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AUTISM AND DEVELOPMENTAL DISABILITIES: CURRENT PRACTICES AND ISSUES

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PREFACE

This book examines current practices and issues related to assessing, instructing and lifelong planning for individuals with autism and developmental disabilities. Due to the inclusive philosophy of educating, training and treating individuals with autism and developmental disabilities, society is being challenged in a variety of ways to deal effectively with the growing number of children and adults with autism and developmental disabilities. Educators, mental health professionals, clinicians and parents are constantly searching for information on best practices and research-based findings related to: identification, characteristics, diagnosis; special, general, early and postsecondary education; and quality of life concerns. In this book, the authors provide information on best practices and research-based knowledge that should be helpful. For example, there are chapters on assessment which examine the emerging field of infant mental health, testing protocols, barriers to diagnosing diverse students and recent developments in the diagnosing and assessment of autism spectrum disorders such as genetic testing, home movies and robots. Also, there are a number of chapters on instructional aspects that delineate curriculum innovations, procedures to implement social skills, the use of assistive technology and planning for postsecondary education. Lastly, there are chapters on lifelong planning that provide readers with unique content on self-determination, the challenges of meeting social competence, sibling aspects and employment and retirement considerations. Finally, there is a case study and a chapter on the reflections of an individual with Autism Spectrum Disorders (ASD) that provide the reader with insightful commentary on the thinking and emotional experiences of persons with ASD.

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THE CHALLENGE OF SOCIAL COMPETENCE FOR STUDENTS WITH AUTISM SPECTRUM DISORDERS (ASDs)

Sandra Burkhardt

From preschool through college the number of students with autism spectrum disorders (ASDs) continues to grow. The prevalence of ASD, estimated to be 1 in 150 children (Centers for Disease Control and Prevention (CDC), 2008a) means the population of students with ASD will increase for several decades. Effective intervention for ASD has gained momentum. Improved public health education for parents and professionals, early screening for hallmark symptoms of developmental delay and intense early intervention to improve language acquisition are often successful (CDC, 2008b).

The biological basis of autism and its impact on cognitive capabilities confirms the profound and pervasive nature of ASD (Bishop, 2008). Support grows for the hypothesis that ASD stems from abnormal neurological "connectivity" related to brain tissue overgrowth during infancy (Dyck, Piek, Hay, Smith, & Hallmayer, 2006). Brain imaging studies of persons with autism suggest "even when people with autism produce normal behavioral output, they tend to do so by abnormal physiological means" (Belmonte & Yurgelun-Todd, 2003, p. 652). Uta Frith's seminal work on autism

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distinguished the unique social cognitive features associated with ASD and the behavior that emanates from those features (Bishop, 2008). In particular social cognition, including the ability to read facial cues, express emotion in words, predict emotional responses based upon social situations as well as explain unexpected emotional reactions, was found to be more significantly limited in children with autism than in children without autism who were cognitively impaired (Dyck et al., 2006).

The growing prevalence of ASD coupled with the promise of successful intervention leads to increasing demands for evidence-based treatments and unrestricted access to services. Additionally, persons with ASD and their families seek input in decisions regarding activities of daily living and treatment goals. The Autism Society of America (ASA) (Grossman & Barrozo, 2007) declared autism "the new human rights frontier". Fundamental human rights for people with autism include the following: the right to independence and a meaningful life; the right to decision-making; access to resources; and freedom from threat, discrimination, social exclusion and cruel and abusive treatment (Grossman & Barrozo, 2007, p. 11).

Successful social functioning at home, school and in the community as evidenced by independent navigation of "needs and wants" defines social competence (Stichter, Randolph, Gage, & Schmidt, 2007, p. 219). Social competence requires the generalization of social skills to the social world for the purpose of achieving interpersonal effectiveness, including friendship and love. Independent navigation of "needs and wants" implies at least two components of social competence. A fundamental aspect of social competence is the ability to communicate one's subjective experiences. Also, social competence implies social acts that are evaluated by both the individual and the social audience.

Thus, the attributions of the social audience are a factor in determining social competence. For example, in terms of academic achievement, adults tend to attribute the success of children with high ability to skill and to attribute failure to lack of effort. Conversely, for students with low ability, adults attribute success to effort and failure to the lack of ability (Hodapp, 2004). These findings, applied to students with ASD in the realm of social competence, suggest that students with high-functioning ASD, including average to above average language and academic skills, may be a risk for having their social competence deficits attributed to lack of effort rather than lack of ability. Students with ASD who are lower functioning, with deficits in language and/or cognitive ability, may be more likely to have their social deficits attributed to lack of ability and their social successes attributed to effort.

UNDERSTANDING SOCIAL COMPETENCE AND STUDENTS WITH ASD

The core deficits associated with ASD pose significant obstacles to achieving social competence; indeed, the deficits, in many cases, define social *incompetence*. The diagnostic criteria for autism include qualitative impairment in social interactions and verbal and non-verbal communication, including delay in the acquisition of expressive language (American Psychiatric Association (APA), 2000). A pattern of narrow, restricted interests and stereotyped behavior are also requirements of the diagnosis. The diagnostic criteria for Asperger's Disorder also include impaired social interaction and restricted interests without delay in language acquisition and with average to above average intelligence (APA, 2000). In sum, ASD is defined by significant impairment in social functioning that is qualitatively distinctive from both typical social functioning and from social functioning deficits associated with other diagnoses.

The Autism Diagnostic Observation Schedule (ADOS) (Lord, Rutter, DiLavore, & Risi, 2001), an assessment and research instrument developed within the past 10 years, delineates features of social interaction and social communication that are specific to ASD and that persist across the lifespan, transcending intellect and social experiences (Lord et al., 2000, 2001). The ADOS includes an hour-long series of standardized, high interest activities requiring social interactions. The strength of the ADOS and its descriptive categories lies in the instrument's capability of capturing the often subtle but qualitatively distinct features of ASD social impairment.

The general criteria of social impairment associated with the diagnosis of ASD, communication, social interaction and restricted pattern of interests, have greater specificity when described by the ADOS categories. Key features of ASD such as difficulty with sustained conversation, awareness of self and others, reading emotions and creating spontaneous communication are elicited and observed within an optimal social environment created by the interviewer. Elements of the social context include readily available joint attention and planned reciprocity provided by the trained examiner.

In sum, the criteria for a diagnosis of ASD include impaired social functioning of a specific quality. The ADOS provides descriptive categories that further refine the characteristics associated with the social functioning of persons with ASD. Thus, the discrepancy between social competence and the social capabilities of students with ASD can be detected with intervention strategies planned to address identified deficits.

Despite advances in defining the task of teaching social competence to students with ASD, teaching social competence remains a relatively abstract endeavor, requiring the reduction of normally rich and spontaneous social development to a set of detailed goals and objectives.

For example, third-grader Jane offers Maria a piece of candy because Jane is Maria's friend. Maria is pleased by Jane's efforts. Jane judges herself as socially competent for offering the candy; Maria sees Jane as competent for being generous.

However, if Jane offers Maria candy as a means of bribing Maria to play with her, Maria may respond in various ways. Maria might refuse the candy and rebuff Jane, refusing to socially interact with someone she does not like, even if candy is involved. Maria might eat the candy and still not interact with Jane, judging Jane's offer of candy as independent of an expectation of friendship. Finally, Maria may eat the candy and play with Jane, but not really enjoy Jane's company despite the candy. Jane's social goal is friendship with Maria, which may or may not occur. Maria may judge Jane as kind, naïve, foolish, desperate or misguided by offering candy as part of friendship.

In sum, Jane's social competence is judged in terms of the effect and effectiveness of the social actions she displays. The challenges faced by Jane in the pursuit of friendship are commonplace; the range of results predictable. Jane and Maria will both be pleased if friendship results. If the friendship effort fails, both Jane and Maria will appraise their respective contributions to the failure.

Routine social interactions are the foundation of social development. The acquisition of language, social skills, social perception, social reasoning, relationship and emotional attachment typically unfold with maturation and experience. For the student with ASD, with deficits in the very domain that governs typical social development, the quest for social competence is far from spontaneous.

TEACHING SOCIAL COMPETENCE

Teaching social competence by encouraging socialization has been an accepted intervention for students with ASD. The call for educational programs designed to improve social competence in students with ASD is loud and clear, with particular emphasis on the need for identification of effective teaching methods and strategies (Wolery, 2000). Programmatic

Table 1. Social Behavior Needed for Friendship.

Recognizing when and how to join in
When and how to provide assistance
When and how to seek assistance
Tolerating criticism
Responding to compliments
Offering compliments
Incorporating the ideas of others into an activity
Indicating agreeing
Resolving conflict
Accepting the opinions of others
Monitor the body language of others
Using body language to indicate interest in others
Appropriate behavior to maintain solitude
Appropriate behavior to end an interaction
Characterization skills – identify and define the characteristics of someone
Identify and define one's own characteristics

Source: Adapted from Attwood and Gray (1999).

approaches to the teaching of social skills, relationship development and friendship have emerged, often accompanied by lists of needed skills and desired goals.

For example, Attwood and Gray (1999) proposed levels of friendship and devised a checklist of social behaviors needed for friendship (see Table 1).

Similarly, Gutstein and Sheely (2002) have an extensive curriculum and training program to promote relationship development for children, teen and adults (see Table 2).

The use of Internet resources, including virtual reality (Mangan, 2008) and small group interactions (Painter, 2006) have been suggested as therapeutic venues for students with ASD.

Indeed, the very lists needed to define and develop social skills are reminders that creating social competence by formula is both awkward and artificial. In her autobiography as a person with Asperger's syndrome, Willey (1999) demonstrates persistence, and resistance, regarding the attempt to achieve social competence. Successful by most standards, employed and married with a family, the author summarizes her strategy for these accomplishments in the title of the book, *Pretending to be Normal.* Thus, Willey's reflections remind others that the mandate for social competence is often burdensome and confusing for persons with ASD who may be quite content with a less challenging and taxing social existence.

