He's so social he cannot have AS"	Trained and experienced teams know that individuals with AS may have a strong desire for social interaction yet lack the skills to interact successfully. There is a widespread misbelief that individuals with AS are loners. Klin and Volkmar state that persons with AS who are socially isolated are not loners by choice (1995)
Lack of stereotypical signs: the individual does not display some behaviors often seen in individuals with ASD. "She looks just like everybody else"	Trained and experienced teams know that ASD is a pattern of symptoms and is not defined by the presence or absence of any single characteristic
Lack of significant disruptive behaviors: often, significant difficulties are dismissed or explained away when they are not disruptive. This is one of the reasons that fewer females are referred	Trained and experienced teams know that individuals who do not exhibit disruptive behaviors may have AS

In summary, assessment of AS has a different set of challenges from evaluation of more classic forms of autism. Never in the evaluation process is training and experience more critical than with this population. Evaluation of AS requires a unique set of skills and specialized knowledge.

Evaluation Procedures

Required elements for evaluation of ASD were provided in Table 1. In order to gather and provide information in each of these areas, the evaluation team conducts interviews and observations, administers specific measures, interprets findings, prepares a detailed report, and provides feedback.

Interviews. Interviews provide a deep and rich picture of an individual in a way that no other aspect of an evaluation can. A detailed developmental history, health history, and social and communication functioning are topics readily explored. Interviews help to identify strengths and needs of the client and to clarify concerns to address in the report recommendations. The evaluation team may interview parents, teachers, practitioners, and the person who is the focus of the evaluation. When evaluating adults suspected of having ASD, it may not be possible to access parent information. Siblings and friends may be alternative informants of this early history.

Parent/Guardian Interview: An interview with the parent/guardian is necessary to gather background information and health history. Historical information helps clinicians to differentiate one disorder from another. For example, even though AS is often not diagnosed until later, some core symptoms should be apparent from an early age. If a client presents with symptoms, such as social isolation that first emerges at 17 years following the death of a sibling, a clinician can rule out ASD because the pattern is not consistent, and there may be a better explanation for the symptoms (i.e., recent significant event). The parent/guardian interview also helps to identify concerns for the evaluators to address (e.g., making friends, learning job skills).

Diagnostic Client Interview: Interviewing the person of focus is a critical component of a comprehensive AS evaluation. In many respects, the interview is actually a specialized observation – one that affords the evaluation team the opportunity for direct interaction with the client. During the interview, it is helpful for the team members to keep in mind the common errors in judgment (summarized earlier in Table 2) that may lead to the failure to recognize AS. Effective team members will identify strengths that may be present – for example, good eye contact, excellent manners, and a sense of humor. A strong evaluation team understands that no single behavior or characteristic, including strengths, can be used to rule in or rule out a diagnosis of AS. Well-trained team members will also recognize behaviors that may be subtle but important signs of AS – such as talking at length about a special interest, not understanding the humor used by others, or taking a figurative comment literally.

Other Interviews: The evaluation team often gathers information through interviews of other individuals or groups of professionals who work with the person who is being evaluated. For example, teachers, administrators, physicians, and speech pathologists may provide critical information. Moreover, professionals who have had input into the evaluation are often more receptive to following through with the recommended strategies.

Observations. In contrast to a disorder that can be identified with a medical test, ASD is a clinical diagnosis meaning that it must be determined through observation by knowledgeable and experienced professionals. "… Accurate diagnosis must be based on observation of the individual's communication, behavior and developmental levels" (Autism Society, n.d.). While interviews provide clinicians with an account of others' observations, it is critical that the evaluation team members conduct their own observations. When assessing children, it is important to observe in both structured and less structured environments (e.g., classroom, recess, lunch).

Observations of clients are made even before the evaluation session begins. Examples of important observations that may be made as the individual enters the session are as follows:

- Displays repetitive patterns in speech – rigidly repeating a lengthy formal greeting to each of four examiners
- Displays intense preoccupations and/or is absorbed in own unique interests – immediately asking – "Do you have a cat?" "What time does the garbage truck come to your house?" or "How much did that watch cost?"
- Makes an unusual response to praise – responding to the compliment "That is such a great shirt" with "Yes"

There are a number of assessment measures that help to create opportunities for the evaluation team to observe behaviors necessary for diagnosis of ASD. For young children, play-based activities are often utilized, while conversation tasks are used for older children, adolescents, and adults. Table 4 lists domains of behavior to be observed during the evaluation and examples of each. The domains and examples are based on the Underlying Characteristics Checklist (Aspy & Grossman, 2008).

Specific examples of behaviors and characteristics of AS that may be observed during the evaluation session itself are as follows:

- Becomes less responsive following loud sounds – giving more detailed answers to questions asked in a quiet voice than to those asked more loudly
- Exhibits literal interpretation of words – responding to the question "What does your father look like when he is angry?" with "A little bit taller than my mother"
- Displays repetitive movements – intermittently making a slight grimace

Additional observations may be made outside the testing session in the home, school, or vocational setting or in the community. Observing clients in multiple settings at school, for example, can provide a rich picture of the individual and his or her strengths and needs. Direct observations lead to a better understanding of the client and to more targeted and individualized recommendations.

An important step in understanding observations is to notice if the person's behavior is the same in different settings. Is the behavior in the office consistent with parent and teacher reports? Did the behavior appear to be different during the school day? Both consistency and inconsistency in observations are meaningful for a number of reasons. Knowing whether or not a person has skills and is able to use those skills across settings (i.e., generalize) can impact both diagnostic decisions and treatment. Tables 5 and 6 list inconsistencies and consistencies in behavior that may be part of the diagnostic pattern of AS.

Observation of skill deficits across settings suggests a true lack of ability. In contrast, some clients display skills in some, but not all settings suggesting that skills have not generalized. Analyzing these differences may lead to a better understanding of environmental supports that facilitate success.

Table 4 Examples of behaviors to observe during a clinical evaluation of ASD (Aspy & Grossman, 2008)

Domains	Behaviors to observe
Social	Has difficulty recognizing the thoughts and feelings of others
	Uses eye contact in an atypical manner
	Has difficulty waiting turn
	Responds to praise in an unusual way
Restricted patterns of behavior, interests, and activities	Exhibits ritualistic behaviors
	Displays intense preoccupations and/or is absorbed in own unique interests
	Repeats words or sounds
	Exhibits problems handling transitions
Communication	Uses hand and arm gestures in an atypical manner
	Displays repetitive patterns in speech
	Fails to initiate conversation
	Has difficulty remaining on topic (especially when not related to special interest)
	Exhibits literal interpretation of words
Sensory differences	Displays repetitive movements (e.g., rocking, finger posturing)
	Covers ears in response to sounds
	Becomes less responsive following loud sounds
	Over- or underreacts to smells or touch
Cognitive differences	Displays extensive knowledge in narrow area of interest
	Has difficulty attending to task
	Has difficulty with problem-solving tasks
Motor differences	Displays atypical muscle tone (e.g., becomes fatigued when sitting in a chair)
	Exhibits atypical or random movements
	Displays awkward gait
	Has difficulty starting or stopping a movement
Emotional vulnerability	Displays rage reactions
	Appears to be sad
	Appears to be anxious
Medical and biological	Displays atypical activity level
	Exhibits difficulties with hearing or vision

Table 5 Inconsistencies in behavior that may be part of the diagnostic pattern of AS

Domains	Behavior A	Behavior B
Communication and restricted interests	Easily discusses train schedules	Has difficulty talking about feeling sad
Social	Plays easily with adults or older children	Watches peers play but does not join them
Social and emotional vulnerability	Tells jokes	Cannot tell when others are kidding

Table 6 Consistent behaviors that may be part of the diagnostic pattern of AS

Domain	Behavior A	Behavior B
Sensory	Startles when the air conditioning comes on at home	Sits as far away from the copy machine at work as is possible
Communication	Interrupts when spouse talks	Interrupts when evaluation team member talks
Cognitive (organizational)	Cannot find shoes and needs help almost every morning	Cannot find work materials and is often late finishing projects

Table 7 Formal measures of Asperger syndrome

Asperger Syndrome Diagnostic Scale (Myles, Bock, & Simpson, 2001)
Autism Diagnostic Interview-Revised (Lord, Rutter, & LeCouteur, 1994)
Autism Diagnostic Observation Schedule (Lord et al., 2003)
Monteiro Interview Guidelines for Diagnosing Asperger's Syndrome (Monteiro, 2008)

Measures. A number of measures that assist in the diagnosis of Asperger's exist. While the format of tests vary (e.g., checklist, interview, observation), it is important to note that no single measure or procedure can be used to diagnose autism spectrum disorder; rather, diagnosis can only be made by synthesizing and analyzing information from a variety of sources. Good clinicians recognize that tests are simply tools used to *assist* in diagnosis. There are no tests that can substitute for clinical experience and judgment.

Evaluators must carefully select measures based on information about the client (e.g., level of verbal communication skills, cognitive level, attention span, and motor skills). Improper selection of measures will have a negative impact on evaluation outcomes. For example, the Autism Behavior Checklist (Krug, Arick, & Almond, 2008) is designed to screen for "classic" autism. A negative result (suggesting that the individual does not have autism) on the ABC would not be very informative, and could even be misleading, when evaluating an individual suspected of having AS.

A distinction is made between "formal" and "informal" measures. Formal measures are those that have undergone extensive development and research by test publishers to support their use in evaluating ASD. Formal measures provide scores and norms with which to interpret test results. Examples of formal measures are listed in Table 7. In contrast, informal measures are not produced by a publisher. Often, clinicians develop their own measures, such as use of pictures of social situations or descriptions of social scenarios. Client's responses are recorded and analyzed based on clinical experience and training. A brief description of results from an informal measure administered to an adult is provided in Fig. 2. A final category of measures, known as research measures, exists. These instruments are developed by professionals in the academic and scientific community. While many of the tools are well researched, Lori was shown depictions of social situations and asked to describe what was happening and how the people were feeling. The pictures are static representations of people who are expressing strong emotions. The most clear facial expressions were misinterpreted by Lori. The general nature of the emotions were consistently misidentified as well. For example, one picture depicted a boy and a man who were eating corn. The boy appeared to be sad, because the older man took the last piece of corn off the plate, while the man appeared to be happy because he had another piece of corn. The corn, central to the picture, was overlooked completely in her response. Lori described a “possibly spoiled brat” at a “luncheon.” She gave a vague description of the feelings expressed- “upset over some type of issue,” indicating that she saw some of the details, but was not able to form a meaningful “whole” in order to interpret the interpersonal nature of the situations depicted.

Fig. 2 Description of response from an informal measure administered to an adult (Grossman et al., in press)

they are not published or sold by a company. Examples include Reading the Mind in the Eyes (Baron-Cohen, Wheelwright, Hill, Raste, & Plumb, 2001) and the Childhood Asperger Syndrome Test (Scott, Baron-Cohen, Bolton, & Brayne, 2002).

Diagnostic Decision Making and Report Writing

Before a report is written, a team must review all the information and make decisions regarding diagnosis/eligibility and recommendations. Assessment results must be interpreted by qualified professionals. It is not possible to rule in or rule out an ASD or to determine recommendations based on a single test; rather, all results, including interviews, observations, and measures, must be considered. Interpretation is complex. At times, data may be consistent, resulting in a relatively straightforward decision. Other times, assessment data are complicated and may seem contradictory. Clinical judgment is the key to this process. Clinical judgment is the use of professional experience and training to interpret data and to make recommendations. The process of interpretation is best accomplished by a team – the most valuable tool in the evaluation process.

One complicating factor in making diagnostic decisions is the overlap of symptoms from other disorders. For example, people with AS often share some characteristics of inattention, anxiety, and obsessive-compulsive behaviors. Clinicians must be able to differentiate AS from other disorders. While AS has unique characteristics, it can be confused with other disorders – especially by team members with less training and experience.

Another complicating factor often present is the existence of more than one disorder. Indeed, the presence of additional disorders is "to be expected" in autism (Gillberg & Billstedt, 2000, p. 327). One study found that 72 % of individuals diagnosed with ASD have an additional disorder such as depression or anxiety (Gjevik, Eldevik, Fjaeran-Granum, & Sponheim, 2011). This means that it is not an either-or situation. An individual who has AS may have another disorder. Alternatively, the presence of a psychological disorder does not preclude a diagnosis of AS.

Another complicating factor in the decision-making process is the age of the individual. Some evaluators take what they describe as a "conservative" approach to diagnosis of AS – especially for young clients. According to these evaluators, when obvious concerns are observed, it is better to "wait and see" than to make a diagnosis. The opposite is actually true. It is actually riskier to delay a diagnosis and needed services when the characteristics are present. The American Academy of Pediatrics is opposed to this approach and recommends diagnosis/identification when symptoms are present (Johnson et al., 2007, p. 1202). "Evaluators should feel no guilt when identifying and diagnosing ASD – rather they should feel comfort in knowing that they are helping to provide the family and client with critical information and directing them toward needed services and support" (Grossman et al., in press).

Recommendations

The two main purposes of a report are to (1) provide diagnostic or identification information and (2) to make recommendations for needed supports, strategies, and interventions. The recommendations are the most important part of a report. Strong recommendations can have a lasting impact on the individual with ASD.

Sample report recommendations for an individual with AS are provided in Table 8. The first column of the table contains items from the Underlying Characteristics Checklist-High Functioning (UCC-HF; Aspy & Grossman, 2008), and accompanying recommendations are listed in the second column. The UCC-HF is an instrument used to identify behaviors and needs related to ASD for the purpose of intervention (not diagnosis). It is ideal for quickly summarizing concerns to address as illustrated in Table 8. Sample recommendations are provided in the second column. This approach helps to ensure that the recommendations actually tie to the specific needs of the individual. Too often, teams fall into the bad habit of "recycling" generic recommendations. Instead, recommendations should be specific and

Table 8 Sample report recommendations (Grossman et al., in press)

UCC-HF item	Sample recommendations
4. Lacks tact or appears rude	Make a video of him in actual interactions – point out how others respond to his statements/questions, labeling their facial expressions and tone of voice. Keep list of comments/behaviors that are acceptable to others, or that make them feel good, and a separate list of comments/behaviors that others thought were rude. A T-chart may be useful Point out times that people laugh and times that people do not laugh (expected/unexpected). Have him identify appropriate times to laugh in role play, story, or video Use "social autopsies" following any bullying episode. This is a strategy where each part of a situation is analyzed in order to understand what went wrong
6. Has difficulty joining an activity	Prior to engagement in social activities (and during social activities), consider sensory modifications, such as chewing gum and sipping from a bottle of water, in environments known to be stressful
18. Has problems handling transition and change	An individualized daily schedule is a critical tool for successful transitioning. Include on the schedule the plan for coping with new activities. Prepare for changes in routine using the visual schedule (calendar). Note aspects of the change that are important to him and practice coping skills. Identify a peer who is available to support him in each situation Practice skills for coping with change, reinforce for successful imitation or demonstration of skills Prime just before change – remind that it is ok and briefly review coping options Use a sensory diet, built into the daily routine and included in visual schedule
63. Has difficulty understanding the connection between behavior and resulting consequences	School staff and parents should recognize that difficulty anticipating consequences is a symptom of ASD. He requires instruction in this area. He needs help to understand how others will likely feel and respond if he behaves a certain way Social narratives, video, and cartooning are helpful visual supports. For example, cartooning can be used to help him to understand the connection between behaviors and consequences Emphasize the "expected" and "unexpected" behaviors and how his behaviors make others think and feel (he needs to understand the "why"). Teach a 5-point scale as a visual guide for responses

targeted for the individual's situation and needs. One excellent personalized recommendation that is tied to the underlying characteristics of AS is of more value than 20 "boilerplate" recommendations.

Feedback

After the report is completed, the team is not finished. A written report cannot substitute for a person-to-person feedback session. Evaluators must acknowledge and be responsive to the feelings and perspectives of the individuals who are receiving the feedback. This can only be accomplished during an in-person session. The goals of the feedback session are to review evaluation findings, answer questions, discuss concerns, and plan interventions.

Summary/Conclusions

A comprehensive autism spectrum evaluation should include a developmental history, observations, direct interaction, interviews, and evaluation of functioning in the following areas: psychological/behavioral, cognitive/academic, language/communication, and sensory/motor. The most critical element of an evaluation is the participation of well-trained and experienced evaluation team members. The expertise of the team is far more important than the specific instruments used in the evaluation. A thorough assessment leads to more accurate conclusions and to comprehensive treatment decisions. The results of the AS evaluation should be summarized in a written report and include specific and meaningful recommendations. The evaluation should be followed by a face-to-face feedback session.

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Counseling and Other Therapeutic Strategies for Children with AS and Their Families

Sherrie Sharp

Introduction

Previous chapters have outlined Asperger syndrome (AS) and how it impacts the social interactions and relationships between individuals with AS and those in their environment. We know that individuals with AS have atypical social and emotional and sometimes cognitive development such that some domains lag significantly behind others. Some of the most striking features that have their families seeking treatment for them include cognitive inflexibility, failure to incorporate context, and missing social cues. It is the shortfall in appreciating social nuances that presents most of the challenges unique to AS. Skills often lag in the areas of abstract reasoning (i.e., understanding a metaphor) and how body language and nuances of voice (tone, pitch, volume, and inflection) influence the meaning of what was said. These underdeveloped skills that others take for granted impact the perceptions, interpretations, and subsequently functioning and relationships of individuals with AS.

This chapter covers what we know about the benefits of several types of therapies for those with AS and will provide some guidelines on choosing relevant treatment. The therapies include those developed for autism, those developed for anxiety and mood disorders that may be comorbid, those that support the family and parenting function, as well as those that involve pharmacologic therapy for comorbid mental illness and core symptoms of autism spectrum disorders. Counseling and medication are often only part of the total treatment in AS, and the need for social skills and academic interventions should be assessed in every case.

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While the atypical behavioral responses of an individual with AS can strain relationships with parents, teachers, and peers, the degree to which individuals with AS thrive is significantly influenced by the quality of those relationships. Given the relationship skills deficits in AS, individuals are more reliant on others' support to keep family relationships, academic progress, and socialization on track. Treatment, therefore, must include monitoring those relationships and the degree to which others approach them with understanding and empathy. Children with AS often require more parent involvement and intervention in their daily lives in activities such as completing tasks, interpreting information, and negotiating interactions in the community. Families may find this stressful and may be able to benefit from support. Such support can include psychoeducation, parent training, family therapy, and individual therapy for family members.

In the medical model, when we consider recommending treatment for a particular diagnosis, we look for the highest quality of evidence-based interventions, and then, we consider whether the studied interventions were successful for patients who have the same characteristics as the patient at hand. In new fields where there is not yet much published about treatment interventions, we look to similar clinical situations and see if the interventions might be suitable for our client. For Asperger syndrome, we have not yet accumulated a substantial body of literature that speaks to therapeutic interventions. Instead, we have a body of literature on treatment interventions for autism, and we have bodies of literature on the treatment interventions for comorbid conditions such as anxiety, depression, mood disorders, and the like. The work group formed by joint efforts of the National Institute of Mental Health and American Psychiatric Association has been working on revising the Diagnostic and Statistical Manual of Mental Disorders for the fifth edition, and it has proposed combining Asperger syndrome with autism and pervasive developmental disorder, NOS. This will undoubtedly influence the direction of further research on treatment. Likely, the application of future treatment recommendations will be driven less by diagnosis than matching the clinical issue and neuropsychologic profile of the individual with literature combining the same. At some point in the future, the neuroimaging pattern and neurogenetic profile of the individual may inform treatment recommendations.

The American Academy of Child and Adolescent Psychiatry Practice Parameters outline the strength of evidence supporting treatment recommendations in descending order as follows:

- Randomized, controlled trial – studies in which subjects are randomly assigned to two or more treatment conditions
- Controlled trial – studies in which subjects are nonrandomly assigned to two or more treatment conditions
- Uncontrolled trial – studies in which subjects are assigned to one treatment condition
- Case series/report – case series or a case report (description of the care and outcome of a small number or a single patient)

While the randomized controlled trial is the type of study considered to provide the strongest evidence, the support for a particular treatment becomes even stronger when a randomized controlled trial is replicated at multiples sites with similar outcomes.

The phrase, controlled trial, means that the study compares the effect of an intervention while controlling for other influences. Typically comparison groups have statistically similar demographic data such that the only difference between them is whether the group gets treatment or not (the group that does not get treatment is called a control group). When a trial is called a randomized controlled trial, it refers to the assignment to the groups being compared being done at random.

The larger the body of high-quality studies, the more confidence we have that a given treatment is effective. Generally, in a new field of study, case reports and case series are published first, treatment suggestions may be proposed, and an uncontrolled trial may be conducted. When the clinical issue gains enough momentum, the more stringent trials are designed and administered. During the course of that process, the hypotheses being tested become more specific and more helpful.

When considering treatment for an individual with Asperger syndrome, it is imperative that the clinician has an understanding of his or her developmental profile. Often, a neuropsychological evaluation can be helpful in assessing how the individual's neurocognitive processing profile differs from what is typical and how his or her level of maturity ranges when comparing developmental domains. When this is taken into consideration along with the history of his or her variable performance under different conditions, the examiner can often speak to how much his or her functioning is impacted by skills deficits, versus emotional upset, versus intentional misbehavior.

With this kind of information in hand, parents and professionals can develop strategies for intervention. Interventions should consistently be aimed at supporting the individual enough to accomplish a balance between achieving the highest level of functioning, reducing the frequency and severity of dysregulated behavior, and executing pro-social behavior more consistently. Dysregulated behavior often occurs when individuals become overwhelmed because the immediate social demands exceed their capacity to access the appropriate skills at that moment. For children with Asperger syndrome, it is often helpful for parents and teachers to have planned strategies for managing behavior at home, at school, and in social settings such as when playing sports or simply socializing with friends.

The earlier a child is assessed and successful interventions are developed, the earlier pro-social behaviors can be reinforced and dysregulated behavioral episodes can be reduced. For some individuals, the sense of feeling overwhelmed can be managed internally over time, but for others, the goal would be to reduce the frequency and severity of episodes. As individuals with AS develop skills to function more independently, the support can be titrated back.

Asperger Syndrome as a Diagnosis

There has been ongoing controversy about the validity of Asperger syndrome as a diagnosis distinct from the other autism spectrum disorders. For quite some time, researchers have been addressing the overlap between the criteria for autism disorder (particularly those high functioning with normal IQ) and Asperger syndrome and pointing out that the overlap can lead to inconsistent categorization (Kerbeshian, Burd, & Fisher, 1990; Mayes, Cahoun, & Crites, 2001; Tsai, 2000).

The work group formed by joint efforts of the National Institute of Mental Health and American Psychiatric Association has posted draft diagnostic criteria for the combined autism spectrum disorder. These criteria and the rationale are available at the website: www.dsm5.org/proposedrevision (American Psychiatric Association [APA], 2012). There is some concern that the DSM-5 draft criteria that lump Asperger syndrome with the rest of the autism spectrum disorders are less sensitive, meaning fewer individuals will meet criteria (Mattila et al., 2011). This may mean that children with milder symptoms will not warrant a diagnosis of autism. In these cases, criteria may be met for the proposed Social Communication Disorder or Intellectual Developmental Disorder.

The rationale posted by the work group points to inconsistently applied distinctions between the former categories of autistic disorder; Asperger syndrome; pervasive developmental disorder, not otherwise specified; and childhood disintegrative disorder and their assertion that a single spectrum disorder better reflects the current state of scientific understanding. A recent publication by Lord et al. (2012) describes the outcome of comparing clinical diagnoses of autism spectrum disorders made at 12 university-based sites. They found significant differences from site to site in best-estimate clinical diagnoses, which have been used as the gold standard, of specific autism spectrum disorders. The number of individuals studied was over 2,000.

Historically, in the evolution of the Diagnostic Statistical Manual, clinical conditions have been reclassified and renamed. No matter what language is used, clinically speaking, these individuals benefit from empathic understanding and therapeutic support. When the new criteria are published, there will likely be a period of adjustment as patients with a current diagnosis of AS are re-diagnosed. Parents of children already diagnosed with Asperger syndrome may want to keep their child's primary clinician apprised of the services that have been facilitative to their child's daily functioning.

Many authors have written about the benefits of the Asperger syndrome diagnosis as a way of understanding these complicated children who often present after failing treatment for other validated diagnoses that will be maintained in the new version of the DSM such as ADHD, anxiety disorder, oppositional-defiant disorder, or mood disorder that only describe part of the problem. In many cases, parents have consented to and embarked on treatment courses for those diagnoses and were subsequently told that their child did not respond typically to the treatment of a particular diagnosis or that their child's case is complicated by multiple diagnoses. Parents may report that attempting treatment of multiple diagnoses at the same time has been overwhelming and/or that treating one at a time has been inadequate. Without a unifying understanding, and unifying treatment approach, parenting the very same child can seem more daunting.

The field is in a transitional state with a large number of children identified as having Asperger syndrome and impending criteria that threatens to nullify the diagnosis. In the course of time, the name assigned to their neurobiologic or neurodevelopmental condition will evolve. In the meantime, clinicians, parents, and teachers need to go about the business of treating, raising, and teaching them. For the time being, we will continue to use the diagnosis Asperger syndrome in this text to identify the individuals whose treatment is being discussed.

Psychoeducation

Psychoeducation usually closely follows a diagnosis of Asperger syndrome. Families usually want to know what causes it, what can be done to treat or cure it, and what they can expect of their child's ongoing development. Sometimes, one of the most helpful interventions is the explanation that AS is a neurobiologic condition and that their child's difficulties are not a result of flawed parenting nor is their child simply acting out when he exhibits atypical behavior. Psychoeducation can help reduce or alleviate feelings of guilt regarding the parenting or resentment toward their child. This, in turn, can help parents be more open to trying new interventions and to be more supportive when needed.

Sometimes parents may want to know if there is a cure for AS. At this point, scientists are still researching the possible causes and mechanisms, and we do not have a cure to offer at this time. Psychoeducation about treatment may involve conversations about any of the topics outlined in this chapter and would be expected to be ongoing throughout the course of treatment.

In many cases, psychoeducation also includes discussion about the appropriateness of the academic supports and environment. If parents do not feel their child's needs are being met, they may need some guidance about advocating for more support. For example, some parents may not be familiar with the Individuals with Disabilities Education Act (IDEA) that was enacted in 1990 and reauthorized in 1997 and 2004. It was designed to ensure that individuals with disabilities receive a free and appropriate public education. At the time of this publication, the federal government maintains a website that is helpful for parents and providers as well as school officials at http://idea.ed.gov. Parents may need to be guided on how to request a meeting with appropriate school personnel, how to prepare for it, and whether to bring an advocate with them.

Families may ask about the future and whether their child will ultimately grow out of AS. They may ask many years in advance whether their child will be able to attend college or what kind of work he or she will be able to do as an adult. While we do not have long-term population-based studies providing estimates of percentages of people diagnosed with AS going on to secondary education or professional employment, we can say that maturity, guidance, and treatment will help the individual's future opportunities to be as plentiful as possible.

Ideally, psychoeducation is offered at a pace that balances parental inquiries and maximizes the functioning of the individual with AS. Some parents are very proactive and seek information in advance of transitions and early in the process if some aspect of treatment gets off track. In other instances, parents may need to be gently guided to attend to and prepare for a transition or some other aspect of education or treatment. In any case, psychoeducation should be viewed as an ongoing part of the clinician's role.

Information Sources

Some parents may seek additional supports in the community or on the Internet. Parent support groups may be available in some areas and may provide a sense of community and camaraderie among other parents working through some of the same issues. Participants attending a support group should be mindful of whether a group is led by other parents or professionals. Any advice received regarding their child's treatment should be reviewed with their child's provider before implementing it.

The Internet can also be a source of information for parents. However, here again parents should be mindful of the quality of the information provided. Generally, sticking to websites of well-known institutions will keep parents in good stead. Again, before pursuing any treatment recommendations, the child's current providers should be consulted.

Considering Comprehensive Treatment

One of the key decisions parents must make for their child with Asperger syndrome is how much intervention is necessary for him to function well. Depending on his or her age, how severe his or her behavioral issues are at school, and the degree to which his or her academic or developmental progress is impeded, his or her parents may consider comprehensive treatment. Comprehensive treatment may go by different names in different communities but generally provides both education and behavioral treatment in one setting. Programs may be called day treatment or therapeutic school or some similar variation. For children younger than elementary school aged, parents would be looking for therapeutic nursery or preschool. Wagner and McGrady (2003) pointed out that many early intervention programs have been evaluated by the National Research Council [NRC] (2001), but none have been tested rigorously enough to ascertain that it consistently works or for what subgroup. For the parents of young children who are seeking daycare and nursery school services in their communities, the Early Head Start and Head Start programs may be helpful.

New regulations for Part C of IDEA were announced in September 2011. This pertains to services for infants and toddlers from birth to age 2. Program administration will be overseen at the state level, and implementation may result in some changes to local programs.

Once a child is in primary school, parents may try to add services at their school and in the community, or they may try to pursue a day treatment setting that combines education and treatment. Many parents chose to work with the school staff to develop an Individualized Education Plan (IEP) or a behavioral plan (often called a 504 plan) at school. Additionally, schools may provide counseling (with psychologist or social worker) as well as any recommended speech and occupational therapy. Sometimes when the school to which the child is assigned cannot meet the child's academic needs the district will fund a transfer to an alternative placement combining treatment and academic instruction. In some instances, families choose to use their own funds to pay tuition for alternative placement. These decisions can be complicated and parents are encouraged to ask advice of trusted professionals as well as parents of other children with similar difficulties who are familiar with local services.

As parents reflect on whether the academic environment is able to provide an appropriate education, there are several aspects to consider. Wagner and McGrady (2003) outlined several helpful questions that may be discussion points in public school meetings or may be screening questions when considering an alternative private placement.

- How successful has the program been for children like mine, with the same diagnosis, similar age, and similar developmental profile?
- Has the program itself been formally evaluated for effectiveness with children with similar issues? If not, are the techniques used based on models and/or theory that have some scientific validation?
- How does the program attempt to move children toward more self-sufficiency and less restrictive educational settings?
- Are staff members trained to work with children with Asperger syndrome? What is the extent of their training?
- How will my child's goals and progress be measured?
- What are the cost, time commitment, and location of the program?

Parent Training for Behavior Management

When children with Asperger syndrome have behavioral problems such as rigidity, tantruming, resisting transition, and poor response to presented stimuli, clinicians turn to the interventions developed for autism to guide treatment. Most of those interventions were developed for use in comprehensive treatment programs; however, most comprehensive treatment programs have a parent-training component to help reinforce and generalize the use of skills in the home and community. See Appendix adapted from Wagner and McGrady (2003) for further discussion of parent training.

The addition of parent training to medication management alone was recently shown to reduce serious behavioral problems in children with pervasive developmental disorders. Aman et al. (2009) conducted a randomized controlled clinical trial that showed combined treatment reduced noncompliant behaviors, irritability, stereotypic behavior, and hyperactivity. However, there was not a significant difference in global functioning between the groups at the endpoint. The parent training in this model involved a behavioral team of two clinicians using a structured treatment manual over the course of 11–17 treatment sessions. Instruction focused on preventive approaches (i.e., visual schedules), effective use of positive reinforcement, teaching communication, adaptive skills, and compliance.

Some families choose to work with a behavioralist or psychologist who may do work with the client and family in their home. When professionals come to the client's home, they can see the client in his or her natural environment and may be able to make suggestions that help the client and family function more easily. Like other services, in-home behavioralist services can be very helpful if the professional(s) are trained to work with individuals on the spectrum.

Family Therapy

Having a family member with a developmental disorder can present significant family stress at times. When one family member has difficulty getting through the daily routines, does not transition well, or cannot be flexible when another family member's needs change, it can have ripple effects in the family. Siblings may have to accommodate by making due with less parental attention, spouses may have to make do with less partner attention, and sometimes family events get canceled or one parent may stay behind with the child who cannot transition and let the rest of the family go to the event.

Particularly when individuals with AS go through big transitions, families may notice a decline in family functioning as the individual's stress impacts the family system. For example, when an individual with AS transitions to middle school, he may find the environment calls for more executive functioning skills to get through rotating class schedule, peers call for more awareness of their social image, and the socializing requires a transition from being rule-bound toward more abstract thinking. This can be a recipe for becoming overwhelmed frequently.

During these times, it may be helpful to have a professional involved in guiding the family to assess their goals for family life and assist them in reaching those goals. Some families may not be mindful of what they would like their family to achieve and may need assistance in establishing goals. Most family therapists would support parents having "date night" with regularity to help maintain a positive relationship between the leaders of the household. Parents need to have fun and relax together in order to co-parent in healthy manner. Similarly, other children in the family should be able to have time with parents as well as some time for activities with just their peers.

Family therapy can be used as the venue for parents and teens with AS to negotiate the progressing independence of the teen. It can also be utilized for parent guidance sessions. Parents may struggle with balancing granting appropriate freedoms versus protecting the teen from his or her peers given his or her comparative naivety. Common areas of concern include giving permission to drive, date, and go off to college.

Comorbid Conditions with Asperger Syndrome

Given the core social difficulties of individuals with Asperger syndrome, their atypical behavior (inflexibility, perseveration, and becoming overwhelmed) can negatively impact how well they fit in with peers and authority figures in social and academic settings. Youth with AS tend to have the insight that they are different from others and do not “fit in” (Myles & Simpson, 2002). Many children with AS have a desire to develop relationships but fail at it; furthermore, adolescents with AS have a greater propensity to view situations as hopeless and themselves helpless (Weiss, Fiske, & Ferraioli, 2009). These situations can lead to anxiety, isolation, and depression.

Many small studies indicate that there is a very high incidence of comorbid psychiatric conditions ranging from 65 % to 97 % (Ghaziuddin, Weidmer-Mikhail, & Ghaziuddin, 1998; Mattila et al., 2010; Mukaddes & Fateh, 2010). These small samples ranged from 35 to 54 in size.

The different studies vary in what was reported as the most common comorbid disorder. The combined results indicate that anxiety disorders are present in 42–54 %, behavioral disorders are present in 44–48 %, mood disorders are present in 37 %, and tic disorders to be present in 26 % of the individuals studied. A larger study, by Simonoff and colleagues, summarized population-based rates of comorbid psychiatric disorders in a group of 112 10–14-year-old children who were assessed for other psychiatric disorders. Seventy percent of participants had at least one comorbid disorder. The most common were social anxiety (29.2 %), attention deficit/hyperactivity disorder (28.2 %), and oppositional-defiant disorder (28.1 %). Of those with ADHD, 84 % received a second comorbid diagnosis (Simonoff et al., 2008).

Some research indicates that the relative prevalence of comorbidities tends to be different at different developmental stages. Ghaziuddin et al. (1998) found that children were most likely to suffer from attention deficit/hyperactivity disorder and adolescents and adults were more likely to suffer from depression. Lugnegard, Hallerback, and Gillberg (2011) recently conducted a study of young adults with Asperger syndrome. The 54 participants were screened with the Structured Clinical Interview for DSM-IV Axis I Disorders. Results indicated that 70 % had experienced at least one episode of major depression, 50 % had recurrent depression, and anxiety disorders were seen in about 50 %.

While the studies cited above are small, they support a recommendation for ongoing monitoring and possibly screening children for comorbid conditions when we know they have been diagnosed with Asperger syndrome. One of the challenges in treating children on the autism spectrum is that they are poor reporters of their internal states (Weiss et al., 2009). Due to the core social and relationship skills deficits, they may have difficulty establishing therapeutic rapport and engaging in identifying therapeutic goals. Poor reporting of internal states also impacts clinician’s measure of therapeutic progress. However, screening instruments may be helpful in this regard.

Therapy for Individuals with Asperger Syndrome

One of the most common and widely supported therapy modalities is cognitive behavior therapy (CBT). When CBT outcomes have been studied, results indicate sizeable reduction in symptoms of unipolar depression, generalized anxiety disorder, panic disorder, social phobia, posttraumatic stress disorder, and childhood depressive and anxiety disorders (Butler, Chapman, Forman, & Beck, 2006). CBT helps individuals to make the connections between their thoughts, feelings, and actions or behaviors. Many different curricula exist with variations on this theme, but most include components on self-monitoring, self-soothing, comparing interpretations with others who are more objective, and generating alternative behaviors or solutions. Mastering these skills would bolster the social and emotional functioning for individuals with Asperger syndrome. While research in this area is still emerging, several recent studies evaluated the treatment of comorbid anxiety in patients with autism spectrum disorders and found it to be effective at alleviating anxiety symptoms (Chalfant, Rapee, & Carroll, 2007; Lang, Regester, Lauderdale, Ashbaugh, & Haring, 2010; Sofronoff, Attwood, & Hinton, 2005).

Modifications to traditional CBT protocols employed in successful studies included use of visual aids, emphasis on relaxation techniques, reduction in abstract language, simplification of tasks, use of role play, use of video modeling, embedding of instruction into perseverative topics, instruction of social skills, instruction of adaptive skills, and reinforcement for progressing through sessions (Lang et al., 2010). Manuals used included The Cool Kids Family Program-Therapist Manual (Lyneham, Abbott, Wgnall, & Rappe, 2003) and Child Anxiety Disorders: A treatment manual for practitioners (Wood & McLoed, 2008).

One group studied the effectiveness of CBT in reducing anxiety symptoms of children with AS and also evaluated whether more intensive parent involvement increased the child’s ability to manage anxiety outside the clinic. In this study, 71 children were randomized to intervention for child only, intervention for child and parent, or wait-list condition. Children were ages 10–12 and the intervention lasted 6 weeks. Both treatment arms were found to result in significant improvement. Active parental participation produced significant benefits for parents and their children (Sofronoff et al., 2005).

Another recent study was conducted to evaluate the effectiveness of a social skills treatment summer program but also compared a treatment arm with behavioral therapy plus social skills treatment on the social behaviors of 6–13-year-olds with Asperger syndrome (Lopata, Thomeer, Voker, & Nida, 2006). In this instance, the behavioral treatment portion was described as the addition of a token system whereby tokens were given immediately after pro-social behaviors were expressed and tokens were taken away when program rules were not followed. Both staff and parents indicated significant improvement in social skills, but results on adaptability and unusual behaviors were not consistently positive. The addition of the token system did not contribute to improvement in social skills.

Recently, several authors have discussed psychodynamic and integrated psychotherapy models for individuals with Asperger syndrome. Munro (2010) outlined Asperger Integrated Psychotherapy (AIP), a model for treatment that addresses particular issues found in cases of Asperger syndrome. His recommendations include relying strongly on strength-based practice and positive psychology (Harris, Thorensen, & Lopez, 2007; Seleeby, 1992) and providing an unconditionally constructive foundation from which to develop positive therapeutic relationships. His model has seven core features:

I. Developing a supportive lifeline to reduce isolation and loneliness
II. Combining individual and family therapy
III. Utilizing cognitive behavioral therapy strategies
IV. Re-composing the narrative of dominant life stories with positive language from a supportive perspective
V. Prescribing physical exercise
VI. Mending "Broken Spirits" including fostering mindfulness and identifying places of solitude and positive visioning
VII. Psychoeducation

Medication Therapy in Asperger Syndrome

The treatment of youth with Asperger syndrome is anything but straightforward. Until now, this discussion of treatment has focused on the comorbid diagnoses assigned based on observation of the client, report by the client, and the completion of rating scales uses to assess the presence and severity of clinical issues. The prevalence literature and the psychological literature align considerably better in this regard than does the psychopharmacologic literature.

In the body of literature on therapy, researchers have typically separated higher-functioning individuals with autism spectrum disorders for more language-based interventions such as cognitive behavioral therapy and less well-functioning individuals for more behaviorally based interventions such as applied behavioral analysis. The same cannot be said for the most recent literature in the field of psychopharmacology. Rather, in anticipation of the combining of diagnoses with the arrival of the DSM-5, researchers have tended to lump together clients on the spectrum, and instead of studying the improvement of comorbid diagnoses such as anxiety or depression, they are reporting on observable behaviors such as repetitive behaviors or aggression.

Given the earlier discussion of applying the literature to the client at hand, the most recent psychopharmacologic studies are difficult to apply. Due to the increasing prevalence of the autism spectrum diagnoses, the NIMH has funded multi-site, randomized controlled trials at academic centers. These are considered the highest quality of study type. However, given the trend of blending the diagnoses and therefore needing to measure improvement in nonverbal clients, the outcome measures do not necessarily line up well with those used in studies on the effectiveness of CBT for example. The sample sizes of these recent studies remain under 200 with a low percentage identified as having been diagnosed with AS or PDD, and few authors address whether the higher-functioning individuals varied in clinical outcome.

Using medications to treat individuals with Asperger syndrome continues to be complicated and for the reasons noted above will likely continue in a trial and error fashion in the near term. Youth with AS cannot clearly be lumped in with the more severe clients with autism, nor do they respond just like clients without developmental issues to medications. Neither do they respond to medications just like adults with AS or high-functioning autism. As such, this section is not meant to be an exhaustive review, rather it is a sampling of some of the key studies.

Psychopharmacologic treatment for youth with AS ought to be done carefully and with low initial doses. Making use of collateral information is essential to understanding what is off track. Collateral information, however, usually consists of observation of behavior and its subsequent interpretation. Due to the difficulty with self-monitoring and reporting of thoughts and feelings, it can be difficult to tease out what the core symptom cluster is.

Given the increase in prevalence in diagnosis, there has been a growing interest in the diagnosing and prescribing patterns of physicians in this group of patients. For example, several states have developed monitoring networks to gather public health data on Medicaid-eligible individuals with autism spectrum disorders. The South Carolina Autism and Developmental Disabilities Monitoring Unit Network data was used as the source in an epidemiologic study which showed that of 263 patients, 40 % used psychiatric medication and 20 % used multiple classes of psychiatric medications. The authors found that common combinations were (1) attention deficit/hyperactivity disorder, antihypertensive, antidepressant or antipsychotic medications, or (2) antidepressant and antipsychotic medications (Logan et al., 2012).