Table 2. Relationship Development Goals.

Other people will feel that they are being seen as real persons not as objects
Communication and humor will be less scripted and more creative, spontaneous
More invitations from peers and greater amount of peer acceptance
Become a good collaborator and valued team member
Contribute to the lives of others
More fun to teach
Friends that genuinely appreciate her
Thinking and information processing
More flexible
More accepting of change
More curious
More creative
Able to generate several alternatives
Think in terms of "gray" not just black and white
Seek out and value the perspectives and opinions of others
Be aware of personal and unique identity

Source: Adapted from Gutstein and Sheely (2002, pp. 16–17).

Educational Programs for Teaching Social Competence Reviewed

Stichter et al. (2007) reviewed educational programs intended to improve social competence. The following target behaviors were identified as components of such programs: functional communication, initiation of social interaction, cognitive problem-solving, group interaction, responding to and engaging others, reduction of challenging behaviors, self-management and physical/motor skills.

Eleven features of effective programs were identified: individualized goals, evaluation of progress, interactions with adults, interaction with peers, interaction in the community, maintenance of acquired skills, use of skills in natural environment, generalization of skills to other environments, improved regulation of challenging behaviors, environmental supports and family support (Stichter et al., 2007).

During childhood, the presence of peer role models that promote the social learning of appropriate social responses has proved effective (e.g., Laushey & Heflin, 2000). An example of an educational program with the goal of improved social competence for students is the Responsive Classroom (RC) approach, a curriculum that addresses both academics and social outcomes (Brock, Nishida, Chiong, Grimm, & Rimm-Kaufman, 2008). Preliminary reports of the effectiveness of RC suggest a positive correlation between teacher RC practices and student outcomes in regard to social competence, although a similar correlation was not established between teacher RC practices and academic outcomes.

One example of a skill-specific approach to social skills training is the Social Skills Training Project (see Baker, 2003). This project assessment of social skills capabilities offers a program to develop a variety of skill groups including conversational skills, cooperative play skills, friendship management, self-regulation, empathy and conflict management (Baker, 2003). Along these lines, Crooke, Hendrix, and Rachman, (2008) suggest teaching *social thinking* as a means of developing the social cognitive skills needed to support generalization of social skills to varied social environments. Positively, Crook et al. defined "expected" and "unexpected" behaviors as well as categories of verbal and non-verbal behavior to provide goals for intervention that are explicit and measurable.

IDENTIFYING CORE SUPPORTS OF SOCIAL COMPETENCE FOR STUDENTS WITH ASD

Social competence educational programs are intended, by their very nature, to reduce the core deficits of ASD as much as possible and to optimize quality of life while promoting normal social development. However, evidence-based guidelines do not exist at present. One approach to advancing education for social competence for students with ASD is identification of "core supports" that are associated with sound social cognitive development.

The core deficits of ASD include impoverished communication, limited reciprocal social interaction, absence of creativity and spontaneity, and presence of stereotyped and restricted interests. Disordered movement and disruptive behavior are also noted. The intervention programs strive to improve communication and reciprocal social interactions as well as reduce challenging behaviors and promote generalization of skills to a variety of social environments. Intervention programs include both behavior modification and cognitive strategies aimed at increasing socially appropriate behavior, reducing inappropriate behavior and promoting accurate social perception and social problem-solving.

The findings of Stichter et al. (2007) suggest the following *Core Supports of Social Competence*: (a) *aptitude for social competence*, the basic capacity for social learning; (b) *social skills acquisition*, social learning which results in social knowledge and the ability to perform social behaviors; (c) *interpersonal* *applications*, social learning that supports spontaneous performance of interpersonal social acts that are both proactive and reactive in response to situational demands and (d) *interpersonal effectiveness*, the degree to which interpersonal applications secure a desired and desirable social outcome. In the social arena, the actor as well as members of the social audience serves as judge of interpersonal effectiveness.

Aptitude for social competence. The basic capacity for social learning requires adequate expressive and receptive communication to support interaction with others. Both instrumental (practical) and social (pleasurable) communication are products of an individual's awareness of self and the outside social world and an innate desire to be involved in that world. A baby learns to point as an instrumental communication technique for requesting desired objects. However, a baby also learns to play peek-a-boo for the sheer pleasure of socially interacting with another person.

ASD is associated with communication delays. Limited capacity for social learning is often evident for young children who display the hallmark signs and symptoms of autism: gaze avoidance, delayed expressive language, failure to point and social withdrawal. Even among young children with high-functioning autism and Asperger's Disorder (presence of expressive and receptive language, average to above average measured intelligence) the ability to learn from social models and to communicate effectively is atypical. Pedantic speech, detailed monologues about special interests, unusual prosody, poor eye contact and an inability to show interest in others are often present from early childhood. Additionally, such behaviors emerge in the absence of social models in the environment.

Educational and clinical interventions that specifically address basic aptitude for social competence include speech and language services, applied behavioral interventions and other efforts that target the development of functional communication using pictures and devices.

Social skills acquisition. Social learning typically results in social knowledge and the ability to perform social behaviors. Social skill also includes the knowledge of cultural conventions and customs as evidenced by the ability to perform prescribed social behaviors. For example, greeting others appears to be a universal social skill; greeting customs, including handshakes, bows, high-fives and kisses, are culturally dictated. Social skill is demonstrated even in infancy when a baby waves in response to the verbal cue "say bye-bye". Similarly, a teen holding the door for a person approaching an entrance is performing a courtesy associated with social skill.

For the student with ASD, acquisition of even fundamental social skills is often delayed and incomplete. The child with ASD may fail to display a social smile or greet others unless prompted to do so. Repeated prompting is often required to achieve minimal social knowledge. Additional prompting is needed to secure awkward interpersonal performances of even simple social behaviors, such as taking turns or calling others by name. Social skills training for students with ASD improves access to social knowledge, provides modeling of social behaviors, promotes social reasoning and reinforces approximations of appropriate social practices while cuing for the performance of desired social behaviors.

Interventions that address social skills acquisition in order to increase social competence are likely to prompt initiation of social interactions, to reinforce responding to and engaging others and to target extinction of challenging behaviors. Effective self-management may be supported with a fading of external positive reinforcements to be replaced with presumed intrinsic rewards such as pleasure and satisfaction for successful performance.

Interpersonal applications. Interpersonal application is contingent upon aptitude for and acquisition of communication, social skills and social knowledge. Interpersonal applications involve social responses, including verbal and non-verbal communication, to varying social situations. Interpersonal applications require continuously reading the social environment, choosing a social response from acquired social knowledge, skillfully performing the response and evaluating the outcome of the social action. An example of the judgment inherent in interpersonal applications might involve a typical junior high student who understands it is appropriate to cheer loudly at a basketball game, but not to behave similarly at a funeral service.

Even in the presence of adequate aptitude for communication and social skills acquisition, interpersonal applications may be difficult for the student with ASD. The goal of correctly reading and responding to the demand characteristics of an ever-changing array of social situations requires social perception, social thinking and social problem-solving. The following is an example from the author's clinical experience which demonstrates the challenges, sometimes humorous, sometimes heartbreaking, that are associated with interpersonal applications for students with ASD. A high school student with ASD who was enticed by the prospect of increased social status when a "popular" peer encouraged the young man to lick a female classmate's ear because "girls really like that". The prompted social action resulted in suspension from school for both boys. On behalf of the young man with ASD, this well-intentioned therapist provided her patient with detailed corrective social information regarding sexual harassment and appropriate ways to engage girls. On return to school following the suspension and counseling sessions, the young man pedantically informed each girl he passed in the hallway “I can’t lick your ear”. The student’s literal application of his newfound social knowledge was not likely to advance the quest for social competence!

Educational programs aimed at supporting social competence by improving interpersonal applications might be expected to promote varied interpersonal interaction: in groups, with adults, with peers and in the community. Additionally, interpersonal applications are likely to target the maintenance of acquired skills in a supported environment while scaffolding the use of skills in other natural social environments and, ultimately, generalization of social interactions to other environments (Stichter et al., 2007).

Interpersonal effectiveness. Interpersonal applications are judged socially competent when the application achieves a level of effectiveness that results in a positive social interaction. Positive social interactions typically involve *joint attention*, two or more people attending to the same task, and *shared pleasure*, the subjective experience of the social event is enhanced by sharing the experience with another. Thus, the achievement of interpersonal effectiveness requires the experiences of more than the actor. Social competence involves interpersonal applications that are judged, fairly or otherwise, by the involved social audience.

There are at least two sources of risk related to interpersonal effectiveness for the student with ASD in the quest for social competence. One source of risk lies within the social environment. The limited communication abilities, awkward execution of social skills and inappropriate interpersonal applications of a student with ASD may be associated with social behavior that is judged interpersonally ineffective and rebuffed. In sum, in the world of social exchanges others do not always respond to even the best interpersonal applications. Students with ASD who are perceived as awkward, naïve, immature, bizarre or confusing are not likely to consistently secure a positive social response.

An example of environmental risks to interpersonal effectiveness involves a college student with ASD who earned a position as a broadcaster at an on-campus radio station due to his knowledge of the history of rock and roll. Admired for his incredible command of trivia while on the air, nonetheless, he was routinely shunned in the cafeteria by students who did not want to listen to his one-sided recitations during lunch. It proved most difficult to explain to him how he could be so valued for talking in one setting and so rejected for the same communication in another social setting.

Similarly, a junior high school girl with high-functioning autism forcibly sat between her "best" friend and another girl with whom the best friend was talking. When asked why she pushed herself between them, she indicated that her intention was to keep her friend from talking to the other girl because it made her jealous to see them conversing. She wanted her friend to pay attention to her. The interpersonal application was judged quite ineffective: she received a detention and her friend would not speak to her for embarrassing her. Still, the student's social intention of "protecting" the friendship is easily understood.

A second source of risk of failure of social competence for the student with ASD resides *within* the student. Even when the student with ASD demonstrates interpersonal effectiveness, he or she may not experience the social exchange as pleasurable or satisfying. Emotional disturbance, including anxiety and obsessive behaviors, were found to impede social functioning for teens with ASD compared to teens with conduct disorders despite average intellectual abilities and the absence of language delays (Green, Gilchrist, Burton, & Cox, 2000).

Interpersonal effectiveness includes the experience of reciprocity that is often limited for students with ASD. Educational interventions that highlight interpersonal effectiveness as the gateway to social competence would be expected to include the development of social cognitive problem-solving, self-evaluation of progress, feedback from environmental and family supports and regulation of emotion (Stichter et al., 2007).

CORRELATES OF SOCIAL COMPETENCE

Correlates of social competence are those features of social cognitive development that are associated with the ability to gain social knowledge and perform social skills. Intelligence was not found to be a major correlate of social cognition: individuals with ASD who have mental retardation were found to be more impaired in terms of social functioning than individuals without ASD with a similar degree of retardation (Lord & Volkmar, 2002). Joint attention and eye contact have been found to be associated with normal social cognitive development (Vaughan Van Hecke et al., 2007).

For the child with ASD, deficient joint attention results in off-task behavior during socializing events. Limited social learning occurs. The baby who is gaze avoidant misses the funny faces made by a sibling. The toddler who screams when another child shows a toy does not learn how to play. The youngster who sorts Pokemon cards when others are telling jokes will not learn humor. Missed and delayed opportunities for social learning are also missed and delayed opportunities to learn and apply social knowledge and skills, to experience shared pleasure and to evaluate one's effectiveness in engaging others. Additionally, a child who does not sustain joint attention is likely to be judged socially incompetent by peers who are denied access to genuine shared pleasure when in the child's company.

Although ASD is associated with inadequate social competence, attachment is not the deficit that is responsible for impaired relationship formation (Lord & Volkmar, 2002). For example, young children with ASD do not systematically display deficits in the "Strange Situation", a laboratory assessment of the bond between child and parent. Social communication deficits, including non-verbal behaviors such as gaze and pointing, that increase social cognition emerge as the origins of social difficulties (Lord & Volkmar, 2002). It is likely that acts of social cognition, or social thinking, are needed to sustain motivation, acquire reciprocity and achieve adaptability in various social environments.

Individuals with ASD are often believed to lack empathy. Recent findings (see Dziobek et al., 2008) suggest that adults with Asperger's Disorder do indeed possess *emotional* empathy, or the ability to understand how others feel. It is cognitive empathy that is lacking, or the ability to understand how and why people feel the way they do. For example, a 10-year old with superior intellect and ASD indicated after the death of his father that he knew his mother cried because she was sad, but did not know why she continued to feel sad since his father remained dead and was not repeatedly dying. Similarly, a young woman with Asperger Disorder communicated sympathy to a roommate because the roommate's boyfriend had cheated on her. The fact that the young woman with Asperger Disorder was, in fact, the person the boyfriend cheated with did not strike the young woman as incongruent.

Correlates of social competence including joint attention, attachment and empathy are likely to serve as markers of changes in social development and successful intervention.

BARRIERS TO SOCIAL COMPETENCE

Progress associated with educational practices to teach social competence for students with ASD includes measuring improvement, monitoring the effects of training and describing the environments in which generalization of skills occurs. The assessment and generalization of social skills for students with ASD includes the measurement of both core deficits and acquired skills as well as transfer of skills to varied environments. The impact of social skills training on students with ASD should be considered, particularly if the degree of ultimate efficacy is unknown and stress created for the student with ASD by the actual social skills training is plausible. Additionally, the social characteristics of social environments should be evaluated in terms of readiness to support students with ASD. A poor fit among ASD core deficits, social competence instructional methods and the impact on students with ASD and their peers is likely to result in limited measurable progress as well as frustration for both pupil and teacher.

Reliable and Valid Assessment of Social Competence

Evidence-based educational practices are a responsible goal when selecting interventions for disorders as potentially handicapping as ASD. At the same time measuring social competence is not easily standardized. The Autism Diagnostic Interview-Revised (ADI-R) (Le Couteur, Lord, & Rutter, 2003) and ADOS (Lord et al., 2001) are standardized instruments that reliably distinguish persons with ASD from persons without ASD across the lifespan. Standardized instruments that can refine ASD diagnoses by differentiating between ASD categories are needed. Lord and Volkmar (2002) have articulated the need for tools that classify and clarify diagnoses within the ASD spectrum and that "quantify the severity" of ASD symptoms. Ultimately, such refined tools would make possible the measurement of progress attributable to intervention. Evaluation methods with norms that measure progress in social competence for students with ASD are essential in determining what educational interventions are truly effective and not merely the result of maturation and experience.

Limited Generalization of Social Skills

Generalization of the social abilities of students with ASD continues to prove difficult. Social skills identified and cultivated in social competency programs often do not translate as social competency in the real social world. Often specific skills are effectively taught and practiced in a controlled environment, only to fade when an attempt to transfer them to other environments is made (Hwang & Hughes, 2000).

Core deficits associated with ASD throughout the lifespan may include unusual prosody, limited spontaneity, one-sided conversations about special interests, irrelevant verbalizations and a paucity of social and emotional content in social communication. Limited insight and self-awareness, disinterest in the thoughts and feelings of others and preoccupations with non-social topics are hallmarks of even the highest functioning adults with ASD (Lord & Volkmar, 2002). Controlled studies that yield estimates of the rate at which acquired social skills actually become interpersonal applications for students with ASD are needed.

Self-Appraisal of Social Competence

Findings regarding self-appraisal of social competence by students with ASD have proven complex. deCastro, Brendgen, VanBoxtel, Vitaro, and Schaepers (2007) found that students with overestimates of their own social competence showed aggression when encountering peers who disputed the self-appraisal. Ostrander, Crystal, and August (2006) link the mismatch between self- and other-assessments of social competence as a contributing factor to adolescent depression.

For students with ASD realistic self-appraisal of social competence may be particularly challenging. The student with ASD may aspire to social competence and may be praised by instructors for improved social skills. Thus, students with ASD come to believe in their own interpersonal effectiveness. However, if they encounter peer rejection even as they attempt to apply interpersonally their hard-earned social skills, a negative interaction may develop. There is considerable risk of aggressive and depressive responses for students with ASD when peers do not find the students with ASD socially competent.

For example, an eighth grade boy with Asperger's Disorder, after a particularly robust session of social skills training at Friendship Group, decides to test his newfound feelings of social competence by pulling his chair up to the "popular" lunch table. He greets, asks questions and awaits the social responses that occurred just an hour earlier in the accommodating environment of group. His questions are politely answered, there are a few subtle snickers, and chairs are slid ever so slightly away from him. He storms off muttering how mean these kids are. The next morning he argues violently with his mother while refusing to come to school. He threatens self-harm. It is days before he is able to verbally articulate his outrage at the violation he has suffered at the hands of peers who did not follow the rules of being socially accepting of his social overtures. He points out their errors and wonders why someone does not do something about THEM! As such, the core deficits of ASD – limited social perception, persistent social awkwardness and the inability to understand why others do not like you – contribute to confused self-appraisal of social competence that may result in diminished self-esteem, social isolation, withdrawal, avoidance and loneliness.

In sum, the test of social competence occurs when social skills result in effective interpersonal applications. Three relevant components of effective applications include accurate appraisal of the social demands of the situation, accurate self-appraisal of social skills and sufficient application of social skills in order to be achieve a desired outcome as judged by both the actor and the audience.

Thus, the rejected eighth grader in the example earlier demonstrated social knowledge when he chose the popular group as the recipients of his efforts. He is interpersonally aware and not unlike his neurotypical peers in his desire to be accepted by this group. Additionally, his estimate of his own social skillfulness may be accurate: in fact, he executes exemplary social behavior. Still, he is at risk for rejection, emotional distress and disciplinary action when his self-appraisal does not match the appraisal of peers and society. Although most adolescents in a similarly problematic social situation may learn from the experience and adjust their future social acts and expectations accordingly, neurotypical students do not display the naiveté of the student with ASD. Further, the student with ASD, unlike other adolescents, cannot easily rely upon improved social thinking to guide future encounters.

Socialization Demands as Environmental Stressor

Although improved socialization is often an unquestioned goal *for* students with ASD, it is, indeed, a goal that is relentlessly questioned and resisted *by* many students with ASD. Most often parents and teachers raise the issue of improved social functioning; peers and the individual with ASD may simply avoid social interaction. Although social skills deficits are painful to witness and awkward to ignore in the classroom, the accompanying discomfort and risk of negative outcomes that students with ASD experience when they do actually attempt interpersonal interactions are realities.

Studies of classroom conditions that promote social competence are emerging. Hennessey (2007) provides evidence for the use of formal social competence instruction. Wilson, Pianta, and Stuhlman (2007) in a study of nearly a 1,000 typical first graders in over 800 classroom determined that student social competence was predicted by the degree of "high quality" social support and evaluative feedback provided by teachers. These findings suggest the crucial role played by the social environment for typically developing children; it is reasonable to predict that the social environment for students with abnormal social development may be even more critical.

The demands for social interactions, group work, giving speeches, field trips, lunch and recess, are intended to be opportunities for enrichment, practice, modeling and integration for students with ASD. However, the stress of such demands often seems to create functional limitations for students with ASD whose academic progress may falter due to social incompetence in the classroom environment. School refusal, meltdowns, self-stimulatory behaviors, increased need for medication and even dangerousness may be stress reactions that are the result of insufficient accommodations in the social environment.