Another summary of medication use in children with autism spectrum disorders was based on the Interactive Autism Network voluntary database, established in 2007. It contains data on over 10,000 children with autism spectrum disorders the medication use of a sample of 5,181 children is summarized below (Rosenberg et al., 2010) Table 1.

Selective Serotonin Reuptake Inhibitors (SSRIs)

There have been consistent findings in the basic research of the autism spectrum disorders indicating the involvement of the serotonin physiologic pathway. Because of that, there has been significant interest in using the SSRIs clinically and studying the outcomes of treatment. To date the clinical research results have been quite mixed and challenging to apply to youth with AS who are considered to have anxiety or depressive symptoms. As described above, the research has more recently measured outcomes involving repetitive behaviors or agitation. While dysregulated clinical signs that are displayed can be interpreted as a display of anxiety or underlying irritable mood, recent randomized controlled trials have shown limited benefit for the SSRIs on the Clinical Global Impressions Scale which captures anxiety and mood improvement.

Table 1 Psychotropic medication use among children with autism spectrum disorders (Excerpt from Psychotropic medication use among children with autism spectrum disorders enrolled in a national registry, 2007–2008)

Diagnosis	Any med	>3 med	Stimulant	Neuroleptic	Antidepressant	Mood stabilizer	Alpha agonist
Total	35.3 %	9.0 %	15.4 %	15.0 %	13.6 %	6.6 %	7.7 %
Autism (2,440)	30.7 %	6.0 %	36.9 %	15.2 %	9.8 %	7.4 %	7.0 %
PDD-NOS (1,229)	31.2 %	8.9 %	15.4 %	10.5 %	12.2 %	7.3 %	7.4 %
Asperger (853)	59.3 %	17.8 %	36.9 %	23.2 %	28.5 %	5.0 %	10.2 %
Other (659)	30.0 %	8.8 %	11.1 %	12.3 %	10.6 %	4.6 %	7.4 %

Permission granted from Rosenberg et al. (2010)

Kolevzon, Mathewson, and Hollander (2006) outlined the studies completed by the time their paper was submitted in 2005, and there were only three randomized controlled trials of individuals with autism spectrum disorders treated with SSRIs, two of which were studies of adults. In their survey of open-label and chart reviews of SSRIs in autism spectrum disorders, the authors summarized that with the exception of one study of fluvoxamine which does not produce therapeutic response (Martin, Koenig, Anderson, & Scahill, 2003), the response rate to the SSRIs ranged from 57 % to 89 %. These authors surveyed reviews of escitalopram (Lexapro), citalopram (Celexa), fluvoxamine (Luvox), fluoxetine (Prozac), and sertraline (Zoloft). Six out of ten of the studies used the Clinical Global Impressions Scale to measure outcome. Behavioral activation, hyperacitivity, aggression, and irritability were among the side effects.

At about the same time, Henry and colleagues (2006) published a retrospective chart review of youth having been treated with SSRIs. They found that in 89 cases (80 males), with ages ranging from 3 to 18 years old, the rate of response to treatment with SSRI ranged from 30 % to 55 %. Of the 89 individuals, six were diagnosed with Asperger syndrome and 33 with PDD, NOS. Antidepressants included in the study were sertraline, citalopram, paroxetine, fluvoxamine, fluoxetine, and escitalopram. The most common side effects were agitation, insomnia, aggression, hyperactivity, and impulsivity.

Due to the need for ongoing progress in this area of research, the federal government passed the Children's Health Act of 2000 and established the Studies to Advance Autism Research and Treatment (STAART) network. It is comprised of eight academic centers that are charged with autism research. Several STAART sites have decided to begin with studies of pharmacologic treatment of repetitive behavior and affective and anxiety disturbance in children who have autism (King & Bostic, 2006).

In 2009, six STAART network academic centers published results of a trial of 149 patients who were randomized to citalopram or placebo and followed for 12 weeks. The authors found no benefit in overall functioning (measured by Clinical Global Impressions Scale) or repetitive behaviors (measured by Children's Yale-Brown Obsessive Compulsive Scales modified for pervasive developmental disorders). Adverse effects of citalopram treatment included increased energy level, impulsiveness, decreased concentration, hyperactivity, stereotypy, diarrhea, insomnia, and dry skin or itchiness (King et al., 2009). In the STAART network study outlined above, children had a mean age of 9.3 years and 4.7 % were diagnosed with Asperger syndrome; 6.7 % with pervasive developmental disorder, not otherwise specified; and less than half were intellectually disabled (Scahill et al., 2012).

The study outlined above is important because it is of the highest quality design and the largest to date studying an SSRI in this population. The negative results overshadow previous positive outcomes in smaller studies. For example, in a retrospective chart review, Namerow, Prakash, Bostic, Prince, and Monuteaux (2003) found 15 youth (aged 6–16 years) treated with citalopram to have improved in core symptoms of pervasive developmental disorder, anxiety, or mood based on the Clinical Global Impressions Scale. Anxiety was found to have improved in 66 % of patients, and mood symptoms were found to have improved in 47 % of patients.

In the only randomized controlled trial of fluoxetine in youth (45 individuals) with autism spectrum disorders, Hollander and colleagues (2005) found that treatment with low-dose fluoxetine had a moderate to large reduction in the CY-BOCS; however, there was no significant improvement in global functioning. Treatment with fluoxetine did not produce statistically significant side effects.

When it comes to adults who are on the spectrum, they seem to benefit more from treatment with fluoxetine. Results published by Hollander et al. (2012) indicate that a 12-week trial of 37 adults produced improvement in overall functioning (measured by Clinical Global Impressions Scale) and repetitive behavior (measured by the Yale-Brown Obsessive Compulsive Scale). Fluoxetine was reportedly well tolerated in this study. A smaller controlled trial of fluoxetine in six adults showed improvement in the Yale-Brown Obsessive Compulsive Scale and Hamilton Anxiety Scale, and 50 % of patients improved in overall functioning as measured by the Clinical Global Impressions-Autism Scale (Buchsbaum et al., 2001).

Additional multi-site randomized controlled trials are needed to address the treatment of AS youth with antidepressant medications.

Psychostimulants (Methylphenidate and Amphetamine Medications)

Several authors have discussed the finding that a high percentage of children with pervasive developmental disorders display high levels of symptoms consistent with ADHD, with estimates ranging from 40 % to 75 % (Hazell, 2007; Jahromi et al., 2009; Lecavalier, Gadow, DeVincent, & Edwards, 2009; Posey et al., 2007). Despite the DSM-IVTR guidelines to diagnose ADHD only in the absence of a pervasive developmental disorder, it has become common practice to treat the inattention, hyperactivity, and impulsiveness symptoms in these children.

Stimulant medications such as methylphenidate (Ritalin, Concerta, and Focalin) and amphetamine products such as Adderall and Dexedrine and Vyvanse are considered standard treatments for ADHD in typically developing children. Generally, the effect of treating children with PDD with methylphenidate to address hyperactivity has been positive but less so than in children with ADHD alone (Posey et al., 2007).

The Research Units of Pediatric Psychopharmacology Autism Network conducted a large study of 72 children with PDD and hyperactivity and found that just less than half of the children were considered to be responders to methylphenidate. A follow-up analysis indicated that additional positive outcomes included reduction in oppositional-defiant symptoms, but there was no difference on repetitive behaviors. Negative side effects included a significant increase in social withdrawal at high dose and a trend for increased irritability (Posey et al., 2007).

More recently the data from Research Units on Pediatric Psychopharmacology Autism Network was used in secondary analysis to determine if treatment with methylphenidate had any impact on social communication and self-regulation in children with pervasive developmental disorders and hyperactivity. In a group of 33 children, a significant positive effect was seen on children's use of joint attention initiations, response to bids for joint attention, self-regulation, and regulated affective state (Jahromi et al., 2009).

Few studies have been done on the benefit of amphetamine agents when autism spectrum disorder is also present. Relevant studies date back to 1972 and 1976 with Campbell, the lead author on both publications. Results indicated nonsignificant worsening in the first study (Campbell et al., 1972). The second study did result in reduction of hyperactivity, but most individuals were rated worse overall (Campbell et al., 1976). The studies were small with 16 and 11 participants, and the mean IQ range was significant 28–96 in the first study and 36–90 in the second study. The amphetamine agents should be further studied before recommendations can be made about their usefulness in AS.

Other Treatment for Hyperactivity and Inattention

The adrenergic stimulation pathway is believed to be involved in the hyperarousal and difficulty filtering out background stimuli. Prescribers have looked to clonidine (Catapres) and guanfacine (Tenex and Intuniv) to address this manifestation in youth with AS and autism spectrum diagnoses. In 1992, Jaselskis and colleagues published a randomized controlled trial of eight subjects with autistic disorder and found that irritability, stereotypy, hyperactivity, and inappropriate speech were reduced during treatment with clonidine on the Aberrant Behavior Checklist; oppositional behavior was reduced on Comprehensive Teacher's Rating Scale. Side effects included drowsiness and decreased activity. At about the same time, Fankhauser et al. (1992) conducted a placebo-controlled crossover study investigating transdermal clonidine in nine individuals with ages ranging from 5 to 33 years (mean 12.9) and found reduction in impulsivity, hyperactivity, and self-stimulation. Adverse effects were sedation and fatigue.

There has not been ongoing replication of this clinical research to provide any further update. However, in the fall of 2011, long-acting formulation of clonidine

(Kapvay) was FDA approved for use in treating ADHD in children ages 6–17. Studies involving the treatment of children with AS with Kapvay have yet to be done.

Guanfacine (Tenex) has been used to treat children with Tourette's syndrome, ADHD, and developmental disorders for years. Scahill and colleagues (2006) conducted a companion trial with the RUPP investigation of methylphenidate and found that in the 25 children with PDD who exited the methylphenidate option due to side effects or poor efficacy benefited with a 40 % improvement per parents and 25 % improvement per teachers. Notably it was shown to reduce irritability, tantrums, aggression, and self injury. A long-acting formulation (Intuniv) was brought to market in 2009 with FDA approval for ADHD in children ages 6–17. A case study of long-acting guanfacine was published earlier this year indicating that improvements were found in inattention, hyperactivity, and impulsivity in two children with pervasive developmental disorders as measured by the Clinical Global Impressions (Blankenship, Erickson, Stigler, Posey, & McDougle, 2011). The authors point out that further study of this medication for use in patients with pervasive developmental disorders is warranted to establish efficacy and tolerability in a larger population. This may be a useful medication for children with AS and inattention/hyperactivity, who do not respond well to stimulants, who require augmentation to stimulants, or who have comorbid tic disorder although there is little scientific evidence to guide clinicians at this time.

Atomoxetine (Strattera) can be another option for the treatment of ADHD symptoms in high-functioning autism spectrum disorders. In one small study of 16 children, 75 % showed significant improvement on a commonly used ADHD symptom measure. There were less strong improvements in irritability, social withdrawal, and repetitive speech (Posey et al., 2006). Another open-label pilot study of 12 children reported significant reduction in symptoms indicated by parents with improvement in cognitive domain as well as hyperactivity (Troost et al., 2006). A randomized control trial of 16 children resulted in reduction in hyperactive and impulsive symptoms but not attention (Arnold et al., 2006). Two of the above research groups considered atomoxetine to be well tolerated; noted side effects of atomoxetine in these studies included irritability, sleep problems, gastrointestinal symptoms, and fatigue.

Antipsychotic Medications

While the first-generation antipsychotic medications have fallen out of favor, atypical antipsychotic medications have been studied for their application in treating those with autism. The Autism Network of the Research Units on Pediatric Psychopharmacology (RUPPAN) has published several studies of trials of risperidone (Risperdal). Risperidone is the only atypical neuroleptic that obtained FDA approval for use in children and adolescents with autism with associated maladaptive behavior. Risperidone was shown to reduce tantrums, aggression, and self-injurious behavior in autistic children over a 6-month period, without dyskinesia or other severe side effects (Research Units on Pediatric Psychopharmacology Autism Network [RUPPAN], 2002). Weight gain and sedation were reported side effects.

The RUPP data was recently analyzed to assess who benefits best from treatment with risperidone. They found that those with more severe symptoms showed greater improvement. Interestingly, those who gained more weight improved less with the medication. Socioeconomic advantage, low prolactin level, and absence of comorbid problems predicted better outcome (Arnold et al., 2010).

Aripiprazole (Abilify) was studied in a placebo-controlled trial of 218 children and adolescents between the ages of 6 and 17 in the treatment of irritability. At 8 weeks, results indicated that aripiprazole was effective and generally safe. The most common side effects were sedation, fatigue, increased appetite, and weight gain that was significant (Marcus et al., 2009). Masi et al. (2009) conducted a retrospective naturalistic study and found that in a group of children with pervasive developmental disorders who were treated with aripiprazole in an inpatient setting, one third had significant improvement in maladaptive behaviors. Agitation and insomnia were frequent side effects.

There has been growing concern about using the atypical antipsychotic medications judiciously due to the long-term effects including weight gain, metabolic syndrome, diabetes, and elevated risk for cardiovascular events. Use of these medications requires monitoring of blood work, EKG, height and weight, as well as neuromuscular exam findings. Other atypical antipsychotics include ziprasidone (Geodon), quetiapine (Seroquel), olanzapine (Zyprexa), clozapine (Clozaril), paliperidone (Invega), and Iloperidone (Fanapt), and they require further evaluation of their safety and efficacy for treatment of youth with Asperger syndrome.

Anticonvulsants and Mood Stabilizers

An alternative to the antipsychotic medications in the treatment of mood lability, irritability, and aggression can be the mood stabilizers or anticonvulsants. These medications have not been as well studied in this population; however, they may be more advantageous when the relative side effect profiles are compared. Divalproex sodium (Depakote) was studied in a 12-week, randomized, double-blind, placebo-controlled trial in 27 people. It was found to be effective, as 62.5 % of the treatment group responded with reduction in irritability. It was also considered to be generally well tolerated. Responders tended to have higher blood levels of the medication compared to non-responders (Hollander et al., 2010). An earlier study of 13 individuals by the same lead author (Hollander et al., 2006) demonstrated a reduction in repetitive behaviors. The use of anticonvulsant medications requires monitoring of organ function via blood work, physical exam including neurologic changes, and height and weight.

Treatments for Sleep Disorders

Children and adolescents with autism spectrum disorders suffer from insomnia and other sleep problems at higher rate than typically developing children with estimates as high as 40–80 % (Cortesi et al., 2010). The causes of this finding are not yet fully understood and may be multifactorial. It is generally accepted that sleep hygiene is the most important first line of treatment for pediatric insomnias. Maintaining a positive bedtime routine with consistent bedtime and low stimulation prior to bedtime is widely recommended. When these interventions have not resolved the insomnia, pharmacologic intervention may be warranted.

There has been a growing interest in melatonin's role in regulating the circadian rhythm. A recent systematic review of melatonin's effect on circadian rhythm showed that nine studies evidenced abnormality in the level of melatonin or its metabolites. Eighteen studies on melatonin treatment in autism spectrum disorders indicated improvements in sleep duration, falling asleep faster, and fewer night-time awakenings. Reported side effects were minimal to none and treatment was associated with better daytime behavior (Rossignol & Frye, 2011). A randomized control trial was conducted with 22 children with autism spectrum disorders, and similar results were found with children falling asleep up to 47 min faster, increasing total sleep by 52 min, but no benefit was found in number of night-time awakenings (Wright et al., 2011).

Possible Treatment for Language Fluency

Recent work has focused on identifying and targeting the underlying brain functions implicated in the core features of autism spectrum disorders. An example of this is work that has been done on utilizing brain imaging during task performance with pharmacologic intervention of propranolol (Narayanan et al., 2010). Preliminary studies indicated possible language benefits, on tasks involving a search of semantic and associative networks. Beversdorf et al. (2011) followed up with a small pilot study of high-functioning adolescents and adults with autism and found a significant improvement in category fluency. The authors concluded there was a beneficial effect of propranolol on flexibility of access to semantic and associative brain networks. While this work is in an early stage of development, it may prove to be an important area of research in the ongoing treatment of individuals with autism spectrum disorders and cognitive profiles deficient in word fluency.

Secretin was the subject of a small number of case studies and uncontrolled trials in which authors suggested improvement in core symptoms of pervasive developmental disorders. However, since then many randomized controlled trials have failed to show significant benefits that can be replicated (Sturmey, 2005). At this time, there is no evidence to support a recommendation of secretin use in the pervasive developmental disorders.

Summary

Treatment of individuals with Asperger syndrome is multifaceted and includes behavioral, social, and academic interventions in addition to counseling and treatment with medication. Treatment should always be focused on maximizing the functioning and independence of the individual and should be carried out in a sensitive fashion taking into account the individual's areas of strengths and weaknesses. Ongoing research informing treatment may be based on the broader clinical category of autism spectrum disorder or pervasive developmental disorders. Applying future research treatment recommendations, therefore, will require more emphasis on moderators and mediators to treatment outcomes on the proposed broader diagnostic group.

Appendix: Parent Training

Adapted from Wagner and McGrady 2003

Behavioral parent training. Methods based on "applied behavior analysis" or ABA for teaching skills and facilitating more appropriate and adaptive behaviors are widely used. ABA methods have also been extensively tested for their effectiveness with children with autism and other developmental disabilities (e.g., Dunlap & Fox, 2001; Lovaas, 1987; McEachin, Smith, & Lovaas, 1993; Sheinkopf & Siegel, 1998; Smith, Groen, & Wynn, 2000). This mode of intervention is the only one that could be said to have accumulated enough scientific evidence that most would agree that "it works" in children with autism spectrum disorders.

ABA and comprehensive programs based on applied behavioral analysis are based on the principle that when a behavior is rewarded, it is likely to be repeated. Behaviors that are not rewarded, or that result in an undesirable consequence, tend to gradually go away. By carefully analyzing the causes and consequences of a particular behavior, identifying an opposite, competing behavior (desired behavior), and consistently altering the consequences so that they reward the desired behavior, one can teach new skills or transform inappropriate behaviors into more acceptable ones. This relatively simple principle has been developed into techniques that have been shown to be highly effective for teaching new skills, increasing the frequency of appropriate or adaptive behaviors, and decreasing the frequency of inappropriate or maladaptive behaviors.

Additionally, when parents are taught how to apply behavioral techniques they can help reinforce and generalize more adaptive skills as well as help to smooth out interactions between the child with AS and his or her family members. These techniques work best when applied to teaching or changing very specific behaviors such as waiting one's turn in a conversation or being more cooperative at bedtime.

There is also a trend, at least when applied to programs for children and adults with developmental disabilities, away from emphasizing the consequences of a behavior to an emphasis on understanding the triggers of a behavior, proactively providing cues or rehearsal of the appropriate behavior, making changes in the environment to avoid or minimize those triggers, and teaching more adaptive or appropriate responses when the triggers cannot be avoided (e.g., "stop and separate" strategies such as time-outs).

Parent involvement in treatment is also key in models based on developmental theoretical framework. Here again, this type of parental support is mostly accessed in comprehensive treatment programs. For instance, the Denver Model (Rogers, Hall, Osaki, Reaven, & Herbison, 2000) emphasizes the need to establish interpersonal relationships as a foundation to achieving other developmental milestones, and so emphasizes the social and emotional aspects of social relatedness. The Developmental Intervention Model (Greenspan & Wieder, 1997) is based on an assumption that the social problems in autism spectrum disorders is caused by abnormal or atypical processing of sensory information and difficulties with emotional regulation. The focus is on addressing sensory processing irregularities and the establishment of emotional contact. Both of these programs place heavy emphasis on improving parent-child relationships. While most of these programs have not been extensively evaluated using rigorous scientific trials, there are theoretical reasons and some preliminary scientific evidence that they can be used for many children with autism spectrum disorders (NRC, 2001; Rogers, 1998) and presumably for some children with Asperger syndrome.

The Learning Clinic Guidelines were written for school personnel but can be helpful for parents as well as professionals. Important features include providing multisensory learning, providing external support of executive function, use of mild-moderate tone of voice, use of proximity in communication, and providing time-off space.

Functional analysis is frequently used in the academic setting as a basis for intervention planning, but it can also be adapted to the home environment. In this model, the first step is to determine the underlying cause of the child's emotional or behavioral response that represents a skill deficit. The next step is to tap into areas of strength that can be used as a foundation for building the skill or using compensatory strategies.

An example of how the functional analysis method can be adapted for use with AS youth is outlined in Appendix 1 of the previous edition of this book (Wagner & McGrady, 2003). It is used to ascertain skill level in the social, cognitive, and behavioral domains and provides a comprehensive assessment of skills in each of these areas. Again, while was designed for use by school personnel, it could easily be adapted by other consultants and taught to parents for use in the home.

Many well-established programs combine elements of behavioral and developmental orientations (TEACCH: Marcus, Schopler, & Lord, 2000; Walden Program: McGee, Morrier, & Daly, 2000). Some have specifically evaluated the effectiveness of the parent-training components of their programs. Parent-training models that are promising based on evidence provided by their developers include the LEAP Program (Strain & Cordisco, 1994), the Denver Model (Rogers et al., 2000), the Individualized Support Program at the University of South Florida (Dunlap & Fox, 1999) and the Pivotal Response Training Model (Koegel, Koegel, Harrower, &

Carter, 1999), and the Douglas Developmental Center Program (Harris, Handelman, Arnold, & Gordon, 2000). Whatever the theoretical underpinning, well-established and effective programs always include an emphasis on the parent-child relationships and overall family support (Dawson & Osterling, 1997). Furthermore, there is evidence that parents can learn to employ these methods and that doing so helps them feel better in general and more satisfied and confident in their parenting role (Koegel, Koegel, Kellegrew, & Mullen, 1996; Ozonoff & Cathcart, 1998; Schreibman, 1997; Sofronoff & Farbotko, 2002).

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Early Intervention for Children/Youth with Asperger Syndrome

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The terms “early intervention” and “Asperger syndrome (AS)” are not typically strung together as is the case for “early intervention and autism.” For example, a literature search using the terms early intervention and AS conducted across four major psychological and medical search engines (i.e., PsycINFO, Pubmed, Medline, Eric) in 2011 found a total of 76 citations. This means that only 76 articles used the terms early intervention and Asperger syndrome together in the article or book chapter. This number is in stark contrast to the 2,543 citations found by using the search terms early intervention and autism in the same health search engines over the same time period. The limited research found for early intervention and AS is most likely due to the fact that AS is recognized and diagnosed at a significantly older age compared to autism. A common interpretation of the term early intervention is the application of programs or services for children under the age of 5. In fact, “early” is now being known as interventions addressing the needs of infants and toddlers, specifically children under the age of 3 years. This reference to very young children is in response to the decrease in age in diagnosing classic autism. Autism is reliably diagnosed at 2 years of age (Palomo, Belinchón, & Ozonoff, 2006), and more recently, a number of studies have reported reliable diagnostic assessment measures used in infancy with the ability to diagnose infants after 9 months of age (Ozonoff et al., 2010). AS, on the other hand, has been found to be reliably diagnosed at 4–5 years of age, at the earliest, in controlled research studies (Mandell et al., 2010) but is more often diagnosed between 7 and 9 years of age within community service systems (Mandell et al., 2009; Shattuck et al., 2009). Many other studies have even reported first diagnoses of AS occurring in adolescents or even adulthood after previous alternative diagnoses (Tantam, 2003). Therefore, children with AS often have missed the so-called early intervention period when they become diagnosed and thus the term is not typically used.

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It is also interesting to describe what was found as the existent literature on early intervention and AS was further scrutinized. It was discovered that the literature on early interventions for AS is even more sparse than the query above mentioned as only about 20 of the original 76 publications actually described AS, or even high-functioning autism for that matter, basically referring to a population with a number of language and social skills already developed. In fact, the majority of articles attended to the very significant communication, social, and behavioral problems present in children with autism but typically not AS. Although it may not be important to retain the term AS when describing children with an autism spectrum disorder (ASD), it is important to understand the functioning differences that often occur with these children which so often lead to their "late" diagnosis. Children with AS do not have the global communication, social, and developmental delays as children with autism. As noted in other chapters, the diagnosis of AS actually requires normal cognitive and language development. For example, children with AS develop speech production on time and often have well-developed vocabularies early. They also often demonstrate basic social skills that include eye contact, turn taking, responsive pretense, and following structured game rules. Last, they have normal to above normal intelligence and often perform well academically with or without supports.

One more observation made about the literature is that only a quarter of the 76 articles reviewed described an intervention as opposed to more generally stating the need for early intervention for ASD conditions. This lack of published information on interventions contributes to the general confusion about what, when, and how to intervene following proper AS diagnosis. Families and the service community are in need of more direction. There is, however, a clear message from the literature that is both strong and consistent, calling for intervention with all children with ASDs including AS conditions to occur as early in the developmental trajectory as possible (National Institute of Child Health & Human Development [NICHD], 2011). Intervening early has been found to not only impact skill development but also alter brain structures and neurological functioning. For example, research has found the development of new synaptic relationships and neural pathways as a result of intervention. However, the exact timing of interventions is less understood. Generally speaking, the brain has much plasticity and is able to continue to develop and change over the course of life so that intervention at any stage may be considered invaluable and "early" for that particular individual because it is preventing difficulties from continuing or intensifying over their lifespan.

Service Systems That Provide Early Interventions

Throughout the United States there is a public system for providing early intervention services under Public Law 94-142, Individuals with Disabilities Education Act (IDEA). This public law serves children from birth to age 22. IDEA part B provides services and supports for children 3–22 years diagnosed with autism or Asperger syndrome (categorized under one term "autism"), and IDEA part C, the Early Intervention Program for Infants and Toddlers with Disabilities, provides services and supports to children from birth to 3 years of age who are experiencing or are at risk for having a disability. Eligibility for part C varies by state but is typically based on a delay in one or more areas of development (i.e., communication, social/emotional, cognitive). Services under part B are typically provided by the school district and often vary for children 3–5 years compared to 5–22. (Note: the youth is supported until he/she graduates high school or reaches the age limit). Children birth to 3 may be provided services under the auspices of the education system, the mental health system, the health and human service agency, and/or the developmental disability agency. States are allowed their own discretion in establishing their service systems per the federal guidelines. Service types, intensity, and amounts vary greatly from state to state and even city by city, especially during the early years (i.e., from birth to 5 years of age) (Stahmer & Mandell, 2007). All states are required to provide an Individual Family Service Plan (IFSP) for each child under the age of 3 which specifies the child's goals and the services needed to reach those goals, including family-centered services. Once the child turns 3, the states are required to provide services through the educational system if the child meets eligibility criteria for special education. According to IDEA, the defined "autism" category includes all ASD conditions: autism, Asperger syndrome, and pervasive developmental disorder not otherwise specified (PDD-NOS). After it is determined that the child qualifies as "autism condition" (or any other qualifying condition), the state is required to provide an Individual Education Plan (IEP) and a free and appropriate public education (FAPE). To provide FAPE to a child with an ASD, schools must provide students with an education, including specialized instruction and related services, which prepare the child for further education, employment, and independent living. The IEP defines the goals, specialized instruction, and related services and placement needed to reach the goals. Federal regulations do not offer any specific guidelines for providing interventions specific to ASDs nor do they determine what constitutes as early interventions. This flexibility in the law may be considered good news as it relates to AS because it does not place any age limits or intervention constraints. For example, if a child is diagnosed with AS after the age of 5 and did not receive early intervention services as defined by part C and part B (during preschool years), he/she may still receive intervention services at the time of diagnosis whatever the age or grade of the child. Further, the purpose of the IEP is for the team to develop goals that address the needs of the whole child from a broad developmental perspective and not have just a narrow academic focus. Remember that the IDEA's definition includes promoting success in education, employment, and independent living which is particularly important for children with AS because they often perform well academically but have many delays in cognitive executive functioning, social-emotional functioning, and communication skills that are needed to be successful in adult life.

Brief Review of Early Intervention Treatments for Autism

Most early intervention programs for children with autism involve intensive behavioral treatment ($\geq$20 h a week). Behavioral treatments use principles of operant conditioning, otherwise described as applied behavior analysis (ABA), to help children progress from learning basic skills (e.g., sitting in chair, using eye contact, or following directives) toward more complex skills (e.g., engaging in play, initiating a conversation, or responding to a social overture). Another set of interventions, used in early childhood, follows a developmental relationship-based model (Odom, Boyd, Hall, & Hume, 2010). While there are numerous interventions found to be effective for children with ASDs based on extensive reviews of the literature (Young, Corea, Kimani, & Mandell, 2010), there is no intervention that has been identified to address the needs of all children with AS because of the large variation in skills related to the condition. However, there are a number of comprehensive treatment programs that have been developed for children with autism (see Odom, Boyd et al., 2010 for a thorough review). It is important to note that the majority of these comprehensive treatments have been established for and tested on young children (<6 years) with classic autism. Specific examples of comprehensive intervention programs include the Lovaas model/Discrete Trial Training (DTT; Cohen, Amerine-Dickens, & Smith, 2006); Pivotal Response Treatment (PRT; Koegel & Koegel, 2006); Learning Experiences – An Alternative Program for Preschoolers and Parents (LEAP; Hoyson, Jamieson, & Strain, 1984); Walden model (McGee, Morrier, & Daly, 1999); Denver model (Rogers et al., 2006); Developmental Individual Difference Relationship-based model (DIR/Floortime; Solomon, Necheles, Ferch, & Bruckman, 2007); Relationship Development Intervention (RDI; Gutstein, Burgess, & Montfort, 2007); Responsive Teaching (Mahoney & Perales, 2005); Social Communication, Emotional Regulation, Transactional Supports model (SCERTS; Prizant, Wetherby, Rubin, Laurent, & Rydell, 2006); and Treatment and Education of Autistic and Related Communication Handicapped Children (TEACCH; Panerai, Ferrante, & Zingale, 2002).

There are also a couple dozen focused intervention practices that have been identified as evidence-based for children and youth with ASDs. The interventions have been described as either behavioral teaching strategies (i.e., prompting, reinforcement, task analysis and chaining, peer-mediated instruction) or positive behavior support (i.e., functional behavior assessment, differential reinforcement, self-management, social skills training group) used to reduce or eliminate interfering behaviors (e.g., disruptive behaviors, repetitive behaviors) and increase skills (comprehensive review by Odom, Collet-Klingenberg, Rogers, & Hatton, 2010). As there is little information about which treatments are best for whom, there is a growing consensus regarding key characteristics of effective interventions put forth by the National Research Council [NRC] (2001). NRC recommends to provide services as early as possible and to include (1) systemically planned and developmentally appropriate services targeting individually developed goals for at least 25 h per week, 12 months per year; (2) goals must be measurable, observable, and monitored; and (3) interventions should emphasize cognitive development, social skill instruction, functional communication, and play skills. Using a guideline approach to interventions allows for youth with AS to be provided services tailored to their unique needs that often differ from their autism counterparts. In fact, the majority of youth with AS have the need for interventions that target skills beyond those addressed in direct ABA, relationship-based, or even eclectic (combinations of various behavioral-based strategies) treatments as mentioned above. That is because individuals with AS have developed basic and even complex communication and social skills through typical mechanisms in their environment (i.e., modeling from others, parent or teacher guidance, children stories, etc.). These basic communication and social skills learned at a young age, and then later lack of more complex skills, are often what contributes to the diagnosis occurring at a latency age. Thus, exclusively using ABA or relationship-based programs may not be the best fit for individuals with AS. Instead, individuals with AS are often in need of interventions that focus more heavily on advanced social, emotional, and cognitive skills using strategies from social-emotional interventions, cognitive-behavioral therapy, and cognitive executive functioning training.

Theories Describing Core Differences of Individuals with AS

Since the diagnosis of AS according to the Diagnostic and Statistical Manual of Mental Disorders Fourth Edition, Text Revision (American Psychiatric Association [APA], 2000) requires that the child began speaking on time and has an average or above intelligence (measured through cognitive assessment and determined by an Intelligence Quotient (IQ) score), the targets of early intervention are often more highly focused on cognitive and social-emotional skills. There are a number of theories to date that have been developed to explain such cognitive and social-emotional differences that range from brain structure variances to social learning absences to environmental contributions. To discuss each of these theories is beyond the scope of this chapter; however, a few will be briefly presented to provide some background for the discussion of the specific intervention targets for individuals with AS presented later in this chapter.

Empathizing-Systemizing (E-S) Theory

The Empathizing-Systemizing (E-S) theory grew from the original “mind-blindness” theory or Theory of Mind (ToM) developed in the 1980s and 1990s to describe the social and communication difficulties in autism spectrum disorders (Baron-Cohen, 2009). Such cognitive theories allow for a better understanding of the numerous behavioral features that are observed in AS individuals. Theory of Mind (ToM) is defined as an ability to ascribe mental states (thoughts and feelings) of oneself and of others and develops automatically by 4 years of age in typically developing individuals (Perner, 1991). When an individual mentalizes or “mind-reads,” it is in order to make sense of another person’s behavior (e.g., Why did they do that?); to clearly understand their intention, meaning, or purpose (e.g., He said that to me because he is jealous of my new computer. She knows that I didn’t finish my homework because she saw my backpack); and to predict what the person might do next (e.g., She is going to remove my computer because she knows I didn’t finish my homework). However, ToM did not account for other important deficits occurring in individuals with AS which are in need of intervention, specifically, *cognitive skills* such as inflexibility, narrow interests and perseverations, attention to detail with deficits in understanding gist (main points), and *emotional skills* related to empathy and emotion management (Baron-Cohen, 2009). The E-S theory includes the original ToM and expands it further. E-S also includes a conceptual understanding of the cognitive and emotional deficits termed together as "empathizing" but also includes the strengths of individuals with AS that includes "systemizing." It presents these traits as dimensional and recognizes there are different degrees of ASDs and how some skills can blend seamlessly into the general population (Baron-Cohen, 2009). To briefly summarize Baron-Cohen *systemizing* is the drive to analyze or construct "systems" which are rule-governed and predictable (examples of systems include collectible systems, mechanical systems, numerical systems, natural systems, and motoric systems). An individual systemizes by noting regularities (or structure) and rules and defining the cause-and-effect relationships (e.g., if b, then c). This drive is hypothesized to be related to the narrow interests, repetitive actions, apparent need for routines/sameness, and cognitive inflexibility that is demonstrated so frequently in youth with AS. *Empathizing* and "empathy" include much more than responding to others with care and concern. Empathy involves the cognitive components described as ToM of perspective taking, hypothesizing, and social-emotional cognitions (understanding what someone else is thinking, especially when it is different from one's own thinking). It also involves emotional components of being able to recognize and identify feelings in self and others, being able to communicate and describe feelings, and being able to experience others' feelings (feel the feeling someone else does after understanding their situation and emotion(s)).

Emotional or Social Intelligence Theory

Another theory briefly described here is emotional intelligence (EI) or sometimes described as social intelligence (SI) which has some overlap with E-S theory but has only more recently been discussed with ASD populations. EI was developed originally with a general population in mind and was first termed in a prominent book by Daniel Goleman (1995). He described three main areas of EI which include (1) emotional skills, (2) cognitive skills, and (3) behavior skills.

Emotional intelligence: key ingredients to social-emotional skills (Goleman, 1995)

Emotional skills	Cognitive skills	Behavior skills
Identifying and labeling feelings	Self-talk, an inner dialogue to cope and reinforce self	Nonverbal – communicating through eye contact, facial expressiveness, tone of voice, gestures, etc.
Expressing feelings	Reading and interpreting social cues including recognizing social influences on behavior and seeing oneself in the perspective of the larger community	Verbal – making clear requests, responding effectively to criticism, resisting negative influences, listening to others, helping others, participating in positive peer groups

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Emotional intelligence: key ingredients to social-emotional skills (Goleman, 1995)

Emotional skills	Cognitive skills	Behavior skills
Assessing the intensity of feelings Managing feelings	Using steps for problem-solving and decision-making as means to control impulses, with steps including setting goals, identifying alternative actions, and anticipating consequences	
Delaying gratification	Understanding the perspective of others	
Controlling impulses	Understanding behavioral norms as what is and is not acceptable within society viewpoint	
Reducing stress	A positive attitude toward life, optimistic viewpoint	
Knowing the difference between feelings and actions	Self-awareness and being able to develop realistic expectations about oneself	

Delays in such social-emotional skills are commonly observed in youth with AS. In fact, lack of social-emotional skills has been argued as the most defining feature of youth with AS and in need of much intervention early on.

Metacognitive and Executive Functioning Theories

Generally speaking metacognition is described as “thinking about thinking” or as the ability to be aware and in control of one’s own cognitions. It is most typically defined as encompassing two broad areas: (1) knowledge of and (2) regulation of cognitive activity (Moses & Baird, 1999). Wellman (1985) suggested that metacognition involves five overlapping categories – four of knowledge and the last of regulation. Table below defines each.

Metacognitive abilities (Wellman, 1985)
Existence: *knowledge that mental states exist*. This is the ability to distinguish between internal (mental) and external (physiological) states or phenomena
Distinct processes: *knowledge that there are distinct mental processes* (*e.g.*, *guessing*, *knowing*, *dreaming*). This is the ability to separate fact from fiction, reality from fantasy, desires from beliefs
Integration: *knowledge that these distinct processes are similar in kind as well as interactive and each is a function of a unitary cognitive ability of the mind*. This is the ability to understand that there are many aspects to cognitions that result in many different types of thinking
Variables: *knowledge that acts of cognition are influenced by a number of variables* (*e.g.*, *age or ability of a person*, *number of items to be remembered*, *mood/feelings*). This is the ability to understand that cognitions are going to be subjected to contextual factors and may be person based or situation based

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Metacognitive abilities (Wellman, 1985)
Cognitive Monitoring: *having the ability to assess one's own cognitive system and to utilize that information to direct behavior*. This is the ability to be aware of and understand one's own cognitive abilities (strengths and challenges) and then act accordingly (i.e., use memorization strategies if aware of having a poor memory for lists of information or use inquiry if aware of having a poor knowledge of beliefs)

It has been observed widely that individuals with AS demonstrate much difficulty utilizing metacognitions (thinking about their own thinking and thinking about others' thinking). It has been suggested that a core deficit of AS is the profound unawareness of their own affects and thoughts and those of others (often described as ToM).

Metacognition is also closely related to executive functioning which involves the abilities to monitor and control the information processing necessary to produce a voluntary action. Many have postulated that individuals with AS have impaired executive functioning. Executive functioning is an umbrella term for the complex cognitive processes that serve ongoing goal-directed behaviors. Most definitions include the following abilities: goal setting and planning; organization of behaviors over time; flexibility, attention, and memory systems that guide these processes; and self-regulatory processes such as self-monitoring and self-control. The result of impaired executive functioning suggests that individuals with AS will have difficulty generating and using strategies to aid in cognitive performance such as those abilities classified under "cognitive monitoring" defined above. Despite these strong conceptual similarities, often the research and discussions of metacognitions and executive functioning occur in independent literatures. A shared arena for the two is neuroscience, the study of brain structures and functions (neurobiology being responsible for cognitive processes).

Neuroscience and Neurological Functioning Theories

Neuroscience is primarily focused on studying the brain structures that are associated with cognitive and behavioral functioning. Research in this field is conducted using brain imagining technologies while an individual performs a specific task in order to link cognitive control processes to neural circuits or specific brain structures. Functional neuroimaging studies have identified key areas of the "social brain" and theorize that lowered activation in these social brain areas, which include the medial prefrontal cortex, temporal parietal junction, anterior cingulate, insula, and amygdala, is responsible for the diminished social/emotional intelligence and poor mind-reading abilities in the brains of individuals with ASDs (Frith & Frith, 2003). Other studies have found that individuals with ASDs demonstrate patterns of brain activity that are consistent with specific cognitions such as feature based, as opposed to holistic (coherence type) processing (Schultz et al., 2000). Executive functioning deficits have been linked to frontal lobe inactivity or diminished activity. Specific areas implicated for executive or metacognitive control include the anterior cingulate and supplementary motor area, the orbitofrontal cortex, the dorsolateral prefrontal cortex, and portions of the basal ganglia and the thalamus, all of which have been found to differ in individuals with ASDs. Neuroimaging studies are continuing at a rapid rate and provide a level of biological confirmation of such cognitive, social-emotional, and behavioral differences between those with AS and those without.

Taken together, these various theories provide explanations for a number of the shared deficits observed in youth with AS that should be a focus of intervention. Each also attends to a dimensional approach to underdeveloped abilities, such that a skill lies on a continuum with one end being a strength and the opposite end being a challenge area, rather than a categorical approach (have a skill or don't have it). Following a continuum approach early intervention should be systematically improving any skills falling on the deficit end so that there is progression along the scale. It also suggests that all brain functions have the capacity to grow and develop so that intervention at any time is critical.

Early Intervention Targets for Youth with AS

Based on the above theories, a proposal is made to view early intervention for AS differently from the previously discussed services approach for autism. The services approach characterizes early intervention predominantly as the age that intervention is started (i.e., <5 years). We argue that early should not refer primarily to the age of the child but rather refer to "early skills." Early skills are defined as precursors or pivotal to the development of other broader abilities and are specifically related to the core deficits of AS. More explicitly we suggest describing these core, cross-cutting skills as early intervention targets because they impact a youth's ability to further develop broader skills within the cognitive, social, and communication domains. These core skills are *self-awareness*, *cognitive flexibility*, *metacognitions*, and *social-emotional intelligence* (which include empathy, social cognitions, and social communication). Each of these is described further with some specific examples of how these core skill deficits can impact the cognitive, social, or communicative functioning of individuals with AS, acting as a prerequisite to many other functioning domains. For example, the early target metacognitive skill is discussed in regard to interventions for development within the cognitive and communication domains.

At our treatment center, the Intricate Mind Institute (IMI) in San Diego, California, we have developed a set of curriculums (pulling from existent interventions for ASD and/or other conditions) to further develop these target skills. The curriculums involve strategies and exercises. We present these as exercises to the youth with AS and explain that because their brains process information differently, it is important for them to build up their brains in some areas that may be a bit weaker and thus "train their brain." We use an example similar to training their muscles to become better at a sport or activity. We emphasize the need to practice frequently in order to develop the ability. The following sections provide a description of the target skills we recognize as core skills to be learned early and a few examples of specific strategies or exercises to increase each skill. We have found that the methods described in each section can be used with children to adults with AS.

Self-Awareness

Self-awareness is the ability to understand and appreciate oneself, being aware of one's strengths and challenges, and being able to notice and identify one's thoughts, feelings, and actions at any given time in any given situation. Sometimes the term "mindfulness" is used. Self-awareness can be considered a precursor to developing a sense of self that includes self-esteem and self-concept. Establishing a positive self-concept is extremely important because positive self-views act as a buffer against negative emotional states such as anxiety and depression. Having a high self-esteem is also associated with more social abilities and higher quality friendships and social relationships.

Individuals with a deficit in self-awareness often are impaired in self-objective understanding. Such challenges can be observed as the difficulty of smooth, integrative movements and speaking, the difficulty in conveying physical or mood states, impairments in expressing feelings intentionally, and the diminished ability to self-evaluate. These deficits in awareness are also strongly reflected in an individual's own intentions, represented by the individual's perception that his/her actions are caused by external forces rather than internal forces as "will" that are in their control.

How Is Self-Awareness Defined in AS?

Understanding oneself is equally important but possibly more complex when an individual has AS. This is the case because of the splintering of abilities and the potentially large disconnect between thoughts, feelings, and actions, reflective of the neurodevelopmental differences. Too often the youth with AS feels different but is unaware of how he/she is different. Other times they have learned they are different by the label that is used to describe them (i.e., I have Asperger syndrome) but unknowing of what the condition entails. Stephen Shore (2003), an adult with ASD writes, "I came to understand that the autism spectrum is, and always will be, a part of me. All I can do is learn better how to work *with*, rather than against, the traits of this differently ordered way of being."

However, an individual can only truly understand social-emotional experiences if they understand themselves, how they think, how they feel, how they act, and how these are all interconnected within themselves. This understanding of self should be viewed as a myriad of parts that all contribute to the whole person. Some of these parts are strengths and positive abilities, and some of these parts are challenges and in need of development or change. These parts should include the broad domain areas of metacognitions/executive functioning differences, the social/emotional differences, and communication differences.

Understanding AS: *Skill-Building Strategies-Exercises*: Start this self-discovery journey for the youth with AS with a thorough description of what AS is and the known differences between the AS and non-AS brains in terms of processing information, cognitions, emotions, social concepts, etc. We have expanded the list originally published by Juanita Lovett (Solutions for Adults with AS; Lovett, 2005) to use to assist in this explanation. See Appendix Table 1. This information should be presented factually but not judgmentally. Although the differences are presented in table format suggesting categorical differences, it is explained that each is dimensional and that individuals should have the abilities to move across the continuum in a dynamic fashion, flexibly applying a skill from either end or in combination purposely for the situation (symbolized by the arrow). All ways of thinking, feeling, and acting are important and valued, just starting at different points in development and allowing for an ebb- or flow-type usage. Viewing of informational videos as those published by Coulter videos (www.coultervideo.com) or books written as self-awareness stories (Asperger's Huh?; Can I Tell You About Asperger Syndrome; All Cats Have Asperger Syndrome; or I Am Utterly Unique) can also be of great value. Next, we discuss as many other individuals with AS as possible specifically including famous folks (i.e., Albert Einstein, Thomas Jefferson, Wolfgang Mozart, etc.), local folks, and own family and friends to adjust for the deficit-based interpretation the youth may be placing on themselves during this self-awareness process. Remember that each youth goes through this first step of understanding AS and applying it to themselves at their own pace ranging from minutes, to hours, to days, to weeks, to months, to years. Our experience is that the earlier and more positively it is discussed, the faster the acceptance and appreciation occurs. Each child will often develop their own description of their condition. As one youth with AS explained to me as he/she was going through this self-awareness process, "AS is a mental upgrade with side effects." What a wonderful self-affirming acknowledgment of his difference. It is critical that the individual accepts and appreciates who they are and/or who they want to become. We all need a strong sense of self. After a sense of appreciation is established, then a detailed self-dissection can occur.

Self-Identification of Strengths and Challenges Strategies-Exercises: As discussed, a positive self-concept is a core precursor to learning and development. Specifically the ability to grow and overcome challenges stems from being open to honest, nonjudgmental feedback. The ability to hear and comprehend this type of feedback is based on an ability to understand that oneself is made up of multiple parts, those that are positives or strengths and those that are negative or challenges (in need of change). An established sense of self must include an overall positive viewpoint in order to allow for consideration of fault and welcome (or at least withstand) constructive criticism or feedback. The motivation in each of us to change or overcome our own personal challenges comes from the willingness to identify those challenges and be open to learning and improve. This applies to all youth with AS or without; however, those with AS need assistance in defining themselves as having "parts" – both strengths and challenges. We use visual diagrams to train this way of "part" thinking. We draw diagrams of their brains, demonstrating through color coding and variations in size, areas that are "activated" or "large" as strengths (i.e., occipital lobe for visual processing) and other areas that are challenges visually presented with a reduced size and/or "less activated" color (i.e., frontal lobe for executive functioning). We also help them make concrete representations based on their own interests utilizing visual communication mechanisms (i.e., PowerPoint presentation, story, illustration, or collages) to convey their own parts including strengths and challenges in regard to numerous domains (cognitions, emotions and actions/abilities, etc.). It is clearly and continuously noted that challenge areas can be overcome or changed just as “side effects” can be treated or addressed. Once a youth is able to understand himself/herself fully then the next step is to develop self-directed goals and use self-advocacy to communicate his/her needs to others. We assist the youth in this process and directly link strategies or exercises to use to reach their goals. For example, a 7-year-old girl learned about her AS and said “Now I know why I don’t have friends; my friends need to know about my AS too,” illustrating a goal and a self-advocacy strategy (to inform her friends about AS). We helped her do this using the Coulter video entitled “Intricate Minds II.” One additional psychoeducational component we use with the youth is called establishing a “balance” or “Yin-Yang.” Balance is discussed in regard to themselves (not allowing the challenge areas to be out of balance – too many to tip the scale). Balance is also discussed in regard to self-advocacy and addressing their needs through the terms of “adaptable” and “flexible.” Adaptable is described as when their need can be addressed by the environment changing, also typically called an accommodation. Flexible is described as when their need is addressed by changing themselves. An example of the environment being adaptable is when someone turns down the volume on the radio because of the child’s auditory sensitivity. An example of a child being flexible is when the child wears earplugs to a school pep rally because of their auditory sensitivity.

Cognitive Skills

Cognition in basic terms refers to the way one thinks, learns, imagines, and remembers things. It has been identified that individuals with AS have different cognitive styles or abilities and therefore, think and process information differently. Often, cognitive skills are referred to as executive functioning. As stated in a book by Dr. Juanita Lovett (Solutions for Adults with AS; Lovett, 2005) there are a number of executive functioning skills that are required for success in life. These include (1) having cognitive flexibility, (2) recognizing what is relevant to the situation, (3) learning from experience, (4) holding in mind and using rules appropriate to the situation, (5) holding a goal in mind at all times, and (6) identifying and executing each step needed to reach a goal. Individuals with AS have been described as deficient in most if not all executive functioning skills (Hill, 2004). Two particular core skill sets appear to be the foundation to many other executive functioning skills: (1) cognitive flexibility and (2) metacognitions. In our experience the inability of youth with AS to use various cognitive flexibility techniques such as gist construction, attention shifting, or generating multiple responses inhibits them from applying other executive functioning tasks related to organizing and problem-solving. We also noticed that youth with AS don’t appear to utilize a metacognitive style of thinking which negatively impacts their ability to stop and think, learn from past experiences, and other related executive functioning tasks.

How Do We Define Cognitive Flexibility?

Individuals with AS often need to develop an ability to think more flexibly. Thinking flexibly is the ability to attend to and process information in multiple ways, ranging from the concrete detail to the abstract main point and shifting from one to the other. It is also the ability to manipulate information in order to generate multiple responses to the same stimuli (perseverations are often described as the opposite – getting stuck on one response). Thinking flexibly also requires an understanding and ability to identify the relevant cues or pieces of information and attend to those more closely but also attend in a cursory fashion to other less relevant contextual information and having an overall ability to know which information should be weighted more heavily or contribute more. Additionally, it requires the ability to think in a dimensional fashion and not just categorical (often described as "black or white" thinking); categorical thinking is considered an oversimplified way of thinking.

Some have described cognitive flexibility as the ability to attention shift and set shift. Attention shift often refers to what cues the individual is actually attending to, and set shift refers to what level or classification the person is using (i.e., detail or main point) while attending. We refer to this level or classification of attention in a common saying "the ability to see the forest through the trees" or in reverse "the ability to see the trees in the forest." Although individuals with AS appear to have tremendous strengths in processing and recalling details (seeing the trees), they often lack a natural ability to generate the gist, main point, or big picture (seeing the forest) (Jolliffe & Baron-Cohen, 2001; Mottron, Burack, Larocci, Belleville, & Enns, 2003; O'Riordan, Plaisted, Driver, & Baron-Cohen, 2001). Therefore, gist construction is a necessary early intervention core skill. This can be more clearly stated as specifically teaching youth with AS how to create the gist, main point, coherence, or global overview of information or inputs. They need to learn how to "lump" information together and not always "split" it as a good systemizer would do (this lack of constructing the main point or lumping information has also been described as a weak central coherence by Frith (1989)). Remember that a systemizer is using a scientific method to understanding the world by looking for exact connections and key differences (details) that enable the prediction of how two things are related or associated (linked) together. However, unless an individual is able to construct the gist or general category of how things go together to form a shared feature, there will be a lack of generalization or application of learned information to other contexts. It has also been found that memory for details is limited compared to gist and gist memory maintains over the course of development while detailed memory declines as one ages (Reyna, 2008).

Gist Construction Strategies-Exercises: Interventions to increase this ability should be based on a youth's with AS already developed cognitive skills in pattern detection. Pattern detection is described as a process of searching and finding associations or linkages of pieces of information or inputs. Youth with AS often display this ability when they talk about something that appears to be off-topic. For example, a parent says “I like your shirt that color blue looks good on you” and the youth responds “I like to fly kites.” The youth is linking the color blue of the shirt to the sky and the sky to flying kites. Unfortunately these linkages are made at a very detailed level quickly (color to sky) and often miss other relevant information (i.e., “I like” and “looks good” which means the main point of the statement was to give a compliment). These abilities need to be expanded to include (1) identifying many details (to be sure to include those that are relevant) and (2) grouping the information or classifying it in a way that allows for broader labels to describe the shared features across the details. This is the step toward abstract thinking, thinking above and beyond the exact observable input. We use visual diagrams to assist the individual with AS in constructing this broader understanding or main point of the information provided. A diagram example is shown in the Appendix Box 1.

Following a scientific approach is also useful for individuals with AS to develop the ability to form higher level abstract or gist understandings. Specifically the youth with AS is guided to (1) gather data, (2) find linkages or patterns of the information and form a hypothesis, (3) design a way to test the hypothesis, (4) draw conclusions from the results, and (5) combine these findings with previously learned or researched information from different contexts to generate a theory. This scientific method matches their existent way of “systemizing” or detailed-focused thinking but also expands it to developing an ability to think more broadly. Theories are described as more coherent, global understandings. The importance of developing theories is explained as necessary for remembering the information and for applying it to multiple contexts (eliminating the need for repeated hypothesis testing). Once a youth has developed a stronger ability to think both in a detailed and gist fashion, he/she can be more cognitively flexible, adjusting his/her way of thinking to the situation (i.e., performing well in spelling, utilizing a detailed way of thinking; writing a book report by conveying coherent main points about the text).

Attention-Shifting Strategies-Exercises: Attention-shifting exercises involve having a youth with AS practice using attention to detail processing and then alternating that with attention to gist processing. We have found using a series of books by Walter Wick, “Can you see what I see?” is a useful mechanism. These books encourage the reader to think flexibly by switching their attention from finding hidden pictures to understanding the broader meaning of the picture and tracking the meaning from page to page to understanding the final conclusion of the book. The books come in different levels (from preschool to ones young adults enjoy). With practice, the youth learn how to switch their way of thinking back and forth frequently between details (necessary for finding the hidden pictures) to global understandings (required to tell the main point of the page or draw conclusions about the story). We then have them apply these attention-shifting skills within conversations to be able to think about both the details of what someone is conveying and construct the main point of the message. We remind them that they need to practice and apply these cognitive flexibility skills frequently. It is interesting to observe and hear comments from the youth with AS about the interest and ease they have in detailed thinking like in finding the hidden picture and their corresponding frustration and struggles they experience in generating the main point(s) of conversations or books/stories.

Generate Multiple Responses Strategies-Exercises: Youth with AS often initially lack the ability to think about something in multiple or divergent ways. They tend to produce and perseverate on only one option/response at a time. This way of thinking, unfortunately, is simplistic and limiting. We teach the youth with AS a rule that every issue or situation requires three responses/options/solutions. Generating multiple options, responses, and solutions is practiced through scenario flashcards and then applied to real-life scenarios. For example, a youth needs to give three options to the following scenario, "what would you do if you can't find your favorite shoes?" and indicate a plan A, plan B, and plan C. We require they state initially out loud each of the three responses to all real-life discussions throughout the session(s) and later have them internalize this way of thinking.

Identifying Relevant Cues Strategies-Exercises: Teaching skills for attending to relevant cues requires providing the youth with a visual representation of what "cues" are and a conceptual understanding of what the terms relevant and irrelevant mean. We do this by creating visual stories that are familiar and unfamiliar to them and construct them in such a way that each piece of information of the story (e.g., characters, context, scene) is a separate individual picture. Basically, we take the picture in the story book and cut it up so that each cue is its own stand-alone picture. We also purposely add in some pictures of cues that did not belong in the original story. We start with a familiar story and ask the child to recite the story in their own words and then put in one pile all the pictures they think are important to telling the story and all the pictures that are not important to telling the story in another pile (separating out the relevant and irrelevant cues). Each picture in each pile is reviewed and discussed why it was or was not relevant. This is repeated for familiar stories until mastered. Next, we present an unfamiliar story by telling the child the story verbally and then having the child sort the pictures. Last, this recognition of relevant and irrelevant cues is applied to real-world scenarios.

Dimensional Thinking Strategies-Exercises: Dimensional thinking refers to defining concepts along a continuum and NOT using black or white categorical thinking. Again we use visual diagrams to support the development of this flexible way of thinking. We create continuum diagrams and put the categorical way of thinking on each end of the continuum and then work with the youth with AS in populating the numerous middle lines. For example, we will put opposite words such as love and hate, friend and enemy, like and dislike, or even black and white on the ends and then take turns populating the middle sections demonstrating that there is a way to think dimensionally about many things.

How Do We Define Metacognitions?

Metacognitive skills are most simply described as the ability to "think about thinking" or "knowing about knowing" as described previously. Flavell (1976) first used the term "metacognition" and described it as one's knowledge concerning one's own cognitive processes or anything related to them. Metacognition can be defined in different ways but commonly refers to the study of memory monitoring and self-regulation, meta-reasoning, consciousness/awareness, and auto-consciousness/self-awareness. Metacognition refers to a level of thinking that involves active control over the process of thinking that is used in learning situations. Planning the way to approach a learning task, monitoring comprehension, and evaluating the progress toward the completion of a task are all metacognitive in their nature. Similarly, maintaining motivation to see a task to completion is also a metacognitive skill. The ability to become aware of distracting stimuli – both internal and external – and sustain effort over time also involves metacognition. As stated in the paragraph on metacognitive theory, metacognition involves two major components: knowledge of cognition and regulation of cognition. Knowledge of cognition "describes an individual's awareness of cognition at three different levels: declarative (knowing about things), procedural (knowing about how to do things), and conditional (knowing why and when to do things)" (Cooper & Sandi-Urena, 2009, p. 240). Regulation of cognition refers to the ability to monitor or change one's thoughts after being aware of them. Individuals with AS do not appear to naturally use metacognitions and thus are unaware of their own thoughts, feelings, or even actions. A youth with AS might say, "I don't know why I did that," because he/she has not thought about his/her thoughts involved in his/her decision-making. Youth with AS often demonstrate a number of the indicators that suggest a diminished metacognition (see Appendix Table 2 for list of poor metacognitive skills).

Metacognition – Knowledge of Cognition Strategies-Exercises: Strategies for promoting knowledge of cognition include teaching a youth with AS to think aloud. This means being able to identify and state their own "self-talk" and inner voice (i.e., what their mind is thinking and saying to itself). We start by modeling this with simple games that require problem-solving like Tower of Hanoi or Master Mind type games. We then request the youth with AS to vocalize out loud all of their thoughts in playing. These vocalizations of their thoughts in solving the tasks are later transitioned to occur internally after mastery is observed. Thinking about thinking progresses into a process of self-reflection and self-monitoring. Understanding their own thoughts is also critical in helping them be fully aware of when they are thinking about fantasy compared to reality (a common characteristic of youth with AS is to think and comment about fantasy during real-world situations). Tony Attwood (2008) has described fantasy thinking as a coping mechanism to escape from difficult situations. Fantasy thinking is also likely related to a general lack of awareness of own thoughts and thinking processes (not knowing when leakage occurs and their vivid imagination is being combined with real situations). We teach them to identify what they are thinking and label it (real or fantasy). We also teach them to become aware of thinking by using self-questioning (e.g., Am I in my fantasy world? What do I already know about this topic? How have I solved problems like this before?). Other strategies we use include teaching the youth to make linkages or associations of new information to previously learned information or existing thoughts. The youth are requested to make graphic representations (e.g., concept maps, flow charts, semantic webs) of their own thoughts and knowledge and establish links across the information. We teach a rubric of step 1. Link a meaning to a decision, step 2. Link a decision to an action and step 3. Describe the meaning of the action based on the linked decisions. Once youth with AS learn how to apply these metacognitive strategies to themselves, they are more conscientious and often display a greater ability to inhibit or control impulses. Additionally, after a youth is able to use metacognitive skills to understand their own thoughts, they can begin to infer how others think and use perspective taking more readily. Metacognitive skills are also necessary prerequisites for organizational and planning activities, both of which are core executive functions.

Metacognition – Regulation of Cognition Strategies-Exercises: Goal-directed actions and active problem-solving are components of metacognitive skills that involve regulation of cognition. For example, expert learners apply metacognitions by constructing a goal, planning accordingly, and monitoring their own learning as they carry out their plans. Novice learners, in contrast, do not use metacognitive skills and do not construct an explicit goal, fail to plan, and often utilize only one learned strategy, which they apply without thinking about whether it is appropriate to the situation. Not surprisingly, novice learners are often disappointed in the results of their solution, while expert learners are generally satisfied with their results (and will make adjustments if not). Youth with AS frequently respond to situations or problems as novices, generating only one solution which may not be appropriate to the situation and then feel frustrated by the outcome. Although youth with AS have been found to have well-developed verbal skills, they differ greatly on standardized tasks that require constructing solutions to routine problems and challenges that occur in the home, school, and community (Griswold, Barnhill, Myles, Hagiwara, & Simpson, 2002). They should be taught cognition regulation in a mechanical fashion such as how to identify the problem, how to notice meaningful contextual factors to understand what they can and cannot control, and how to analyze the situation, determining cause/effect relationships. They also need to learn the basic steps to problem-solving which include finding an effective solution through (1) identifying the problem, (2) brainstorming options, (3) evaluating options, (4) prioritizing options, (5) choosing the best three solutions, and (6) trying them in order until a successful outcome is reached. Other aspects of regulation of cognition that we address are related to prioritizing thoughts and actions as well as time management.

Once an individual with AS is able to think more flexibly, think about thoughts, and problem-solve, then they can apply this way of thinking to learn other developmental, social-emotional, and communication skills. One might view executive functioning cognitive skills as one of the first early intervention goals in which social-emotional skills can be built upon.

Social-Emotional Skills

As we have learned from the E-S theory, individuals with AS have a strong ability to understand information and concepts that are lawful (conforming to or recognized by rules/laws). Emotions, on the other hand, are not lawful as different people can express the same emotion differently or an emotion may not be observably expressed at all. As Leslie (1987) pointed out, mental states play havoc with "truth" relations because of the lack of measurable, observable evidence and the murkiness of mental states like belief or pretense. For example, the sentence "Joey believes that John took his ball" is true if Joey believes it, regardless if John really took the ball or not. A belief can be true or false which makes this type of understanding others as "abstract" and not easily systematized through observable concrete connections. In fact being able to use "social thinking" may actually be a trade-off between empathy and systemizing ways of thinking. Since youth with AS are natural systemizers, as discussed earlier, they tend not to demonstrate age-appropriate social-emotional skills without intensive intervention. Social-emotional interventions can also be considered critical early intervention targets because social/emotional problems appear to be the most major source of difficulty as the youth with AS ages and can consequently result in co-occurring conditions of depression and anxiety (Ghaziuddin, Weidmer-Mikhail, & Ghaziuddin, 1998; Hutton, Goode, Murphy, Le Couteur, & Rutter, 2008) or even suicide (Wolff, 1995).

How Do We Define Social-Emotional Intelligence and Empathy?

As stated earlier in this chapter in the description of emotional intelligence, empathy is considered a major component of social-emotional intelligence. Empathy includes much more than the common viewpoint of showing care and concern for others. It includes the full gamut of emotional understanding from identifying feelings in oneself and others, to communicating/sharing feelings through words and expressions, to managing feelings and calming self down, to perspective taking and experiencing the feelings of others. Early development of empathy begins with building a knowledge base of feeling words and then progressing to identifying feelings in oneself and others using information from a number of cues that include both nonverbals (expressions, posture, tone of voice) and verbals (words used, contextual descriptions) and drawing an inference on the actual feeling being experienced from the contextual information. Additionally, research has found emotion perception deficits (inability to recognize emotional expressions) remain in children with autism who have completed intensive behavioral treatment programs (Downs & Smith, 2004), suggesting a need to provide specific intervention in developing empathy skills.

Social-Emotional Intelligence Strategies-Exercises: There are a number of well-established and empirically supported social-emotional curriculums available. Each is geared to develop empathy through skill-based learning and the use of strategies. Most have been implemented as school-wide prevention or interventions to reduce aggressive acts and bullying at school sites. Some specific examples are the Promoting Alternative Thinking program (PATH) program (Kusché & Greenberg, 1994) and the Second Step program (Frey, Hirschstein, & Guzzo, 2000). Both of these programs have curriculums available from preschool to high school youth. Although these were developed for the general youth population, they can be used with minor adaptations at an individual or group level for youth with AS. The major adaptation we have found necessary is to implement the staged curriculums by emotional age or functioning level and not necessarily chronological age as is suggested by the program manuals. Another program already designed for the AS population and for use at the individual level that we use are the Social Thinking curriculums by Michelle Garcia-Winner (i.e., Thinking about YOU, Thinking about ME second edition; Winner, 2007). Although the Social Thinking curriculums are not researched to the extent of other non-AS-specific social-emotional curriculums, they do provide interactive activities and worksheets geared specific to individuals with AS, and the curriculums are designed to be used in a tailored fashion to each youth. In general, the social-emotional programs share similar lesson plans that can be more narrowly described as developing a similar set of skills. The skills are the following:

(1) Emotional identification
(2) Communicating feelings and thoughts
(3) Emotional management
(4) Perspective taking
(5) Experiencing others' feelings
(6) Responding to others with care and concern
(7) Identifying problems
(8) Conflict resolution
(9) Using assertiveness

In addition to these nine core skills, we teach youth with AS to learn and attend to social conventions through the concept of the "unwritten rules of life" (a term put forth in the book Unwritten Rules of Social Relationships by Temple Grandin & Sean Barron, 2005). We expanded Grandin and Barron's original list of ten unwritten rules (aka social conventions) to many more and added a catalog system to aid a youth during their mental search for finding and applying the correct rule from memory. Examples of categories of unwritten rules are friends, family members, strangers, authority figures, school settings, home settings, community settings, work settings, general life, etc. We have them create their own lists of rules and add visual pictures or symbols to also aide in memory. For example, one youth created the following for friends: F – friends care about you and you care about them; R – respect your friends; I – ignore what is bad about your true friends; E – each day talk and play something different; N – notice what your friend likes; D – do things that make your friend happy like letting them choose activities; and S – state your feelings and ideas so your friend will understand you.

A general approach we apply to all strategies is teaching concepts visually and orally through graphics, pictures, and diagrams. We request each youth develop his/her own vocabulary and visual representations for each of the skills so that he/she is more motivated and interested in the curriculums. We also use active teaching strategies that include modeling, role-playing, filming and reviewing, and assigning homework to practice the strategies in other settings.

Communication Skills

Although the DSM-IV criteria for AS state that there is no general delay in language, as noted in other chapters, there is often a communication impairment. Specifically, pragmatic communication is impaired and interventions are needed that attend to conversational skills rather than language development skills such as articulation, vocabulary, and syntax. Conversational skills often include an ability to decipher nonliteral language, irony, idioms, and nuances as well as comprehend the speaker's intent and main points. We have found it particularly important to focus on the cognitive aspects of language displayed by youth with AS, which includes literal thinking and filtered attention (missing relevant cues necessary to infer intent and main points).

Literal-Detailed Communicative Thinking

The cognitive style of detailed thinking and lack of cognitive flexibility, as discussed previously in this chapter, plays a significant role in the conversational challenges in youth with AS. The AS brain frequently attends to the specific details of what a speaker is saying and makes literal interpretations of what is being said without applying the flexibility in thinking necessary to focus on the intent or point of what is being said and therefore missing the intended meanings behind idioms, irony, figures of speech, innuendos, etc. This lack of flexible thinking about words or phrases can lead the youth with AS to feel confused and upset during a conversation but also to react in ways unexpected by the conversational partner, possibly portraying the individual with AS as rude, stupid, naïve, or even worse oppositional.

Flexibility in Communicative Thinking Strategies-Exercises: Teaching the youth about flexibility in communication can only take place after learning the cognitive flexibility skills described earlier. We start by reminding the youth with AS about their newly learned "thinking flexibly" skills and practice how to apply it during conversations by thinking about both the details and the main points of what is said to them. We use a series of fun child books by Tedd Arnold (*Parts*, *More Parts*, and *Even More Parts*; Arnold, 1997, 2001, 2004) for communicative flexible thinking exercises. These books present a detailed, literal way of thinking in fun graphic pictures fully displaying the ridiculousness of literal thinking. The first book, *Parts*, displays how a child character uses literal thinking when someone speaks to them and when shown visually it clearly doesn't make sense to do so. The books continue in a progressive way with the same character thinking literally (visually depicting his thoughts) and getting confused by what others say as it introduces more words and phrases with inferences. We describe these to the youth with AS as words/phrases with "hidden meanings." The last book in the series (*Even More Parts*) shows pictorial representations of a large number of common idioms again showing how the literal meaning can't possibly be what is intended. After the youth with AS learns how to think that words may have either a literal or inferred meaning, we teach them how to attend to multiple cues (or we use the term "clues" to be consistent with a detective theme) to assist them in applying detective work to figure out what the inferred or hidden meaning is. We also use two other books that were written (one is geared toward children and one is more for an adult audience) that also provide illustrations to guide the understanding of metaphors and common expressions (An Asperger Dictionary of Everyday Expression; Stuart-Hamilton, 2007; What Did You Say? What Do You Mean? An Illustrated Guide to Understanding Metaphors; Welton & Telford, 2004). We encourage the youth to make their own illustration on paper or create an image in their mind and think about it to help them figure out if there is a hidden meaning to decipher. Last, we provide the youth with a script to use "what did you mean by that?" when they are unable to figure out the meaning on their own and need assistance from the conversational partner.

Metacognitions and Prosody Problems

Individuals with AS are observed to show difficulties with prosody in their speech. Prosody refers to the melody or intonations in spoken language that includes aspects of pitch, stress, and rhythm. Prosody problems can be described as the lack of attention to such cues in speech. To truly understand the intent of others and to convey a clear intent, words need to be delivered with an attention to prosody. For example, stating a set of words with a rising pitch indicates a question. Using a specific tone of voice to say "yeah right" could indicate sarcasm carrying an opposite meaning of "no way." Saying a word like "look!" with a specific emotional tone of voice indicates a feeling and can infer if a person is happy or mad about something they see. Applying stress to a word or phrase can indicate a level of importance or change the meaning of a sentence all together. An example presented by Tony Attwood and taken from Andrew Matthew's book, *Making Friends* (Matthews, 1991, p. 129) illustrates this point so clearly (each italicized bolded word is inflected).

I didn't say she stole my money [but someone said it]
I *didn't* say she stole my money [that was not said]
I didn't *say* she stole my money [but it was implied]
I didn't say *she* stole my money [but someone stole it]
I didn't say she *stole* my money [but she did something with it]
I didn't say she stole *my* money [but she stole someone's]
I didn't say she stole my *money* [but she stole something]

Metacognitions and Prosody Strategies-Exercises: We verbally state the phrase above multiple times, each time exaggerating the one word to demonstrate to the youth with AS the importance of tone during communication. Youth can grasp this concept when it is presented both visually and orally in this format. We also add in facial expressions as another cue to attend to and think about in deducing the speaker's intent and main point. We link these thinking skills back to metacognitions and the importance of thinking about your own and the other person's thoughts. We again have the youth practice by first thinking out loud about what they want to say and then say it so they can be aware of their own use of prosody. We have observed that the youth are not attending to their own prosody, which is why their speech can sound flat, odd, or unusual in stress pattern. We link this back to self-awareness. We also audio- or videotape them (with permission) during a conversation and play it back to them so that they have an easier time observing their use (or lack) of prosody skills. Since metacognitions are heavily linked to self-awareness and overall use of verbal and nonverbal communicative skills, we demonstrate how to use metacognition skills to think about what they are or another person is thinking and again use modeling, role-playing, and practice assignments to reinforce and generalize these skills.

Conclusion

Early intervention for Asperger syndrome (AS) means treatment at the earliest possible moment for that individual in order to prevent future disability or problems and to alleviate any type of suffering. Due to the nature of AS, having many functional abilities, the age of diagnosis may vary. Children with AS on average are diagnosed in latency age which is significantly later than autism. Thus, early intervention should be described as attending to and treating core deficits – self-awareness (mindfulness and self-control), cognitions (cognitive flexibility and metacognitions), social (social-emotional intelligence), and communication (prosody) – and NOT based on the age of the child. Treatment methodologies should extend beyond applied behavior analysis techniques to include self-awareness training, cognitive enhancement training, social-emotional skills training, and social communication training.

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Appendix

Table 1 Differences between Asperger syndrome (AS) and non-Asperger syndrome brain processes

Brain Differences	
Non-AS Brain	AS Brain
Multi-channel input processor	Single-channel input processor
Preference for gist, gestalt level of information	Preference for detailed level of information (even if not exactly relevant)
Memory for gist, gestalt level of information	Memory for details, facts, accuracy
Perceives information as part of a context	Perceives information independent of context
Attention to feelings/emotional states	Attention to cognitions and logic
Preference for novelty and change	Preference for sameness and routines
Focus on others and others perceptions including how others perceive them	Focus on self and own sensations
Preference for abstract, inferences	Preference for concrete, literals
Dimensional style of thinking and feeling (continuums)	Categorical style of thinking and feeling (black or white)

Adapted from Lovett 2005

Table 2 Metacognition indicators

Youth with metacognitive needs may

- *Have difficulty with planning and setting goals, such as*
  - Have difficulty anticipating future events that would require them to plan and set goals for themselves
  - Have difficulty in planning how they will do their assigned work
  - Not be able to plan short-, medium-, and long-term objectives
  - Have difficulty in deciding what is important to focus on and what is not important
  - Have difficulty in imaging a work goal and stating the steps required to meet that goal
  - Have difficulty independently generating ideas, responses, or problem-solving strategies
- *Have difficulty in initiating tasks, such as*
  - Have difficulty in getting their work started
  - Procrastinate, rather than getting to work
- *Have difficulty following through, such as*
  - Have difficulty sustaining work on future-directed tasks
  - Have difficulty with managing and completing school work
- *Be ineffective at monitoring their work for accuracy, such as*
  - Rush through their work and make careless mistakes
  - Lack work-checking habits to assess his or her own performance and therefore let careless errors stand
  - Fail to find their own errors, even if they do check
  - Be unable to describe the part of the work that they find difficult
  - Not realize when to ask for assistance or how to ask

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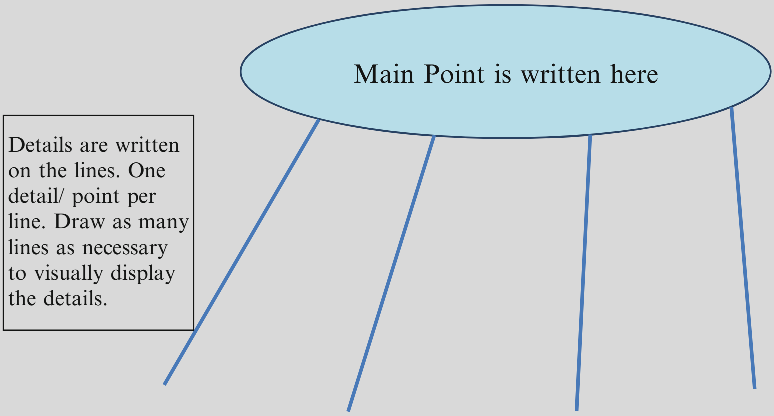
Box 1 Visual Diagram for Thinking Flexibly Between Details and Gist



(Baker-Ericzén, 2011). Intricate Mind Institute Therapist Training Materials

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Building Social Skills Instruction for Children with Asperger Syndrome

Brenda Smith Myles and The Ziggurat Group

One of the greatest challenges faced by learners with Asperger syndrome throughout life is understanding the social world. The impact of social skills difficulties is pervasive, even in structured settings designed to elicit prosocial behaviors. Social skills challenges range from difficulties in developing and maintaining friendships to being ridiculed by peers to not being able to keep a job due to a lack of understanding of workplace culture and relationships among subordinates and supervisors (Koenig, De Los Reyes, Cicchetti, Scahill, & Klin, 2009).

In order to help individuals on the spectrum experience, various researchers have culled from scholarly articles of evidence-based practices (EBP; National Autism Center [NAC, 2009], National Professional Development Center on ASD [NPDC on ASD, 2009], Centers for Medicare and Medicaid Services [CMS, 2010]), many of which were used to address the social challenges. Each holds in common an emphasis on supporting and developing skills rather than trying to eliminate inappropriate skills through behavior reduction procedures. In addition, most are cognitively based – focusing on explaining to the individual when a specific strategy is needed, how it can be used, and why it is needed.

EBP, the focus of this chapter, are tools that target specific social skills. However, these interventions do not fully appreciate the complexity of social interventions as they have often targeted only one element of the social process. Loomis (2008) has identified ten factors that should be considered when programming for social situations (see Fig. 1). These factors provide the first step in the recognition that social skills are more than the sum of its parts (Koenig et al., 2009). They vary across events, thus creating challenges that differ depending on the social event. A brief review of these factors is provided in Table 1. For a more in-depth discussion, please refer to Loomis' excellent book, *Staying in the Game: Providing Social Opportunities*

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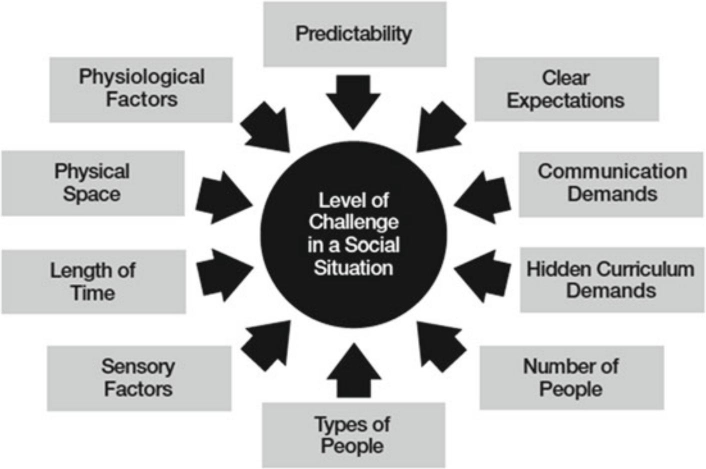


Fig. 1 Loomis' factors that make social situations challenging (Loomis (2008). Used with permission, www.aapcpublishing.net)

Table 1 Brief overview of Loomis' ten factors that impact social interactions

Factor	Brief description
Predictability	Routines and regular activities facilitate social success. Activities that are less than predictable can cause anxiety and the learner's focus is on personal stress experiences rather than social exchanges
Clear explanations	Answers to these questions must be provided: Who do you approach? How do you join the activity? When can you talk, sing, yell, etc.?
Communication	Verbal and nonverbal communication, emotions, opinions, jokes, and metaphors relative to an activity must be understood by the learner with AS
Hidden curriculum	Unstated rules, assumptions, and expectations can serve as a roadblock to successful social experiences
Number of people	The fewer people involved, the lower the social challenge
Types of people	Certain individuals are easier to socialize with than others. It is important, especially in new social situations, to ensure that people who are easy to socialize with are included in activities
Sensory demands	All environments have sensory demands and the majority of individuals with AS have sensory challenges. A mismatch between the two can cause regulation problems
Length of time	Social processing can be exhausting for learners with AS. The longer a social event, the more taxing it is
Physical space	Crowded spaces, large open areas, noisy environments, and echoing environments can be difficult and/or exhausting for the individual with AS
Physiological factors	Physiological factors, including fatigue, hunger, thirst, and illness can influence social interactions

Loomis (2008). Used with permission, www.aapcpublishing.net *for Children and Adolescents with Autism Spectrum Disorders and Other Developmental Disabilities*. It should be noted that all EBP are not discussed in this chapter. This chapter highlights interventions and supports that can specifically facilitate school success.

Criteria Used to Identify Evidenced-Based Practices

The NPDC on ASD (2009), the NAC (2009), and the CMS (2010) independently conducted reviews of literature to identify interventions for individuals with ASD. Each identified specific criteria by which to identify interventions and supports as EBP.

In order to determine whether studies on interventions were scientifically rigorous, the NPDC on ASD used the following criteria for articles on interventions used with individuals with ASD (excluding intervention packages): (a) at least two experimental or quasi-experimental group design studies carried out by independent investigators, (b) at least five single-case design studies from at least three independent investigators, or (c) a combination of at least one experimental/quasi-experimental study and three single-case design studies from independent investigators. Nomination of strategies was secured from NPDC staff and their advisory board. Searches by NPDC on ASD staff using educational and psychological databases were conducted for the targeted practices until the aforementioned number of single-case or group design studies were identified. Studies included individuals with ASD at the preschool, elementary, and secondary levels.

The authors of the second report (NAC, 2009) conducted a search for EBP that included search engines, conference proceedings and abstracts, book chapters, and identification of abstracts by an expert panel. Identified practices were not initially excluded because of design or sample size and were inclusive of practices used with individuals with ASD from 0 to 21. The NAC developed a Scientific Merit Rating Scale (SMRS) that analyzed within an article (a) research design, (b) measurement of the dependent variable, (c) measurement of the independent variable or procedural fidelity, (d) participant ascertainment, and (e) generalization. Each of these elements was subsequently rated on a 5-point Likert scale with scores of 3, 4, or 5 indicating scientific rigor. Articles were evaluated independently by field reviewers who were recognized leaders in ASD.

The third report, commissioned by the CMS (2010), sought to determine scientific evidence of the efficacy, effectiveness, safety, and availability of ASD-related psychosocial services and supports for children, transitioning youth, and adults with ASD. Manuscripts were identified through an environmental scan healthcare literature databases, books, integrated reviews of literature, meta-analyses, unpublished reports, and conference proceedings. The process included an analysis of study quality using a modified Campbell Collaborative Rating System (Schuerman et al., 2002). Interventions were classified as evidence-based using the criteria adopted by the NPDC on ASD and the categories identified by the NAC.

Evidenced-Based Practices

The following EBP practices that relate specifically to social skills instruction and support are discussed below: (a) antecedent-based interventions, (b) group-based interventions, (c) modeling, (d) multicomponents interventions, (e) self-management supports, (f) social narratives, and (g) visual supports.

Antecedent-Based Interventions

Antecedent-based interventions are put into place prior to the occurrence of a behavior to increase the likelihood of success and/or reduce the occurrence of problem behavior. There are multiple interventions in this category, including visually based supports (see Visual Supports), incorporating students' special interests into activities (see Social Narratives for a discussion of Power Cards), priming, and the hidden curriculum.

Wilde, Koegel, and Koegel (1992) defined the purposes of priming as (a) to familiarize the student with schedules, activities, and/or materials before their use and (b) to introduce predictability into the information or activity (cf., Sawyer, Luiselli, Ricciardi, & Gower, 2005). Within the context of social situations, priming the learner with AS for an upcoming social interaction using Loomis' ten factors (see Table 1) can reduce anxiety and behavioral challenges while increasing student success in describing. Table 2 overviews the four steps of priming (Wilde et al., 1992).

The hidden curriculum is assumed knowledge – the expectations, rules, or guidelines that are not directly taught because they are universally known. It also addresses the incongruities of how skills are executed differently across communicative partners and environments, making it an essential set of skills for individuals with AS who often do not detect the subtleties of situations and are often routine bound, literal, and rule enforcers. The absence of instruction of the hidden curriculum, however, does not belie its importance. It is significant and can impact social interactions, school performance, and safety. Despite its considerable value, little information on hidden curriculum has been published because it has been largely considered "common sense" and is often only recognized after a hidden curriculum error has occurred (Myles, Trautman, & Schelvan, 2004). Table 3 contains some hidden curriculum items surrounding airplane trips (Myles et al., 2004).