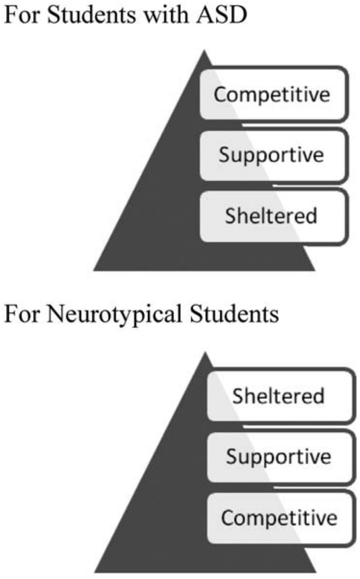
In sum, barriers to social competence for students with ASD include the lack of normed, reliable and valid measures that delineate progress made in response to intervention. An additional complexity for measuring progress occurs when social skills that emerge in a controlled environment do not generalize to other environments, indicating a performance deficit rather than a skills deficit. Even when interpersonal applications are attempted by students with ASD in social environments, there may be a discrepancy between the individual's self-appraisal of social competency and the level of social acceptability perceived by others. It is unsurprising that emotional disturbances for students with ASD, such as social anxiety, obsessiveness, depression, anger and frustration, often appear to be triggered by the stress of interpersonal interactions. Whether emotional disturbance is a part of ASD itself or is reactive to the demands of social situations, the discomfort experienced by at least some students with ASD much of the time, and all students with ASD some of the time makes it difficult to determine if all opportunities for socialization are necessarily positive. Finally, the demand characteristics of various social environments are relevant to a discussion of social competence as the performance of the student with ASD will be judged by the degree of skill and application needed to be judged interpersonally effectiveness in a particular setting.

A HIERARCHY OF SOCIALIZATION ENVIRONMENTS

A hierarchy of social environments for students with ASD is suggested by the needs of three related constituencies: the students themselves, parents and general educators, and special educators and researchers. The proposed hierarchy (see Fig. 1) includes descriptive levels of the characteristics of the social environments in which students with ASD develop social aptitude, acquire social skills, attempt interpersonal applications and evaluate interpersonal effectiveness.

As proposed, social competency at one level of the hierarchy represents significant achievement and should be celebrated and reinforced. However, social competency at one level does not guarantee competency at another level of the hierarchy. This realistic stratification of social environments systematically recognizes the lack of generalization across environments that are inherent in ASD and social competency education.

It should be noted that the hierarchy for students with ASD may be inverted compared to that of neurotypical students. For example, the proposed hierarchy for students with ASD suggests that more socialization may, or should, occur in sheltered and supportive social environments, with



For Students with ASD

For Neurotypical Students

Fig. 1. Hierarchy of Socialization Environments.

a relatively modest emphasis on competitive social efforts. The reversed hierarchy for students with ASD would serve to remind all constituencies involved in the pursuit of ASD social competency that the core deficits of ASD are enduring, posing lifelong challenges. The proposed hierarchy is expected to reduce emotional distress and unrealistic self-appraisal by students with ASD as interpersonal effectiveness is attainable within many accommodating social environments. Finally, assessment of social competency is made more meaningful if it is required that the characteristics of the environment in which the socialization occurs are specified.

Thus, it is possible that social competency achieved at the sheltered level in one environment, for example, Lunch Bunch in the social worker's office or pragmatic language group at the speech clinic, may actually generalize to other sheltered socialization environments, such as Boy Scouts with father as the leader. Social incompetence is more likely to be perceived when the gains associated with one level of social environment are minimized or dismissed when compared to other, more demanding social environments. It is difficult to determine whether social competency achieved in one environment is not being generalized when, in fact a change in *level* of demand, not merely a new location, occurs. Thus the leader at Lunch Bunch is judged socially incompetent when he attempts competitive socialization in the cafeteria.

The characteristics of each level of socialization as well as examples for students follow.

Competitive socialization may be defined as a level of socialization that demands sufficient interpersonal effectiveness to be judged socially competent by others. The term, *competitive*, like its linguistic derivative, *competent*, implies a level of performance in which some win and some lose. Successful competitive socialization results in reciprocal peer relationships, spontaneous and generative social interactions that are intrinsically motivated and shared pleasure experienced by both actor and target during the social interaction. Competitive socialization will have as its benchmarks friendship, intimacy, thoughtfulness and concern.

Typical social environments in which competitive socialization may occur include going outside to play with the children in the neighborhood, being invited to a peer's home, school recess and lunchroom, seating on the school bus and gym class.

Supportive socialization can be defined as a socializing environment that involves social interaction with familiars, those with whom a social relationship exists and from whom a degree of social acceptance can be anticipated.

Typical social environments in which supportive socialization occurs include teacher-directed classroom activities, play dates arranged by parents, field trips with adult chaperones and peer mentors and buddies who are selected for their social competence to serve as accommodating social models for the student with ASD.

Sheltered socialization involves a socializing environment in which a skilled and accommodating person structures and prompts the social interactions of a student with ASD.

Sheltered socialization involves high levels of social accommodations made by others in order to involve a socially incompetent individual in social interactions.

Examples of sheltered socialization environments include Applied Behavioral Analysis intervention sessions, one-on-one aides, play involving parents or trained professionals and family members serving as social coaches in order to provide prompts for social interaction.

Characteristics of Socialization Levels

In the competitive socialization environment, students with ASD need to engage peers, demonstrate joint attention, express pleasure and choose varied social responses to social demands. Beginning in infancy, the competitive social environment rewards social smiles, parallel play, sharing and taking turns. In elementary school, competitive socialization is likely to involve adequate social skills to work in a group, deliver a presentation beginning with Show and Tell and culminating in speech class, ask for help, sing happy birthday, call a classmate by name and socially communicate with others for pleasure. By middle school, the competitive socialization environment involves eager participation in sports or clubs, going to a friend's house after school and riding bikes in the neighborhood. By high school, competitive socialization involves placement in regular education classes with or without resource services, involvement in extracurricular activities, acquiring a driver's license and attending social events including football games, dances, club meetings for the purpose of enjoyment of shared tasks and opportunities for social communication. Online competitive socialization may involve instant messaging and making friends on personal webpages. The college environment's competitive socialization requirements involve attending classes, working in and leading groups, consulting professors and living with a roommate. Job skills include navigating a job interview with a degree of interpersonal effectiveness that makes being hired possible.

Supportive socialization is often created at home or school. This socialization environment acknowledges and accommodates the core deficits of ASD while challenging the student with ASD to demonstrate social skills and interpersonal applications with neurotypical peers. Supportive socialization environments partner a student with ASD with a known peer or sibling. Interactions with older accommodating children or adults are encouraged. Pairing a student with ASD with a person with similar special interests is an additional feature of a supportive socialization environment. Thus, a student with ASD might attend a social event with an accommodating peer or family member who can help monitor and modify social interactions. Examples of modified supportive social environments include: Lunch Bunch or designated seating in the cafeteria or on the school bus; Scout meetings that are attended with a sibling or relative; and a parent coaching a sports team or attending a field trip to support the student's involvement. Social events arranged by school personnel or parents and socialization with persons selected by supervisors for their accommodation capability may serve as supportive socialization environments for students through high school. Supportive socialization environments related to employment include the use of a job coach, assisted job placement, or working for a person known to the family.

Sheltered socialization environments include high levels of supervision as a requirement for social interaction for a student with ASD and others. Parental and clinical supervision might include play with siblings or relatives, adult-supervised play dates or the use of an aide to support the student with ASD as he or she interacts in the classroom. Sheltered socialization environments allow for sensory breaks and redirection as needed. Teacher or parental prompts are used to initiate and sustain social interactions at social events. Sheltered socialization environments adjust the intensity, duration and frequency of demands for joint attention and social engagement of others based upon the communication and social skills capabilities of the student with ASD.

Home-schooling, self-contained classes and therapeutic day programs are examples of sheltered environments. Online classes related to special interests and abilities may also be sheltered environments if the primary purpose is avoidance of the need for social interaction. Sheltered workshops, employment within a family business and eligibility for social security disability are examples of sheltered socialization.

Benefits of a Hierarchical Model of Socialization Environments

A hierarchical model of socialization environments provides for the selection of a goodness of fit that may permit building the social skills needs of the students with ASD while scaffolding interpersonal applications and interpersonal effectiveness in ways that minimize destructive rejection and emotional distress. Additionally, it is proposed that a good fit between the capabilities of the student with ASD and the socialization demands of the environment are likely to reduce disruptive behaviors. Positive possibilities lie at the intersection of educating students with ASD for the social competency needed to acquire activities of daily living while requiring the social environment to recognize and respond to the needs of a person with ASD.

Competitive social environments, the high school cafeteria, the college dorm, a job interview, are worthy pursuits for students with ASD. However, success for students with ASD, their families and teachers, and researchers attempting to quantify response to intervention is likely to be best assessed by measures that incorporate the core deficits of ASD, the correlates of social competence and the demand characteristics of genuine socialization environments.

Pledger (2003) indicates that the current paradigm for understanding disability requires the assumption that the environment itself plays a major role in individual functioning. Disability is traditionally viewed in terms of the medical model leading to an inherent bias in assessing the deficits of persons with disabilities (Pledger, 2003). However, functional limitation may be increased by the nature of the environment in which a person with a condition must function. Although the medical model has as its focus the patient's needs, often with limited concern for environmental forces (Brandt & Pope, 1997), the demand characteristics of the socialization environment, including psychosocial stress may actually constitute an obstacle rather than a support for the student with ASD.