Group-Based Interventions

Interventions that target social skills in a group format have been shown to positively impact learners on the spectrum. Social interventions have included the use of social narratives, peers, technology, naturalistic procedures, video modeling,

Table 2 The four steps of priming

Step	Brief description
Collaboration	It is important to determine up front who is going to prime and what activities/lessons will be involved in priming. A resource room teacher, a general educator, a parent, a paraprofessional, or an older student may prime the learner
Communication	An open line of communication must exist between the teacher and the primer. Some of the questions that must be addressed are as follows: 1. Who will prepare the priming materials? 2. Where and when can the primer access the priming materials? 3. How will the primer notify the teacher that the priming has occurred? 4. How will the primer *and* teacher handle last minute changes in the activities/lessons that may not have a priming opportunity? 5. How will it be determined that priming is an effective strategy? 6. How will problems be addressed? 7. Is a scheduled meeting time needed to overview how priming is proceeding?
Priming	The primer shows the learner what will occur during the lesson by introducing the materials and class expectations. The primer may condense the activities onto an index card that the child can carry to class and refer to as needed. The student is reinforced for attending to the material
Feedback	The teacher and primer should determine how feedback should occur. Some may choose to use a form that reports how priming went during the session and its results during the lesson/activity. This type of communication is efficient without being time consuming. If problems occur during priming, brainstorm sessions may be needed to alter the sessions

Adapted from text: Wilde et al. (1992)

reinforcement, self-management, and PRT (see discussion of each in this chapter). Successful group-based interventions should be structured, ongoing, and providing multiple opportunities for practice across environments (Koenig et al., 2009).

The instructional sequence that facilitates learning of social skills includes the following: (a) rationale, (b) presentation, (c) modeling, (d) verification, (e) evaluation, and (f) generalization. In order for social skills instruction to be effective with children and youth with AS, they need to understand the *rationale* – why concepts required for mastery are relevant and how they fit with the knowledge they already have. That is, the rationale for a social skill should include (a) why the information is useful, (b) how the individual can use the information, and (c) where it fits in with the knowledge he already possesses. The *presentation* should be active and multimodal, encouraging learners not only to listen and/or view content but also to respond to questions, share observations, and provide and receive meaningful corrective feedback. Direct instruction does *not* mean presenting a worksheet and telling the child or youth to follow the directions. The use of manuals, a quality indicator in social skills and other intervention research (Smith et al., 2007), is becoming

Table 3 Sample hidden curriculum items on airplane trips

When riding on an airplane, use only one armrest. If you are sitting in an aisle seat, it is usually best to use the armrest on the aisle side
Avoid placing any part of your body over the armrest and into another's seating area
Soft drinks, water, and snacks are usually free on airplanes
Do quiet and sedentary activities during the flight (reading, computer, writing, etc.)
If you are playing a video game or walkman/MP3 player/iPod, turn the audio volume off or wear headphones. Make sure that your iPad, Kindle, MP3 player, iPod, etc., is powered up before the flight
The temperature on an airplane may not be comfortable for you. Think about wearing or bringing a light-weight shirt and jacket/sweatshirt
When listening to music, sing quietly to yourself, not out loud
Unless you are in the aisle seat, try to limit the number of times you leave your seat
Airlines usually do not provide a variety of food during a flight. It is best to bring a small snack if you think you will get hungry and have specific tastes
No one is allowed to smoke on an airplane
Do not tell the person sitting next to you that he is too fat for the seat
When sitting in your seat, do not push, pull, or kick the seat in front of you

From Myles et al. (2004). Used with permission, www.aapcpublishing.net

increasingly apparent in the presentation of material. Two types appear in the social skills research: treatment manuals developed specifically for individuals on the spectrum (cf., Paradiz, 2008; White, Koenig, & Scahill, 2007) and those adapted for use with other populations (cf., Webb, Miller, Pierce, Strawser, & Jones, 2004). *Modeling* follows presentation. During *modeling* learners are shown what to do by the instructor or via video. One common mistake must be avoided: instructors often tell learners with AS what *not* to do without providing the alternative – what they are supposed to do. Generally, it is preferable not to present negative modeling or show learners how "not" to engage in the behavior appropriately because the student may focus on the misapplication of the behavior and attempt to use these negative skills (see Modeling for Additional Information). At the *verification* stage, the facilitator closely monitors learners' understanding of what is being taught and his emotional state, providing opportunities for students to practice the skill in a controlled setting. Social skills acquisition requires *evaluation* from both adult and learners with AS. A variety of methods should be employed to assess learners' understanding and use of the skill. For example, children and youth with AS should self-evaluate their skill performance and set goals for generalization and skill maintenance. Finally, *generalization* programming should be a part of each lesson. Opportunities for individuals with AS to use newly acquired social skills in a variety of settings and structures (i.e., lunch, music, recess) must be provided. Assistance from parents is also invaluable to ensure generalization as they can set up and/or observe home- and community-based events in which children and youth are expected to use the skill. Parents, depending on their time constraints, knowledge on how to observe and provide feedback, or level of social understanding, may require different levels of support in helping their children with AS generalize social skills (cf., Meadan, Ostrosky, Zaghlawan, & Yu, 2009).

Modeling

Modeling involves learning skills through either in real time (in vivo) or video observations (Stahmer, Suhrheinrich, Reed, Bolduc, & Schreibman, 2010). Based on Bandura's (1977) social learning that posits that individuals learn from watching each other, different types of modeling exist: including "*direct modeling* (simply copying the model), *synthesized modeling* (combining several observations to create a new behavior), and *symbolic modeling* (copying fictional characters from television, books, etc.)" (Aspy & Grossman, 2011, p. 205). Recent research on video modeling has focused on the model; the strategy has been reported as successful in the formats of (a) self as model, (b) adult as model, and (b) visual point of view. The latter is structured such that the learner observes the target behavior as if she were engaged in it. A meta-analysis found that video modeling was successful in teaching a variety of skills, including self-help, social, transition behavior, play, on-task, and speech and language skills (Bellini & Akullian, 2007). In addition, McCoy and Hermansen (2007) found that participants, regardless of type of video modeling used, were successful in learning new skills.

Multicomponent Interventions

Multicomponent interventions, which often include more than one theoretical orientation and involve a combination of interventions, include (a) naturalistic teaching strategies, (b) parent-implemented interventions, (c) peer-implemented interventions, and (d) pivotal response training.

Naturalistic teaching strategies. Naturalistic teaching strategies were developed based on concerns related to applied behavior analysis (ABA) instruction resulting in (a) lack of spontaneous use and generalization of skills and (b) instruction divorced from communication and socialization (cf., Sowden, Perkins, & Clegg, 2011). Naturalistic teaching strategies are embedded into child-directed play schema. Their ultimate goal is to provide the learner with functional skills that can be used in the multiple natural environments. The most commonly used techniques are as follows: (a) modeling a response and correcting or expanding a child's interaction (see Modeling), (b) providing a verbal label that is supported by a desired object or activity, (c) providing time delay, and (d) incidental teaching that emphasizes intentionality by arranging the environment around preplanned learning objectives that include student preferences and "teachable moments" initiated by the learner (Kroeger & Nelson, 2006).

Parent-implemented interventions. Research has demonstrated repeatedly that parents can be effective instructional agents of social skills instruction (cf., Meadan et al., 2009). According to Matson, Mahan, and Matson (2009), commonalities exist in successful parent-implemented programs: being organized; targeting specific behaviors for intervention; establishing consequences, such as reinforcement; maintaining consistency; and identifying limits (Matson et al., 2009). The latter is the best predictor of fewer challenging behaviors (Osborne, McHugh, Saunders, & Reed, 2008).

The majority of research on parent-implemented interventions has focused on mothers as instructional providers. A recent review of family involvement in the instruction of young children with autism found that 90 % did not include fathers in instruction. The authors support father involvement by suggesting that it may result in developmental gains for the child, reduced stress for parents, and greater family cohesion (Flippin & Crais, 2011).

Peer-implemented interventions. Involving neurotypical peers as instructors and facilitators for individuals with ASD is collectively known as peer-mediated interventions (Wang & Spillane, 2009). Peer-mediated interventions, which incorporate myriad instructional strategies, occur when trained peers teach or support the use of social skills for learners with special needs, including those with ASD. Peers who support learners with ASD are typically male and have high status. They are often described by classmates as “smart, athletic, helpful, good problem solvers, leaders, self-confident, influential, and admired” (Jackson & Campbell, 2009, pp. 274–275). Interventions, which can occur in school or community, include (a) peer networks, (b) class-wide peer buddy programs (Kamps, Barbetta, Leonard, & Delquadri, 1994), (c) peer buddy assignment (Baker, 2003; Bellini, 2006), (d) friendship clubs (Carter et al., 2004), (d) initiation training (Lee, Odom, & Loftin, 2007), and (e) circle of friends (Kalyva & Avramidis, 2005).

Pivotal response training. Developed by Koegel, Koegel, Harrower, and Carter (1999), pivotal response training (PRT) is a naturalistic child and family-centered intervention built around child-centered activities based on ABA. Through PRT, the individual with ASD learns (a) how to respond to multiple cues and stimuli, (b) how to self-regulate and manage behavior, and (d) how to initiate with others. The motivation of learners is critical in all instructional opportunities; thus, reinforcement is built into the model (cf., Koegel et al., 1999). Although PRT focuses primarily on young children in early intervention, it is suitable for individuals with autism across a range of ages. The primary areas of PRT are described in Table 4.

Structured teaching. Structured teaching, the principle program of the Treatment and Education of Autistic and Communication Handicapped Children founded by Eric Schopler, was one of the first strength-based instructional approaches for learners with ASD (cf. Mavropoulou, Papadopoulou, & Kakana, 2011). The program elements include the following:

1. *A structured and predictable environment and activities*. The physical environment is carefully arranged to minimize distractions, to create physical boundaries, and to create a predictable series of events.
2. *Visual supports*. Myriad visual structures, such as written directions, photographs, and pictures, are used to create organized work and living spaces.

Table 4 Brief description of pivotal response training steps

Activity	Description
Responding to multiple cues and stimuli	Lessons contain more than one cue to which the learner must attend, such as size, color, shape. An example would be asking the child to sort toy cars into colored baskets. If the child is asked to put the toy car into the red basket while there are other baskets in different colors, the child has to respond to colors and make a correct differentiation
Improving learner motivation	Schreibman, Kaneko, and Koegel (1991) suggested ways to improve motivation: 1. Choice is embedded into reinforcement. Choice should include materials, topics, and toys used into teaching sessions 2. Natural and direct reinforcers are incorporated into instruction. These reinforcers assist in attention and motivation 3. Previously learned tasks are interspersed with new tasks. This allowed the learner to maintain competence while gaining new skills. A strong possibility of completing tasks results in high motivation and increasing responses 4. Reinforcement is provided to goal-directed attempts by the learner. Attention to task increases when the learner receives encouragement for attempts
Increasing self-management skills	According to Koegel, Koegel, and Surratt (1992), the following self-management strategies should be supported and taught: 1. Identify target behavior. A measurable objective is identified by the teacher and learner. Emphasis is placed on socially valid behaviors that positively impact the learner 2. Identify reinforcers. The adult and learner choose rewards that are reinforcing. In addition, internal reinforcement be paired with external rewards to increase self-motivation 3. Select self-monitoring method. The adult identifies a means of data collection that the learner can easily incorporate into activities 4. Provide instruction on self-monitoring. The learner is taught how to collect data 5. Generalization. The adult helps the learner to use the self-monitoring system across his or her many environments
Increasing self-initiations	Adults implementing PRT teach the learner to make initiations using natural cues. Specifically, the learner will be taught to initiate using wh-, assistance-seeking, and information-seeking questions

3. *Meaningful*, *functional social communication*. TEACCH encourages the use of communication systems such as signs, pictures, and speech to facilitate expressive language.
4. *Special interests*. Special interests are incorporated throughout the learner's program as instructional materials and reinforcers to increase motivation and encourage learning.

Structured teaching is founded on research-based principles and is appropriately considered to be an evidence-based practice because of the multiple studies that have been conducted on the model (for a review of these studies, see Aspy & Grossman, 2011).

Fig. 2 Sample *Incredible 5-Point Scale* (Buron and Curtis (2002). Used with permission, www.aapcpublishing.net)

Obsessional Index

1	I can't control it. I will need lots of support.
2	I am feeling very nervous and will probably need some support.
3	I am thinking about my obsessions but I may just need to talk to someone about it. I think I have some control.
4	I am feeling pretty relaxed. I can probably think about my obsessions but still do well in the classroom.
5	It is a great day! My obsessional personality is a neurological work of art!

Self-Management Supports

Strategies that support the independent use of skills are of great value to learners on the spectrum. Self-management procedures, designed to teach the students themselves to self-initiate, select reinforcers, monitor performance, evaluate performance, and deliver reinforcers (Aspy & Grossman, 2011; Southall & Gast, 2011), are one such support. Designed to teach choice making and self-advocacy (Paradiz, 2008), self-management strategies encourage independent social skills use (cf., Palmen, Didden, & Arts, 2008). Two self-management procedures are described below.

The Incredible 5-Point Scale. Buron and Curtis (2002) created the *Incredible 5-Point Scale* to help individuals with AS understand themselves. The 1–5 scale system is applicable for a variety of social and self-regulation behaviors and responses to those behaviors, including feelings of anxiety, concepts of personal space, and feelings of anger. The scale is unique in that it can be used as an obsessional index, a stress scale, a meltdown monitor, etc. Children and youth with AS are taught to recognize the stages of their specific behavioral challenges and methods to self-calm at each level. Figures 2 and 3 provide two illustrations of how the *Incredible 5-Point Scale* can be used.

Stop, Observe, Deliberate, and Act (SODA). SODA is a visual, problem-solving rubric that children and youth with AS can use to navigate unfamiliar social situations (Bock, 2001). It was designed as a multipurpose strategy that individuals with AS could use in almost any social gathering. SODA attempts to develop a schema for the child to understand novel environments and be an active decision maker in determining how she will fit in. Bock has created the following series of questions

Fig. 3 Sample *Incredible 5-Point Scale* (Buron and Curtis (2002). Used with permission, www.aapcpublishing.net)

The Stress Scale

5 – I could lose control

4 – Can really upset me

3 – Makes me nervous

2 – Bugs me

1 – Never bothers me

about salient environmental factors that learners with AS should ask themselves at each stage of SODA:

Stop: What is the room arrangement? What is the activity or routine? Where should I go to observe?
Observe: What are the people doing? What are the people saying? What is the length of a typical conversation? What do the people do after they've visited?
Deliberate: What would I like to do? What would I like to say? How will I know when others would like to visit longer or would like to end this conversation?
Act: Approach person(s) with whom I'd like to visit and say, "Hello, how are you?" Listen to person(s) and ask related questions. Look for cues that this person would like to visit longer or would like to end this conversation. End the conversation and walk away.

This strategy can be successful but relies heavily on good social skills instruction. That is, the students using SODA should have the social skills required to execute each of the stages of the strategy.

A review of studies on self-management revealed that these procedures have been successful regardless of components, learner's age, and learner's cognitive level (Southall & Gast, 2011).

Social Narratives

Social narratives, which include cartooning (cf., Gray, 1995); Power Cards (Gagnon, 2001); social scripts (cf., Wichnic, Vener, Keating, & Pouson, 2009); Social Stories™ (Gray, 1995); Situation, Options, Consequences, Choices, Strategies, Simulation (SOCCSS, Roosa, 1995); and social autopsies (Bieber, 1994) were designed to help learners understand social situations. Some are designed to be used prior to a situation to facilitate social success (i.e., cartooning, Power Cards, social scripts, Social Stories™). Specifically, they provide information about what may occur/what to expect, when something may occur, what the learner can do in a given situation, what the learner should try not to do in a given situation, and so forth. Others, such as SOCCSS and social autopsies, occur after an event to help the learner understand a previous interaction to help future success. These also emphasize problem-solving skills, brainstorming, and generalization. Typically they (a) provide for flexibility and the possibility of change using words such as *may*, *probably*, *usually*, *will try to*, and *might* and (b) are developed and presented in a manner appropriate to the learner, whether through the use of words only, pictures only, or a combination of the two, all of which are social narratives. Another type of social narrative is the Nurturing Narrative (Franke & Durbin, 2011). This intervention "… involves systematically facilitating mastery of new language skills during engaging, interactive story-based activities" (Franke & Durbin, 2011, p. 12). They target (a) social communication and conversation; (b) grammar, syntax, and vocabulary; (c) story comprehension and retelling; (d) interactive symbolic play; and (e) theory of mind. Table 5 describes the various social narratives and identifies some of the salient research on them.

Technology-Based Interventions

Recent advances have technology more accessible to learners with AS and, in fact, are compatible with the way that children with AS learn (Moore, McGrath, & Thorpe, 2000). Electronic technology can highlight, change instructional pace, and repeat critical information, thus providing instruction in a controlled format (cf., Doyle & Arnedillo-Sánchez, 2011). Not only is technology compatible with the learning style of those with ASD, it may be the preferred manner in which to receive instruction. Research has shown the learners on the spectrum may prefer electronically presented information, may learn more quickly with technology, and may be more motivated than when accessing traditional adult-directed instruction (cf., Stromer, Kimball, Kinney, & Taylor, 2006).

Increasingly more popular for learners on the spectrum (and neuroytpical individuals alike) are computers and personal digital assistants, including iPods, with multiple prompt levels to increase various skills, including social skills (cf., Mechling & Savidge, 2011). Similarly, Reed, Hyman, and Hirst (2011) found that one-half of the 20 technology studies centered on videos/DVDs to teach (a) conversation, (b) play, (c) social convention, (d) responses, (e) nonverbal social behavior, (f) social problem solving, (g) emotion regulation, and (h) friendship/peer relationship skills. In their review of technology applications to teach social skills, these authors supported the integration of technology into social skills instruction and called for additional research on the efficacy and efficiency of the use of this medium, particularly in schools.

A new technology is virtual reality (VR) that provides a computer-generated, three-dimensional, interactive environment. Based on the idea that multimodal processing is more effective than single mode, VR creates a computer-generated environment that resembles the real world and promotes a sense of presence for the user. Thus, people can visualize, manipulate, and interact with simulated environments. The research on VR appears promising (cf., Cheng, Chiang, Ye, & Cheng, 2010).

Table 5 Descriptions of types of social narratives

Type	Brief description	Selected references
Cartooning	This intervention uses thought bubbles, conversation bubbles, and cartoon or stick figures to illustrate people's thoughts and words during interactions in a comic strip format. Figure 4 provides a sample cartoon	Pierson & Glaeser, 2005, 2007
Nurturing narratives (Franke & Durbin, 2011)	A story-based language intervention approach that embeds building language skills into the context of sharing personal narratives and retelling fictional stories using a blending of ABA and social pragmatics. Narrative understanding is the primary tool through which people make sense of the world and is the best predictor of outcomes in preschool and elementary school	Botting, Faragher, Knox, Simkin, & Conti-Ramsden, 2001; Lyle, 2000 (research on the elements of nurturing narratives)
Power card strategy (Gagnon, 2001)	Based on a learner's special interest, this strategy contains two components: (a) a text-based scenario that describes a target behavior related to a special interest and encourages the student to use the strategy employed by the person of special interest and (b) a small card that synthesizes the text-based scenario (see Fig. 5)	Campbell & Tincani, 2011; Davis, Boon, Cihak, & Fore, 2010; Keeling, Myles, Gagnon, & Simpson, 2003
SOCCSS (Roosa, 1995)	SOCCSS provides an extensive analysis of social interactions by helping individuals with AS learn choice making, cause–effect relationship, and problem solving. This adult-directed strategy helps children and youth with AS logically work through the situations by defining (a) the problem situation, (b) options the child may have in how to respond to that situation, and (c) consequences that would logically follow each option. The youth is then supported in making a choice among the options that were generated and developing a strategy to implement that choice. Finally, the child practices or simulates the strategy to ensure that he could actually carry out his choice in a social setting	–
Social autopsies (Bieber, 1994)	An adult-directed exchange between a student and a mentor in which a social error is defined and methods of (a) making amends and/or (b) interacting successfully in future events are discussed. Figure 6 provides a sample worksheet that can be used when conducting social autopsies	–

(continued)

Table 5 (continued)

Type	Brief description	Selected references
Social Stories™ (Gray, 1995)	These written stories inform or describe an activity and the anticipated behavior associated with it. They also provide information to teach appropriate social behaviors. Gray developed specific guidelines regarding types of sentences, language level, audience, and use. See Fig. 7 for an example Social Story™ from Hudson and Coffin (2007)	Test, Richter, Knight, & Spooner, 2010
Social scripts	Written sentences or paragraphs that contain brief descriptions and text that can be used verbatim in academic and/or nonacademic settings. Figure 8 provides a sample script created by Loomis (2008)	Ganz, Kaylor, Bourgeois, & Hadden, 2008; Wichnic et al., 2009

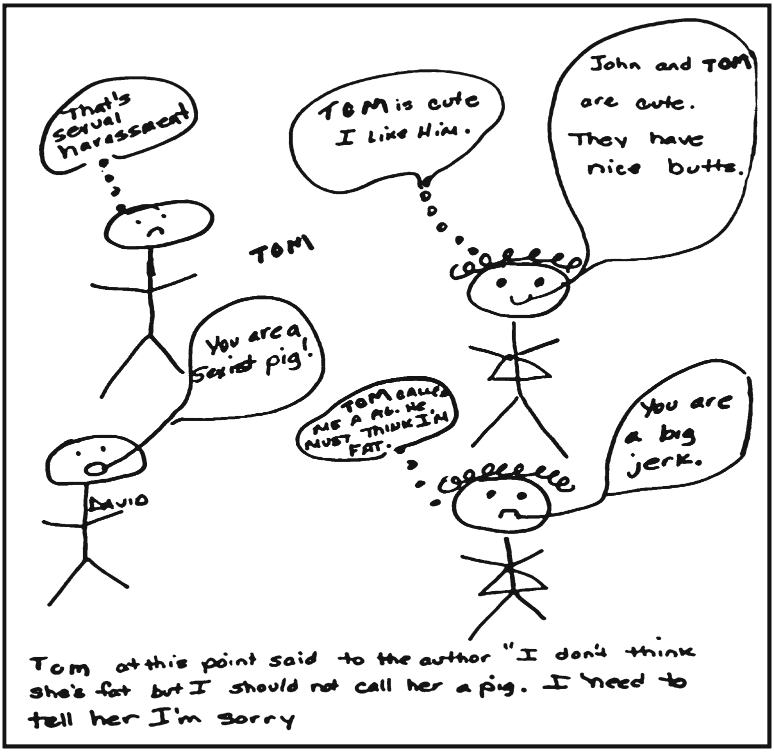


Fig. 4 Sample cartoon (The final, definitive version of this paper has been published in Rogers and Myles (2001), All rights reserved)

Angelica Says, "Wash Those Hands"

by Rachele M. Hill (Hill, 2001)

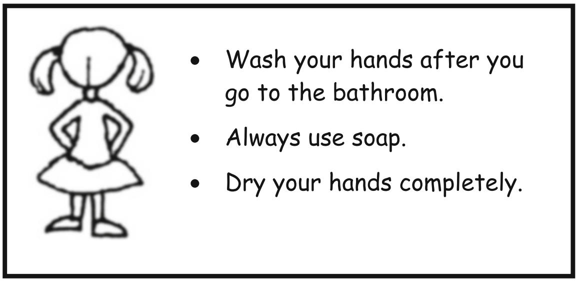
Angelica knows how important it is to keep her hands clean. She does not want to catch any yucky germs from "those babies!" Germs can cause coughing, sneezing, and runny noses. Angelica definitely does not want to catch a cold! She washes her hands often and always after using the bathroom. She knows that washing her hands helps her from catching a cold.

Angelica wants you to have clean hands, too. She wants you to remember to wash your hands often and every time after you go to the bathroom.

Angelica wants you to remember these three things:

- Wash your hands after you go to the bathroom.
- Always use soap.
- Dry your hands completely.

Angelica can be very bossy, but she does have manners when it comes to having clean hands. Angelica says, "Please wash your hands!"



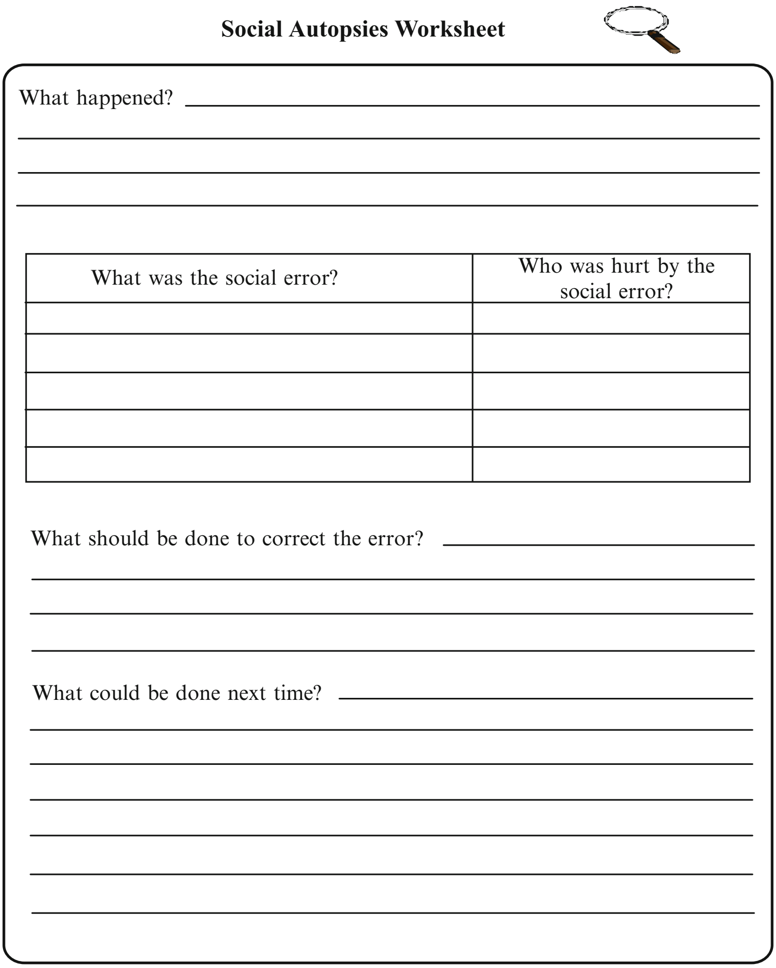
- Wash your hands after you go to the bathroom.
- Always use soap.
- Dry your hands completely.

Gagnon, E. (2001). *The Power Card strategy: Using special interests to motivate children and youth with Asperger Syndrome and autism*, pp. 41. Shawnee Mission, KS: AAPC Publishing. Used with permission. www.aapcpublishing.net.

Fig. 5 Sample power card (Gagnon (2001). Used with permission, www.aapcpublishing.net)

Visual Supports

Numerous types of visual supports have been used in students with ASD, including visual schedules, lists, and signals/cues. They have been introduced to learners with ASD as a means of positively impacting myriad skills, including establishing conversational skills and enhancing attention to and understanding social messages, social skills, and social understanding (cf., Ganz, Bourgeios, Flores, & Campos, 2008; Johnston, Nelson, Evans, & Palazolo, 2003; Wheeler, Baggett, Fox, & Blevins, 2006).



Social Autopsies Worksheet

What happened?

What was the social error?	Who was hurt by the social error?

What should be done to correct the error?

What could be done next time?

Fig. 6 Sample social autopsies worksheet (Myles and Southwick (2005). Used with permission, www.aapcpublishing.net)

What Do People Do at the Library?

A library is a place filled with books. Sometimes people go to a library to read books. Sometimes people borrow books from the library. Before taking the books home, they sign the books out with the librarian. Everyone at the library tries to talk quietly. People reading their library books like it when it is quiet. I will try to read my library books with a quiet voice when I visit the library.

Fig. 7 Sample Social Story™ (Hudson and Coffin (2007). Used with permission, www.aapcpublishing.net)

Fig. 8 Sample social script (From: Loomis (2008). Used with permission, www.aapcpublishing.net)

Marty's Script

- Hi (peer's name). How are you?
- Did you see (television show) last night?
- What did you think was funny?
- I liked it when everybody fell into the swimming pool.

Table 6 Issues for future consideration and research

Identification of skill hierarchies in social skills
Assessment of social skills across multiple environments
The impact of negative role models in social skills instruction
Assessment of vicarious learning – when and how it occurs
Determination of how technology can be used to assess social skills
Parents' role in selecting social targets and priorities and providing social support
Optimal peer group composition for social skills acquisition
How to establish criteria for mastery of social skills
Determination of the best match of type of social support needed to teach specific social skills

Visual supports can have an indirect as well as a direct impact on social skills. Collateral impact includes creating predictability that can result in decreased anxiety and behavior rigidity that will allow the learner to focus on the social agenda rather than the environment (Johnston et al., 2003; Koenig et al., 2009).

Future Considerations

We are in the initial stages of understanding the types of social skills supports for children and youth with AS. What is known, however, is that solely teaching rote skills will not lead to successful interactions with others across environments. Children and youth with AS need to understand specific social skills as well as when, where, why, and how they are to be used. Additional research is needed to identify which techniques are most appropriate for specific youth and specific situations, types of generalization supports needed to ensure that those with AS can use the skills they have learned, and the level of adult direction required for child success. Table 6 outlines additional issues for future consideration.

Summary

The interventions required to teach social skills must allow persons with AS to participate in interactions that occur in complex social environments and use skills in a flexible manner. A social program that takes into consideration the complex demands as outlined by Loomis (2008) and includes instruction using EBP practices that match learner needs can help a child or adolescent with AS meet those goals. As instruction and supports are developed, it is important to remember that social skills are not rote-based skills. They are complex and are more than the sum of their parts (Koenig et al., 2009).

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Evaluating Evidence-Based Instruction for Children with Asperger Syndrome

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This chapter examines reliable approaches to the instruction of students who have an Asperger syndrome (AS) diagnosis. Evidence-based instruction and treatment are preferred to approaches based on informal data, such as interviews, single classroom observations of the student, and case studies without controlled experimental design. Judgments about the efficacy of particular models of instruction must be based on evidence. This chapter presents an educational model that relies on reporting extensive data on each child. For an example of a report that reviews data and describes one adolescent student's progress, please see the Appendix at the end of this chapter.

Today, increasing numbers of children are being identified as having AS, and there is a proportional increase in valid, reliable research. A review of the research on AS on the Eric and PsycINFO databases identified 385 articles (DuCharme & McGrady, 2003).

A clear description of experimental design and setting is important criteria for selected studies.

The same criteria for studies were applied to the studies in the Journal of Autism and Developmental Disorders over the year 2010 to assess trends in current studies using separate autism spectrum disorder (ASD) diagnoses. Abstracts of articles were written for those that focused on autism disorder, AS, high-functioning autism (HFA), pervasive developmental disorder (PDD), pervasive developmental delay-not otherwise specified (PDD-NOS), and studies that mixed diagnostic categories and combined diagnostic groups for analysis and discussion. Note that some authors use the diagnosis of ASD.

Studies were grouped under the diagnostic categories, counted, and compared for diagnosis and for the use of the label autism spectrum disorder, ASD, for analysis and discussion of data. The number of studies in each category is shown below.

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R.W. DuCharme and T.P. Gullotta (eds.), *Asperger Syndrome: A Guide for Professionals and Families*, Issues in Children's and Families' Lives, DOI 10.1007/978-1-4614-7016-8_6,

Category	Number
Autism disorder	26
HFA	7
Asperger syndrome	15
PDD-NOS	3
Mixed diagnoses	21
Autism spectrum disorder	58
Total	130

The number of children, adolescents, and adults in a research sample varied greatly from 1 to 87,677 for a group of combined diagnoses in the South Carolina Medicaid Program. Autism spectrum disorder, or ASD, is a diagnosis of particular interest because ASD is neither a phenotype nor a diagnosis under the DSM-IV classifications. A phenotype is a classification that rests on the clear understanding of heredity and development. If individuals were to show observable physical or biochemical characteristics determined by both genetic factors and environmental influences, only then could ASD be considered a phenotype (Gadow, Roohi, DeVincent, Kirsch, & Hatchwell, 2010; Georgiades et al., 2011; Ingersoll, 2010; Totsika, Felce, Kerr, & Hastings, 2010).

The methodology that combines diagnostic categories into one group of students for analysis confounds the interpretation of data. Students on the spectrum show wide variability in intelligence, social skills, cognitive abilities, and developmental ages within each diagnostic group. Asperger syndrome is qualitatively different from classical autism. The practice of combining groups of students, including those with AS and those with classical autism, into one group labeled autism spectrum disorders competes with the valid interpretation of data. Nevertheless, many studies do combine groups and conclude that all students on the spectrum are similar enough to generalize from the data.

Educators can expect the disagreements about diagnostic categories to continue as researchers discuss the occurrence and meaning of various symptoms. Only one of the 130 examined studies attempts to assess the issue of the category and dimensions of AS by examining the nosologic or lexical validity of Asperger syndrome. The authors did not support the thesis that autism spectrum disorders are discrete phenotypes. The authors found that autism and AS are degrees of the same disorder and not separate disorders (Kamp-Becker et al., 2010, pp. 921–989). Their conclusion is that autism is “a heterogeneous concept involving a multitude of symptoms at different levels of development and function.”

Another study reported that no norms can currently be found that support the use of the category Asperger spectrum disorders to describe diagnosis, prognosis, or specialized treatment options. However, the trend is to increasingly classify children by the autism spectrum disorder label. In summary, the 58 studies that referred to ASD reflected the current trend to combine groups into the ASD category for analysis and discussion. Even those studies (21) that measured groups separately by diagnosis later combined data for their total assessment and discussion. However, this practice negates the view that Asperger syndrome is both qualitatively and quantitatively different from other diagnoses and requires distinct education and treatment programs.

Typically researchers draw from comprehensive studies to develop evidence-based criteria. Many types of sources will be analyzed and may include genetics, psychiatry, pharmacology, neurology, and statistics. The variables or issues under study will be "reliable" that is defined operationally as having observable characteristics. Comprehensive study and analysis of variables is needed to rule in or out phenotypes, expressions of phenotype, and symptom clusters. Reliability checks are also completed regarding the definition of variables observed and measured (Anholt et al., 2010; Bauminger, Solomon, & Rogers, 2010; Bigham, Boucher, Mayes, & Ann, 2010; Chlebowski, Green, Barton, & Fein, 2010).

Within the now separate diagnoses of autistic-like disorders lies a great range of symptoms, behaviors, and responsiveness to treatment, management of medication, education, and prognoses. Take as an example the psychiatric management of medications; the factors that influence a child's response to medication encompass genetic, developmental, environmental, and neurological issues. Such variability does not lead to a clear, linear quantitative progression of differentiated indices of symptom domains or reliable and valid treatments for education settings (Anholt et al., 2010; Freeth, Chapman, Ropar, & Mitchell, 2010; Ghaziuddin, 2010).

Clear descriptions of experimental design, sample size, developmental age, diagnosis, and setting must inform evidence-based approaches. Judgments about the efficacy of methods of instruction must stem from controlled studies with defined samples and established research designs. One such design is the "single-subject, multiple-baseline" design. Another is defined samples of adequate size matched on developmental age with a control group. Studies that compare and contrast clinical groups on the autism spectrum have been able to identify neurological symptoms that differentiate autism groups from non-autism groups (Chlebowski et al., 2010; Odom et al., 2003).

Parents and teachers best serve their children by using descriptions of symptom clusters rather than diagnosis to plan instruction. The current status of theory and research about autism spectrum disorders requires that the teacher and clinical team develop data for each child, one child at a time, within observable pragmatic protocols. Educators have the responsibility to use methods of instruction and observation to develop competencies for each student. The information in this chapter will assist the education team to develop procedures that will yield data to assess the benefit of the student's instruction.

Research-to-Practice Gap: Why?

Even when research produces valid instruction and treatment, the methods and treatments described often fail to find their way to AS students in classrooms. The application of research findings that demonstrate an empirical basis for best practice in applied settings is limited (Dingfelder & Mandell, 2011). The authors identify two reasons why effective treatments for autism are rarely implemented in public health and public education settings. One reason is the lack of research that demonstrates a fit between children and adolescents' needs and specific interventions. The other is the lack of capacity of the education and treatment setting to adapt its findings to "real-world settings" (Brookman-Frazee, Taylor, & Garland, 2010; Brown et al., 2011; Koning & Magill-Evans, 2001).

Efficacy research is not parallel with systematic research on the best way to implement interventions in settings where children receive care, education, and treatment. Dingfelder and Mandell (2011) indicate that a number of significant factors limit the application of research to practice.

Payers for services often fail to require research-based practices.

Practitioners are often not trained in empirically based procedures nor are they required to apply such practices.

Families are not empowered to have access to new knowledge or to participate fully in treatment decisions that would rely on evidence-based practices.

Professionals perceive the characteristics of innovative research according to whether the new evidence has advantages over other methods. Dingfelder and Mandell (2011) explain how, why, and at what rate new technologies are applied and spread through social systems. Rogers (1962) describes four stages in the adoption of new practices.[1]

Stage 1. Dissemination of research evidence
Stage 2. Adoption by professionals
Stage 3. Implementation of practices
Stage 4. Maintenance

Professionals may be further influenced by whether new practices are compatible with existing practices and with the limitations of prior training in those who will implement the practices. In addition the existing service delivery system may have difficulty with the complexity of new practices. In some situations professionals may not have the ability or the opportunity to assess the advantages and disadvantages of new practices. The current system is often viewed as supportive of older practices and therefore an obstacle to newer ones. In many places the social service system does not have the ability to observe and define practices, train staff, provide a database, collect and analyze data, and, most important, endorse data-based decisions that are both effective and practical.

Outcome Measures

How will decision makers know whether new technologies and practices work better than existing ones? The answer to this basic question requires the ability to identify the criteria for "evidence" and to understand who, meaning which

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[1] For elaboration on the four stages, please see Dingfelder and Mandell (2011) and Freedman (2002).

children or adolescents are the target of the new practices. Standard, well-defined, relevant outcome measures for the specific targeted group of children must be developed and applied.

Valid, well-defined outcome measures – where we can say precisely what we are measuring – must match the needs and wants of all constituents and participants in the system. When people talk about education ecology or ecologically valid procedures, they refer to the interdependence of strategies, methods, procedures, treatments, and professionals – working to improve the experience of a particular group of students in a specific environment. For administrators of social service systems to risk push back against change, they must rely on groups of people who can complement and balance different parts of the system. The best way to justify the reallocation of scarce resources is by clearly communicating the potential benefit from new research. This means answering the following questions affirmatively:

Are the research variables, methodologies, and measurement procedures consistent with the education and treatment environment?
Is the research methodology rigorous and appropriate?
Are there studies that demonstrate applications in similar communities?
Are there sustainability studies of applications that fit with current needs and ongoing resources?

Positive answers to these questions make it more likely that professionals will have or obtain the education and training to implement and maintain research-based practices.

Children and adolescents diagnosed with AS and who attend general education programs without research-based teaching methods may not benefit from the instruction offered them. If the aim of their education is to enable students, including those who have autism spectrum disorders, or to make the transition to the larger community, then important criteria must not be overlooked. These include effective teaching of skills needed for self-regulation, self-care, self-administration of medication, skills for employment, and independent living and for friendship, family, social, and professional relationships (Adreon & Stella, 2001; Brown et al., 2011; de Vries, Noens, Coehn-Kettenis, van Berckelaer-Onnes, & Doreleijers, 2010; Ekas, Lickenbrock, & Whitman, 2010; Frankel et al., 2010).

An estimated 30–40 % of elementary and middle school students with autism spectrum disorders attend public school classes (Sanford, Levine, & Blackorby, 2008). Teachers of these classes may have special education backgrounds but not training in research-based teaching procedures. About 60 % of high school students with ASD are educated within public settings (Newman, 2007). But teachers who are trained in research-based methods report that up to 85 % of students over 14 years old who are referred to them by local and state referral agencies are not prepared with necessary student role behaviors or independent living skills (Church, Alisanski, & Amanulla, 2000; Jones & Frederickson, 2010).

Federal legislation requires consideration of the least restrictive environment for students (IDEA PL 101-476). But the efficacy of inclusion of autistic students in integrated classrooms is difficult to assess because of threats to the validity of current research, in large part due to inadequate assessment and measurement procedures (Campbell & Barger, 2011). Developmental age, rather than chronological age, is more reliable for the selection of a study sample of students with autism spectrum disorders. Further, a developmental approach can be applied not only to the study sample but to measurement procedures (DuCharme, 2002; DuCharme & McGrady, 2003; Pollman, Finkenauer, & Begeer, 2010).

The current economic and political climate requires cost and loss benefit analysis. Certain practices may be perceived as "costly." Examples of high-cost procedures are precision teaching methods and teaching methods requiring high use of computers, tablets, data plans, and tech support. The key issue is often whether staff can implement new practices with existing resources. Will staff need additional professional education and training to practice and maintain data-based programs? If so, who will pay for those costs? These factors are compared with probable outcomes and weighed by the impact of results on the targeted children and the community. Another consideration is the teachers and other professionals who may or may not accept the innovations associated with new standards of practice.

Developing Competencies and Assessing Benefits

The remainder of this chapter focuses on the ways and means for collaboration by those responsible for the child or adolescent or young adult. To develop the AS student's competencies, the teacher must follow a comprehensive approach that personalizes instruction for each student. A comprehensive approach requires obtaining and understanding each student's history and characteristics, modifying instruction, and assessing the benefit. A comprehensive approach is described below (Kuhlthau et al., 2010; Oosterling et al., 2010).

First, a description of a child's history and behavior characteristics provides a summary of development and leads to a developmental approach to his/her learning (Milshtein, Yirmiya, Oppenheim, Koren-Karie, & Levi, 2010).

Second, diagnostic issues are discussed along with tools for assessing educational/treatment needs of neuroatypical learners and choosing appropriate instructional settings for instruction, integrated classroom, special class, community site, or residential treatment (Cohen, Gomez et al., 2010, Cohen, Tsiouris et al., 2010; Odom, Boyd, Hall, & Hume, 2010a; Odom, Boyd, Hall, & Hume, 2010b; Rodman et al., 2010; Sawyer et al., 2010).

Third, optimal methods are presented for increasing educational performance using task analysis and modifications to personalize instruction. "Individualization" is not the same concept as "personalized" instruction. Individualization typically applies to progressive part curricula applied to a diagnosed group. Personalized instruction focuses first on the student characteristics, present skill sets, neurology, behavior patterns, deficits and strengths in all aspects of student role, psychopharmacological benefit, developmental history, previous performance, and other personal data. The ability to describe the student comes before choosing the curricula and developing strategies (Reichow & Volkmar, 2010; Rodman et al., 2010).