The social behavior of persons with autism certainly impacts the social environment; accommodations by others are both needed and possible (Hodapp, 2004). However, it is the delicate interaction between an individual's limitations and the demands of the environment that often serve to define *functional limitations*. Thus, a building without a ramp imposes a functional limitation upon a person in a motorized wheelchair. That functional limitation is qualitatively different from the limitations associated with actual reduced mobility in the limbs. For students with ASD, the social demands of the school environment are intended to promote improved social functioning and adaptability. Still, the social demands themselves that are inherent in the typical school environment may serve to create functional limitations for some students with ASD. The short- and long-term effects of educational programming for social competence should be measured not only by the judgments of others in the social environment, but all by the subjective reports of students with ASD and their parents.

FUTURE DIRECTIONS

The promotion of social competence for persons with ASD is essential. Discovering evidence-based interventions that result in the development of social competence must remain a priority if individuals with ASD are to be successfully included in community life. However, careful preparation of the community at large, including family members, peers, educators and employers, is also needed in order to prepare an accommodating (and welcoming) environment for persons with ASD. Growing numbers of students will, through no fault of their own, display a degree of social incompetence throughout the lifespan. A compassionate society, beginning at home and school, must find the means of supporting skill development while accepting the limitations imposed by both ASD itself and the limited knowledge available at this time to rehabilitate social communication deficits for persons with ASD.

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CURRICULUM INNOVATION TO EDUCATE STUDENTS WITH AUTISM IN GENERAL EDUCATION

Gathogo M. Mukuria and Festus E. Obiakor

Autism is considered to be a severe disability because of the intense lifelong effect it has on an individual; yet, it remains one of the least understood and most mysterious of the pervasive developmental disorders (Chez, 2008). Autism cuts across racial, ethnic, and socioeconomic categories, but it is four times more prevalent in boys than girls (Grandin, 2006). It is a disorder present from birth or early childhood that impairs social interactions, communication of ideas and feelings, and imaginations and relationships with others (National Research Council, 2001). According to the American Psychiatric Association (1994), autism coexists with mental retardation in approximately 75% of those with the disorder. Others disagree with this finding and state that the percentage is lower (Edelson, 2006). It is estimated that half of those with autism do not have functional speech (Prizant, 1996; Wing & Attwood, 1987). These associated disabilities may present overwhelming challenges to parents, families, and communities beyond those characteristics solely presented by autism. Parents raising a child with autism have reported extreme difficulties in dealing with challenging behaviors, especially in teaching their child to communicate, to learn basic

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life skills to survive problems, and prepare for adult life (see Randell & Parker, 1999; Richman, 2000, 2006).

Supporting children with autism in the acquisition of academic learning and adaptive skills of language and communication, as well as reduction of inappropriate behaviors are the traditional treatments of choice to help such children in developing personal responsibility (see Ramsey, Vitiello, Cooper, & Hirtz, 2000; Wilder, Dyches, Obiakor, & Algozzine, 2004). Since Leo Kanner, a psychologist at John Hopkins University first brought the disorder to public attention in 1943, professionals have debated the extent to which autism is a complex biological condition that is brain-based and developmental in nature. And, they all agree that it is a disorder in which multiple areas of functioning are affected. Very often, students with autism are misclassified and misdiagnosed due to: (a) previous lack of diagnostic educational labels, (b) the ambiguous nature of the disability, and (c) family cultural and linguistic interpretations and reactions to the diagnosis and service offerings. From 1975, when The Education for All Handicapped Children Act was enacted, until its reauthorization in 1990, as the Individuals with Disabilities Education ACT (IDEA), autism was not recognized as a separate disabilities category. In addition, Asperger's disorder was not recognized in the United States until 1994, when it was added to the Diagnostic and Statistical Manual of Mental Disorders (American Psychiatric Association, 1994). Prior to these classifications, students with these disorders could receive special education services only under a different label (Wilder et al., 2004). Fortunately, diagnostic and educational categories now exist to serve children with pervasive developmental disabilities. At times, parents of students with autism are exposed to a myriad of diagnostic procedures and labeling attempts. The process is often both psychologically traumatizing and financially demanding. These parents often receive conflicting and confusing reports from professionals. For instance, at kindergarten and elementary school levels, parents may be told that their child with autism has a developmental delay, mental retardation, or multiple disabilities. Initially, older children with autism may receive diagnoses of learning disabilities, emotional disorders, obsessive-compulsive disorders, or anxiety disorders. Normally, autism is not diagnosed until age five and Asperger's disorder around age seven (Klin, Paul, Shultz, & Volkmar, 2005), but parents have noticed symptoms in their children since they were as young as two years. Researchers (see Center for Disease Control and Prevention, 2008) often report that parents experience a definite sense of relief when the diagnosis of autism is made because they know it is correct.

KNOWING WHAT TO LOOK FOR IN AUTISM

It is imperative to understand the salient characteristics of autism before selecting and embarking on curricular experiences. One cannot engage in any innovative programming for students he/she does not understand. The American Psychiatric Association (2000) indicates that children with autism exhibit three, namely, (a) impairment in reciprocal skill interaction, (b) impairment in verbal and communication, and (c) restrictive, repetitive, and stereotyped patterns of behavior, interests, and activities. These characteristics have direct impact on curriculum innovation and instructional strategies for teachers, parents, and community (see Brock, Nishida, Chiong, Grimm, & Rimm-Kaufman, 2008; Crooke, Hendrix, & Rachman, 2008; Palmer, Didden, & Arts, 2008). The three characteristics should be viewed as a framework that educators and families might employ when communicating about services and planning curricular experiences (Park, 1996). Because on the impact these characteristics have on learning, they are highlighted in the following subsections.

Social Skills

There is a consensus among scholars and other professionals that autism is a social disorder. A growing body of research indicates that social integration for students with autism is not automatic (see Randell & Parker, 1999; Stichter, Randolph, Gage, & Schmidt, 2007). Rather, integration needs to be planned for the autistic learner in order to provide opportunities to learn social skills. Deficits in social skills of learners with autism greatly affect their ability to communicate, interact, and behave appropriately with others (see Clements, 2005; Painter, 2006; Zeedyk, 2008). Social skills are most often unusual and delayed, resulting in restricted or poor interactions with peers and others. Many students have difficulty using nonverbal behaviors such as sustained eye contact, natural facial expressions, body postures, reciprocal affections, gestures, and indicators of interest in an activity (Reinehart, Bradshaw, Moss, Brereton, & Tonge, 2000). Students with autism tend to appear oblivious to the social world around them. In addition, some of them lack a theory of mind, a term referring to the ability to understand the feelings of others. They may act as though they are not interested in being around others and may ignore social conventions (Sigman & Ruskin, 1999).

Deficits in social skills may be difficult for some families to accept. These deficits have cultural implications. Families in some cultures place a high value on proper behavior in relationships. It is critical for teachers to understand the social deficits of learners with autism in the context of familial expectations. Through this understanding, general and special educators can prioritize interventions for the autistic learner to acquire social skills congruent with family values and expectations (see Gutstein & Sheely, 2002; White, 2006).

Communication Skills

Communication impairments are some of the greatest challenges facing learners with autism. When inappropriately managed, they compound problems in social skill acquisition as well as personal expression. Autism spectrum symptoms that fall within the communication domain include delays in, or lack of spoken word development, stereotypical or repetitive use of language, and lack of age-appropriate make-believe or social imitative play (American Psychiatric Association, 2000). Speech for students with autism is clearly abnormal in rhythm and has an old intonation or inappropriate pitch and stress. In addition, it has a literalness of meaning, an idiosyncratic use of words and phrases, and an abbreviation of phrases to convey basic needs (see American Psychiatric Association, 2000). In addition, the communicative defects in speech described include pervasive defects in pragmatic or social use of communication (see Welton, 2003; Volkmar & Pauls, 2003).

Repetitive and Restrictive Behaviors

Restrictive, repetitive, and stereotypical patterns of behaviors and activities of many learners with autism often hamper them from learning effectively (see Anderson, 2007; Clements, 2005; Landa, 2003). These behaviors become problematic when their duration and intensity are excessive and interfere with productive academic and social activities. In some cases, learners with autism are over- or under-responsive to sensory stimuli such as noise, touch, and light (see Larkey, 2006; Reebye & Stalker, 2007). Such behaviors may be interpreted differently based upon one's cultural orientation (Park, 1996). For example, in certain cultures children are expected to follow adult directions precisely without diversion or creativity.

They are expected to trust teachers instead of learning through inquiry and debate (Lian, 1996). Most learners with autism are naturally reluctant to actively engage in social learning.

Behavioral activity in autistic learners may be related to both culture and disability. Some learners with autism, including many who are African American, may demonstrate higher energy in the classroom, causing a label of hyperactivity by their teachers (Benson, 1996). They may be exposed to "simultaneous variable simulations" (Benson, 1996, p. 259) at home, where energy levels are high, where people move about frequently, and where visual/auditory entertainment is ongoing. Inevitably, such learners may be bored in school environments where stimulation is low, and movement is restricted. They may require frequent movement, touching, and play to facilitate learning. Some students with autism exhibit repetitive body movements such as rocking, hand flapping, pacing, and spinning. The self-stimulating behaviors range from mildly odd to extreme self-encompassing. Consequently, families wishing to avoid societal attention to behavior considered "deviant" may shelter their children from the community (Dawson, Meltzoff, Osterling, Rinaldi, & Brown, 1998).

Despite the fact that there are many characteristics which, when holistically viewed, are responsible for the condition called *autism*, some argue that autism has its own culture (Dyches, Wilder, Sudweeks, Obiakor, & Algozzine, 2004). Many scholars agree that the symptoms of autism are innate within the individual, not necessarily learned through observation or imitation. This interpretation is congruent with the finding that many learners with autism have poor imitation skills and are oblivious of societal norms. Behaviors of autistic learners may be viewed prejudicially through different cultural lenses. It is therefore imperative to administer nondiscriminatory evaluations in order to avoid misidentification, misclassification, and misplacement for children who have autism (see Dyches, Wilder, Sudweeks, Obiakor, & Algozzine, 2004).