Finally, an Appendix follows "Research to Practice, A Personalized Educational Application." This case study demonstrates how instruction and treatment are personalized based on the team members' periodic review of data related to the AS student's functioning in different settings.

Choosing Treatment and Education Options for the Child

Parents are eligible, through legislated entitlement, to obtain empirically based education and treatment for their child. Sufficient empirical information is available to assist in the accurate determination of the developmental age of the child. Medication therapy, treatment options, and education strategies are limited in availability however. While federal and state regulations ensure due process protection for the provision of mandated services, there is no guarantee that the services chosen to meet the child's diagnosed needs will actually do so.

Most parents experience a long and stressful journey to gain access to appropriate services and positive outcomes for their child. Without the use of effective professional advocates for the child, the family often finds itself in a system with little accountability and support for the child. Parents of children, who have an autism spectrum disorder, are increasingly well informed about the need for early intervention. Long-term planning also is important for the child's success throughout the years of schooling and throughout the individual's adult life. Current researches of the long-term needs of autistic children support these concerns (Jones & Frederickson, 2010).

Diagnostic Issues Affect Placement and Treatment

ASD, as a diagnosis, has a major flaw in the interpretation for planning education and treatment. The criteria for high-functioning autism, pervasive developmental delay, and Asperger diagnoses are overlapping, making differential diagnosis difficult. A significant problem is associated with how intelligence is measured and applied to these diagnoses. A diagnosis of autism disorder is generally associated with an intelligence quotient of 75 or below, and 75 % of autistic individuals fall into this IQ range. Asperger disorder is associated with average to high IQ. Individuals with pervasive developmental delay may fall within a range from mentally deficient to bright or intellectually gifted. In one study of young children, IQ scores accounted for more differences between groups than did diagnoses (Rodman et al., 2010) on measures of object exploration, diversity of play, and taking turns on tasks. IQ data is helpful within an overall developmental perspective (Ingersoll, 2010; Jones & Campbell, 2010; Russell-Smith, Maybery, & Bayliss, 2010; Villa et al., 2010).

Intelligence measures rely on chronological age for norms and may not be used as reliable guides to the abilities of children with developmental delays. Such delays are by definition already outside the norms related to chronological age. The determination of a child's developmental age is therefore relevant to planning for the needs of child, adolescent, and adult. Intelligence quotient alone, assigned through testing, may be less reliable and less predictive of a person's future performance in key developmental areas. An intelligence quotient typically creates an expectation for the child's ability to perform academic tasks but may not reliably predict the child's performance (Chlebowski et al., 2010; Foley Nicpon, Doobay, & Assouline, 2010; Kenworthy, Case, Harms, Martin, & Wallace, 2010a; Kenworthy, Case, Harms, Martin, & Wallace, 2010b; Oosterling et al., 2010).

Chronological age of 21 ends the person's eligibility for services under federal law, the only educational mandate to ensure comprehensive transition to adult services. Developmental delays make apparent the discrepancy between chronological age and skill levels and readiness for independence. Developmental age is a better guide than chronological age to assess the child's current and future needs. Both parents and children with Asperger syndrome are highly reactive to a placement of their child or adolescent in groups of individuals with low levels of intellectual function or mental health diagnoses. Children are aware of intellectual differences and resistant to inclusion in lower performing groups. Thus, a mismatched placement may result when child and parent refuse to participate in education or treatment settings. If placed in such a setting, children may become actively resistant to the classroom or the treatment interventions (Heumer & Mann, 2010; Kenworthy et al., 2010a, 2010b; Spek, Scholte, & Van Berckalaer-Onnes, 2010; Valla et al., 2010).

The child with a diagnosis of Asperger syndrome or high-functioning autism or pervasive developmental delay may not be accepted or function well in the integrated classroom (inclusion) model of public education. Children diagnosed, as ASD, may have a range of functional levels that makes grouping children problematic for social skill, pragmatic language, and development of self-management (Jones & Campbell, 2010; Jones & Meldal, 2001; Kenworthy et al., 2010a, 2010b; Mesibov & Shea, 2010).

If the inclusion option is not appropriate and grouping children by diagnosis is problematic, what guide can parents use to assess choices of placements? Parents face a dilemma. They may be provided with a placement that is designated for the diagnostic category of their child, such as autism spectrum disorder, but is inappropriate because the classroom consists of a peer group of far lower function and performance than that of their child. Another problem may arise when an AS child enters a classroom with peers who demonstrate aggressive or dangerous behaviors. Some parents report that they have few options or one option only or must "take the placement or have no appropriate available service." Although Individuals with Disabilities Education Act (IDEA) is meant to meet a child's need for education and related services at no cost to the family, the result may be far from free. Some parents report that they locate and provide the appropriate services at their own cost or are faced with costly litigation (Grace, 1998; Jones & Meldal, 2001).

Developmental Changes and Learning

Individuals on the autism spectrum differ in their rates of developmental change, the pace of their learning, and their acquisition of social skills and academic skills in language arts and mathematics. The prerequisites for success in academic tasks must be taught to the child. Prerequisite tasks for academic success include levels of information processing, development of appropriate social perspective, social judgment, and pragmatic language. But each child on the autism spectrum develops at a different pace. Thus, performing prerequisite skills will take some children longer than others. The higher-order development of the cognitive skills of analysis, synthesis, and evaluation of data is also associated with a child's developmental age and IQ and, to a lesser degree, diagnosis. Integrated classrooms may present a range of student needs and abilities difficult to meet by the assigned teacher.

The child's diagnosis is intended to predict a prognosis for the child. The diagnosis should also guide the selection of a treatment regimen that results in reliable progress. But for this to occur, accurate diagnoses require empirically based indices to be valid and reliable. The current level of science yields no phenotype for autism, high-functioning autism, Asperger syndrome, or pervasive developmental delay (Milshtein et al., 2010; Oosterling et al., 2010).

The differences among the diagnoses on the autism spectrum are confusing to parents. Yet the combining of diagnoses into one category, autism spectrum disorder as a single diagnosis is no less confusing. ASD as a diagnosis is problematic for selecting the correct psycho-educational strategy, clinical therapy, and psychopharmacological choice. The most useful diagnosis will result from periodic, thorough review of the individual's case history to elicit the characteristics of the disorder and the priority for ameliorating the characteristics, such as impaired self-regulation, and social interactions that interfere with cognition and behavioral adaptation (Baker, Messinger, Lyons, & Grantz, 2010; Brown et al., 2011; Carbone, Behl, Azor, & Murphy, 2010; Griffith, Hastings, Nash, & Hill, 2010; Taylor & Seltzer, 2010).

Key Question: Asperger Syndrome: Category or Dimension?

A key question that must be resolved prior to planning treatment rests on whether autism spectrum disorder is a dimensional structure of symptoms. Corollary questions involve the validity of discrete phenotypic classifications or nosologic types of ASD, that is, autism, high-functioning autism, pervasive developmental delay-not otherwise specified, and Asperger syndrome. A question that plagues researchers, parents, and professionals is whether the subtype diagnoses are qualitatively distinct disorders or quantitative manifestations of the same disorder (Kamp-Becker et al., 2010).

No clear empirical data exist at this time to answer these questions (Mayes, Calhoun, & Crites, 2001; Owley et al., 2010). The current trend in the literature is toward the acceptance of an autism continuum without empirical support for the concept. In 2010 and 2011 researchers in one journal may label subjects as ASD or by separate diagnosis or by small groups that blend diagnostic labels. Not only do researchers now blend subjects with different diagnoses but also often combine subjects with different developmental ages in the same sample group. The most important threats to the validity of research outcomes are small samples, combined diagnoses in the sample, and combined developmental ages.

Neuroscience provides insights into the etiology of behavioral characteristics associated with Asperger syndrome and other autism spectrum disorders. Parents, teachers, school psychologists, and other members of the multidisciplinary team often look to pediatric neurologists and neuropsychologists to help interpret behavior patterns. The goal is a comprehensive plan that includes therapeutic and educational strategies to compensate for deficits and capitalize on strengths (Anholt et al., 2010; Bal et al., 2010; Cohen, Gomez et al., 2010, Cohen, Tsiouris et al., 2010; Congiu, Schlottmann, & Ray, 2010; Dereu et al., 2010; Georgiades et al., 2011; Gold & Faust, 2010; Semrud-Clikeman, Walkowiak, Wilkinson, & Butcher, 2010).

Focus on Behavioral Characteristics

Neurological factors specific to developmental delay, learning disabilities, and characteristics of AS students are associated with the dominance of the right hemisphere of the brain over specific functions (Devinsky & D'Espositio, 2004). Functional brain imagery and electrophysiology studies indicate that the right hemisphere has dominance over critical factors that influence how we experience an awareness of "self," of our abilities, and of the results of our activities. The lack of such awareness influences how we present ourselves to others. Sense of self results from our ability to process interactions with others (Bigham et al., 2010; David et al., 2010; Gadow et al., 2010; Huang, Cheung, & Akbarian, 2010; Rinehart, Bradshaw, Brereton, & Tonge, 2002).

Persons diagnosed with AS may be inferred to have limited self-awareness due to impaired right hemisphere dominance over not only self-awareness but also an awareness of how their presentation affects others. Asperger students have deficits in their learning of social skills and their perceptions of behavioral expectations communicated to them by others. Dominance of the right hemisphere controls the recognition of one's own face and the ability to describe one's feelings of fear, grief, morbid thoughts, and joy. Right hemisphere functions influence our feelings of depersonalization and the ability to report those feelings. The ability to connect relationships between past and current experiences, our source memory, has a locus of control in the brain's right hemisphere (Mazefsky, Conner, & Oswald, 2010; Rinehart et al., 2002; Roberts et al., 2010).

Asperger students are observed to create a false persona with conviction and belief. This is due in part to the lack of interference from actual memories of authentic past experience. Students understand as they become teenagers that they "should have" an interesting personal history. One boy of 18 who attended The Learning Clinic reported to his physician that he was a college student (false) at Harvard and that he has a challenging part-time job that paid very well and enabled him to live off campus. All that the boy reported was false but was said with such personal conviction that it was believed. The lack of a personal, historical memory of events influences the development of an accurate, consistent, reliable persona. In their use of social media, Asperger students used false names, made up histories, and exaggerated descriptions. While typical students may exaggerate also, Asperger students do so more often and to a greater degree. Absence of "source memory" over the course of a child's development competes with the formation of an accurate self-image (Bigham et al., 2010; Foley Nicpon et al., 2010).

Tangential thought and rambling, vague, loquacious speech are characteristic of Asperger syndrome and are associated with right hemisphere dysfunction. Concurrent subvocal editing while speaking is missing in Asperger students. The lack of prosodic communication and expressive gestures is evident along with flat affect and impaired awareness of social contexts. These behaviors are often misinterpreted as evidence of depression (Koenig et al., 2010; Lane, Young, Baker, & Angley, 2010).

Volition, Planning, and Reasoning

Another characteristic sign of right hemisphere dysfunction is impoverished modulation of volition (will). Volition relates to the ability to select an action and follow through or engage in metacognition where a judgment is made by comparing and contrasting data to act on options. The result of inadequate operation of right hemisphere function impacts ability to think ahead, plan, predict consequences of actions, and delay gratification. Right hemisphere disorders impair social awareness and result in the inability to comprehend emotional and social cues.

The student's high IQ does not overcome the lack of social pragmatics needed to form friendships and other close personal relationships. Nor is lack of motivation for social acceptance overcome by intelligence. And high IQ does not ensure that the Asperger student will understand the nuances of inferential reasoning required to interpret figures of speech and sarcasm. The right hemisphere also has dominance over performance in mathematics, visual-spatial skills, and motor persistence. The ability to perform two motor acts simultaneously is also associated with right hemisphere functions (Fournier, Hass, Naik, Lodha, & Cauraugh, 2010; Frankel et al., 2010; Valla et al., 2010).

The human brain is malleable. Lost skills may be rehabilitated. The acquisition of new skill sets is obtainable if the instructional ecology is supportive and behaviors engaged in routine application. Objectives require a personalized fit to the developmental age and observed talents of each person.

Wing and Gould (1979) and Wing (1988) reported three separate dimensions to the behaviors associated with Asperger syndrome. Wing later added a fourth dimension. These included (1) aloofness; (2) passivity; (3) active, odd, and inappropriate approaches to other; and (4) failure to acquire social rules through the course of normal development. While social rules may be learned, rules are applied rigidly by the Asperger syndrome person. These behaviors are components of social communication deficits (SCD) (Georgiades et al., 2011; Lasgaard, Nielsen, Eriksen, & Goossens, 2010; Loth, Happe, & Gomez, 2010).

More recent research shows an autism spectrum of disorders (Baron-Cohen, Wheelright, Skinner, Martin, & Clubley, 2001; Kim et al., 2011; Lauritsen et al., 2010), but the defining criteria that differentiate subgroups are not clear (Van Meter et al., 2010). As a result many individuals are diagnosed incorrectly (Hilton et al., 2010). Diagnostic error may also be a consequence of cultural bias or measurement and case identification methods (Kim et al., 2011) or retrospective data. AS, HFA, autism, and PDD-NOS are described to have overlapping symptoms that differ in degree (Georgiades et al., 2011; Mayes et al., 2001). These diagnostic groups as well as schizophrenia require more research to specify firm differentiating characteristics (Russell-Smith et al., 2010). Clear diagnostic genotype and phenotype categories are needed to help explain etiology, academic performance, and social development. However, the medical model of classification used by the DSM-IV and ICD-10 may be ineffective for prescribing treatments. The degree of severity of characteristics may best be described as points on a continuum of symptoms (Klin, Volkmar, Sparrow, & Cicchetti, 1995) rather than as a single diagnostic classification of symptoms. The problem remains that there are no age-related norms for ASD characteristic expressions of phenotype differentiation (Oosterling et al., 2010).

One such characteristic is intelligence. Educators and clinicians are often asked to interpret the meaning of intelligence in the context of a PDD-NOS diagnosis, or an Asperger syndrome student profile, or a child described as high-functioning autistic. The current state of knowledge provides little clear guidance to professionals who are required to provide answers.

Intelligence

Intelligence test scores do not necessarily predict classroom success nor do the scores predict skills associated with higher-order cognitive task. Information processing, retention of higher-order skills, and problem-solving strategies are idiosyncratic and different for each Asperger syndrome student. Intelligence is one factor and, often, an important asset. However, the level of cognitive inflexibility observed in the behavior of Asperger syndrome, HFA, and PDD students competes with the adaptability required to solve novel problems or similar problems in novel situations. Intelligence measures of normal to gifted cognitive ability are not a reliable predictor of executive function and adaptability (Rinehart et al., 2002) among students with AS, HFA, or PDD.

Rourke (1995), Klin, Lang, Cicchetti, and Volkmar (2000), and Schopler, Mesibov, and Kunce (1998) state that normal and higher intelligence quotients are more frequently reported for students with an Asperger syndrome diagnosis. Asperger syndrome students demonstrate, but not to a statistically significant degree, higher verbal intelligence than performance scores by about two standard deviations on WISC III test (Meyer & Minshew, 2002). Intelligence scores indicate greater learning potential for Asperger syndrome students than for students with an autism disorder diagnosis who may score in the 70-point full-scale range. The WISC-R or Stanford Binet IQ score is a helpful guide to teachers in planning instructional programs since intelligence scores are typically stable and reliable overtime (Canivez & Watkins, 1998). But even higher intelligence test scores require further analysis. The full-scale score places the student on the normal curve in relation to others of his chronological age. The detail in the subtest score pattern on each of the two types of tests, verbal or performance, provides a profile of specific strengths and weaknesses (Ozonoff, South, & Miller, 2000).

Memory, "Anxiety," and Performance

Other dimensions of Asperger syndrome are memory, information processing, and "anxiety," as well as the four dimensions reported by Wing and Gould (1979) and Wing (1988). All dimensions of Asperger syndrome may compete with learning and are associated with academic performance deficits. These same factors may be similarly present in the variations in performance of students with autism, HFA, and PDD. Aloofness, passivity, active, and odd inappropriate approaches to others and the inability to acquire social rules through typical developmental experience may impede the AS student's attempt to meet the classroom role requirements (Bowler, Gaigg, & Gardiner, 2010).

Little (2001) reports that Asperger syndrome students experience ridicule and peer "shunning" in 94 % of the cases in a survey of over 400 parent reports. Peer rejection may contribute significantly to school avoidance and to declines in academic performance. If the child avoids attending school, he is less likely to learn and socially interact with peers. Certainly AS symptoms contribute to social isolation and to the ongoing inability to develop social and communication skills with peers. Left to his own devices, the AS student has the odds against him for school success. Positive social contact is necessary to develop the social skills needed for effective communication with others, at home, at school, or on the job (Ekas et al., 2010; Gulsrud, Jahromi, & Kasari, 2010; Stichter et al., 2010; van Roekel, Scholte, & Didden, 2010).

Communication

The research on levels of pragmatic language skills demonstrated by Asperger syndrome students over the last decade reveals a consistent pattern of pragmatic language deficits (DuCharme & McGrady, 2003). Asperger syndrome students have more difficulty communicating with peers than with adults. And they have more difficulty communicating with peers and adults than do "typical" comparison groups (Koning & Magill-Evans, 2001; Koenig et al., 2010; Lasgaard et al., 2010).

Reliable self-estimation is associated with reliable, safe social reciprocity with both adults and peers. Standards for the school community that endorse and monitor freedom from bullying, shunning, and ridicule are important. Standards are necessary to be defined and endorsed by administrators, teachers, and peer role models. Sense of threat increases anxiety and impedes social risk taking needed to communicate openly (Foley Nicpon et al., 2010).

AS is, in large measure, a communication disorder. Understanding language processes illustrates that language is the partner of memory and shapes the essential concepts for social learning, pragmatic skills, and internal control over behavior (Jolliffe & Baron-Cohen, 1999; Koning & Magill-Evans, 2001). Language and behavior patterns become increasingly difficult to remediate as the child moves from preadolescence to young adulthood. Odd behaviors such as self-talk, isolation from peers, cognitive distortion, and denial of aberrant behaviors become ego-syntonic and highly resistant to treatment (Golan et al., 2010; Jolliffe & Baron-Cohen, 1999).

AS students often appear, at first view, to be verbally bright, facile, and effective in their communication. A more careful analysis of their language structure, cognitive flexibility, word use, and especially their ability to process connotative meaning reveals substantial deficits (Church et al., 2000).

The AS student is often characterized by teachers as literal, concrete, inflexible, and tangential in verbal expression. These behaviors become more frequent as the child moves from elementary to middle school, junior high, and high school. The AS child is then subject to an increasing number of teachers with academic content specialties. As these teachers establish personal instructional styles, classroom routines, and grading expectations, the AS child's performance becomes more discrepant with peers. As grade level increases, the level of symbolic and abstract language used by teachers also increases. The child's immersion in such language creates a situation that accentuates the child's difficulties (Adreon & Stella, 2001).

The AS student demonstrates uneven language skill development (Barnhill, Hagiwara, Myles, & Simpson, 2000). Language levels are acquired through the curriculum at developmental stages: sounds (phonemes), word bits (morphemes), semantic skills, syntax (sentence structure), discourse (large meaningful "chunks"), and metalinguistics (higher-order thinking). As the AS child grows older, these skills appear to be more delayed. To further complicate the child's educational life, the teacher and the curriculum require receptive language skills, reading ability, and expressive language. Teachers also demand written summaries, research reports, notes, and homework that challenge the AS student executive functions (DuCharme, 1972; Fondacaro, 2001).

The central point here is not to be misled by intelligence scores. Early language fluency and topical, narrow bands of expertise are often characteristics of the Asperger syndrome child. Further, we need to recognize that the child's language experience may be limited by his having few social contacts and few language models. Television programs and computer games are not known for high levels of language, syntax, or metalinguistic examples. Many children demonstrate receptive language deficits that add to poor language structure and pragmatics.

Task Analysis Guides Optimal Instructional Personalized Methods

Individualization most often refers to breaking down curricula into component parts and then into a linear progression toward a predetermined solution. Personalizing instruction focuses on the person's strengths and adjusts curricula accordingly. The instruction may use backward chaining steps, modeling solutions or imitative rehearsal, peer collaboration, and team-based solutions (Brusilovsky, 2004).

Professor Brusilovsky has researched adaptive navigation support using adaptive hypermedia to compete with the idea that one-size curricula fit all.

Task analysis is defined as the identification of the set of behaviors and abilities students need to perform a task. The AS student's initial experience with an unfamiliar task depends on the structure of the task along with the student's ability to perform the prerequisite skills needed to complete the task. Brusilovsky (2004) describes in detail how technology may be adapted to capitalize on tech-knowledge, student knowledge, and uniqueness to benefit from user-friendly technology-based curricula.

Teachers at The Learning Clinic (TLC) use a task analysis approach to instruction. The first step is to classify the task by its type, size, and kind. For example, to determine the kind of task, the teacher looks at content, interaction, and prerequisite skills. In a *content* task, the teacher determines teachable components, the relationships among components, and the sequence of instruction. In content analysis, each component represents a response or set of responses. The teacher states each component clearly as a behavioral objective. The objective needs to meet the criterion of appropriateness for the child's developmental age. The objective must emphasize consequent prerequisite skills and adaptive technology applied to curricula. The relationship among components may be as follows:

Superordinate (A must be learned before B)
Coordinate (components may be learned in any order)

Interaction analysis requires the teacher to specify the teaching procedures for each component of the task. The teacher must define the degree of practice (i.e., massed or distributed). The teacher must also describe the degree of interaction with the student, such as ways to prompt, confirm, or model students' responses. The teacher's method of presenting the task must be stated. The teacher might prescribe forward chaining, backward chaining, or total task presentation.

- In forward chaining, you present the elements of the task in the order that is needed to complete the task.
- In backward chaining, you begin with the final product and work back to identify elements and their relationship to one another.
- In total task presentation, you present the complete task along with all its elements.

The teacher prescribes the emphasis on elements and the effective presentation to match the Asperger syndrome students' interests and developmental age-related capabilities.

The third type of analysis is *prerequisite* task analysis. This type of analysis defines the abilities and previous experiences needed to perform the components of the task. If the Asperger syndrome student is weak in prerequisite ability, the teacher may do the following:

- Teach the prerequisite skill before beginning the task.
- Adjust the material to compensate for a student weakness (e.g., dysgraphia, compensated for by use of the computer).

The *size* of the task refers to the number of units or to a skill hierarchy. The *kind* of task might be perceptual-motor as in catching a ball or buttoning a shirt. Another kind of task is *symbolic* – conceptual as in reading, writing, and computing. The more abstract the final objective, the more complex the task. Bloom's (1956) taxonomy of the cognitive domain offers examples of kinds of tasks.

The purpose of task analysis is to examine the requirements of the classroom and, more precisely, the teacher's expectations of the AS student. Teachers often act on expectations for prerequisite behaviors that the AS student has not yet learned. When prerequisite behaviors are not clarified or taught, the AS student is likely to fail.

Content Task Analysis

The student's classroom role behavior can be examined using content analysis of teachable coordinate components. Fourteen components of behavior are described below:

1. *Attending Behaviors*. The teacher expects the student to demonstrate the following abilities:
   - (a) Sit in a chair at a desk for a specified period of time.
   - (b) Follow teacher directions.
   - (c) Orient to the task.
   - (d) Scan information from printed text.
   - (e) Discern task expectations from material presented.
   - (f) Demonstrate necessary visual–spatial capabilities.
   - (g) Focus attention on relevant stimuli.

   (h) Control attention to apprehend and start the task.
   (i) Shift attention to the appropriate task.
   (j) Repeat the task.
   (k) Ignore irrelevant, tangential stimuli and attend to relevant stimuli.
   (l) Perform multitask operations relevant to completing the task.

   The AS student is subject to distraction from sound (Bettison, 1996) and from sight (Burack, 1994). An unfamiliar task or a task that requires an association between a previously taught concept and new application of skill will shorten task perseverance (Minshew, Meyer, & Goldstein, 2002) and increase error rates.

   One-to-one or small teacher-to-pupil ratios help the student to sustain attention (Fondacaro, 2001). Conversely, large classrooms with high student-to-teacher ratios may lead to inattention.

2. *Responding Behaviors*. The teacher in a grade level or special education classroom expects specific levels of responding behaviors such as the following:

   (a) Verbal skill sufficient to communicate answers to teacher's questions or to articulate an academic content-based question or a reliable statement of feeling
   (b) Pragmatic language skill at a sufficient level to comprehend communication based on social judgment that is typical for peer and adult interaction in the classroom
   (c) Visual motor skill prerequisite for response to the typical task format, instructional method, or assistive technology
   (d) Writing skills prerequisite to basic task format and academic level required for classroom performance
   (e) Adequate level of comprehension of written or verbal material that requires a student response
   (f) Organizational, executive function skill to negotiate the classroom environment, academic task demands, homework, and/or independent organization of classroom-related materials such as teacher handouts, notes, and note-taking
   (g) Reading skill and reading comprehension ability required by text, CAI, or other instructional materials
   (h) The ability to reliably demonstrate a level of perseverance required by the typical classroom assignment given as class work or as homework
   (i) The ability to sequence information at different levels of cognitive complexity so as to meet the academic task requirement of the instructional material
   (j) Memory Skills
      1. Short-term memory
      2. Long-term memory
      3. Memory for facts
      4. Associative memory
      5. Memory for denotative and annotative items

The ability to demonstrate sufficient memory skills to acquire and retain academic content is often assumed. The student is expected to recall and apply the strategies and content when elicited by task requirements. All of these skills are part of the expectations inherent in the student role (Bigham, 2010).

The behaviors described as responding present problems for the student who shows the characteristics of AS. Verbal skills are present within a narrow band of interest, but broad-based knowledge and skill are typically absent. Problem-solving, facile recall of past solutions, and verbal negotiation are also absent skills. Students demonstrate consistent and persistent deficits in four categories of communication: topic, purpose, abstraction, and use of visual–gestural cues. Organization skills, inferential comprehension, memory, perseverance, sequencing, and ordering part-whole relationships are reported to be problems for AS students.

3. *Reinforcement Behaviors*. This pertains to a student's ability to the following:

   (a) Provide contingent positive social reinforcement appropriate to setting, situation, and persons (peer or adult).
   (b) Assert negative reinforcement in a contingent and appropriate way.
   (c) Receive, process, and respond appropriately to positive reinforcement and other classroom incentives such as grades, awards, status.
   (d) Perceive, accept, and understand negative reinforcement offered by authorities, peers, adults, and other persons.
   (e) Demonstrate a level of motivation in response to either positive or negative reinforcement used in the classroom setting.
   (f) Demonstrate evidence of a hierarchy of internal self-reinforcement consistent with classroom values and sanctions.
   (g) Create hierarchical menu of positive reinforcers.
   (h) Show a positive response to vicarious reinforcement used in the classroom such as imitation of student behavior following the positive reinforcement of that student's behavior.

The student's under-reaction to reinforcing stimuli is observed in relation to motivation. Reinforcement is observed as a cue to associate behavior and responses and as a motivator for future performance. Sustained, goal-oriented behavior is absent, thereby making delayed reinforcement ineffective. Little reinforcement, positive or negative, is offered by the students at TLC in their spontaneous interactions with others (Koegel, Singh, & Koegel, 2010).

Punishment, on the other hand, through response cost systems, loss of activity, status, or privilege is observed to elicit anger, threat, avoidance, and defiant behavior and may regress progress previously demonstrated in areas other than the target of punishment.

4. *Initiating Behaviors*. Task initiation includes the following abilities:

   (a) Direct oneself so as to anticipate and comply with classroom routines.
   (b) Follow directions provided by computer-assisted instructions.

  (c) Follow teachers' directions to begin classroom tasks, activities, transitions.
  (d) Start a task according to the directions in the text.
  (e) Begin tasks that require the student to use visual-graphic-icon cues.

  It is observed that self-direction, teacher direction, and written direction are unreliable methods to elicit task initiation. Computer-assisted rehearsal, teacher-coached performance, and the use of icons and visual-graphic directions are effective. These conclusions are based on single-subject, multiple-baseline, repeated measure designs assessed over time at TLC.

5. *Complying Behaviors*. This refers to the student's ability to meet task criteria and teacher standards. Task compliance is shown by the following:

  (a) Accepting correction from teachers, aides, and sometimes peers
  (b) Accepting correction in the public, open situation of the classroom
  (c) Correcting assignments, reading assignments, and redoing assignments in a way that corresponds to a predetermined standard

  These behaviors – attending, responding, reinforcement, initiating, and complying with standards – present major obstacles to a student with a diagnosis of AS. The ability to meet task criteria and teacher standards is dependent upon the fit between the student, the task, and the task analysis.

  If the task analysis is correct, and a mastery learning model is used that allows the student to repeat trials and to correct errors, then standards are predictably met (DuCharme, 2001). Teacher-centered instructional methods, lecture formats, and delayed correction and feedback to students are not effective, as measured by student performance on academic tasks. Additional expectations that may reveal problems for the AS student are examined below.

6. *Completing Behaviors*. The ability of the student to finish the assignment depends on the following:

  (a) Performing specific tasks according to the presented method
  (b) Working independently or dyad or small group
  (c) Returning a completed product to the teacher

7. *Transitioning Behaviors*. The ability to move from one task to the next and to recognize when to stop one task and begin another depends on the following:

  (a) Taking independent steps between tasks (e.g., the student can follow a multistep strategy to solve a math problem and then change from math to science or other kind of task)
  (b) Recognizing and using prompts that signal the need to move from one task to another or one task segment to the next

8. *Cooperating Behaviors*. Students are expected to display and maintain a demeanor appropriate to the classroom such as the following:

(a) Taking turns in discussion
(b) Waiting for another person to finish speaking
(c) Avoiding arguing
(d) Maintaining appropriate speech volume
(e) Sharing equipment (e.g., computer time)
(f) Avoiding ridicule of peers or responding to peer ridicule
(g) Displaying appropriate posture
(h) Maintaining eye contact
(i) Requesting to exit the classroom

AS students, though desiring positive peer relationships, are ill equipped to control their odd behaviors, clinical symptoms, and poor pragmatic language deficits. Soderstrom, Rastrum, and Gillberg (2002) report on characteristics of adults with an AS diagnosis. The most common AS temperament is characterized by obsessive, passive dependent and explosive features. The Asperger syndrome individual demonstrates a desire for peer relationship and attempts to fit into mainstream expectations (Jones & Meldal, 2001). Little (2001) conducted a peer-victimization survey with a response rate of 441 (70 %) parents of AS and NVLD students. The survey data is arranged by age, gender, and diagnosis. Ninety-four percent of the respondents reported assault or shunning by peers and siblings.

9. *Competing Clinical Behaviors*. The classroom norm expects AS students to work without distracting or disturbing others. The teacher must prescribe instruction that competes with the clinical symptoms listed below:

(a) Perseveration on a topic not related to the classroom instruction
(b) Obsessive thought
(c) Inability to shift topics from personal view to data-based view
(d) Threatening behavior, verbal aggression
(e) Dichotomous thinking – win–lose orientation to discussion
(f) Confabulation
(g) Affirming false (data) information
(h) Not taking responsibility for own actions and resisting accountability
(i) Stealing
(j) Sexually inappropriate comments
(k) Violation of personal boundaries
(l) Cognitive disorientation and distortion of information

The combination of adaptive technology in direct guidance to users for “intelligent CAI tutoring,” evidence-based instruction, medication therapy, and cognitive behavioral therapy is recommended for treatment. Behaviors such as speaking out, exiting the classroom without permission, expressing tangential ideas, self-talk, or other behaviors may be reduced (DuCharme & McGrady, 2003) and overcome by personally matched curricula and supportive technologies (Brusilovsky, 2004).

10. *Adapting Behaviors*. The ability to move from class to class and to follow the teacher’s prescribed schedule requires explicit directions. Different teachers may

have different classroom procedures and schedules. Some teachers have unpredictable, flexible routines that present change in each class. Such classrooms may be described as unilateral and unreliable. To adapt to classroom routines, the student must learn to do the following:

(a) Identify the particular schedule and routine of each classroom.
(b) Follow the schedule and routine.

"Closed" classroom environments, such as self-contained classrooms or schools that prescribe consistent routines, provide greater structure and predictability. The AS student will more readily learn the reliable expectations of a closed setting. Such classrooms are described as unilateral and reliable (Tharp & Wetzel, 1969).

"Open settings" are environments that require multiple transitions within and between classrooms. The "open setting" requires that the student initiate and regulate performance and cooperation. "Open settings" are most suited for group activities that are interactive and oriented toward symbolic–conceptual tasks. The complexity of the task requires a high degree of ability to solve abstract problems. "Open settings" are the most difficult for the AS student to negotiate.

11. *Cooperating with Medication Administration*. The ability of the student to accept his need for and use of medication may be prerequisite to performing in the classroom. The student's ability to accept the need for medication on a prescribed schedule may also be prerequisite. The probability that an AS student will require medication as part of a dual diagnosis with comorbid conditions for treatment is increasing. Attention deficit disorders, bipolar disorders, depression, and other mental health conditions require a regimen of medications (Ghaziuddin, Weidmer-Mikhail, & Ghaziuddin, 1998; Kim, Szatmari, Bryson, Streiner, & Wilson, 2000).

Important skills to teach are as follows:

- Following prescribed schedules of medication
- Managing one's own medication

12. *Depending on Structure*. It is reported in anecdotal and clinical observations that students with an AS diagnosis are structure dependent. The researches at TLC over the past decade support such observations. The general school curricula include recess, physical education, music, art, and lunch visits as part of a weekly student schedule. These types of activities are less structured, more open, and more dependent on self-initiation and self-regulation. Most AS students have problems with less structured activities and unreliable expectations for interaction with adults and peers. Poorly designed curricula mismatched to student abilities and interests are too dense to process and compete with student performance.

Art and music are particularly important experiences for AS students since these activities often coincide with abilities, talent, and interests. The structure of the activity, task type, size, and kind and technology applications are related to the student's successes. In physical education classes the student's gross motor awkwardness may compete with success or participation. Students have demonstrated, with sufficient support and routine, ability to participate in cross-country running, swimming, tennis, baseball, archery, and other sports. Students are also able to meet appropriate curricular expectations in academic content areas like the ISIS-Tutor system or ELM-ART electronic books. These are examples illustrated by Brusilovsky (2004) in his work.

Recess and cafeteria time are most problematic for AS students. At these times the student's social oddity, poor pragmatic language, self-talk, and fast walking offer targets for peer ridicule and shunning.

13. *Completing Homework*. The completion of homework to fulfill standards and submission of work on time are two of the most frequent complaints of parents and students about teacher requirements. The lack of homework preparation and failure to complete the work on time result in poor grades and discipline issues. Independent work at home and study time at school require that students remember academic strategies and apply them appropriately. The student is also expected to be sufficiently organized to remember books and materials needed for independent work. Technology may provide user supports that transfer tutorial assistance through web-based access across settings and personalize interests to increase both support and motivation.

14. *Attending School*. The ability to maintain regular attendance at school is a critical component of classroom performance. Mastery of patterns and expectations are associated with regular attendance. All of the above components of performance expectations are factors in a student's attendance or avoidance of school and the classroom.

    Regular school attendance doesn't always predict classroom attendance. A recently referred student produced a record of excellent school attendance. The vice-principal was his "best friend" as he spent most of his school day in the principal's office and not in his classroom.

    Our content analysis of classroom expectations is not all inclusive nor have we presented teachable subcomponent skills hierarchies. However, the list of tasks does present a picture of misfit between the characteristics of Asperger syndrome and the expectations inherent in a classroom.[2]

Cognitive Resources

Cognitive load theory (CLT) offers research that is particularly relevant to precise task analysis of academic content. CLT is concerned with the manner in which cognitive resources are focused and used during learning and problem-solving (Sweller &

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[2] A TLC classroom Student Performance Assessment protocol is available at www.thelearning-clinic.org.

Chandler, 1991). The main goal is to guide decisions about instructional design. CLT explores the relationship between instructional task design and the memory requirements associated with the academic performance of AS students (Jones et al., 2011).

CLT is based on assumptions about human cognitive structure. The theory postulates the relationships between long-term memory capacity, schema of mental representation of knowledge, and limited processing capacity of working memory. The mechanisms of working memory have executive control over visual–spatial information such as text and pictures and the phonological loop for spoken text or music. Understanding the limits of capacity and independence of function of these systems may shed light on mastery issues associated with AS.

Measuring cognitive load depends upon self-report measures and objective measures such as physiological, behavioral, and learning outcome measures. The measurement of cognitive load as part of task design and analysis helps us to define the difficulty of different types of learning materials. Learned information may be recalled and applied by AS students according to its cognitive load measures.

Toward an Optimal Classroom

The recommended instructional methods were tested at TLC with students diagnosed with AS according to DSM-IV criteria, male and female in a ratio of eight-to-one, of adolescent age, and demonstrating a dual diagnosis that includes attention deficit disorder, depression, anxiety disorder, specific learning disability, obsessive compulsive disorder, and aggressive patterns of behavior. All the students demonstrated normal to gifted intelligence quotients as measured by the WISC-R III.

During a 10-year period, 150 Asperger students were referred for services because of school failure, school avoidance, and clinical issues. All the students were identified through the IDEA procedures and standards in order to be eligible for special services and meet section 504 criteria.

The following list of instructional modifications for the student with an AS diagnosis is outlined by topic and key factors. An “optimal” modification is stated as a general recommendation. For example, if *identification of staff* is the topic and key factors are listed as follows:

- Number of staff interacting with each student
  - Each period
  - Each morning
  - Each afternoon
  - Total individual staff each day
- Definition of staff role
  - Primary staff – self-contained classroom
  - Content specialist teacher
  - Teacher – disciplinarian

- Academic teacher and social skill teacher and counselor
- Teacher – subject, tutor, technology

Then the recommendation is as follows:

Optimal. Optimal is defined to be the staff role that will yield the greatest benefit to the student. The optimal staff role in the example above prescribes one "coach" for monitoring student performance and providing academic tutorial and social skill instruction in vivo, all classes.

Instructional Setting

The "open" versus "closed" environmental influence on social learning and compliant behavior is described by Tharp and Wetzel (1969) in their examination of the variables connected to behavior modification in the natural environment. Open environments require self-regulation of transitions, interactions with others, and movement in space. "Closed" environments provide external control over behavioral options, number and type of transitions, pre-planned schedules, social and instruction prompts, and degrees of personal freedom earned through reinforcement menus based on standards for performance.

Optimal. Behavioral standards and choices designed for AS students are limited, precise, and based on the level of self-regulation ability. A closed environment is more effective for instruction and social skill development than an open environment.

Class Size

Adolescent students in TLC programs report that the size of the group is important to them. The instructional task and level of complexity also influences their ability to master new academic information. There appears to be, according to student reports, a relationship between the task, the size of the instructional group, and the rate of learning (DuCharme & McGrady, 2003).

Optimal. Teachers' experience over the past 20 years shows that the optimal group size is over three students but fewer than ten. One-on-one instruction, in tutorial format, is best to introduce new, complex cognitive material and to monitor the acquisition rate and retention of skills. KBS-Hyperbook, AST, SIGUE, and InterBook have shown navigation support that is non-sequential to assist the user achieve better access to new knowledge (Brusilovsky, 2004).

Environmental Structure

According to *Webster's New International Dictionary, Unabridged* (1934) definition, structure refers to "the interrelation of parts as dominated by the general character of the whole, as the structure of society or the structure of a sentence ….” Structure, then, is an organization of parts in order to make a unified whole. The student with an AS diagnosis requires a cohesive, precise educational structure. The student’s success depends on the way in which the structure of the child’s experience at school is defined and communicated.

A whole school approach is designed to coordinate expectations, standards of conduct, sanctions, and student–staff roles across settings. This appears most beneficial when designed on the basis of the student’s developmental needs (Grace, 1998).

TLC accomplishes the aim of designing a defined structure by employing the whole school with fidelity of treatment model. An example of the effect of fidelity of treatment is shown by an orchestra. In a group of wonderfully talented musicians, one might perform a solo, the strings would have their part, and the brasses theirs. An orchestra leader conducts. The sheet music keeps everyone focused on the piece. Each musician plays particular notes. Harmony passes to our senses and we experience melody. But what happens when a musician plays an unrelated sheet of music? Discord. Discord in the experience of children with AS is a negative and serious outcome.

A school demonstrates fidelity by defining role expectations, creating standards for the behavior of community members that are in agreement with the school mission and developmental needs of children. Procedures are used to ensure accountability of all members. Specific processes for open grievance and conflict resolution require written description and open access.

There are various means to communicate structure to the student. The structure may be cued by the adult staff with clear, succinct verbal messages. The environment may be arranged to prompt student behavior. A procedural education and treatment approach is used by TLC staff in the form of a written manual for staff, students, and parents.

Optimal. Cues and prompts are needed to maintain the student’s perception of the structure designed for him. Guided instruction is optimal for successful task completion through adaptive technology applications.

- Daily plans and standards for self-monitoring their performance during and at the completion of an academic task are consistently reported as helpful by students.
- Checklists and digital devices (organizers) provide prompts and reminders that assist students in keeping schedules through CAI tutorials.
- Assigned workstations, individual computers, prewritten daily plans, and schedules for each student can serve as prompts.
- Peer coaching or tutorial may guide student performance with text or script for additional guidance.
- Icons and ideograms illustrate steps needed to perform tasks.

Discipline

The need for a reliable system of discipline is one of the most frequent requests of students when they arrive at TLC. Many students perceive rules in their previous schools as not enforced reliably. The “inflexible” approach of Asperger syndrome students to rules and their reliance on predictable structure contribute to their sensitivity about "rule breakers." Students report that they want to "know the rules." They want rules to be consistently applied. They want the whole school to have the same rules, standards, and sanctions.

Students with AS are frequently the "junior attorneys" of the school. They quickly recognize violations of rules in others that go unpunished. They explain how their behavior doesn't quite fit the description of a violation however if they are confronted with their violation.

The effectiveness of the clarity of direction given to students, the time allowed understanding the direction, and the consequences increases student compliance with rules. The clarity of direction states what the student has to do. The direction is precise, brief, and within the response repertoire of the child. Then, at least 10 s is given for the student to process the request and to respond. The 10-s time for response is based on researches by DuCharme in 1972 that measured response latencies for children of different development ages when given verbal learning tasks. The use of the flow chart results in consistent improvement in compliance and decreases the need for negative consequences.

The teacher's ability to wait a sufficient amount of time for a student to process a request and to respond is critical to the student's ability to comply with the request. We have observed students who had been defined as "elective mute." The "mute behavior" is indicative of the student's inability to respond within the time allowed by the teacher. The child may require more time to formulate and express a response than is allowed. In such cases, the child is not mute. He simply requires more time than the teacher typically allows him to answer.

Optimal. A precise, reliable, school-wide behavior management system in combination with clear verbal directions and sufficient time allowed for response is best for Asperger syndrome students.

Student Diagnosis and Classroom Mix

The diagnoses of other students in the classroom are important. The diagnosis of AS, even with comorbidity, is compatible with some diagnostic groups and not others. First, the comorbidity associated with an AS diagnosis determines inclusion criteria. Analysis of the mix of AS students with students who have other disabilities raises certain questions. Is the ratio of diagnosed to non-diagnosed students discernible to the teacher? If so, is the teacher able to teach children within the range of diagnoses? Can students who have medical needs be served given the mix of clinical issues? Is the student intelligence quotient a factor for inclusion or exclusion in the class?

AS students are diagnosed within a normal to gifted intellectual range. Frequently, in our experience students with intelligence quotients of 75 or lower have an erroneous AS diagnosis. The instructional methods and curricula for a student with an IQ of 75 are profoundly different than those for students with a 136 quotient.

AS students do not perform well socially or academically in classes with students diagnosed with conduct disorders, disruptive, or aggressive behaviors. The AS student is intimidated and/or exploited by students who are prone to victimize their more vulnerable peers (Guttmann-SteinmetzKenneth, Gadow, DeVincent, & Crowell, 2010; Semrud-Clikeman et al., 2010; Staples & Reid, 2010; van Roekel et al., 2010).

Optimal. The absence of students who have below average IQ, conduct disorder, and acting out–aggressive behavior is optimal for a student with an Asperger syndrome diagnosis in the classroom.

Teacher-to-Student Ratio. The teacher-to-student ratio depends upon a number of variables such as type, size, and kind of task, number of classroom distractions, clinical issues, and level of skill that the student is able to demonstrate. The range of options for instructional ratios also depends upon school resources. The optimal group size for general instruction is over three and under ten students. But within that range, it must be noted that the preferred ratio is one-to-one when new information, instructional strategy, or novel application is to be taught.

Optimal. One-to-one tutorial instruction is best for the AS student in the classroom; focused supervision model, for example, selected targets for intervention, is prioritized for instructors. The flexible applications of adaptive electronic textbooks assist in teacher or CAI tutor management of personalized instruction.

Instructional Methods

Earlier in this chapter, we discussed why educators face obstacles to innovation in the classroom. But methods to overcome these obstacles are available to teachers and administrators in the form of computer-assisted instruction and newer, more sophisticated approaches called intelligent tutoring systems.

Brusilovsky has been a significant influence in the development of student-driven learning model. In this model students are put into problem-solving roles with assistance from digital tutors and avatars in dialogue with students. Such applications incorporate learning theory into the curricula and manage instruction of students by engaging them in formats that teach, correct, and advance academic content as appropriate to self-paced responses. For strategies to match students' interests, capabilities, and talent, please refer to the extensive work of Professor Brusilovsky in adaptive technology to personalize instruction through web-assisted digital text and CAI tutorials (Brusilovsky, 2004).

A recent article in *Monitor on Psychology* (Graesser, 2011) describes interactive computer-assisted curricula designed as intelligent learning environments that build on students' preexisting knowledge of technology and gaming experience. Teachers can insert specialist tutors and avatars into the curricula to engage students with academic content as well as with skills involved with writing and correcting essays.

One characteristic of AS students – the tendency to misread social cues – makes Asperger syndrome students particularly vulnerable to methods using collaboration. On the other hand, students can benefit from methods that are consistent, reliable, impersonal, individually paced, and interesting. Resistant learners and students who are interested and familiar with computer-assisted instruction (CAI) benefit from the use of CAI.

The best methods for students with an Asperger syndrome diagnosis are based on the individual's characteristics. The general characteristics of Asperger syndrome students are also important. The significant identifying markers of Asperger syndrome in current literature Klin et al. (1995), Schopler et al. (1998), and Frith (1991) are as follows:

1. Absence of desire for social interaction and avoidance of social interaction and misperception of social cues
2. Pragmatic deficits and decrease in competence with complex and abstract levels of language processing requirements and preference for picture cues and ideograms
3. Restricted, repetitive patterns of behavior
4. Language processing difficulties and expressive language response latency
5. Resistance to criticism and performance evaluation by teachers and others
6. Sensory overload response to loud noise, too much verbal information, textual material with a "dense" level of content, unregulated pace of questioning, and short-time interval in response requirement
7. Negative responses to personal judgments of correct–incorrect performance
8. Deficits in short-term memory and recall of previously learned material

Optimal. The methodology that competes best with the issues listed above is academic task presentation through computer-assisted instruction (CAI). Such instruction provides the following:

- Consistent format
- Reliable mode and pace of presentation of tasks
- Progressive increases in task complexity based on performance evidence
- Rapid, contingent, correct–incorrect response feedback and scoring
- Controlled learning pace
- Impersonal presentation and assessment
- Motivation based on interests of Asperger syndrome students
- A controlled pace for reading text to the student

The computer-assisted tutorial format has been effective for hundreds of students over a 20-year period at TLC based on individual (single subject) performance reviewed weekly and quarterly as measured by an 80 % criterion.

CAI is a flexible method that may be used in a tutorial format, in dyadic collaboration, or in small group collaboration under teacher direction. TLC staff have recorded daily performance in each type of instructional format for Asperger syndrome with high degree, 80 % or above, successes during repeated application.

Interpersonal Style

The teacher's interpersonal styles are related to the student's success in the classroom. Observations of 50 different staff–student interactions over the past 20 years suggest that the teacher's characteristics make a difference. Asperger syndrome students appear to consistently benefit from teachers who are calm, clear, and positive in their communication.

"Directness" in communicating expectations and performance results avoids the problem of misunderstanding. "Directness" also decreases the need to revise messages, repeat directions, or correct student responses.

A *nonjudgmental* approach to student behavior is helpful. Asperger students are observed to react negatively to being told what they do wrong. The focus on "what to do" rather than "what was done wrong" is most productive. The Asperger syndrome student often seizes on the negative correction and perseverates. A calm, low-key personal demeanor appears to have a reassuring and calming effect on student behavior. The teacher who is precise, relevant to the student's interests, organized, and consistent has fewer problems with Asperger syndrome students. Further, student productivity rises in nonjudgmental settings.

The most effective teachers are those who focus on positive behavior and on behaviors that, if demonstrated by the student, will compete with or replace problem behaviors. Allowing negative or task-irrelevant behavior to occur is risky for both teacher and student. Learning a replacement behavior or corrective action is more difficult than practicing a correct response from the start.

Avoiding correction, with an emphasis on what is incorrect or with review of the error and attention to why the answer is wrong, produces unintended outcomes and resistance to redirection.

Optimal. Much better, in our experience, is a "backward" chain task analysis. Demonstrate the correct answer, solution, or sequence of steps from the desired result to the first step. Provide the student with a model of the correct answer and then teach the components.

Task Design and Academic Risk

The complexity of the task and the requirements of answering a question are variables that risk the student's success. Noncompliance and symptoms of perseveration, rigidity, oppositionality, and "anxiety" may be a response to a transition, especially if the transition is out of the ordinary routine and is not well rehearsed in advance.

Optimal. Take the needed time to rehearse the student by explaining the need for a transition. State precisely how and when the transition will be made. Allow sufficient time for rehearsal prior to the transition. Maintain continuity during rehearsal, the transition, and the completion of the transition. A staff "coach" should have the role to support transitions with rehearsal.

Before presenting a question the teacher should ask: What are the parts of a multilevel question? What is the cognitive level required by the vocabulary in the question? What is the student to infer that the answer requires? The cognitive "load" of the question is dependent on previous learning and memory and must fit the student's level of ability (Bloom, 1956). The structure of the question, the student's pre-assessed knowledge, and exposure to evaluation and judgment are risk factors to control and to gradually increase. Response modes available to the student may add or detract from risk. If a written response is required, and a time limit is placed on the answer, the risk is increased. If the student must read an answer aloud, additional risk is present.

Too much risk will prevent a student from demonstrating skills and abilities. The lack of an answer may not signify a lack of knowledge, but rather the student's inability to answer a question with the level of risk present. The manner in which the teacher enables the student to develop a tolerance for academic risk may vary. But the principle is the same: Taking risks is a skill and can be taught.

The teacher's level of sensitivity and creativity cannot be overestimated as an influence on the student's success. A teacher was observed speaking quietly, almost secretly, with a student who had a distressed look on his face. He stated that a scary movie about two girls would not leave his mind. The child said that he could not do his work. The teacher took an empty plastic container that had previously held a cookie and calmly said, "When the scary thought comes into your mind, then blow it into this box and cover it with the lid." The boy blew into the box and calmly reported to his teacher that, "It works!" He was very concerned when later that morning the lid fell from the box. He scurried to replace it.

Optimal. Control the level of academic risk in task design. When matching a teacher to a student with an Asperger syndrome diagnosis, stress the importance of an organized, calm, reliable, and creative approach.

Classroom Routine

The standard expectation at TLC is that each student, given an appropriate task and curricula, will complete 26 graded assignments to a minimum standard of 80 % correct each academic quarter. Academic performance is self-paced and governed by the completion of designated objectives, not by time spent in class.

Each student, with the teacher's help, establishes a daily schedule of academic subjects with time allotted and specific objectives for each subject. Academic performance is assessed by the end of each day, and a plan for the next day is started.

The number of assignments to be completed each day is recorded as well as the number of assignments that are incomplete and do not meet the 80 % standard criterion. Higher level cognitive material requires a higher standard of 90 %. The number of assignments and number of times assignments are redone to meet criteria is also recorded. The teacher adjusts the number of assignments per subject each day to ensure a practical expectation for performance. Assignments are adjusted according to ability level.

The student is given time in the schedule to select topics and tasks of interest. Opportunity for collaborative activity with selected peers and other adults is part of the student schedule. No homework is required other than reading or independent non-graded researches based on student interest. Note-taking in class is rarely a requirement.

A balance is necessary between tutorial instruction and collaborative learning. Most important is the teacher's opportunity to schedule focused dialogues with each student. Talking about their writing, music, and art is important to students who are developing a pattern to externalize their thought and to consider the responses of others.

Optimal. Schools should use *all* the strategies and procedures described above with significant effect for AS students.

Transitions

Transitions are defined as the changes in locations, attention, and responses to tasks that are required of a student.

An examination of transitions required by textbooks, workbooks, teachers' interpersonal styles, methods, and daily movements of people reveals hundreds of changes each day. If a child's symptom profile includes decreases in competencies and self-regulation during transitions, then we have probably created too many changes for the child. Programs with significant numbers and types of transitions are not easily negotiated.

Transitions in "performance" expectations on a single page of text may be too numerous for the student to handle. Attentional shifts required by changes in task demands or because of distractions alter the AS student's performance.

The teacher is advised to assess the degree of self-regulation expected of the student in the classroom. Expectations may change from one setting to another during and after transitions. Consider expectations of self-regulation along a continuum of supervision by staff, from continuous supervision to 90 % supervision, then 80 %, 70 %, 50 %, 25 %, and finally none. The behavior of the student at different locations, during different activities, and at different times with different instructional groups will provide the data needed to select optimal levels of supervision.

Students have reported difficulty during physical education classes, particularly in locker rooms. At this time when the instructor is providing "privacy," the Asperger syndrome student is most frequently victimized by teasing or aggression. The teacher must identify when maximum supervision is necessary. Asperger students, if supported, compete well in activities of cross-country, baseball, weight lifting, and many other sports.

Optimal. During transitions the teacher must provide 80–90 % supervision unless the data indicates that it is not needed. The decision about the level of supervision is best made by direct staff observation during various activities at different times. Such decisions are not based solely on the student's report of incidents.

Noncompliance and symptoms of perseveration, rigidity, oppositionality, and "anxiety" may be a response to a request for a transition, especially when the transition is not well rehearsed. Teachers must take the time to rehearse the student by explaining the need for a transition and the steps to follow. Allow sufficient time prior to the transition for rehearsal, but maintain continuity in time from the rehearsal through the transition to its completion. A staff "coach" should have the role of easing transitions by necessary rehearsal.

Summary

Diagnosis is a priority concern in the education and treatment of children and adolescents on the autism spectrum of disorders. Researchers and direct service providers use various diagnostic classifications and combinations of classifications or rely on autism spectrum disorder as a single classification of diagnosis. However, empirical justification is yet to be provided for the validity of each disorder on the autism spectrum. Nor does the present lexicon clarify symptom characteristics to help resolve problems related to phenotypic expression of disorders on the spectrum. Nonetheless, the diagnosis of children and adolescents on the autism spectrum of disorders has increased exponentially since 2002.

No clear answers exist as to whether students on the autism spectrum of disorders express a dimensional structure of symptoms. The validity of discrete phenotypic classifications is also in question. The diagnoses of autism, high-functioning autism, pervasive developmental delay, and Asperger syndrome require differentiation. An empirical foundation for convergent knowledge is needed to underpin types of instruction and treatment to obtain desired behavioral change for the child.

Public policy at state and federal levels endorses the need for evidence-based instruction and treatment for students. Thirty to forty percent of students on the spectrum attend public elementary and middle-school classes. Empirical methods are preferred over informal and anecdotal data and studies lacking reliability and validity. Problems most frequently cited as threats to research, reliability, and validity are size and diversity of research samples, definitions of dependent and independent variables, and methods of measurement. The controls needed for research are not typically present in applied settings where services are provided.

Until researchers improve methodology, educators struggle to select and apply empirically based procedures in school settings. A significant impediment to reliable practices in the classroom is the failure of those who pay for services to require rigorous research-based educational practice. Families too need access to new knowledge and participation in the decisions made for their child's access to valid, reliable instruction and treatment.

A student's accurate developmental history and empirically based diagnoses are necessary predicates for a baseline of the child's strengths and challenges. Assessment of the student's manifestation of operationally defined symptoms offers a best approach to develop and modify a personalized education and treatment plan.

Psychopharmacological management of symptoms is a frequent choice of treatment for diagnosed children on the spectrum of autism disorders. Defined symptoms may establish baselines for tracking learning and behavioral changes associated with medication and subsequent change in dosage or type of medication.

Medication alone is not able to predict academic performance gains or self-regulation at school or home. Task analysis provides a reliable method to develop and measure the instruction and management to fit each child's existing level of knowledge and ability, to acquire skills, and improve behavior. Content analysis provides a method to revise and personalize instruction based on the components of the task that the student is required to master. Content task analysis may be a helpful method for the analysis of typical expectations for a student's behavior in the classroom or home ecology.

The use of content analysis enables teachers to clearly define expectations for mastery of each instructional task. Interactional analysis, on the other hand, enables the teacher to specify the teaching method for each component of the assigned task. "Forward chaining" and "backward chaining" are examples of alternative methods of organizing instructional tasks. A third type of analysis is prerequisite task analysis. Its purpose is to assess the required component skills and knowledge the student needs to be able to perform to master the new task. The analysis of the child's existing ability helps to identify absent prerequisite skills needed so that the student is able to master the prerequisites prior to the introduction of new tasks.

Ecological variables in the learning setting influence instruction and treatment outcomes. We need to better understand the effects of the pertinent factors in the ecology of the setting for instruction of academic skills and social learning. Such variables include the clinical composition of the group of students and competing student needs, size of the group, arrangement of the room, types of tables, chairs, bookcases, desks, movement patterns, instructional resources, ready access to materials, staff-to-student ratio, exposure to risk and criticism, and other factors. The emphasis for change may be on the school setting, but particular attention must also be paid to relationships among medications and the student's ability to regulate her behavior, manage stress, anxiety, and other effects on executive functioning and information processing during the acquisition of skills and during social interactions.

Each child's diagnostic characteristics are manifested in the child's behavior in the classroom and at home, during the performance of different tasks, with different degrees of structure and support. Each child may manifest those characteristic symptoms in a way that is uniquely personal. The Appendix that follows illustrates the way in which education and treatment may be operationally defined to compare child baseline performance with treatment and education outcomes. A personalized psycho-educational approach offers a model to clarify the aims of treatment and the measurement of results from interventions. By presenting the student's performance data over a specific period of time, in various settings with different instruction methods, it is possible to measure the educational benefit of prescribed and applied accommodations and implemented treatments with increased reliability of the benefit to the child.

Evidence-based approaches to education and treatment must not overlook the uniqueness and complexity of individual students. The overarching concern is the recognition of the individual, personal educational, and clinical needs of each AS student.

Changes in educational decisions without consideration of the development of the unique persona of the child and the values of the family may alienate both parent and child. A personalized approach to the student may be able to enable his or her expression of strength and capability within a system of education and social learning. Social and academic success may be made personal and concrete when students engage with professionals to understand and express their experiences and plan their futures based on the evidence of their efforts.

Whether a truism or not that Asperger syndrome is adequately clinically defined, it is certainly true that we meet, in our daily lives, those with Asperger characteristics, who are children, adolescents, and adults. These AS individuals may be best served by not including them in a broad category of variable characteristics, under the rubric of an autism spectrum disorder, for education, clinical treatment, and psychopharmacological management.

The differences among individuals are too great to apply a one-size diagnosis to fit all as an approach to addressing the needs of each Asperger diagnosed person. How can a student relate to being identified as on the "spectrum?" A person who loves biological sciences, music, drama, and people of similar interests often prefers small groups and quiet settings. Educators must provide opportunities to choose activities and predictable routines in collaboration with their students on the spectrum.

Appendix: Research into Practice: A Personalized Education Application

By Raymond W. DuCharme

The author acknowledges the significant contributions of the following persons:

Linda Baade, Special Education Administrator; Kathleen McGrady, Neuropsychologist; and Robert LeGary, Doctoral Candidate in Education. Without their careful attention, analysis, and reporting and that of the teachers, clinicians, and house parents, the report below would not be possible.

Introduction

The case study discusses outcomes for one adolescent student whose education team collaborated to identify, treat, and assess strategies to meet the student's identified needs. The single-subject research design is applied as a structure for both planning and providing services. Teachers, clinicians, and parents establish multiple baselines for specific student behaviors and develop successive strategies. The aim is to assess relationships among target behaviors and treatment strategies and results.

In large-sample studies, students' diagnoses are combined and often lack clarity about how diagnoses are manifest in different settings, under different degrees of structure for different individuals with the same diagnosis. The diagnosis is given and treatment variables are assessed and generalized to other students with the same or similar diagnosis, for example, Asperger syndrome versus high-functioning autism. Single-subject studies assess treatment in relation to the individual characteristics of students on the autism spectrum of disorders and how their behavior is manifest.

The first, most important step in designing a single-subject design is the confirmation of the primary diagnosis and how it is manifest in the priority settings of classrooms and home. During this process the team reviews the child's developmental history and the results of past interventions associated with the child's identified education and clinical needs. In addition the planning team designates observers and describes the ways the student manifests the diagnosis in her performance in each of the settings, home, school, and community.

Next, the team collects baseline data in each of the settings. Decisions about methods of observation and standard assessments are made at this point, prior to implementing new strategies. Factors such as available resources and staff skills are taken into account prior to introducing new interventions and procedures in order to provide the best fit of procedures to student needs.

The single person study approach adds meaning to the treatment process by enabling teachers and clinicians to present qualitative and quantitative data related to the team's primary concerns about the child. When data supports or fails to support the need for intervention and/or efficacy of treatment, an argument can be made for the need for specific modifications to the student's program. Standardized measures are useful to show the priorities of need across different settings as perceived by the child's self-report, parent, and teacher assessments using the same protocols.

Scheduled reviews of child, teacher, and parent data are necessary to assess intended and unintended results of treatment during the course of the intervention. Behavior management procedures may be applied after student's strengths and challenges are clarified. The AS student's academic performance and rate of skill acquisition may be significantly influenced by anxiety, depression, compulsion, ADD, and other conditions (Gillberg, Billstedt, Sundh, & Gillberg, 2010; Semrud-Clikeman et al., 2010). The team identifies the student's behaviors, from most to least important, as the behaviors compete with academic success. Target behaviors such as prompts, redirection, task reframing, time off, or time-out are recorded and charted over time in each setting identified by the team.

A cohesive approach is needed in each instructional setting and during activities such as recess, lunch, and sports (Spek et al., 2010; Stichter et al., 2010). The roles of the clinical staff, school psychologist, psychiatrist, and nurse must be clarified in relation to treatments that they develop to support the student's instructional programs.

Anna: Personalized Education and Treatment

The goals and objectives developed for Anna are identified as the result of collaboration among the child, parents, teacher(s), clinicians, developmental specialists, and psychiatrist. A collaborative effort is needed to develop a cohesive set of interventions and relevant outcome measures (Soderstrom et al., 2002; Totsika et al., 2010). The team identifies treatment and education methods, measurements for baseline, and ongoing monitoring methods.

Specific methods to assess intended and unintended outcomes are determined by the team. Their decisions to maintain or modify priorities and methods are data based.

Anna's atypical development is documented in terms of how atypicality is manifest. The team plans to assess any variation in Anna's responses, pace of change, stability of results, and unanticipated regression. It is given that all variables that influence outcomes are not fully under control in applied settings, for example, treatment at home and in classrooms. This is especially true in the school and home. Open settings are not designed for children with multiple co-occurring diagnoses.

The staff managing treatment strategies have distinct roles. They demonstrate reliable levels of relevant training. Cohesion of effort requires a team leader capable of managing the ongoing collaboration of parents, teachers, and professional specialists. In this case Anna's clinician is the team coordinator. Anna's program staff use operational manuals, defined personalized strategies, and ongoing scheduled meetings to review progress.

A single-subject, multiple-baseline design with continuous data collection across settings is planned and implemented. Specific behavioral targets are chosen as well as methods to measure the results provided by Anna.

Anna's behaviors are operationally defined. Instructional staff and parents are trained by the clinical staff assigned to the child and family. Data collection is done in the classroom and during after school activities, as well as at the residential setting and during Anna's home visits.

Staff and parents are provided with observation formats, recording sheets, and schedules for observation of the targeted behaviors for intervention. Video training tapes are prepared to provide checks on observation reliability. Interval frequency and interval spoilage methods of recording observations are applied. Rating scales using Likert-scale formats for classroom assignments are also used concurrently by parents, teachers, and the clinician.

Behavioral Therapy Matches Clinical Needs

A cognitive behavioral therapy approach and self-determination theory offer guidelines to Anna's teacher and therapist for their interactions with Anna. Students with an Asperger diagnosis are typically self-referenced and inflexible in their response to criticism. Anna may refuse to cooperate when she perceives that she is under the control of other people. She also demonstrates difficulty with objective self-criticism and self-evaluation. The teacher's logical, critical assessment of the student is often perceived by Anna as inconsistent and invalid. She typically responds with self-justification and entrenchment if she perceives criticism as false.

Anna requires an approach that helps compete with her inflexible response to criticism. She responds well to structured options that allow her choice; she does not perform well with open-ended choices or lists of multiple choices. Her teacher ensures contiguity between Anna's performance and timely discussions about her performance. Comparisons to agreed-upon standards are important to future cooperation and collaboration between Anna and her teacher.

Anna does best when she is asked to assess her performance before the teacher provides independent assessment for comparison. This approach helps to establish the value and validity of Anna's judgments compared to the standards that Anna and the teacher selected. Collaboration and comparison provide a basis for the concurrence of applied standards between Anna and her teacher over time. A review of standards periodically and prior to a collaborative discussion assists in establishing a focus on agreed standards prior to assessing specific student performance.

Anna has proprioceptive processing difficulties. She is at risk for confusing locations within her classroom. She does not reliably find her way in her classroom or her school. She cannot cross the street in a way to safely assess her position in relation to the distance of oncoming cars.

Anna's moods and emotions are unstable and interfere with her ability to enjoy her successful experience and fully participate in activities. She communicates verbally that she does not hold herself in high regard.

She has low self-esteem as indicated by negative statements about her appearance, her future plans, and her current relationships. Anna predicts that she will fail when trying new activities and avoids exposing herself to risks that a similar aged person would accept. She compares herself negatively to peers and siblings, often identifying qualities that her friend has but that she does not have, such as popularity or academic success.

Anna shows insufficient social judgment in her application of pragmatic language skills in comments to peers. She violates boundaries of the personal space of others. She cannot reliably estimate her own abilities or those of others. Her acceptance by peers depends on their initiation and their coincidental interest, not her initiative.

Behavioral Observation, Database, and Charts

A database is used to record the teacher's direct observations of behaviors in the classroom. Anna's behavior targets include her inability to follow directions, rude comments, inappropriate language, incomplete work, time off, time-out, warnings, redirections, prompts, restricted days assigned outside the classroom, supervised status (in sight of staff at all times), age-inappropriate behavior and interfering or interrupting behavior, frustration with task, and the ability to self-initiate scheduled tasks. Negative attention-seeking behavior is also targeted for observation across settings. Charts are produced from the database to show weekly and quarterly progress. Two charts are included below and illustrate changes in Anna's behaviors in relation to other events in her experience, medication changes, for example. The database is also used to analyze Anna's pattern of behaviors identified in each setting and compared with her behavior in other settings. Her negative attention-seeking behavior, for example, decreases to zero occurrences in both the classroom and residential living settings over time. Anna's other behaviors do not follow a unidirectional pattern. At one point Anna requires fewer prompts at school than at her residence. A prompt occurs when Anna's residential staff or teacher initiates a cue to maintain Anna's on-task behavior. Anna may be on task but temporarily stalled or perhaps she misunderstands a direction. At another point in time, the teacher's redirections to Anna increase from the previous quarter at school, while redirections at her residence decrease significantly from 483 to 310 occurrences. A "redirection" is a cue initiated by the teacher or parent to direct Anna away from tangential behavior and toward on-task behavior.

Discussion of Goals and Progress

Anna's teacher and her clinician discuss her goals and progress with her daily and weekly. In those discussions Anna identifies what she has done well and areas where she can improve. Reminders of successful strategies are provided. Anna and her parents receive quarterly summaries of data with percentage scores. In her classroom Anna has goals for academic performance, social skills, and self-regulation.

Anna demonstrates improved ability to regulate her mood. Her moods are less labile. She also demonstrates improved social interactions. She is an engaged and willing participant in therapy. She initiates collaboration. She is showing age-appropriate interests. She demonstrates motivation to develop competence in social relations and self-regulation of behavior. Anna will begin to initiate social activities with peers in the community as she develops skills to establish and maintain healthy relationships.

Anna's teacher gives her verbal praise at a ratio of five-to-one over critical comments. Anna's work is selected as a positive example of standard performance. Anna perceives the possible selection of her work as a reasonable risk because she seeks the validation of peers and their positive reinforcement. Building risk into Anna's program requires careful consideration, given her history of perceived failures in the education setting. Her teacher designs learning opportunities to counter Anna's inability to bounce back after temporary setbacks.

Her ongoing goals include the following:

- Demonstrate effective and appropriate communication with her parents and peers.
- Initiate age-appropriate social interactions across settings.
- Demonstrate ability to self-regulate emotions of anxiety and depression.
- Demonstrate appropriate self-care skills.

- Demonstrate improvement in activities of daily living across environments.
- Increase demonstration of prerequisite vocational skills.
- Increase evidence of reliable application of pragmatic language skills.

Praise and Autonomy Build Resiliency

The methods that helped Anna succeed are based on self-determination theory and applied behavioral analysis (ABA). Her teacher provided alternative schedules that focused on Anna's "need" for evidence of her competence. By offering choices rather than imposing a controlled schedule, Anna was allowed the opportunity for self-regulation and autonomy. When she completed her task or assignment, Anna assessed her performance with her teacher. The teacher provided verbal praise for their mutual attention focused on Anna's positive performance and choices. Anna accepted gradual increases in her acceptance of social risk, self-initiated assignments, application of skills, and self-directed transitions. Anna's resiliency increased as she engaged in graduated levels of social risk and met challenges to her skill levels.

Over time, Anna's data indicates that she is able to accept positive feedback from individuals that she perceives to be reliable and competent. She seeks feedback after she engages in performing arts (drama), chorus, and art. Her perceived competence in the arts is associated with the increase in her ability to initiate academic assignments, accept prompts and redirection, and collaborate with her teacher. Anna now accepts different instructional models, such as research with another student (dyadic learning), collaborative assignments in peer seminars, and participation in social events at school, and maintains her emotional stability.

The improvement in Anna's behavior, ability to negotiate the classroom, and school expectations and environments is evident by the data. Anna's quality of life is also significantly different. She has friends, is dating an age-appropriate peer, and attending social events. She advocated for her inclusion in a field trip with a group of age mate girls. Her goals for self are becoming clearer and articulately expressed. Her resiliency is now a concrete aspect of her experience and provides additional evidence of her confidence in her ability. She demonstrates fewer searches for reassurance from adults and peers. Anna's new confidence has enabled her to confront disparities between the goals of adults for her and her own goals. The divergence of goals of her parents from her wants and objectives is also better articulated by her. She is becoming a young adult with confidence about her future independence.

Assessment of Performance Guides Sustained Intervention

The combined approach of self-determination and an ABA approach are recommended for other students as well as Anna. Generally, research suggests a significant difference in strategy between the student's autonomy versus the teacher's unilateral control and restrictions for maintaining motivation in learning (Barkley, 1997; Grolnick, Deci, & Ryan, 1997). Anna's results reveal that student autonomy with teacher support increases motivation and desire for challenge; in addition students are more curious and compliant. The student's interest is accommodated. It makes sense to provide an alternate, more appropriate setting and treatment strategy when a student engages in a behavior that is disruptive to his learning. In summary the approach is to build student self-regulation by providing autonomous acceptable choices. The teacher may need to modify the strategy to provide external support and reinforcement for the students. The role of teacher and student is to align with student-driven interest and desire for autonomy.

AS children deviate from typical development and infrequently outgrow their atypical communication and executive functioning without sustained intervention. Their overall functioning is compromised by developmental difficulties that affect significant aspects of their lives. Their education, relationships, and economic independence are greatly affected by their developmental delays. Their well-being depends on parents and professionals who are dedicated to providing needed focus on the child's development to help increase self-regulation and resiliency. Self-regulation may be inferred from the low frequencies of redirection and prompts the child needs to meet classroom role and academic performance requirements. Building on specific objectives one can devise strategies to master classroom behavioral expectations that are part of the student role.

Assessment of classroom performance helps to identify the behaviors for intervention that are significant influences on the acquisition of academic skills. Likewise, the fit of instructional methods affects the child's success with academic performance. For example, one aspect of self-regulation is the ability to accept correction and redirection. It follows that the teacher must instruct the child in ways to accept correction along with ways to demonstrate factual knowledge. In class discussions of academic topics, the teacher may focus also on the child's functional social judgment and appropriate disclosure of personal information in their personal communications with both peers and adults. In the long term, the aim is toward demonstrating new effective ways to relate to family, friends, and community as an independent adult.

The charts below show associations over time among frequencies of Anna's behaviors. The changes in medications, adjustments based on genotyping results, are marked on the charts.

Tics decreased in frequency, for example, from 160 per monthly events to 91 over an 8-month interval. See Fig. 1. The chart indicates a range of frequency of tics from a high of 160 to a low of 59. Prescribed interventions are maintained during the observation period.

In Fig. 2 three behaviors are observed and charted concurrently. Target behaviors are assessed as adjustments are made to medications (Figs. 3 and 4).

Figure 5 shows the teacher's observation of age-appropriate behavior.

Psychopharmacological management is implemented based on genotyping data associated with the student's ability to metabolize her medication.

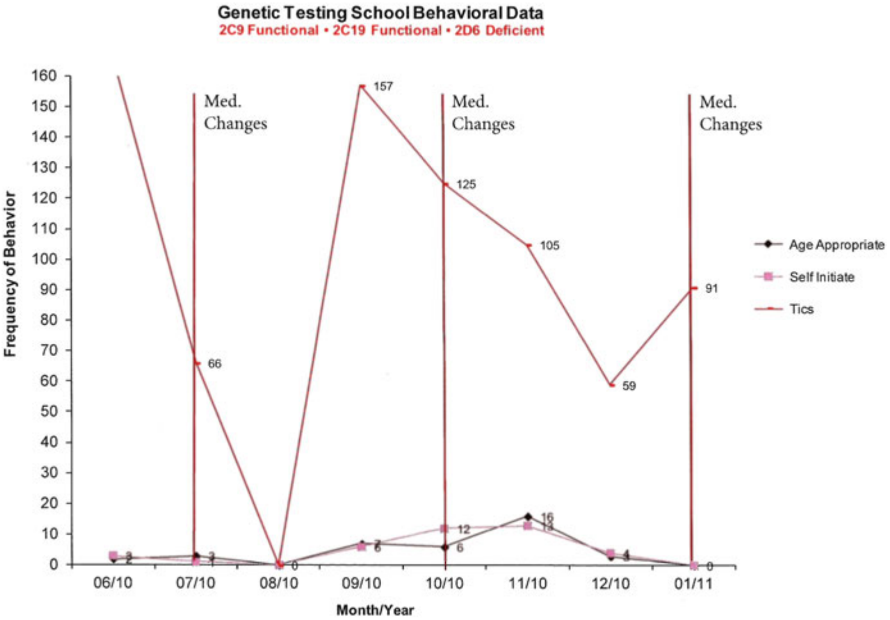

Fig. 1 Fifteen-year-old female student behavioral data collected by teaching staff at The Learning Clinic from June 2010 to January 2011 (The Learning Clinic [TLC], 2010–2011)

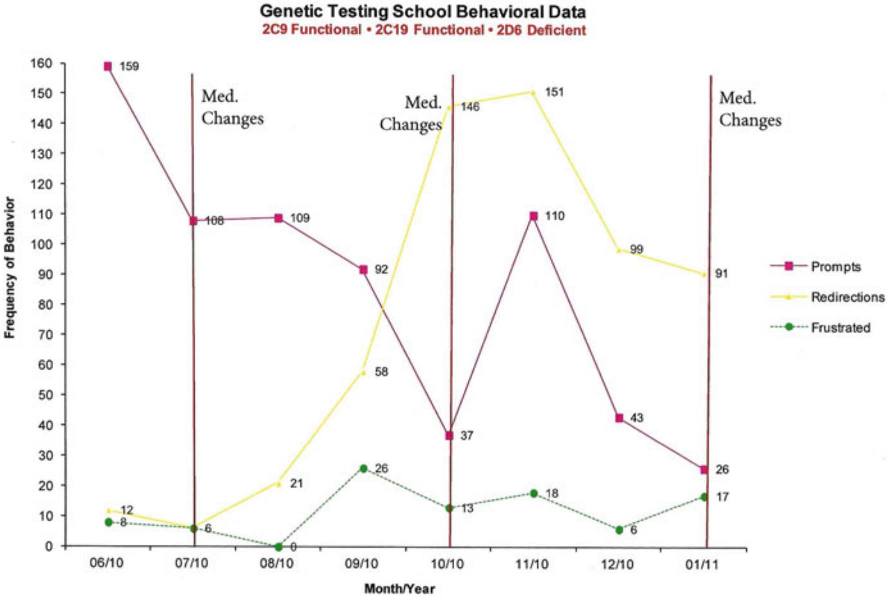

Fig. 2 Fifteen-year-old female student behavioral data collected by teaching staff at The Learning Clinic from June 2010 to January 2011 (TLC, 2010–2011)

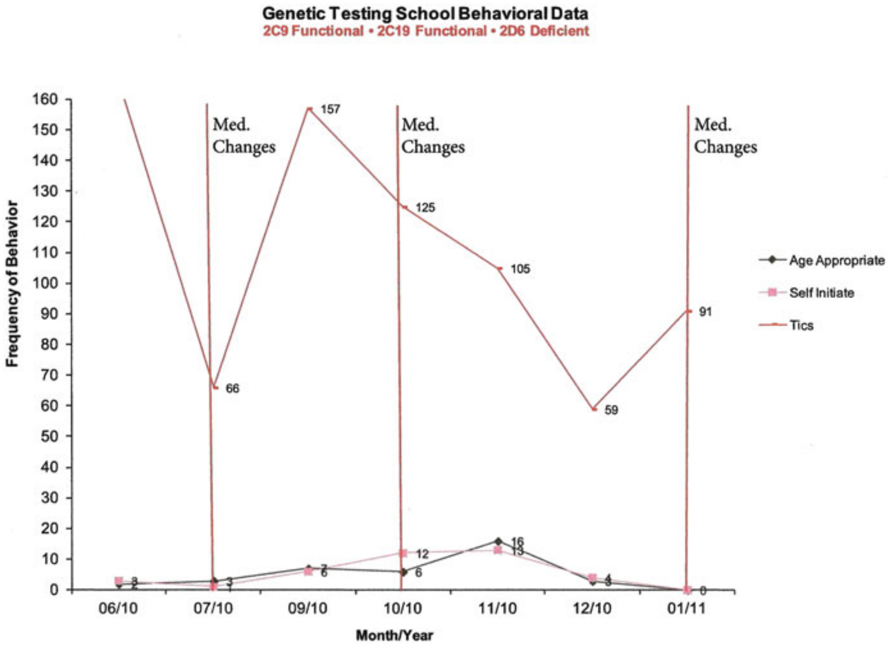

Fig. 3 Fifteen-year-old female student behavioral data collected by teaching staff at The Learning Clinic from June 2010 to January 2011 (TLC, 2010–2011)

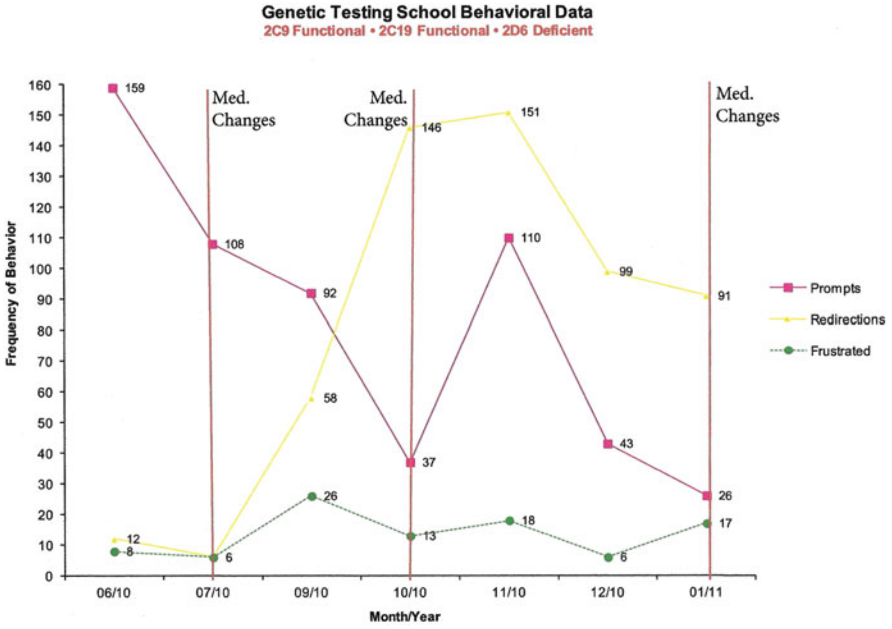

Fig. 4 Fifteen-year-old female student behavioral data collected by teaching staff at The Learning Clinic from June 2010 to January 2011 (TLC, 2010–2011)

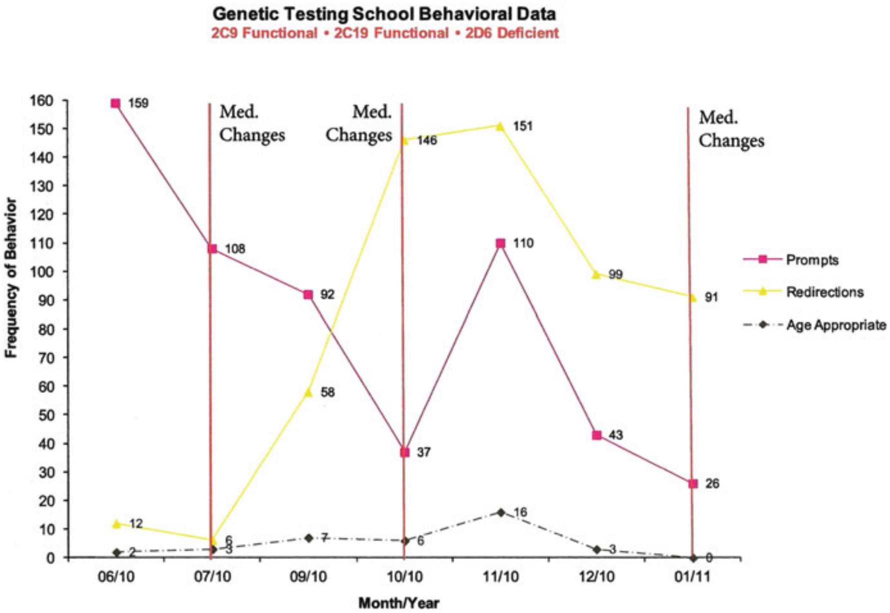

Fig. 5 Fifteen-year-old female student behavioral data collected by teaching staff at The Learning Clinic from June 2010 to January 2011 (TLC, 2010–2011)

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Comprehensive Education-Based Mental Health Services for Students Diagnosed on the Autism Spectrum

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Introduction

The purpose of this chapter is to describe clinical strategies that parents and professionals can use to improve treatments provided to students on the autism spectrum. The focus of the chapter is to explain the complexity of treatments that may be effective with Asperger students and others on the spectrum.