ASSESSMENT AND CLASSIFICATION OF CHILDREN WITH AUTISM

Special education assessment can be defined as the systematic process of gathering educationally relevant information for legal and instructional decisions (see McLoughlin & Lewis, 2008; Mukuria & Obiakor, 2004). Appropriate assessment should ensure that students with disabilities have been placed in an educational program that is congruent with their intellectual ability. Assessment should be conducted when students experience difficulty meeting the academic demands of the general education program and are referred for potential special education. For students with autism, as is the case so often for children with disabilities, early identification is critical so that appropriate intervention can be developed and initiated as soon as possible. Curriculum innovation will be impossible without appropriate assessment. In other words, in order to adequately address educational needs of individuals with disabilities, assessment should be carefully administered to avoid unwarranted labeling or misdiagnosis. Although IDEA recognized autism as a separate category of disabilities in 1990, misidentification, miscategorization, misplacement, and miseducation are not unusual (Obiakor, 2001). It is assumed that autism occurs across racial, ethnic, religious, and socioeconomic groups, yet, there are reported differences in the prevalence of autism across racial categories. Dyches et al. (2004) found that students with autism of Asian/Pacific Islanders or African American cultures were served at approximately twice the rate of students with autism who were Latinos or American Indian/Alaska. These discrepancies have yet to be explained, but relationships to proper identification and assessment efforts bear consideration. Families who are not Caucasians may be reluctant to have their children identified as having autism, and services to very young children may vary in the prevalence from community to community.

Currently, the Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition (DSM-IV) (APA, 2000) is used to diagnose children with autism. Like other assessment tools, this tool is not error free! Given the framework of its salient characteristics, autism is not an easy disability to diagnosis differentially. Appropriate identification requires multidimensional tools that include extensive observations as well as functional assessment and analysis. Assessors must be trained as observers as well as in the use of established tools. Despite improvements in testing, a great need remains to develop valid instrumentation and identification protocols that would minimize, if not eradicate the prevalent misdiagnosis, misplacement, and misdirected instruction of children with autism. Critical steps of referral and testing should be conducted with utmost caution and professionalism. When identification and referral are poorly and prejudicially administered, the process of assessment, categorization, labeling, placement, and instruction usually yield prejudicial results (Mukuria & Obiakor, 2006; Obiakor, 2001). Referrals are initiated when parent, teacher, or other related professionals complete a referral form, a document which describes the type and magnitude of the problem the child is having (Mukuria & Obiakor, 2006; McLoughlin & Lewis, 2008). The referral process is therefore somewhat subjective. Care must be taken in the follow-up assessment because the moment a student is erroneously identified and wrongly placed, inappropriate programming will follow.

Because of the adverse debilitating consequences of autism, early identification and intervention are critical (see Brereton & Tonge, 2005). Any comprehensive and meaningful diagnosis and intervention should involve multidisciplinary collaboration that includes professionals from medicine, psychology, education to mention a few (Obiakor, 2001). The rationale for a multidisciplinary approach can be found within the autism framework, the wide variety of the characteristics presented in this disorder. Family dynamics must be an integral part of early identification and intervention. While the diagnosis of autism emerges quite early, usually around three years of age, parents often observe and worry about signals they see prior to that age. As a result, parents often have established a relationship with a physician. Based on their early interactions with families, physicians play an important role in establishing multidisciplinary collaborations. As differential evaluation unfolds, assessments in multiple skill areas are required, including communication and language, intelligence, and social interactions (Gillberg, 2006). The supportive multidisciplinary team for each autistic child is therefore comprehensive, consisting of professionals such as child or school psychologists, behavior modification experts, speech-language pathologists, occupational and physical therapists, and psychiatrists. Once a comprehensive assessment is completed, collaboration of the team should move forward to into prescriptions for intervention. In this phase, input from developmental specialists and education professionals are critical. Intervention begins once this process has been completed. From the parents' perspective, the important outcome of this collaboration is appropriate service for their child (see Beaumount & Newcombe, 2006; Boran-Cohen & Klin, 2006).

INNOVATIVE PROGRAMMING FOR CHILDREN WITH AUTISM

A major aim of educational programs in today's world is to place individuals with disabilities in the least restrictive environment conducive to maximizing their full potential. Under IDEA, students with autism are entitled to a free appropriate education in such an environment. Educational placements and instructional programming are dependent somewhat on the student's age and functional level (Galinat, Barcalow, & Krivda, 2005). In most cases, contingent on the severity of disability, the ultimate goal is to prepare an individual with autism to live and be independent in the community (Beeghly, 2006; Green, Brennan, & Fein, 2000).

To adequately help children with autism, individualized education programs (IEP), including statements of short- and long-term goals should be developed. The intensity and complexity of academic and social challenges faced by students with autism require comprehensive interventions across a range of overlapping domains. Interventions should be aligned with the results of an individual student's assessment data and functional needs. However, because of the multiplicity of needs and limitation of time, intervention should be geared to key framework elements of academic performance, social/behavior functioning, and language skills. The following are subsections that further explain critical innovative strategies to reach learners with autism.

Focusing on Social Skills

As has been discussed, students with autism exhibit impairments in reciprocal social interaction. Even students with mild autism often require instruction in social skills, perhaps on one-on-one with an adult. In order to improve social skills for these students, it is imperative for special and general education teachers to first consider the student's culture, including what may be expected and deemed appropriate in the students. Individualized education plan team members should place priority on culturally appropriate social skills in planning social goals for the IEP. It important that teachers and service provides must task analyze the specific social skill into small teachable steps and teach each step at a time until the student gains mastery (Kearney, 2007). To effectively meet the educational needs of children with autism in an inclusive setting, the impact of disruptive behaviors on communication problem, and social the disruptive behavior, communication problems, and poor social skills on academic performance should be taken seriously (Clements, 2005). These factors are interrelated and mutually inclusive.

Using High with Low Imagery to Teach

Recent research may give clues to appropriate interventions for academic growth in learners with autism. Research (see Kana, Keller, Cherkassky, Minshew, & Just, 2006) using brain scans now shows that individuals with autism process information differently from other individuals. Researcher Nancy Minshew and her colleagues at the University of Pittsburgh and Carnegie Mellon University found that people with autistic spectrum disorders process both high-imagery and low-imagery sentences in the visual parts of brain (Kana et al., 2006). Math operations such as adding and subtracting are examples of low-imagery sentence. An example of high-imagery is seeing the number "8" the way a child does, as a pair of glasses. A non-autistic individual shuts off visual imagery areas of the brain to process a low-imagery sentence. When a person with autism reads a low-imagery sentence on subtraction and addition, he/she immediately sees the imagery of the teacher who is doing the teaching, not the concept. Understanding how individuals with autism process information is critical for enhancing how educators make meaningful connections and selective effective instructional strategies for these learners. Using pictures, concrete objects, and other cues when teaching seems to be effective in stimulating the strong visual response of learners with autism (see Dyrbjerg & Vedel, 2007; Elliott, 2006; Nikopoulos & Keenan, 2006). Educators should capitalize upon the knowledge of their learning styles. Clearly education must incorporate behavioral improvement. As was mentioned earlier, children with autism often engage in inappropriate behaviors, which if not replaced with appropriate behaviors, may interfere with their learning and interpersonal relationships. Inclusive classrooms are one place where friendships between children with and without disabilities have the opportunity to flourish. However, just placing children with disabilities with typical peers does not necessarily ensure interpersonal exchanges (Boutot, 2007). In order for friendship to develop, there must be first an acceptance of a child with disabilities by other children. At the elementary school level, early intervention and education, with special attention to communication and social competence, are essential for children with autism and their families (Koegel, 2000; Rogers, 2000).

USING SOCIAL STORIES AND PHYSICAL STRUCTURE TO TEACH

A strategy that is applicable across all ages for children with autism is the use of social stories (see Gray & White, 2002; Howley & Arnold, 2005). Because children with autism perceive and interpret information differently from other individuals, they need additional instruction. They need to learn how to interact appropriately, what to say, what is accepted and not accepted, and how other people perceive the world. As Gray and Garand (1993) posited social stories can be utilized to describe the situation and the expected behavior. Social stories can also be used to assist students with autism in learning written and unwritten codes of conduct that are critical to school success (Myles & Simpson, 2001). Social stories written by educators, parents, or students should be geared to depict social situations, social cues, and appropriate responses to naturally occurring situations (see Gast & Krug, 2007; Vittorini & Boyer-Quick, 2007). Teachers and service providers can effectively utilize social stories to enhance good behavior and communication among all learners. Educators must have clear expectations for students with autism in all places and activities in school (e.g., cafeteria, hallways, library, bathrooms, and playgrounds). They must make sure that students with autism know, practice, and meet these expectations. In response, educators must praise, recognize, and/or reward students with autism for positively meeting the expectations (see Smith, Donlan, & Smith, 2008). The physical structure of a classroom communicates expectations and supports appropriate behavior, and temporal structure influences motivation and availability of learning. Students with autism need structure. Therefore, furniture should be placed so that the expectation of the activities is obvious. Also, physical structure should be arranged to communicate boundaries and facilitate engagement (Schopler, Mesibow, & Hearsey, 1995).