The second focus is to present detailed technical information about specific gene variations that affect student's abilities to metabolize drugs intended to help improve their behavioral and academic skills. Readers interested primarily in clinical implications may want to focus on the third purpose of this chapter, that is, to describe personalized treatment considerations. A case study presents findings related to one student whose treatment is analyzed and modified to minimize unintended consequences and bring about desired results. Personalized treatment strategies are described to support the student's success.

The content in this chapter should not be considered a substitute for medical or other professional advice. The publisher and the authors intend to offer accurate information that reflects current knowledge of the subject covered. The publisher and authors make no representations as to the accuracy or efficacy of specific medications or dosages presented in this chapter.

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The National Association of State Boards of Education (NASBE) recently identified the importance of integrating delivery of mental health services into public schools. Their belief is that schools can overcome the risk factors that are associated with school violence, substance abuse, and early drop out. The policy report indicates that students' social and emotional health is related to the improvement of standardized achievement scores by as much as 17 percentile points and to reduced conduct problems, special education referrals, and students' time away from school.

The "policy update" focuses on three areas to address the mental health and emotional needs of students:

1. Screening to identify student needs
2. Increasing educator awareness of student needs
3. Providing treatment within the school environment

The report suggests that early identification and treatment can save money due to lower special education referrals. The report states that "in 2007, one in five children suffered from mental disorders, and one in ten children has a serious emotional disorder that affects their ability to function daily . . . Schools are the primary place students can receive supports; in fact 70–80 % of students that receive mental health services do so within the school setting." The need for collaboration with teacher training institutions is a key component in the effort to address student mental health needs. Treatment strategies, the report identifies, along with teacher awareness and early screening and identification are critical to the maintenance of a positive school environment. Teacher training institutions are critical partners in strategy development to address teacher needs.

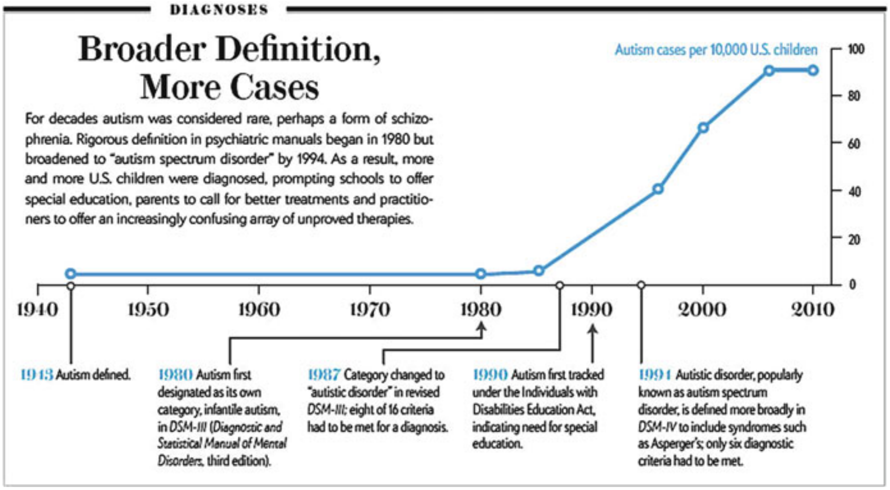
The Individual Education Plan (IEP) entitled under IDEA and/or 504 plans under anti-discrimination federal legislation are the existing means to provide necessary services to students. School and district psychologists are the primary personnel, says NASBE, to assess students and determine eligibility for their services. The adequacy of school environments, staff preparation, and professional consultation to meet the complex mental health needs of children and adolescents on the autism spectrum represents significant challenges to the public school. The local schools and boards at the state and regional levels will coordinate service.

There are disagreements among experts about the causes for the significant increase in the prevalence of those persons identified to be on the autism spectrum disorders (ASDs). ASD is the group demonstrating the largest increase in prevalence, over 300 % since 2000. Different diagnostic criteria (DSM-IV and ICD-10) have been applied to the identification of Asperger syndrome (AS) in children. Chronological age is an inaccurate indicator for behavioral expectations. Behavioral norms based on developmental age are better measures of the AS person's characteristics. The process of differential diagnosis has to include reliable methodologies based on empirical validation. Many problems reside in the interpretation of results from parent interviews and self-reports. Reliable identification of AS characteristics, assessment procedures, and outcome criteria is necessary for diagnosis and treatment.

Cross-cultural studies also point to problems with accurate diagnosis. Disabilities and mental disorders are stigmatized in some cultures (Kim et al., 2011).

Cross-cultural application of standardized tests and retrospective reports by parents present problems as to reliability. Various methodological influences affect the changing increases in prevalence data. Below is a chart that shows changes to the prevalence of identified disabilities over the past decade (Shute & Christie, 2010).

Prevalence of autisms over time (Source: Shute and Christie 2010)



Broader Definition, More Cases

For decades autism was considered rare, perhaps a form of schizophrenia. Rigorous definition in psychiatric manuals began in 1980 but broadened to "autism spectrum disorder" by 1994. As a result, more and more U.S. children were diagnosed, prompting schools to offer special education, parents to call for better treatments and practitioners to offer an increasingly confusing array of unproved therapies.

1943 Autism defined.

1980 Autism first designated as its own category, infantile autism, in *DSM-III* (*Diagnostic and Statistical Manual of Mental Disorders*, third edition).

1987 Category changed to "autistic disorder" in revised *DSM-III*; eight of 16 criteria had to be met for a diagnosis.

1990 Autism first tracked under the Individuals with Disabilities Education Act, indicating need for special education.

1994 Autistic disorder, popularly known as autism spectrum disorder, is defined more broadly in *DSM-IV* to include syndromes such as Asperger's; only six diagnostic criteria had to be met.

The importance of education as part of a child's habilitation or remediation program cannot be overstated. Educational settings teach more than academic skills. School is a primary setting for an individual child's sense of social competence and self-confidence. Appropriate education creates confidence in the child's ability to learn and master specific academic and social skills. The performances of the child at school often predict and validate medication choices for the treatment strategy prescribed and the educational strategies proposed. Most educational settings are too open, unstructured, and unreliable for predicting treatment results for specific child medication choices and educational interventions.

There are educational norms, however, for expected student behavior at school. So there is a typical student role expected as well as a level of child resiliency to maintain the role through self-regulation throughout the school day. But the expected performance of the student role may vary significantly in different classrooms with different teacher management and instructional methods, and these role performance requirements may not be able to be met by some children, given their "developmental age."

The schools' ecological arrangements may support a student role and academic mastery or compete with child's success given a child's level of co-occurring symptoms related to the primary diagnosis. The school environment must be fitted to a child's needs. The number of students in a classroom and the different child behavioral and cognitive issues present in the peer group are relevant to how the child adjusts. The teacher style and instructional orientation, as well as the methodologies used for instruction and task organization, may compete with a child's successes at school.

Educational Support for Asperger Students

When classroom environments are mismatched to the student's needs, performance suffers. Environmental factors that threaten performance may lead to increases in the child's medication and other adjustments to treatment that may be detrimental to the child. Educators may make accommodations in an attempt to help the child perform in a mismatched learning environment. A better alternative is to change the child's environment. We recognize, however, that change may not always be an option.

Teachers can take steps to support Asperger students even when the overall learning environment cannot be overhauled. First, the teacher must recognize the behaviors that pertain to the student's ability to meet expectations. The next step is to rate "student role" behaviors, such as sitting, following directions, getting oriented to the task, scanning information, and others. Then teachers can help develop structures to support the student's completion of tasks. The outline below lists essential components of special education services.

Outline of Special Education Services

A. Support student role performance:
   1. Assess "attending behaviors" through time and over time.
   2. Ensure reliability of observations (in vivo) by teacher, mother, father, and self.
   3. Target student performance over time (minus baseline data = treatment benefit).

B. Develop levels of intervention for in-school services through time–over time, for example, full inclusion, partial special classroom, shadow monitor, full special class, in-home supports, outplacement day, and residential placement.
C. Specify evidence-based outcomes and unintended outcomes.
D. Maintain evidence of communication with parents.
E. Plan time for collaboration among professional disciplines: pediatrician, psychiatrist, developmental specialist, special educator, and speech and language specialist.
F. Develop cohesive treatment and integrated services particular to an Asperger student's requirements.
G. Modify academic evidence-based procedures such as teacher verbal or visual demonstration, rehearsal, prompting, redirection strategies, backward chaining for sequential instruction, active learning instructional methods, and Virtual Lab and CAI instruction.
H. Design school and classroom ecology to structure support and elicit student role behaviors for individuals with ASD diagnoses.
I. Ensure student safety by providing operationalized standards of accountability for staff and students regarding bullying, victimization, mutual respect, and peer support.

J. Develop IEP that lists personalized strategies to accommodate student strengths and deficiencies with related assessment protocols:

   1. Student role performance
   2. Measures of retained academic skills
   3. Measured ability to apply knowledge to real-world problems
   4. Self-regulation and classroom performance commensurate with the individual's developmental age
   5. Transition plan for post-high experience to strengthen social judgment, pragmatic language skills, self-regulation, vocational skills, independent living skills, and participation in college and competitive employment

The teacher can provide intensive, moderate, or no level of support to the student depending on the student's ability to function independently. Assessments should follow the schedule of the education planning team, or the IEP team. Teachers will have more control over some variables than others. Teacher-directed instruction, reinforcement, and planned transitions are well within the teacher's control, while class size is most likely determined by others.

In the sections that follow, we compare symptoms of students on the autism spectrum. We offer a chart of comparative symptoms with definitions and a rating scale. The rating scale shows levels of behaviors and characteristics by diagnosis. A teacher with IEP team can use the rating scale to assess and compare skill.

Next are the Asperger syndrome criteria according to the DSM-IV and the World Health Organization. Diagnostic concerns and medication management are then discussed in relation to personalized treatment; individual student data is presented. Since teaching and treatment strategies must match student characteristics, we provide tools and definitions to clarify symptoms and personal traits.

Assessment of Comparative Symptoms

The need to assess the level of classroom skill functioning for students is clear. The rating scale is designed to be useful to parents, professionals, and paraprofessionals who are involved with the care and treatment of children and youth who demonstrate skill deficits. These ratings may be used to establish treatment objectives that are observable, modifiable, and measurable.

Below is a scale to be used to rate students with regard to cognitive traits, social skills, physical behaviors, emotional dysregulation, and future goals. A list of definitions follows the rating scale.

Ratings Scale

A rating score of zero to five (0–5) may be awarded to each index in the survey. Score values are as follows:

0 = No behavior observed (0 out of 10 times)	Behavior is never observed
1 = 1–20 % of the time (1–2 out of 10 times)	Behavior is rarely observed
2 = 21–40 % of the time (3–4 out of 10 times)	Behavior is sometimes observed
3 = 41–60 % of the time (5–6 out of 10 times)	Behavior is evident in many settings; performance is inadequate and inconsistent. Skill still dependent on external prompts
4 = 61–80 % of the time (7–8 out of 10 times)	Demonstrated in most settings. Evidence of a level of persistent behavior
5 = 81–100 % of the time (9–10 out of 10 times)	Demonstrated consistency in all settings

How to Score Your Student

Compare your student to the ratings listed on the "Chart of Comparative Symptoms." For example, how does the skill level of the student compare to the skill level rating for each diagnostic category? Specifically, base your rating on the behavior, or lack of it, that you directly observe in your daily interaction with the student. The chart reflects traits rated by the teacher for two students, one diagnosed with classical autism, the other with Asperger syndrome.

Chart of Comparative Symptoms

	Classical autism	Asperger syndrome
Cognitive Traits Observed		
IQ ≤ 75	5	0
Intelligence quotient is the product of measurements of a series of subtests in both verbal and nonverbal competencies compared to a norm-based group		
Perceptual difficulties	5	2
Measurements of abilities to perform subtest tasks that assess visual, tactile, auditory, and motor developmental level performance		
Executive function	1	3
Cognitive abilities necessary for complex goal-directed behavior and adaptation to a range of environmental changes and demands. Executive function includes the ability to plan and anticipate outcomes (cognitive flexibility) and to direct attentional resources to meet the demands of non-routine events		
Proprioception	1	4
Knowledge about the position of one's body in space that is based on sensory information from receptors in the muscles, tendons, and viscera		

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	Classical autism	Asperger syndrome
Cognitive rigidity	5	2
Concrete thinking often associated with inability to transfer attention away from one stimulus to another or to pay attention to more than one stimulus at a time. Impedes ability to benefit from verbal self-regulation and even verbal instructions received. Often manifests as an inability to modify behavior according to feedback or responses from others		
Sensory sensitivity	5	3
Deficits in sensory sensitivity manifest as either over (hyper)- and under (hypo)-responsive to sensory stimuli. Perceived intensity of the sensory stimuli can be either high or low		
Apprehension of context or cues	1	3
Awareness and understanding of the setting or circumstances in which an event occurs. Also awareness and understanding of verbal or nonverbal behavior that serves as prompts for a response		
Connotative and denotative language deficits	5	4
Denotative meaning of a word is its literal meaning; connotative meaning of a word is its figurative meaning, associations related to the word. These associations can be personal or general to one's culture		
Communication disorder	5	3
A speech or language disorder which refers to problems in communication and in related areas such as oral motor function. Can manifest as saying sounds incorrectly to being completely unable to speak. The inability to demonstrate the social pragmatics of reciprocal communication		
Metacognitive deficits: analysis, synthesis, evaluation, and social pragmatics	5	3
Analysis and synthesis are prerequisites for evaluation		
Analysis – is the process of breaking a complex topic into smaller parts to gain a better understanding. Closely examining something to understand its parts and the ways they work together		
Synthesis – to combine separate elements or components in order to form a coherent whole, bringing together information from several sources to make a new point	0	3
Evaluation – the systematic determination of merit, worth, and significance of something using a criteria against a set of standards. Your informed judgment	0	3
Social pragmatics – social language involving learning rules for interacting with others in socially acceptable behaviors. Includes language development of vocabulary and grammar into meaningful speech patterns for communication	0	2
Expressive–receptive language deficits	**5**	**3**
Expressive language deficits – distinctly limited vocabulary, errors in tense, difficulty recalling words or producing sentences with developmentally appropriate length or complexity, and general difficulty expressing ideas		
Receptive language deficits – difficulty understanding words, sentences, or specific types of words	5	3

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	Classical autism	Asperger syndrome
Developmental delays–source memory	5	4
Developmental delay – any significant delay in a child's physical, cognitive, behavioral, emotional, or social development in comparison with established norms for the child's age		
Source memory – memory for the circumstances in which an episodic memory is formed. Episodic memory is context-specific and often personal, preserving the time and space aspects of past events	1	3
Social skills		
Prospective planning	1	3
Ability to develop future plans, e.g., appointments and actions		
Self-regulation	1	3
The ability to exercise self-control and includes the skills of planning, self-monitoring, other awareness, and delayed gratification and goal setting		
Social judgment impairments	1	3
The ability to choose a socially appropriate behavior in response to a social interaction		
Reciprocity impairments	1	3
Turn taking in communication and other interactions. Providing others with an opportunity to respond and/or provide input during a conversation or social interaction		
Structure dependent	5	4
Dependence on preplanned schedules, routines, and advance rehearsal		
Resiliency difficulties	1	2
The ability to recover readily from disappointments, adversity, performance errors, and embarrassment		
Limited interests	5	4
Restricted range of interests. Narrow band of activities or hobbies in which the person engages		
Delayed gratification difficulties	1	4
The ability to postpone pursuit or attainment of a desired activity or object		
Redirection	5	4
Verbal direction to return to behavior that is task relevant		
Prompt	5	3
Verbal, ideogram, or diagram that provides assistance to stay on task		
Social and tangible reinforcements unreliable Inconsistent response to the availability of social or concrete/physical rewards and ratio of positive reinforcement	2	3
Social development delays	5	4
A delay in the development of social interaction skills and social competence in children. The child lags behind the normative schedule for acquiring social skills		
Physical behaviors		

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	Classical autism	Asperger syndrome
Self-harm	4	2
Demonstration of self-injurious behaviors		
Self-stimulation dependent	4	1
Stereotyped, functionally autonomous behaviors. Repetitive body movements or repetitive movement of objects used solely to simulate one's own senses		
Physical development delays	5	3
A delay in the physical development of children. The child lags behind the normative schedule for biological milestones		
Emotional dysregulation		
Anxiety	5	4
A dysregulated psychological or physiological state in response to a perceived stressor; a state characterized by somatic, emotional, cognitive, and behavioral components, such as fear or nervousness about what might happen (anticipation) and worry		
Aggression	5	2
A forceful act or procedure, intended to dominate or master. Behavior aimed at causing harm or pain, psychological harm, or personal injury or physical distraction		
Naïve	5	3
Lack of experience or knowledge: lacking in worldly wisdom or informed judgment		
Isolative	5	3
Tendency or desire to seek solitude; avoids social contact		
Impulsive	5	3
Tendency to behave without forethought and without considering the consequences of one's actions. To act suddenly without careful thought		
Goals		
Responsivity to nonverbal ideograms	4	4
Ability to demonstrate a physical or verbal response in a presence of symbolic language, such as icons and pictures, that illustrate concepts or actions		
Supported living during high school	5	4
Provision of the necessary support, training, and assistance to students with developmental disabilities during high school years		
Supported living post-high school	5	3
Provision of the necessary support, training, and assistance to students with developmental disabilities during post-high school years		
In-home services	5	2
Services to provide functional analysis of child-parent-sibling interaction. Intervention protocols are provided by professional and paraprofessional staff at the child's residence		
Independent living	0	3
Adolescents over 18 and young adults provided residential living within the community. Support services are typically provided and monitored		

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	Classical autism	Asperger syndrome
Supported employment	1	3
Employment provided in conjunction with agency advocacy, training, job coaching, and monitoring		
Modified employment	1	5
Student or young adult is able to have the employment expectations modified to suit their needs, level of supervision, specific challenges, and schedule by their employer		
Competitive employment	0	3
Student aged 16 or older; self-initiated contact with employer for interview and paid employment		
High school-applied instruction and experiential training	1	5
High school instruction is modified to provide the employer the required skill sets, and applied onsite training		
Post-diploma training or education	0	3
Achievement of academic requirements is met and diploma deferred until transition to work or college skills are met by demonstration and application		

The Learning Clinic (2011)

The characteristics and their definitions are based on the review of diagnostic researches reported in the literature. The aim of the classification of characteristics and their comparison is based on the need to assess the behavior of the person prior to selecting curricula, behavior management, or psychopharmacological management options. The purpose is also to enable the education planning team to compare the individual student profile to symptoms characteristically associated with a diagnosis for a person considered for special education, behavior therapy, and psychopharmacological management specific to autism spectrum disorders, that is, autism and Asperger syndrome.

Children with demonstrated characteristics associated with autism spectrum disorders are complex. A differential diagnosis is difficult due to overlapping symptoms and comorbid diagnoses. Expressions of a phenotype may or may not precisely fit a diagnosis. Measurement of the student's traits provides the best basis for planning education and treatment.

Asperger Syndrome Criteria

The best agreement of criteria is between the ICD-10 and DSM-IV criteria. The Asperger diagnosis is associated with normal IQ, desire to engage socially with others, and absence of language delays. How these criteria are operationalized is frequently problematic. The IQ measurement criterion is often limited to the verbal scores of the WISC. Asperger and autistic students' self-report data rarely correlates with observations by trained observers. Both types of measures may indicate false positives for differential diagnostic. It remains to assess the results of the new DSM-V on the diagnosed prevalence of autism spectrum disorders.

	DSM-IV	ICD-10
Qualitative impairment in social interaction	X	X
Restricted repetitive and stereotyped patterns of behavior, interests, and activities	X	X
No general language delay	X	X
No delay in cognitive development	X	X
Normal general intelligence (most)		X
Markedly clumsy (common)		X
No delay in development of the following:	X	
• Age appropriate self-help skills		
• Adaptive behavior (excluding social interaction)		
• Curiosity about environment		

Diagnostic Concerns

The key diagnostic concern reported by parents and educators, as well as therapists, is related to the following question: What is the best choice of clinical treatment and educational strategy for the habilitation or rehabilitation that fits the diagnosed child's needs? Key corollary questions are as follows:

1. How reliable is the diagnosis of the child and, does the diagnosis change over time?
2. How does the pattern of co-occurring diagnoses influences treatment approaches?
3. Which medications have evidence of researched effects with the specific developmental age and diagnosis of the child?
4. What are the side effects and unintended results of medications that are measurable and predictable?
5. How do medications influence the cognition, memory, and self-regulation of the child?
6. Is there evidence of polypharmacy (e.g., layering of medications over time) in the child's current medical profile or history? Maintaining one medication while adding another is an observed occurrence indicated in a child's medical history. And the parent often does not know which medication influences the child or to what degree.
7. Does genotyping provide evidence for more effective psychopharmacological management and alternative algorithms for medication trials?

Another focus after diagnoses and medical therapies is the selection of educational programs and instruction. What are the empirically based modifications to the instructional tasks recommended for intervention? How are these modifications specific to the individual child or adolescent needs? Teacher support must reinforce improvements in student specific skills.

Failure to achieve intended therapeutic effects impedes the child's ability to progress academically and achieve the expected milestones socially, emotionally, and behaviorally. Behavioral data for 19 of the students in the pilot study reveal high levels of staff support these children require. The chart below "Behavioral Data" lists frequency counts over a 45-day period of four behaviors that require staff intervention. The average number of teacher interventions for the 19 students was 620, with a range from 87 to 1,763. The behaviors addressed were related to skills required to complete academic tasks, such as following directions and staying on task.

N = 19 Students	Does not follow directions	Requires warnings	Needs redirections	Teacher prompt	Total teacher interventions
1	49	48	252	231	*580*
2	22	27	238	292	*579*
3	47	130	387	272	*836*
4	35	32	317	304	*688*
5	36	95	231	207	*569*
6	0	2	63	135	*200*
7	132	72	546	299	*1,049*
8	4	18	53	108	*183*
9	20	14	273	205	*512*
10	37	133	181	232	*583*
11	56	93	404	260	*813*
12	9	39	159	301	*508*
13	68	79	341	245	*733*
14	23	4	26	68	*121*
15	267	6	790	700	*1,763*
16	250	46	272	401	*969*
17	14	25	159	271	*469*
18	4	3	50	30	*87*
19	31	53	207	251	*542*
				Total	*11,784*
				Average	*620.21*

TLC 2011. Fig. 1, Behavioral Data 2011

Associated Comorbid Conditions

The effort to obtain an accurate diagnosis and treatment for an Asperger child is usually not straightforward. AS is a multifaceted disorder with subtle manifestation of deficits (Mesibov, Shea, & Adams, 2001). The diagnostic process is further complicated by comorbid conditions, or other secondary problematic behaviors. These may include difficulties with attention and concentration, anxious behaviors, depression, motor or vocal tics, obsessive-compulsive behaviors, noncompliant or aggressive behaviors, or learning disabilities (Klin, Volkmar, & Sparrow, 2000). The behaviors associated with these conditions tend to be disruptive and therefore become the focus of treatment and diagnosis. Before it is recognized that a youngster has AS, the child may be given one or more of the following diagnostic labels: attention-deficit/hyperactivity disorder (ADHD), depression, anxiety disorder, obsessive-compulsive disorder (OCD), oppositional defiant disorder (ODD), or schizophrenia. In some cases the child may have a comorbid condition, which warrants the diagnosis. In other cases, the behaviors are a manifestation of one of the many features of AS and do not meet the criteria for a second diagnosis (Mattila et al., 2010).

Attention-Deficit/Hyperactivity Disorder

Difficulties with attention and concentration are not uncommon with AS children, especially in younger children (Klin et al., 2000). According to the authors, 28 % of AS children have a comorbid diagnosis of ADHD. Our clinical experience indicates that the modal number of co-occurring diagnoses is three additional diagnoses for 40 identified AS students. New data suggests that about 8 % of elementary-age children are diagnosed with ADHD. However, the AS child can present with impaired attention without having ADHD. Some features of AS that interfere with attention include sensory overload and fixated attention. With sensory overload, the AS child has difficulty filtering out irrelevant stimuli and becomes "overloaded" by sensory input or cognitive demands. Instead of focusing attention on what is relevant, she/he is "distracted" by too much sensory input, failing to attend to what is important. For example, "Allan" has a hypersensitivity to auditory input. He was so distracted by the sound of a bumblebee buzzing around a bush 30 ft from the house that he could not stay on task to complete his chores. He repeatedly put his hands over his ears, trying to muffle the sound of the bumblebee.

With fixated attention the AS child becomes intensely preoccupied and selectively focused on an object or activity. Because of this fixated attention, the child fails to apprehend other stimuli (verbal information or interactions) in the environment. For example "Allan's" teacher was reviewing plans for a class trip the next day. "Allan's" attention was so focused on the ducks printed on his teacher's tie that he failed to "hear" what his teacher was saying and did not respond to the teacher's question.

Anxiety Disorders and Depression

Anxiety and depression are more common among older AS children and adults (Klin et al., 2000). As AS children mature, they become increasingly aware of how they differ from their peers and the difficulty they have in social relationships. They are aware of "standards" of behavior and achievement which are difficult for them to attain. Frequently, as a result of these differences, the AS child becomes the victim of peer teasing or ostracizing. In response to these very real differences, taunting, and social consequences, the AS child may become depressed. Adolescent depression tends to manifest differently than in adults. Instead of expressed sadness or withdrawn behaviors, it is manifested through acting out or an irritable demeanor.

Suicidal ideation is one manifestation of adolescent depression. Comorbidity and the inherent deficits of the AS child combine to create increased vulnerability to suicidal ideation. For example, the deficits in communication, perspective taking, and metacognition interfere with effective problem-solving skills. Behavioral and verbal responses are often inappropriate for the setting and situation.

When the child receives corrective feedback, his anxiety and frustration increase, resulting in a “fight or flight response” and impulsive behavior. The apparent “suicidal ideation” may be without substance because of its use, by habit, to avoid tasks. Suicidal statements require follow-up in the form of increased clinical supervision and monitoring versus repeated hospitalizations. Building resiliency is related to the child’s competency in dealing with anxiety and frustration – rather than being removed from the source.

If the AS child responds with anxious behaviors, it could manifest as nail-biting, tugging at clothing, hair pulling, avoidance of school or other social situations, etc. In some cases, the anxious behaviors may meet the criteria of an anxiety disorder such as social anxiety or school phobia. Similarly, if the depression becomes chronic and significantly interferes with daily life, it may meet the criteria for a mood disorder. In a study by Klin et al. (2000), 15 % of AS children have had a coexisting mood disorder.

Distinguishing between anxious and depressed behaviors that meet the criteria for a disorder requires professional consultation. Generally, if the anxious or depressed behaviors are short lasting, or are a normal response to an event, then the anxious or depressed behaviors should remit. If they are chronic, and significantly interfere with daily life, professional treatment is indicated.

Obsessive-Compulsive Disorder

Although OCD does occur in some individuals with AS, 19 % according to Klin et al. (2000), some features of AS can be mistaken for obsessive-compulsive disorder: a cognitive rigidity, an adherence to routines and schedules, and a restricted range of interests. For example, it is common for AS children and adults to have a consuming interest in a specific topic, for example, trains, elevators, dinosaurs, or presidents of the United States. They typically develop extensive knowledge about their specific area of interest. What distinguishes behaviors associated with these interests from OCD is that the AS individual does not feel compelled to read about “trains” or “ride a train” as a means of reducing feelings of anxiety – they simply find pleasure in pursuing their area of interest. For example, “Allan” has a consuming interest in trains. He collects books, magazines, catalogues, and videos about trains, train schedules, model trains; he knows the history of trains and how they are built; and he frequently rides trains. However, he is able to go through his day without train-related activities interfering with his daily routines. Given the opportunity, however, to read a book or talk about something he likes, he will inevitably discuss/read about trains.

Another feature of the AS child’s restricted range of interests is that the dysfunction becomes ego-syntonic, that is, the AS youngster does not see anything wrong with engaging in the absorbing interest. An OCD youngster is generally bothered by the obsessive thoughts and compulsive behaviors and experiences them as intrusive and disruptive to his/her life and as a source of anxiety.

Oppositional Defiant Disorder

AS children can be difficult to manage and exhibit noncompliant behaviors. However, the reasons for the apparent noncompliance are different. An important difference between an AS child and an oppositional defiant child is volition. While the oppositional defiant child will planfully disobey the "rules," the AS child will generally make an effort to follow the rules as he understands them. However, his understanding of the rule may be impaired either because of a miscommunication (comprehension or language pragmatics), a sensory overload, a misreading of contextual (nonverbal) cues, or an inattention or because he acted impulsively. Additionally, when an AS child learns a rule in one environment, the behavior will not generalize to a new setting. In the new setting the contextual cues are different, and the AS child will perceive the similar setting/situation as entirely different.

Schizophrenia

Many aspects of AS can be confused with psychotic behavior. An untreated AS child can present as a solitary individual, uninterested in social interaction and intensely preoccupied with internal thoughts. Limited language to illustrate cause and effect, distortion of meaning, neologisms, and limited pragmatic language application are the characteristics observed in the AS individual's behavior patterns.

Psychopharmacological Management of ASD

The most frequently used intervention in school-based settings is medication. The following is a discussion on the relationship between the person's ability to metabolize medication and the medication prescribed. Pharmacogenetics is a science that measures an individual's genetic variations in relation to doses of certain medications.

In order to manage this enormous variability, Dr. Mrazek (2010) classifies persons into four broad clinical CYP2D6 metabolic phenotypes:

1. Poor metabolizers
2. Intermediate metabolizers
3. Normal or extensive metabolizers
4. Ultra-rapid metabolizers

Research laboratories are not uniform in how CYP2D6 phenotypes are categorized. Dr. Mrazek (2010) describes two most common methods: current and historical. The "historical" method refers to research done prior to 2000 and was approved by the Food and Drug Administration in 2004. The "current" methodology identifies more individuals as being potentially sensitive to medication and who may require lower doses of CYP2D6 substrate medications, according to Dr. Mrazek, to minimize possible side effects.

The current method of classification would identify 40 % more persons as intermediate metabolizers in contrast to the historical method of 4 %. Current definitions of the metabolization level are defined differently, depending on the methodology used by the laboratory to classify phenotypes: poor metabolizer, intermediate metabolizer, extensive metabolizer, or ultra-rapid metabolizer phenotype.

Some laboratories have adopted a seven-category phenotyping strategy. Some researchers believe the seven-category system is more precise (Mrazek, 2010, p. 42). The important point is to understand that there are different criteria for phenotype identification according to different methods of classification criteria. Environmental factors may also influence gene expression or enzyme function resulting in altered metabolism of medications.

There are implications for a person's ability to metabolize psychotropic medications. The result is that decisions may be based on subjective and anecdotal information. Phenotype classification of metabolizing abilities for different substrate medication choices for individuals requires more investigation. Treatment result studies associated with phenotype classifications are needed. Research models of single subject, successive treatment, and multiple baseline studies may help assess a person's chromosomal variability.

Genotyping for Personalized Medicine and Treatment

An article in Technology Review March/April 2009 written by Emily Singer (2009a) reports new DNA findings resulting from genome research studies that focus on missing pieces of alleles DNA that are related to different diagnoses: autism, schizophrenia, and other disorders. Research studies described "architectural flaws" in DNA too small for microscopes. These DNA variations in structure range in size from 1,000 to more than 100,000,000 base pairs that comprise part of a gene or more than the entire gene. These findings have heuristic value but are nonconclusive for diagnostic purposes.

Structural DNA abnormalities have been reported by Dr. Heather Mefford, a pediatric geneticist, and Evan E. Eichler (Mefford & Eichler, 2009). Hot spot genes with a tendency for instability may be the troublesome ones associated with mental retardation, autism, and to some extent schizophrenia. All of these diagnoses are developmental and diagnosed in childhood or adolescence. It should be noted that enzyme maturity occurs at 5 years. Genotyping prior to 5 years is contraindicated.

Disruption in the 1q21.1 genome “address” of the chromosome and allele, inherited from one parent, can cause fundamental development to go off course says Singer (2009b) in her article. Brain development and cognitive function may be accounted for in genome variability and mutation.

The effect of medication on behaviors is influenced by the ability for genetically determined receptors in the person to utilize the medication. If the receptors are shutdown the medication may have no positive effect. Medication in fact may become a toxin in the child’s system through unutilized medication buildup. Other complex interactions between receptor alleles and unintended synergies may alter metabolism levels.

An article by Ruaño et al. (2008) reported a significant association between a gene address and the influence on the drug metabolism capacity for mental health patients in high levels of inpatient care. Patient carriers of sub-functional polymorphisms in the CYP2C9 and CYP2D6 genes were identified. These genes influence metabolic pathways of numerous psychotropic drugs including antidepressants and antipsychotics such as risperidone, often used to treat Asperger syndrome and other co-occurring diagnoses.

Two pharmacogenetic studies published as companion papers Ruaño et al. (2011) and Villagra et al. (2011) have demonstrated the clinical implications of a systems approach to CYP450 genotyping and its physiogenomic analysis for the personalized management of psychotropics. CYP450 combinatorial indices for innate drug metabolism function may be superior in accuracy and utility to phenotype descriptors of metabolizer status (e.g., poor, intermediate, extensive, ultra-rapid) due to the resolution and scope of this approach. The combinatorial index ranking curves are useful in benchmarking innate drug metabolism reserve and identifying patients at the extremes of metabolic capacity to correlate with clinical outcomes. The results demonstrated that combinatorial CYP450 genotyping and corresponding quantitative indices of pharmacogenetic functional status have potential clinical utility in psychiatry for evaluating the risk of iatrogenic cardiometabolic effects of psychotropic treatment.

The authors note that antipsychotic and antidepressant medications have significant side effects that could build up if not properly metabolized. In addition, significant alterations in CYP450 function will alter the ratio of precursor drug to psychoactive metabolite in several psychotropics, which will result in lesser therapeutic efficacy. And the non-metabolized medications would not have the desired influence on behavior. And drug toxicity then may be an unintended outcome of medication therapy. A review of the literature by Black III, O’Kane, and Mrazek (2007) focused on the effects of psychopharmacological interventions with antidepressant and antipsychotic medication. Their findings suggest that 35–45 % of patients return to pre-morbid status following medication interventions.

The authors further reported the benefit on the new field of pharmagenomics. Pharmacological agents are selected based on the genotype of the patient. The convergence of psychiatry, genetics, and biobehavioral science and technology enables genotyping to be a new aide in selecting and dosing medication. The article further reported that 57 % of referred psychiatric patients may be severely compromised in drug metabolism capacity identified for two or three genes among the CYP2C9, CYP2C19, and CYP2D6 genes. These findings suggest that genotyping could be useful for individuals who have histories of drug resistance. Genotype-guided prescriptions may prevent trial and error prescription of medications for children and adolescents. Genotype-guided prescriptions may assist in correct medical intervention for children on the autism spectrum.

Medication effects are dependent on the individual's chromosomal structure for effective medication utilization and influence on behavior. Malhotra, Goldman, and Mazzanti (1998) researched pharmacogenetic strategies as prospective biological predictors of psychotropic drug response as a means of determining drug efficacy or induced adverse side effects. The authors report that the most commonly used pharmacogenetic studies are associated with antipsychotic drug efficacy, antidepressant drug response, and drug-induced adverse effects such as weight gain. Their antipsychotic drug research suggests that polymorphisms within serotonin 2A- and dopamine-related genes may influence drug efficacy in schizophrenia, for example. Malhotra, Murphy, and Kennedy (2004) also report that "the initial research into the pharmacokinetics of psychotropic drug response suggests specific genes may influence phenotypes associated with psychotropic drug administration." This conclusion is supported by replicated studies.

Physicians may be able to augment diagnoses through the use of genetic testing. But clearly the more science and technology we apply, the more we realize the complexity of the human being and its development. It is premature to associate the ability to metabolize medication with a diagnosis or outcomes derived from genotyping for psychopharmacological management at this time (Salyakina et al., 2010).

Personalized Medicine and Treatment: Theory into Practice

Our clinical experience over a 30-year period is that the clinical response to psychotropic drug treatment remains a problem in medication management of children and adolescents in outpatient and residential care. A research by Malhotra et al. (2004) with adult patients reports similar difficulties after the start of drug therapy.

Replication of research studies on the evidence of medication efficacy in reducing symptoms and preventing adverse effects is needed before recommendations may be made. The delay in obtaining positive therapeutic effects from medication results in child and adolescent ongoing vulnerability to persistent negative life events and lost time for effective treatment.

The ability to identify predictors of psychotropic drug response targeted for specific symptoms remains a priority for future research. The multiple biological variables and ecological variables are difficult to co-correlate with drug responses for individuals. Malhotra et al. (2004) point out the positives of new abilities to assess results. They are as follows:

1. An individual genotype is invariable and is therefore a reliable independent measure.

2. Molecular biological techniques provide assessment of an individual's genotype.
3. Increased feasibility for routine DNA collection for genotyping enables large scale clinical trials.

Genome research is providing new directions and hope for accurate understanding of bio-neurological associations with DNA and the diagnosis and medication therapy of children (see www.genome.gov/19516567, National Human Genome Research Institute, 2012).

The development of effective educational and clinical services for students on the autistic spectrum is not a straightforward process. In large part, the comorbidity and polypharmacy of these students contribute to the complexity and difficulty of providing the appropriate services for each child.

The threats to the reliability and validity of the association between medication adjustment and therapeutic interventions co-occurring over time are apparent. Time in treatment and coefficients associated with treatment or medication are difficult to separate in an applied setting, for example, school. Even so, the standard protocol is the use of matched single subjects with the same medication prescriptions to provide the reliability of genotyping to influence both medication metabolism and treatment outcome for children and adolescents.

However, the practical application in providing treatment in a school setting requires a different research design. The single-subject, multiple, baseline, successive treatment model enables assessments of the effects of treatment in school settings. The student's rates of behavior over time are charted to show the efficacy of genotyping to select medications and/or other interventions. The successive treatment model can be used to show the effects over time of different clinical strategies on the student's behaviors.

With the recent advances in genetic research, it is now known that another confounding factor exists: alterations in a person's ability to metabolize these medications. Therefore, personalized medicine is increasingly becoming the public's expectation and standard of the pharmaceutical/medical industries. Genetic testing for medication metabolization is emerging as the essential first step in achieving personalized medicine. The push for personalized medication results from concern over the dangers of prescription medications.

According to Brenda Smith (2012) in the Monitor on Psychology, psychotropic drugs are prescribed four out of five times by non-psychiatrists in geriatric settings. Prescription drug errors are the leading medical cause of death in the US after cancer, heart disease, and stroke. Eight percent of children and youth have been diagnosed with ADHD and over 50 % of them take medication. Smith also reports that eight million children receive prescribed medications without adequate research to justify the medication prescribed.

Pilot Study: Altered Drug Metabolism in 28 Students

Concern with the possible dangers of prescribed medications has led to more frequent use of pharmacogenetic testing. For example, over the past 2 years, the clinical staff at one treatment program for special education students has referred 28 students for pharmacogenetic testing. The 28 students are from various states and schools; they demonstrate histories of co-occurring DSM-IV diagnoses. Each student has a history of multiple medication trials and concurrent multidrug treatments. Parents of the children and adolescents also stated that their children showed little benefit from psychotropic medication. Parents expressed concern for increased dosages prescribed for their children over time and secondary side effects of weight gain, behavior dysregulation, and variable response latency associated with medication changes. Adolescent self-reports also demonstrated testimonials of little or no benefit from their psychotropic medication.

Results from the pharmacogenetic testing revealed that 26 of the 28 individuals (92 %) have altered drug metabolic function. In such individuals, the altered drug metabolism function for psychotropic medications was identified as ultra-rapid, deficient, poor, or null. Fourteen percent (14 %) of these individuals were determined to be null metabolizers on one of the major metabolic pathways: three on CYP2D6 and one on CYP2C9.

Results for the three primary metabolic pathways for psychotropic medications (CYP2D6, CYP2C19, and CYP2C9) revealed a higher percentage of difficulties with the CYP2D6 pathway: 21 individuals (75 %) had altered metabolism on CYP2D6, whereas eight individuals (28 %) had altered metabolism on CYP2C19 and 11 individuals (39 %) had altered metabolism on CYP2C9. Note that some students may have altered metabolism on more than one genetic pathway.

Deficient metabolism by genetic pathways in 28 students with mental health diagnoses

Deficient genetic pathway(s) 2C9 and/or 2C19 and/or 2D6	Number of students (26)	Percentage of total (N=28) (92 %)
2C9	11	39 %
2C19	8	28 %
2D6	21	75 %

Data collected by clinical staff at The Learning Clinic from January 2010 to December 2011. Genetic tests results provided by Hartford Hospital, Hartford, CT

A high percentage of psychotropic medications are metabolized through the CYP2D6 pathway. Therefore, it is critical to know in advance if a particular psychotropic medication has the potential of producing the intended therapeutic effect. The figure below shows three classes of drugs that are metabolized by the 2D6 genetic pathway.

Stimulants	66.7 %
Antidepressants	76.9 %
Neuroleptics	86.7 %

Metabolic function may also differ by diagnostic categories. Of the 28 students, 17 (60 %) are on the autistic spectrum. Thirteen of these individuals (76 %) had altered metabolism on CYP2D6. Of the 21 individuals who have a comorbid diagnosis of a mood disorder, 18 of these individuals (90 %) had altered metabolism on

CYP2D6. Students with certain diagnosis show deficient metabolization of one or more genetic pathways. In the sample of 28 students, the diagnoses associated with deficient pathways were bipolar disorder, Asperger syndrome, and autism spectrum with any mood disorder.

As shown below, for "Comorbid Diagnoses per Student," of the 28 students in this pilot study, 60.7 % of them have 3–4 psychiatric diagnoses and 78.57 % range between three and six diagnoses per child, as follows:

- Six students have two diagnoses.
- Nine students have three diagnoses.
- Eight students have four diagnoses.
- Five students have five diagnoses.
- Six students have six diagnoses.

A similar complexity is revealed when assessing the number of psychotropic medications: "Psychotropic Medications per Student." Of the 28 students referred for genetic testing, 42.8 % were receiving four psychotropic medications and 64 % received between four and eight psychotropic medications (TLC, 2011). Polypharmacy is a complicated process which requires high levels of oversight by the prescribing physician to assess for potential side effects, synergistic effects, and dosage, type, and frequency to achieve the intended therapeutic effect.

Number of psychotropic medications	Number of students (N = 28)
1	2
2	4
3	4
4	12
5	0
6	4
7	1
8	1

Further review of our 28-student sample showed 10 students with problems metabolizing medications on 2C9. For those 10 students comorbidity was associated with the incidents of deficient metabolism. Below is a table listing comorbid diagnosis and numbers of students who show deficiencies on the 2C9 receptor.

Number of diagnoses	Number of students (N = 10)
1	0
2	1
3	2
4	5
5	1
6	1

A Case in Point: Personalized Treatment

Each person referred to TLC is monitored for behavioral changes across settings, for example, classroom and residential settings. A multiple behavior baseline of 45 days is obtained in order to determine changes in behavior through time and over time. It is important to note that the ability of a person to metabolize prescribed medications may also affect treatment efficacy for the many psychotropics with active metabolites. Therefore, the baseline comparison to future observed behavior enables TLC clinicians to assess results of medication changes and other significant life events on rates of behavior change.

This personalized approach to pharmaco-genotyping, psychopharmacological management, and multiple measurements of treatment effects over time and across settings has enabled clinicians to have greater influence over treatment results and medication efficacy. The following is a review of one student's behavioral data over a period of 5 months, subsequent to the date of genetic testing. This student has comorbid diagnoses of PDD NOS, bipolar disorder NOS, ADHD, and oppositional defiant disorder. Genetic testing was conducted in June 2009 and it was determined that the student had a significant alteration in the CYP2D6 enzyme, being an ultra-rapid metabolizer, but was a functional metabolizer on CYP2C9 and CYP2C19.

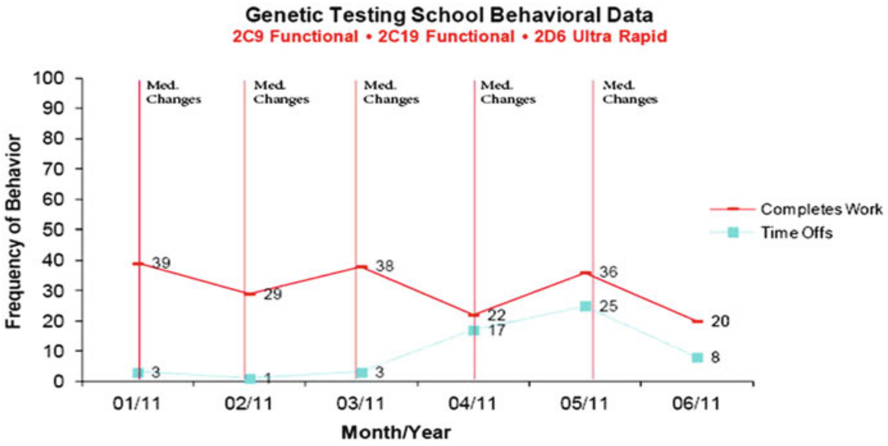
Following the genetic testing in June 2009, the student's psychotropic medication regimen included two medications, Abilify and Seroquel, which are metabolized through the CYP2D6 pathway, respectively, at high and moderate substrate affinity, and one medication (Lamictal) that is not metabolized through CYP2C9, CYP2C19, or CYP2D6. Multiple medication changes ensued to achieve a more effective treatment response, but with mixed results. In late February 2011, the student received two significant medication changes: The dosage for Abilify was split into two smaller doses to achieve a therapeutic steady-state response. Additionally, Lithobid (not metabolized through CYP2D6) was added. Throughout January and February 2011, Depakote was reduced and then discontinued in late March. From February to June 2011, further downward adjustments in the level of Abilify occurred. The ultra-rapid status indicated a need to increase dosing in the steady state, which was achieved initially by twice-a-day prescription of Abilify. The significant alteration in CYP2D6 indicated a need to avoid drugs dependent on this pathway for metabolism, which was achieved by the eventual phasing out of Abilify.

Over this same time period (January 2011 to June 2011), behavioral data revealed an improvement in multiple areas. For example, inability to follow directions decreased from 121 at baseline to 68 (43.8 % decrease), academic incomplete work decreased from 125 at baseline to 65 (48 % decrease), self-imposed time offs (self-control indicator) increased from 11 at baseline to 45 (309 % increase), and negative attention-seeking behaviors decreased from 41 at baseline to 18 (56 % decrease). Although anxious coping increased to 44 from a baseline of 13, the frequency had decreased over the 5-month period from January to June 2011. The student remained dependent on staff support (Prompts, Redirections, Warnings), but the general trend was decreasing.

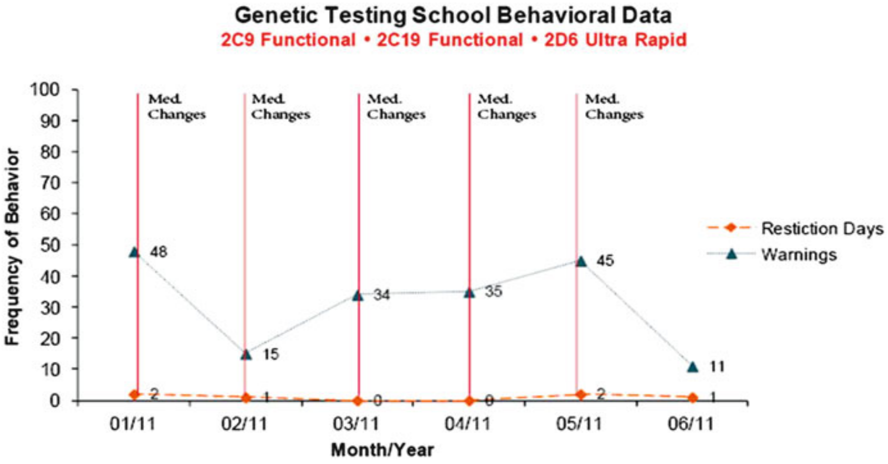
Frequency of school behaviors

Behavior	4/2/10–6/2/10 (Baseline)	1/22/11–4/1/11	4/2/11–6/10/11
Inability to follow directions	121	98	68
Incomplete work	125	89	65
Time offs	11	6	45
Warnings	123	72	79
Redirections	55	341	269
Prompts	254	288	245
Restricted day	11	3	2
Anxious coping	13	68	44
Negative attention seeking	41	60	18

TLC (2011)



(TLC, 2011)



The study reveals the complexity of coordinating medication regimens with clinical interventions to achieve a therapeutic effect. It is not a simple, straightforward process. The salient message to learn from the case is that personalized medicine is not just a preferred method; it is a prerequisite to achieve the intended therapeutic results. Comorbidity increases the complexity of medication regimens. The compromised ability to metabolize medications presents a unique problem that requires a personalized approach to select psychopharmacological treatments to match available "genetic addresses." The aim is to adjust treatment so that the person may effectively metabolize medication. Instructional methods, task selection, and clinical strategies also need a personalized approach, rather than a "one size fits all" approach to the person's diagnosis.

Research methods, like single-subject design, fit the need to assess the results of medication management. The medication influence on instructional and clinical outcomes may also be observed and measured. A multiple baseline database enables the treatment team to monitor positive effects and the unintended outcomes of interventions, in both educational and treatment settings. The single-subject research methodology may be most appropriate for school-based mental health service delivery.

Summary

This chapter discussed key issues in the treatment and education of children and adolescents who have diagnoses on the autism spectrum disorders. The educational setting is the most probable setting to observe the child's diagnostic characteristics that reveal developmental delays in behavioral self-regulation, cognitive function, social reciprocity, and pragmatic language skills. The school is the primary place where 70–80 % of students receive mental health services under federal and state regulations.

The setting where mental health services are provided may be defined under IDEA guidelines for the student's individual education plan. Such settings need to be modified based on personalized assessments of the child and analysis of ecological factors that influence the child's behavior. Comprehensive delivery of mental health treatment in schools will reflect the integration and cohesion of education and treatment services.

Prior to introducing new practices into the education and treatment setting, the demonstrated results of such interventions, procedures and methods are to be assessed. The aim is systematic use of evidence for the modification of treatment strategies based on a diagnosed need defined operationally. For each child or adolescent on the autism spectrum disorders, the treatment is to be based on empirical information that fits the child's needs and setting resources.

Differential diagnosis among autism spectrum disorders is problematic. The ability to distinguish phenotypes does not currently exist. Developmental age and symptom clusters are the most reliable guides to each student's needs and to provide the basis for effective interventions. Comorbid diagnoses are associated with the clinical presentation of children and adolescents on the autism spectrum disorders. Comorbidity typically impedes academic performance and complicates effective treatment planning for the educational environment.

Medication is the most frequently used intervention through school-based mental health services. Pharmacological management of students' medication lies increasingly within the scope of school-based mental health treatment. New research suggests that genotype data is associated with both positive and negative outcomes in mental health treatment.

Pharmacogenetic tests now exist to measure a person's metabolic function related to specific drugs. When such tests are used as a prerequisite to medication choices and service delivery, the results are generally more effective. Personalized psychopharmacological management of medications is an important consideration in school-based treatment.

Many factors influence a child's or adolescent's performance at school, at home, and in the larger community. New knowledge of genetics, medication management, and neurobiology can be applied to older principles of child development, readiness to learn, cognitive behavioral science, self-regulation, instructional technology, and ecological variables present in all settings. The convergence of knowledge from different disciplines may benefit children and adolescents on the autism spectrum disorders.

"Plasticity" and its impact on brain structures is an area of ongoing research. We are still discovering how this influences the development of such structures as the amygdala and prefrontal cortex and therefore the child's ability to self-regulate. What we do know for certain is that the "one program/solution fits all" approach is unable to meet the personal needs of these children.

Many challenges exist and need to be managed to effectively bring comprehensive treatments to the school environment.

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Living with AS: Real Issues, Practical Advice for Families with School-Aged Children

Jennifer Blackwell

As a parent of children labeled “high-functioning autism” and Asperger syndrome, I have spent many years reading books and articles, attending conferences, speaking with other parents and professionals, and generally searching for answers as to how to best help my children navigate their way through and around the obstacles in life associated with their diagnoses. I have come to the conclusion there are neither “easy answers” nor any suggestions that work for all kids, all of the time. There is no way in these pages to cover all the ideas out there for working with our kids; I will include a list of resources at the end of this chapter.

It is with those thoughts in mind that I approached this chapter, hoping to share some of the lessons we have learned from those who know and from our own experiences with our children – they are truly my best teachers.

Children with AS face many different struggles; which means that we, as parents and families, face many as well. One thing I want to say upfront is that we make many mistakes – just as any parent does with any child. You will find throughout this chapter the theme of “no guilt”; it is difficult enough to parent a child, add the special needs involved with a child with AS, and the task can be overwhelming. The lesson I feel has helped me the most is to not add to the situation by adding blame or guilt.

That lesson begins prediagnosis. Often the symptoms that lead to an Asperger syndrome diagnosis are difficult to sort out in a young child. We may see “quirks” or wonder about language development; we may experience tantrums and meltdowns that have us – and others – questioning our ability to parent; we often find ourselves creating schedules, rituals, and incredible accommodations to get through the day. These are all marks of having a child with AS. Comments from strangers at the store, professionals in the school, and, possibly, our own extended family members can lead to feelings of guilt and frustration – even to the point of questioning

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whether we just need to be stricter in order to solve issues we are seeing. I think the hardest struggle can be when parenting partners disagree – and that happens quite often. My husband speaks of his denial and the remorse he feels now – he views his actions during those early years as creating an obstacle for our oldest son receiving services. After attending a meeting for dads, he came to understand he was not alone in how he felt. Knowing there are others out there with similar obstacles and struggles can make a huge difference; support is crucial.

Living with a child with AS is not just about home life or dealing with the school system, it spills over into all phases of life, but for the sake of this writing, I will address three main areas – home, school, and community. Much will overlap, but this gives us a place to begin.

Let's Start with HOME

As I began to attend conferences and read about Asperger syndrome, I realized our experiences were very common. We saw little things early on that just didn't seem quite "right," but this was our first child and everyone had an opinion about what it could be: he had hearing issues, he was a math and spelling wiz, he was oversensitive, and his grandparent had speech delays so it was nothing to worry about; you name it, we heard it. It wasn't until we entered the school years that we really faced that he struggled. Even though he received speech services before kindergarten (mainly for pragmatics and echolalia), when he entered public school, we were told he was just immature. It was not until he showed signs of rigidity in routine and social interactions and began having meltdowns due to sensory overload that enough red flags popped up to warrant an evaluation through the school.

In the meantime, life at home included many schedules and rituals – things I had no idea that had to do with an autism spectrum diagnosis – but were purely survival based from living with this child and his needs. As I have spoken with more and more families, that seems to ring true universally. The child tends to create around them the things they need, and we, as caregivers, do what we can to accommodate. When we do not accommodate, the reaction of our child can be explosive, leading to more and more difficulties – and many times, misdiagnosis. It is often during this phase that some of the harshest comments are expressed concerning the child running the family. Those of the generation of "spare the rod and spoil the child" can be especially penetrating. Let me remind any of you dealing with this, even after diagnosis, of the theme of this chapter, "no guilt." We just need to love our child(ren), do the best we can, and search out support for the rest.

Some of the most common HOME concerns include the following:

> I feel like I am neglecting other members of the family (and MYSELF) because of the demands of my child with AS.

It is true that a child on the spectrum can be overwhelming to the caregiver. I heard a speaker at a conference once who talked about "fair" being about people getting what they need, not necessarily getting all the same thing; I had many thoughts about that as I sat there, but it has come to mean to me that I can balance my time and efforts by taking time with each member: my two on the spectrum, their two siblings, my husband, and others in my life. "Balance" does not occur by spending the same amount of time and effort on each person – it comes over time and by spending quality time with each person. When a child has a large school project, is feeling under the weather, or has any type of personal need, I naturally spend more time with them at that moment. My husband and I try and have weekly check-ins with each child; sometimes it is playing a favorite computer game and talking, other times I may take one child to eat while the others are at a school function. Of course, before I can do much of this, I had to set up a foundation of sorts at home so we were not always dealing with perpetual crises. This was also harder to do when they were in elementary school and younger, and it is something to work up to; yet there are ways to adapt the idea so it becomes part of the family ritual or tradition from an early age. We try to blend needed therapy and skill building for our two on the spectrum into daily activities at home so everyone's schedule is not so interrupted by more formal therapy all the time.

Making time for ourselves and our spouse or significant other is important as well. If we are not on the same page with our partner, it causes stress and leads to confusion for ourselves and our child(ren). A little quality time to talk, or just enjoy an evening out, is so important. The hardest of all can be making time individually to take care of ourselves. The primary caregiver(s) often feels the load of the child's needs, as well as of the rest of the family, and often feels they are the only one who can take care of those needs. This falls under my "no guilt" umbrella. Respite can be found, whether through an agency, a family member, or a friend – but it is imperative. They will survive a short time away from you, and you will be a better caregiver for having taken that time away to refresh and regroup. When our oldest struggled with being away from me, we recorded his favorite game show, "Wheel of Fortune," for him to watch while I left him with a neighbor friend and took a walk or went to the store.

Our child was diagnosed with AS, what do we tell our extended family and friends?

Who to tell, what to tell, and when to tell are three of the biggest questions when it comes to sharing information – the other we will address in a moment, what to tell the child. Let's start with family members – we felt it was important to let them all know, to the extent they could understand, about our sons' diagnoses, as they would be intimately involved with our kids to different degrees. Our children would be around them at family gatherings for birthdays and holidays, at the very least, and in order to make everyone as comfortable as possible, knowledge and understanding are important. Beyond just natural family gatherings are family relationships on a more individual basis. I have talked with many grandparents who are dealing with changed expectations, who want to be a part of their grandchildren's lives, and who have not grown up in a world where Asperger syndrome was even a diagnosis. My husband often refers to the change in family dynamics that having a child on the spectrum causes; traditionally, parenting styles were taught from one generation to another (ever heard yourself say something and then think “I’m turning into my mother?”), but when you have a child with AS, most likely your parent has not experienced the issues you face. Explaining in simple terms that your child has a diagnosis of Asperger syndrome, which means mainly that their brain works a little differently, their way of seeing the world is from a different perspective, they may face sensory and/or language processing struggles, and there are ways to still be involved with this child, can be a place to start. Helping family members to understand accommodations is important, especially when grandma wants everyone to help make cookies – and the idea of touching something that slimy is throwing the child with AS into a meltdown. Preparing both the family member and the child ahead of time can lead to positive interactions. Having a visual schedule of the day’s events or the steps for the activity may bring peace of mind to the child, while it can also let the family member involved understand what might be a challenge to the child. Modeling how to get into the child’s world first may be a less threatening way for all to have a fulfilling time together. If family or friend visits are overwhelming, make “appearances” to stay connected and use opportunities that have a place for the child to “chill out” for longer visits. Many times, I have heard of families isolating themselves from their extended family and friends due to the behaviors or needs of their child. This only serves to weaken the support system a family needs and can cause issues, especially with siblings who then are not involved with others as well. While not all friends and family members will always understand, much is gained from sharing and allowing others to be a part of the life of your child and your family. Just like we need to learn to accept our children for who they are and what they can handle, the same is true for others in our lives.

Should I tell my child about their diagnosis?

In a word, YES!

Children catch on quite early that “something is different” about themselves, and if they don’t catch on, their peers will point it out for them; Dr. Tony Attwood suggests starting to explain AS at an early age, before they start to develop “inappropriate compensatory mechanisms” (Attwood, 2008). To me, it was important to make any differences as understood and accepted as possible, as early as possible, while my sons were open to the information. Once a child gets a little older, they may be less likely to be open to talking. They also may have developed deep-rooted negative thoughts about themselves or actions that will be more difficult to replace.

Talking with your child about AS is often compared to the “birds and the bees” talk, give them information as they are ready for it and as on their level as possible. Younger children, especially, usually benefit from something visual and that explains AS as it relates to them. There are wonderful books for children available that introduce and explain autism spectrum disorders. They can be used individually, with family, and also with classes at school. I will list a few at the end of this chapter.

I have talked with numerous teachers who say they deal with parents who don’t want their child told about their diagnosis because they don’t want them to feel bad about themselves. When we speak as a family at conferences, the “hot topics” that my sons and I are asked about are when they were told, what they were told, and how they felt about it. We tried to make it an open subject; we always used the terms "autism spectrum disorder" and "Asperger syndrome" around the house. Our older son was diagnosed with AS at age 8, within a few months of his 2-year-old brother's ASD diagnosis. This gave us many opportunities for family discussions, but it was the individual conversations that were some of the hardest for me personally. I wanted my child to know how wonderful he is and how many gifts he has – not to focus on what is considered a negative, a "disability." Dr. Attwood (2008) uses an activity he calls "the attribute activity" in which "qualities" and "difficulties" are listed in two columns. The facilitator (often a parent or some kind of counselor) helps with the listing, but ultimately the child lists their own attributes. It is important not to dwell on things that are negative, but to point out that everyone has these two types of attributes, and we all need to see how we can overcome or compensate for the "difficulties" while appreciating our "qualities." I remember one particular conversation with our Aspie son, soon after his diagnosis. We had already identified Asperger syndrome to him, but on this occasion, he was frustrated with a situation and came to me and asked why he had AS and his brother had autism, but his other two siblings didn't. I had to quickly put aside my own feelings for this child's pain in the moment and find a way to help him see himself as the incredible young man he is. We sat there and verbally went through a kind of "attribute activity," pointing out things he was good at and things he struggled with – as well as those same kinds of things for his siblings and parents, discussing that everyone has struggles, they are different for different people, and for many of the attributes of AS we discussed, we were able to shine some form of positive light on to help him feel better about himself. At this time, he was struggling in school with the social aspects, especially with the other kids' behaviors that he found inappropriate. He felt compelled to be the class "police," reporting on their behavior, which obviously did not set well with his classmates. We talked about ways he could handle this, such as writing down what he saw instead of verbally doing it in front of the class, when he felt it was something he HAD to report; but then the conversation turned to how much I appreciated his sense of right and wrong, and I knew I could always count on him to tell me the truth and to do his best to make good decisions. That seemed to help his feeling of self at that moment. Since that time, we have done many activities, both at home and at school, to make him, and others around him, aware of AS and how he is a worthwhile individual.

When to approach your child is very important. In the book *Asperger Syndrome and Difficult Moments*, Dr. Brenda Smith Myles (2005) describes the "rage cycle" and how when a child is in this cycle, it is not a time for teaching. That is so true. It is important to look for times to talk with your child when they are calm and relaxed and when they are open to conversation and can best understand what you are trying to explain to them. Often it is their question that opens the door to conversation. Trying to tell a child what it means to have Asperger syndrome when they are in the middle of a meltdown is not usually going to lead to a successful interaction. Helping them cope with their needs at that moment comes first, then, later, when the child has calmed down, you can talk about what happened and why it may have affected them so much.

One of the other reasons I feel so strongly about talking with our children about their AS is that it is THEIR diagnosis… and while they are young, as parents and caregivers, we tend to do a lot of their advocating, and eventually, they need to take over. Owning who they are, diagnosis and all, helps create a strong sense of self and, hopefully, helps them to feel confident about who they are and what they need to succeed. By fourth grade we had set up weekly check-ins for our youngest with his special needs coordinator, his regular ed. teacher, and assorted therapists (occupational and speech) – HE was put in charge of discussing what he felt were his needs at the time; he looked at successes and challenges with his team – no mom present unless he requested it or the team felt it was important, and then, it was with his permission – and it strengthened his sense of self awareness and self advocacy. The meetings were short most of the time, but it empowered him a great deal. The team could bring up anything they felt was important, but ultimately, he had to accept and work with their comments and suggestions.

We also worked quite a bit on self-regulation, teaching him to recognize how his body feels and how to utilize different sensory input, etc., to help settle himself. Parents or teachers won't always be around to go through the necessary steps to calm sensory overload. Early intervention is more than just speech or occupational therapy – social and emotional skills are just as important to be taught and practiced.

School

School is often where our children with AS get very overwhelmed, leading to meltdowns either at school, or as is often the case, once they get home where it is "safe." Many with Asperger syndrome are diagnosed during the elementary school years, when social and sensory challenges are upped dramatically. What may have been rationalized or ignored when a child was younger can impede their progress and cause disruptions in the classroom or other areas of school. Working with a school (district) can be very complicated and sometimes frustrating. Just like each person with Asperger syndrome is different, each district, each school, each teacher is different, so what may be successful in 1 year may not work out as well the next. We view those in our child's life as part of our team, and teams are most successful when they can find ways to work together. Sometimes that includes some give and take, it needs to include cooperation, and it can occasionally include a little demanding – but only after gentler means have been exhausted. As with all areas of life with our children, it is important to remember that we are trying to remove obstacles to their success – and sometimes those obstacles cannot be removed, so our job then is to find a way to make those obstacles less of a factor in their success. Defining "success" takes on a new meaning as well. While this is true in all areas of life, it can especially be challenging at school, where there are so many different people involved and they can change year to year. Some of the most common questions/comments that come up where school is involved include the following:

I have a meeting with the school personnel, I hear I need to bring an advocate and demand what my child needs.

It never hurts to have someone there for support, but going in "guns blazing" is usually not the best way to begin a meeting. At one of the first conferences I attended after my sons' diagnoses, I heard a speaker present about successful IEP meetings. I was surprised when her first point had to do with setting an atmosphere of friendliness by bringing brownies (or whatever)! She also encouraged the parents to always be the one to speak first – introducing their child, pointing out things that were going well (especially if a teacher or staff member was doing something helpful), and explaining a few concerns that the parent was hopeful could be addressed as a team. This can be a very intimidating thing to do when you are sitting across from what is often a tableful of professionals with degrees associated with teaching or diagnosing, but the key to remember is you know your child best of all. Help them to get to know your child as a person, with unique skills and talents – as well as struggles – and let them know you understand they deal with many children each day; you want to help them succeed. As budgets get tighter, caseloads get bigger and stress for those working with our children increases; a parent who tries to find ways to work together can go a long way.

It can be very challenging, as a parent, when you feel the needs of your child are not being met. While you would hope that concerns could be addressed in a spirit of cooperation, that is not always the case. I have been in some incredibly productive meetings, where I felt those involved had been amazingly insightful and creative, and I have been in tears and frustrated with hitting brick walls – sometimes with some of the same people. I have been relieved to have someone along at times when I have run out of ideas or explanations, but I have also felt a more relaxed atmosphere when I have gone by myself. Having an advocate there is a very personal decision for a parent, and it is one that can change from meeting to meeting. One thing I would remind parents, if you are in a meeting and you feel uncomfortable about what is going on, you have the right to stop things where they are and reconvene when you can have someone there to support you or you have had a chance to look into other options. Before you choose this option, remember how complex it can be to coordinate schedules, so try to work out what you can first. Just because you have an advocate does not mean you will get everything you want or are asking for – it is always a good idea to come in with a prioritized list of ideas, or at least of concerns to be addressed – and with some flexible ideas for how to accomplish your list. The thing to remember is your child's needs are important, and your job is to help create the best plan possible for them. You are as much a part of the team as anyone sitting in that room.

My child has no friends at school.

This can bring heartache to a parent, sometimes much more so than to the child. Just like with the term "success," we need to redefine "friend" and open our expectations to include what is best for our child. One of the hardest things for me was to let go of my perspective – what I wanted for my child to feel about others – and to work on understanding and then expanding their perspective. School is both a sensory and social challenge for my sons. The first thing that needed to be taken care of was biological needs (including sensory overload) in order to clear a path for both academic and social learning (Aspy & Grossman, 2007). If you think about it, most of us would have a difficult time studying or accomplishing our daily tasks with loud noises, flashing lights, itchy skin, or foul smells around us, and yet, our children are constantly trying to do this with all sorts of these kinds of distractions. Working on making them as comfortable, physically, as possible is actually a good first step. Sensory breaks, downtime, movement, or maybe a place with as few sensory challenges as possible can all help calm sensory overload. Getting a drink of water or chewing some gum or sucking on a piece of hard candy can help with calming. Whatever it takes, those biological (physical) needs must be taken care of enough to leave the child's capacity to learn on a higher level.

As mentioned earlier, adults are usually more predictable than children, so using adults to model some behavior or having an adult supervising social situations can be very helpful. For our oldest, recess was spent every day pacing the outer edge of the playground. I drove the preschool carpool past the elementary school a couple days a week, and it would be painful to see my son not engaged at all, just walking the path around and around. In his meeting we addressed this in two ways: a walking club was formed and the children earned shoelace beads for laps walked – so he was soon a leader in a club; and on other days a teacher who was supervising recess would take a jump rope, and a group of children (including my son) would take turns. He got the input he needed in both circumstances, as well as opportunities to interact with other students at play. This eventually led to other supervised activities (remember, adults tend to follow the rules – children make them up as they go along at times, which can truly frustrate our kids), teaching him how to enter a game, how to accept changes as they come along, and how to step out, if need be. I will never forget the day, when he was in fifth grade, his special education coordinating teacher called me at home to tell me she was watching out her window and my son had just entered a game all on his own and was successfully playing with his peers – with no adult in the immediate vicinity. We both shed a tear while on that call.

This ability did not lead to sudden invitations to hang out, but the part that I had to accept was my son was happy with the level of social interaction. The trick was to keep pushing ever so slightly to increase his comfort zone. Clubs were the next thing on our list. He loved chess; so chess club was a natural choice. Another mom worked with a teacher to start a Star Wars club – Star Wars was her child's special interest – and the members of this club all wanted to talk about Star Wars; it was a perfect opportunity for her child to fit in and share with a group of peers. The mom took it a step further and hosted a themed party for the club at the end of the year. Beginning band was huge for our sons. For the oldest especially, musical instruments became his special interest, and his love of all aspects of band led to much respect from his peers.

I should mention here, but will go into it more elsewhere, that our sons were always open about their diagnoses, throughout school. It was a topic not hidden, which led to it being more accepted by their peers. Sadly, bullying still occurred, but by standing up first and explaining some of the differences, a lot of the power behind any potential teasing or bullying was taken away.

While on that subject, another way we found to both address the issue of potential bullying and building relationships was "lunch bunch." This was a once a week (which became twice a week at times) social skills of sort of group that included my son, another young man on the spectrum, and some handpicked peers. The peers were picked by looking for students with some similar interests, who would be in the same track of classes down the road so they could continue to be his "wingmen" for as long as it would work out, and one was a gifted athlete who was respected by his peers. The handpicked peers were also told to the extent they could understand of the importance of their role, so they had a chance to accept the responsibility that came with it. Each week, they would have lunch in the coordinator's classroom, with that teacher and maybe another member of my son's team (occupational therapist, speech therapist, etc.), and different social skills were addressed in a fun way so as to not feel like a social skills class. The teacher and I often laughed when we knew she had been successful in our goal to have him acquire the social skills of a "typical" 10-year-old boy when his favorite lunch bunch had to do with an iPhone app that involved bodily function noises! As Dr. Brenda Smith Myles often explains, "social skills" are not just "manners classes" (Myles, 2004).

These lunch bunch peers not only became friends, but their friendship modeled for other students how to approach my son.

> My child has meltdowns at home after school but when I ask the teacher, she says they don't see any of the problem behaviors there.

It is common for a child with AS to hold it together through a school day and then fall apart when they reach the safety of home. You can be as prepared as possible, with different sensory activities or chill out opportunities, and it still may not matter. In our case, the overload at school eventually reached a level where he could no longer hold it in all day. I know of some parents who have gone to the drastic measures of recording their child or calling the school when their child is melting down upon arrival at home. The main thing here is communication between home and school is essential for the success of all involved. If something goes wrong at home before school, having a plan in place for giving the staff a heads up so there may be extra breaks or sensory input available for the child is very important. Hopefully, this helps the child have a more successful day where learning can take place as well as potentially avoiding an embarrassing meltdown. Communication in this instance can also let staff know that that particular day may need to involve fewer challenges. We all have days that we are not at our best; for the most part we have to power through, but there are times all of us need a little break before we get overwhelmed. The same is true for our kids.

Knowing when something has happened at school that might cause a reaction at home is helpful for much the same reasons. Challenges can often be lessened for the evening, with priorities placed on what is truly important to try and accomplish.

While on the subject of communication, one thing that has proven helpful in our cases has been email. Now before I go on, let me just say that there is a very fine line between "helpful" and "hovering" when it comes to parenting, and that line is not always easily defined. Different teachers define it differently, and that can be very frustrating (remember how frustrating it is for our kids when peers change the rules or make them up as they go along?). Building a trusting relationship as best as you can is very important. As a parent, I acknowledge that my child is one of a large caseload, so I look for ways to let that staff person know I understand that, I appreciate her efforts on my child's behalf, and want to help make her job easier. If my child is in a good space by some accommodations that hopefully can be blended into the day, then the teacher or assistant does not have to deal with stressful meltdowns all the time. One way we accomplished this was through team email. If any of us on his team noticed a (potential) problem, we would shoot a quick email to all involved in his immediate world (regular ed teacher, special ed teacher, therapists). Often that email would result in another team member adding an observation within a few emails; we often would either nail down the problem or have some ideas to try to adjust to see how to help. No major changes to his program, no meetings that take 3 weeks to schedule, and make a small need a big deal. The bottom line is communication between home and school is a huge key to success for our children.

School is stressful for my child, should I homeschool?

As a parent, this decision and the decision regarding medications are two of the most personal decisions we face. There is no set answer that is right for every child, so you take into account as much information as possible, you look at your findings with your child's specific struggles and characteristics in mind, and you make the choice as best you can, given you have no crystal ball into the future. For us, we worked our way through the school system (and still continue to do so). There have been bumps along the way, and for one child in particular, we definitely considered an alternative during a very challenging year in middle school. We have friends who pulled their child out of seventh and eighth grade due to the amount of bullying going on – after trying both public and private school. Their child returned to public school in high school and was successful (he found a niche there socially and academically). Homeschooling him during the very difficult middle school years was the right decision for them personally. Remember from the beginning of this chapter; make decisions as best you can, then "no guilt." It is difficult enough being a parent, second guessing constantly makes it even harder. And while gathering information is important, listening to the opinions of others can be overwhelming. Keep in mind that you are purely gathering information to make a decision for your child, and each child's experiences and personalities are different, so what worked – or didn't – for one child does not define your child's future.

Middle school/junior high may seem like it is far in the future as you are going through elementary school, but it comes faster than you can imagine. I was grateful for the advice given in a presentation by Dr. Cathy Pratt, director of the Indiana Resource Center for Autism, when she said that as parents we should be looking ahead to skills needed in elementary school when setting goals in preschool, and skills needed in middle school when setting goals in elementary school… we should always be looking at the needs of the next level (Pratt, 2010). You can't foresee everything, but setting up a foundation and a plan for the future during these years is so important.

One further thought while on the subject of not being able to foresee the future, the present does not have to equal the future. What appears to be an insurmountable obstacle to our child at this moment, does not mean it can never be overcome. Through proper supports (often creative, flexible supports), they can make incredible strides. Keep looking for ways to inch the comfort zone bigger and expand skills. If you choose to homeschool, look for ways to gain social skills. Sending your child to public school? Seek opportunities to get your child involved in activities without overwhelming. Daily struggles are a piece of a bigger picture, and some days we just have to keep our eyes on that bigger picture.

Community

“Community” can overlap both the home and school parts of life with a child with Asperger syndrome. Community involvement can be like a chess game for parents, constantly looking for strategies to support our children and knowing when and how to nudge them out of comfort zones that they may cling to for dear life or when it is too much. As with everything else mentioned here, there is usually not a definitive right or wrong for all children. We have spent countless hours as parents worrying if we made the right choices, hopefully we have more often than not (once again, can I just say “no guilt.”). While the comments/questions referred to below may be specific in nature, as always, the ideas supplied are meant to be a general idea of ways to approach working with our children. For instance, your child may not be involved with community sports, but by taking some of the suggestions for involvement and generalizing them to a different activity, you can hopefully find a way to support your child’s involvement in whatever activity you choose as a family.

My son is on a soccer team, but practices are overwhelming for him. How can we help?

Anyone who has witnessed a youth sports team, especially if it’s a beginning league, knows it can be total chaos out there. We found one way to help, and it was to teach the rules of the game separately from team practice. That lessened the pressure on our child at practice – he didn’t have to try to pay attention in order to learn all the rules and he could focus on skill building and dealing with all the sensory issues involved. One of our children was very interested in video games, so we purchased older sports games (as true “gamers” always want the newest and most updated versions of games which means the older versions were far less expensive), and that was how he learned the rules and terminology. We laughed at how he also picked up some light hearted “smack talk” as well – lesson there, know what they are playing! – but seriously, that gave us opportunities for social skill instruction, not only for what is appropriate to say but also how to deal with it coming from other children. As our kids got a bit older, the family joke became there wasn’t a toy, game, or activity that didn’t have some “therapeutic/teaching” value. Learning the rules of the game, learning the vocabulary, and seeing how the game is played gave our son information he needed but could not pick up from his vantage point on the field, with others whirling all around him and people yelling from the sidelines.

One more thought while we're here – expectations of parents need to be appropriate for our children (isn't this the case whether there is a diagnosis or not?). For a child whose movements may be a little awkward or coordination may be somewhat affected, an athletic activity can be challenging. Having a parent yelling from the sidelines can be both confusing, and depending on the comments made, devastating. This may be another of those times when we need to check our personal definition of "success" and make it fit to what is truly "success" for our child. The goal may be to just be a part of the team. It may be to stay out on the field for half the game without being overwhelmed and needing to leave. This is so individual. We need to be open to celebrating small victories, and we need to be persistent in trying to find ways to help our child grow. We paid for 4 weeks of swimming lessons, only to watch our son sit on the poolside for three of those weeks and then have a death grip on his instructor once he finally let go of the side. But our feeling was this was not an insurmountable task for our child, so we persisted, going to the pool often as a family where he could explore the kiddie pool and water park and inch by inch get more comfortable. We used steps author Kristi Sakai describes in her book *Finding Our Way* (Sakai, 2005) of priming and preparing our child for trips to the pool. He had a visual schedule of the events surrounding the trip, and we tried to have an activity he would not be as challenged by (and would enjoy) following the pool trip. For him, getting to watch one of his "Thomas the Tank Engine and Friends" videos was a great way to chill out after the pool. Today he is a swimmer who enjoys time at the pool, so our persistence and preparation paid off. On the other hand, our other son on the spectrum has some difficulty with balance and movement which affected him in learning to ride a bike. When he was younger and smaller, he had a bike with training wheels, and he enjoyed riding it, but as he grew it became apparent that he was not progressing to the level where we could take off the training wheels, in fact, as he physically became bigger and his balance and comfort level on the bike decreased. In the meantime, the neighbor kids were out riding their bikes, and he wanted to be a part of that. It was time to look for an appropriate alternative – an adult-sized "tricycle" was not "cool" – but a Big-Wheel Green Machine was! This low to the ground, oversized Big Wheel could handle a medium-sized adult but still was appropriate for a kid. Our son was able to be a part of the group out there riding and soon another boy down the street had one as well. I'll never forget the look on his face and the excitement in his voice when he rode it for the first time, "Mom, it's like riding a REAL bike!" When an obstacle cannot be overcome directly, find a way around it. You may have to change your perspective to see how to help your child succeed, but this is a life lesson we need to teach our kids, what better way than to model it.

> My child just wants to sit at home with their special interest. How can I get them involved in the community? How hard do I push?

When we face challenges, it is only natural to want to stay in our comfort zone. It is important to remember this when trying to work with a child who does not want to leave theirs. Beginning with the end in mind can be a guide to parents in this situation. The statistics out there tell us that our children will face some difficulties in adulthood with employment especially, and one of the major reasons for that are social skills. Whether it is getting through an interview or the daily challenges of workplace social interactions, our kids are facing staggering under – or unemployment rates. If we want them to be on track to live independently (or as independently as possible), we need to be supporting them while they are young in getting the skills necessary to interact with others. “Play” is a child’s “work.” Encouraging them to play with peers or siblings is imperative in developing skills needed later in life. Even if our child’s goal is to do something individual such as work on computers someday, they still have to get through job interviews and survive in the workplace. So if that child is interested in computers, look for ways to use that interest to interact with others. Clubs were mentioned here earlier. Some local school districts or colleges offer community classes for kids, this could be a good resource. Boy and Girl Scout organizations can be an option, as can religious or other organizations, as they often have programs for children. Our YMCA not only has many opportunities for children, they run a physical education-type class for children who are homeschooled. If you are having trouble locating opportunities in your area, there should be some kind of resource organization, whether on a local or state level that could help. For many of us, money is an issue when looking at some of these programs. Many are free, but if you find something that could be a good fit but pushes your budget – first…no guilt! – then, be creative. There may be some kind of scholarship-type assistance available or a way to trade off services (“will work for therapy” was our slogan early on). If all else fails, trying to recreate the opportunity with other families can work. The idea is to not let limitations limit you in your search for growth opportunities for your child. Remember, both when dealing with a child who resists social interaction and with organizations that provide opportunities for your child, it’s a marathon, not a sprint. Difficult days happen, but they do not define the whole race. There will always be roadblocks and obstacles in the way, but as you look for ways to continue the journey, there will be incredible successes – make sure you look for and celebrate them. They can carry you through the next time you hit an obstacle.

Conclusion

Having a school-age child with Asperger syndrome brings with it many challenges and many unique opportunities to see life from a very different perspective. The statement “It takes a village to raise a child” is especially true when it comes to our kids on the spectrum; each member of the team has an important role, and each member can learn from the others on the team. It’s up to each member to hold up their end and to be willing to be flexible while looking for creative ways to support the child.

Parents are often the translator for their child and the coordinator for all those providing services. The job can feel overwhelming, and it is important to take time to refill our own tanks to better be able to provide what is needed. Obstacles come along; teaching our children how to circumvent them will give them a skill they will need throughout their lives, long after we are gone, and though it is difficult to picture that as they are so young, it is so imperative that we keep long-term success as the goal.

Getting a diagnosis just gives us information and options; it doesn't change who our child is. Yes, there can be a period of adjustment when you find out this is a lifelong challenge, but avoiding the "A" word only makes it harder. It may put off dealing with some feelings, but eventually, decisions must be made. For me, making sure my child felt my love and acceptance overcame all other feelings. As I have done that, I have learned they are my best teachers – and what incredible, insightful human beings they are.

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About the Editors

Raymond W. DuCharme, Ph.D., is the founder and Executive Director of The Learning Clinic, Inc. (TLC), a private, not-for-profit educational and treatment program for children and adolescents. Dr. DuCharme has been a researcher, teacher, and Assistant Professor at Brown University, Adjunct Professor of Educational Psychology at the University of Connecticut, and Associate in Psychiatry at the University of Massachusetts Medical Center. He is a national consultant and author of *Asperger Syndrome: A Guide for Professionals and Families*, textbook chapters, papers, assessment protocols, and articles on the subjects of treating and educating students with autism spectrum disorders. The overarching goal is the student's success – a goal that (1) defines our core purpose, (2) is feasible for each child, (3) poses challenges to teacher and student and family, (4) has larger significance than any singular goal, and (5) sums up everyone's endeavors at The Learning Clinic.

Thomas P. Gullotta, Ph.D., is C.E.O. of Child and Family Agency and a member of the psychology and education departments at Eastern Connecticut State University. He is the senior author of the fourth edition of *The Adolescent Experience*, coeditor of *The Encyclopedia of Primary Prevention and Health Promotion*, and editor emeritus of the *Journal of Primary Prevention*. He is the senior book series editor for *Issues in Children's and Families' Lives*. Tom holds editorial appointments on the *Journal of Early Adolescence*, the *Journal of Adolescent Research*, and the *Journal of Educational and Psychological Consultation*. He has published extensively on adolescents and primary prevention. Tom was honored in 1999 by the Society for Community Research and Action, Division 27 of the American Psychological Association, with their Distinguished Contributions to Practice in Community Psychology Award.

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