Engaging in Systematic Planning

Given that individuals with autism do not acquire information incidentally, it is crucial to directly teach skills and concepts systematically. Systematic instruction refers to the use of instructional technologies with demonstrated effectiveness, including those based on applied behavior analysis techniques (see Kearney, 2007; Schreibman, 2000). To effectively instruct students with autism, activities should be varied and shortened to keep them motivated. The addition of visual elements in instruction and the use of concrete objects are critical. Visual cued instruction can facilitate (a) attention to relevant stimuli, (b) organization of information, and (c) understanding of concepts and expectations. Difficulties in shifting attention (Wainwright-sharp Bryson & Bryson, 1993) can be reduced by providing a cue that stays in place (Bryson & Landry, 1994), and sufficient time for shift to occur (Townscend & Courchesne, 1994). Rules in the classroom can be depicted graphically accompanied by symbols.

USING POSITIVE BEHAVIOR SUPPORTS

In the end, no curriculum innovation for children with autism can be made without utilizing positive behavior support (PBS) programs since they reduce the occurrence of challenging behavior and allow meaningful teaching to take place. By definition, positive behavior support is a proactive, problem-solving, and data-based approach to improving appropriate behaviors and achieving important academic, social, and communication outcomes (Segei, Lewis-Palmer, Todd, & Horner, 2001). When using this method, teachers and service providers must endeavor to teach students to replace inappropriate behaviors with appropriate behaviors, enabling them to benefit much more effectively in general education curriculum. Clearly, positive behavior support programs incorporate environmental scans and recommendations. School environments are assessed and changed to prevent students from engaging in problem behaviors in the first place. Positive behavior support calls for the redesign of environments to decrease problem behavior and increase lifestyles goals such as improved learning, access to social networks, employment, and involvement of full range community activities (Catania, 1992).

Students often engage in inappropriate behavior as a result of a failure to provide individualized and comprehensive support (Turnbull & Ruef, 1996). Positive behavior support seeks to tailor learners' environments to their preferences, strengths, and needs. This should not be viewed as a new idea because it is congruent with effective teaching. Teachers and service providers should always capitalize in students' preferences, strengths, and needs. Another key to behavior intervention and success is functional assessment. Functional assessment is a step-by-step way of finding out the function and cause of inappropriate behaviors. It involves observation of the student across settings, and interviews with people with whom the student frequently comes into contact. The analysis provides teachers and service providers with knowledge of the cause of the disruptive behavior, making it possible to develop an effective intervention program. Techniques such as positive behavior supports may be used to build a functional behavior intervention system for the student. There is a growing recognition that the outcomes of behavior support should include not just the elimination or reduction of problem behaviors but also an improvement in adaptive behaviors and overall quality of life (e.g., Meyer & Evans, 1989; Newton & Horner, 2004). To be successful, the outcomes of the behavior support must be referenced to the personal value of the student receiving support and his/her family.

Taking Advantage of the Students' Home Background

Although the most critical responsibility of schools is to educate learners, it should be realized that students do not exist in vacuum. Whatever happens at home finds it way to schools and has a direct or indirect impact on the learning environment. Schools occupy only 9% of children's lives. Consequently, parents and families must be accepted as critical partners in the education of their children, since such an involvement is positively correlated with student's school achievement (see Drummond & Stipek, 2004; Fisher, 2003). Parental involvement is critical in that there is a role in the education of children that cannot be occupied by anyone else apart from the parent. Parents possess a wealth of information which may often be unavailable even to those professionals who interact with children daily (see Firestone, 2007). For example, an individual may exhibit certain behaviors at home which may be quite different from those observed at school. Such behaviors could be detected early in elementary schools with parental support. The nature, extent, and circumstances under which these behaviors occur could be critical for educational programming for students with autism. School administrators, teachers, and other personnel may have advanced degrees, but there is crucial knowledge about children and families that are lacking and can only be addressed by parents (see Gordon, 2002; Warner, Duane, Garvan, & Conway, 2002). The impact of this missing information is especially significant because of the magnitude of expected outcomes to be accomplished through general and special education programming. For any curriculum innovation for children with autism to be effective, the collaboration of parents and professionals is critical.

CONCLUSION

This chapter has highlighted the salient challenges pertinent to autism. Autism is a heterogeneous condition with varying characteristics. Because of the challenges autism presents, it is imperative for educators and service providers to thoroughly understand the characteristics to best meet need educational needs of learners with autism. One cannot make any curriculum innovation for students he/she does not understand. The characteristics of autism have direct impact on curriculum innovation, instructional strategies for teachers, parents, and community. The three characteristics of students with autism should be viewed as a framework that educators and families might employ when communicating about services and planning curricular experiences (see Harper-Hill & Lord, 2007; Park, 1996). Needless to say, multidimensional approach is required in order to meet the challenging problems of educating children with autism.

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IMPLEMENTING SOCIAL SKILLS FOR STUDENTS WITH AUTISM

Michael Eskay and Keith Willis

Autism is defined as a mysterious brain abnormality that inhibits normal social and cognitive development in infants and children (see Chez, 2008). It is seen as mysterious because up till now, no one can pinpoint exactly what causes this abnormality. According to the United States Center for Disease Control and Prevention (2007), 1 in 150 has the disorder. Children with autism and other autism spectrum disorders typically display a range of identifiable symptoms. By being aware of these signs, parents can help spot the disorder at an earlier age, which greatly improves a child's overall prognosis (see Wright & Williams, 2007). These symptoms are classified under communication and social interaction. Many students with autism have delays in or total lack of development of spoken language, difficulty initiating conversation, echolalia (repeating words or phrases instead of using normal language), unresponsiveness to name, and a lack of use or response to gestures and other nonverbal cues (see Anderson, 2007; Silver, 2005). Some of them find it difficult to point to objects or show them to others and fail to make eye contact at appropriate times or look at other people's faces as much. In addition, they fail to respond to facial expressions or body language and fail to smile back at others or engage in peer relationships appropriate to age level (Wahlberg, Obiakor, Burkhardt, & Rotatori, 2001). According to Simpson and Myles (2007), they engage in highly repetitive play; obsessively preoccupy themselves with a specific interest or object; depend on routines, rituals, and familiarity; and exhibit

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repetitive body movements (hand or finger flapping, eye rolling, twisting, spinning, and rocking).

As it appears, knowing these autism signs and symptoms will help parents and service providers intervene by providing appropriate educational strategies to buttress social success (see MacKenzie, 2008). It is important to note that children with autism may appear normal for the first few months of life and may become more and more unresponsive. Many parents may first notice a problem when their child does not develop language and social skills like other children of the same age. However, the implementation of social skills training for students with autism in both educational and noneducational settings can help develop and maintain acceptable social skills (Smith, 2007).

SOCIAL SKILLS: DEFINITIONS AND CONCEPTUALIZATIONS

A social skill is similar to a skill found in a workplace that involves social interaction. The hallmark of a social skill is the smooth progression toward a goal. As with other workplace skills, social skills have both cognitive and behavioral components (Attwood, 2003). According to Webster's New World Dictionary (1986), a social skill is a "developmental tool used to interact and communicate with others to assist status in the social structure and other motivations" (p. 23). This means that social rules and social relations are created, communicated, and changed in verbal and nonverbal ways creating social complexity useful in identifying outsiders. The process of learning these skills is called socialization (Barry & Burlew, 2004). Specific examples of social skills may include initiating, responding, and keeping interactions going; greeting others and conversing on a variety of topics; giving and accepting compliments; taking turns and sharing; asking for help and helping others; and including others in activities (Wahlberg, Rotatori, Deisinger, & Burkhardt, 2003). Simply put, social skills are the behaviors we use to work and socialize with other people. As Walker, Todis, Holmes, and Horton (1988) pointed out, social skills are defined as social responses and skills that (a) allow one to initiate and maintain positive relationships with others, (b) contribute to peer acceptance and to a successful classroom adjustment, and (c) allow one to cope effectively and adaptively with the social environment.

Mastropieri and Scruggs (2007) noted that many different types of behaviors or responses can qualify as social skills. These include:

- *Conversation skills*: These include joining a conversation, interrupting a conversation, starting a conversation, maintaining a conversation, ending a conversation, use of appropriate tone of voice, and use of appropriate distance and eye contact.
- *Assertiveness skills*: These include asking for clarifications, making requests, denying requests, negotiating requests, and exhibiting politeness.
- *"Play" interaction skills*: These include making friends, sharing with others, inviting others to play, encouraging others, and praising others.
- *Problem-solving and coping skills*: These include staying calm and relaxed, listing possible solutions, choosing the best solution, taking responsibility for self, handling name calling and teasing, and staying out of trouble.
- *Self-help skills*: These include good grooming (clean, neat), good dressing (wearing clothes that fit), good table manners, and good eating behaviors.
- *Classroom task-related behaviors*: These include on-task behavior, attention to tasks, completing tasks, following directions, and trying your best.
- *Self-related behaviors*: These include giving positive feedback to self, expressing feelings, accepting negative feedback, and accepting *consequences*.
- *Job interview skills*: These include being prepared (dress and attitude), being attentive, listening skills, asking for clarification, and thinking prior to speaking.

STRATEGIES FOR TEACHING SOCIAL SKILLS

Adequate social skills are necessary for successful functioning in school. Beyond the classroom, effective social skills are necessary for success in job interviews, and once employed, in maintaining employment. All students must know how to interact with others appropriately in group learning experiences, how to engage in classroom discussion, and how to distinguish between classroom behavior that promotes learning and classroom behavior that disrupts learning (Mastropieri & Scruggs, 2007). Classrooms are well managed when students stay on task academically, but also feel free to participate actively in activities, take risks, and interact positively with others. Appropriate behaviors are often limited because some students lack adequate knowledge of certain social skills. Since students with autism are referred for special education services because of deficits in social skills, teaching social skills in school may be necessary to help them learn and socialize, and be more accepted by their peers (Burkhardt, 2007). Specific strategies for teaching social skills are discussed in the following sub-section.

ECOLOGICAL VARIABLES

McConnell (2002) noted that social interactions of children with autism spectrum disorders are modifiable and that ecological variables can be used for intervention. Ecological variables may exert a weak to moderate impact on the social interaction of children with autism. Establishing a non-threatening environment appears to be an essential step that is needed before social skills training can take place. This is particularly important since the child with autism may perceive even “neutral” cues or people as threatening. In other words, low environmental stimulation may lead to increased social behaviors (see Gammeltoft & Nordenhof, 2007). In addition, the presence of activities preferred by the child or predictable, structured activities may increase the frequency of social behaviors. The particular modifications of the classroom or learning center will vary depending upon the age and development of the child, but some general ideas for students with nonverbal learning disorders may also apply to students with autism (see Klumper, 2002; Mamen, 2007; Martin, 2007). Tanguay (2002) makes several recommendations for the child with nonverbal learning disabilities. Among them are allowing the child to have a “safe space” and a “safe person.” In addition, the child may choose to bring a “security blanket” or an object that reminds him/her of a safe place or home.

DIRECT TEACHING

One way to teach social skills to students with autism is through direct teaching, an approach used to identify social skills that need to be developed and to determine the steps necessary for building those skills (Koegel & Koegel, 1995). Like many other skills, social skills for students with autism can be taught directly because these students may not easily acquire those skills naturally from their environment, like their typically developing peers. In addition, these students have greater difficulty reading subtle social cues, which makes interpreting meaning challenging (see Zeedyk, 2008). Teaching social skills directly can take many forms. Using a method called Applied Behavior Analysis (ABA) is often successful (see Anderson, 2007; Keenan, Henderson, Kerr, & Dillenburger, 2006). ABA involves breaking down a task into its component parts to teach it and using positive reinforcement to motivate the desired behavior (Attwood, 2003). Each skill is broken down into its component parts and taught in a structured teaching environment. In each case, appropriate behaviors are rewarded and inappropriate behaviors are redirected or ignored. Teaching social skills with ABA requires multiple trials of the same target (Kearney, 2007). Once a skill is mastered, then a new target is introduced. Methodical records are kept of each teaching trial to assure mastery of a target. The data is reviewed by a behavior consultant who oversees the program. From the data, the consultant may decide to hold off on targets, put the target on a maintenance schedule, or introduce a new target (Attwood, 2003). This is very helpful in an inclusive setting.

SOCIAL INTERACTIVE TRAINING

Hwang and Hughes (2000) acknowledged that Social Interactive Training (SIT) can be used to increase social skills in young children with autism. They identified four broad strategies that were used, separately or in combination: time delay, environmental arrangement, naturally occurring reinforcement, and contingent imitation. Time delay involves presenting an object to a young child, waiting briefly for a response, and giving a verbal prompt when no response was initially given. Environmental arrangement involves arranging or modifying the environment to encourage requests from a child. An example may be to provide toys or place a favorite object in a manner to encourage a request for help. An example of naturally occurring reinforcement occurs when a child's minimal request for an object results in receiving it. Contingent imitation involves imitating a child's desirable action within the child's sight and immediately following the action. Hwang and Hughes examination of 16 empirical studies revealed that all strategies are helpful in increasing social competence. However, these researchers concluded that time delay strategies alone are less effective with children lacking language skills, and social skills (including eye contact and expression of positive affect or affection) were not as strongly impacted as others with this type of training.

PEER INITIATION PROGRAMS

In peer initiation programs, socially competent peers initiate and encourage social interactions with children with autism (DiSalvo & Oswald, 2002).

The socially competent peers are paired with children lacking in social skills to engage in social activities in natural settings. The outcome of this social interaction has been found to yield positive results (Bakken & Bock, 2001; Odom & Wolery, 2003), including consistent increases in the response rate and initiation and length of interactions of participants with autism. Earlier, Lord and Hopkins (1986) found that socially competent peers as well as peers of similar age or slightly older age facilitated increased social interactions with children with autism. This approach can also be used from a variety of disability areas and with nondisabled students who exhibit some social withdrawal. Several advantages and disadvantages are noted through this strategic application. One advantage is the use of natural social interaction environment. Further, valid interaction behaviors are ensured because these programs depend on social interaction behaviors of socially competent peers. Sasso (1987) found that peer-initiated interventions resulted in increased levels of initiations and responses from both participants with autism and their competent peers. Similar results were found by Kamps, Dugan, Leonard, and Daoust (1994) when they examined the effects of training elementary peers to help increase the social interactions of students with autism, while involved in other activities, such as cooperative learning, peer tutoring, and social skills training. However, a weakness with peer initiation programs is that there is little evidence of the generalization and maintenance of interactions (Kennedy, Shukla, & Fryxell, 1997).

PEER TUTORING PROGRAM

Peer tutoring is an approach that uses peers who are socially competent to apply teaching techniques and positive reinforcement to teach academic subjects to classmates with autism (see Simpson & Myles, 2007). Peer tutoring sessions are usually structured, with both tutor and tutee having assigned roles. Students work in dyads, with socially competent peers serving as tutors and students with autism taking role of tutee (Attwood, 2003; Koegel & Koegel, 1995). To bring this approach to a successful conclusion, students (both those with autism and their socially competent peers) need to have some interactional experiences and familiarity with each other. This first step is supposed to be informal. Thereafter, group and individual instruction of tutors commence. Group instruction involves teachers' explanations of procedures for working with students on various learning tasks. Here, teachers describe (a) materials to use for tutoring; (b) how to give short, clearly stated directions (e.g., "point to the table," "read this word"); (c) how to give reinforcements (e.g., "great spelling" and "that's great you are doing well"); and (d) how to manage inappropriate behavior (e.g., "look at your book" when the student is not concentrating). Additional ways of managing inappropriate behavior suggested by Koegel and Koegel include physical guidance (e.g., touching the student's arm to encourage working on a task) and ignoring (e.g., attending to a separate task when the student displays inappropriate behavior). Attwood recommends that any behavioral management strategy should be selected by the supervising teacher based on his/her knowledge of its effectiveness with a particular student.

CIRCLE OF FRIENDS PROGRAM

The main purpose of the circle of friends program is to encourage classroom peers to initiate social interaction, thereby relieving the individual with a disability in this area from the burden of initiating contacts (see Attwood, 2003; Frederickson & Turner, 2003). In this case, papers are distributed with four concentric circles drawn, and a stick figure in the middle. Students are told to write in the first circle the most important people in their lives, such as family members. In the second circle, they are told to put their best friends, and in the third circle, they are to put other people they enjoy playing with or interacting with. In the fourth circle are people who are paid to be in their lives, and such people may include doctors and dentists. When students have filled out the circles, the teacher should ask the class how they would feel if they only had their mother in the first circle and no one in the second and third circles. After students have shared their feelings (e.g., "I would hate myself"), they should be informed that they might not have very many people in the second and third circles, because not everyone needs to be the student's best friends, but all can be friendly and interact well with each other. The point of this kind of activity is to show that everyone needs a circle of friends, with people in every circle. Frederickson and Turner (2003) found this approach to be successful because of its increase in social acceptance.

SPECIAL FRIENDS PROGRAM

The special friends program involves an interaction between upper elementary students who are trained to interact with students who have a severe disability in the area of autism (see Voeltz, 1983). The training session covers rules, procedures, and disability awareness. The students interact with their special friends 2–4 times per week and at least 20 min for 8 weeks. Students with disabilities who were enrolled in this program, according to Favazza, Phillipsen, and Kumar (2000), enjoyed the interactions with their special friends and also improved their social skills.

POSITIVE REINFORCEMENT STRATEGIES

Reinforcing appropriate behaviors is one way to promote acquisition of social skills. When the desired behavior is exhibited, an immediate reward will reinforce the behavior and make it more likely to occur again in the future (Smith, Donlan, & Smith, 2008). For example, the child is asked to greet a friend at the door at the beginning of a play date. The child says "hello." Immediately, a pat on the back or "good job saying hello" is whispered in the ear to reward the appropriate social interaction. Direct training in social skills interactions such as initiating contacts with peers has shown fairly consistent outcomes, particularly with special procedures such as "high-probability requests" and "priming" (i.e., increasing the density of reinforcement). Careful selection of rewards for the child with autism may lead to increased behavioral change. It is important to note that praise, food such as popcorn and M & Ms, movement, touch, verbal cues, music, and physical activity may not be equally rewarding for all children with autism. Sonders (2003) described an insightful method for adults to encourage social interaction with young, low functioning children with autism. An adult carefully observes the youth and imitates any social behavior of the child to establish a repetitive series of interaction called a "turn-taking sequence." The sequence ends with a simple activity involving positive affect shared between the adult and child. One example of this activity is gently swinging the infant in a circle. According to Sonders, through this process the child with autism learns that his/her behavior impacts others in a positive way.

SOCIAL SKILLS AND SCHOOL INCLUSION

Social skills are important for inclusion in the classroom (Autism Special Interest Group, 2007). Inclusion in a school environment with typically developing peers is often not dependent solely on a child's IQ or intelligence. Children with autism and Asperger syndrome are often capable of working at grade level, but are at risk of not being included in a classroom because of behavioral issues or poorly developed social skills (Adams, Gouvousis, VanLue, & Waldron, 2004). Social skills groups may be found through community organizations. Many schools also offer social skills groups that take place during the school day within the context of school. This type of social skills group may require an individualized education plan (IEP) in order for the child to participate (see Magnusen, 2005). The purpose of a social skills group is to teach and guide social interaction of children participating in the group so as to teach them how to establish and maintain friendships (see Painter, 2006).

Together with obvious academic challenges, there are social difficulties facing children with autism in the mainstream setting. It is generally recommended and viewed as beneficial to focus primarily on a student behavior, including good sharing and friendship skills, to enable inclusive academic learning later on. Some students are keen to make friends and join in, and although each new socializing opportunity is met with enthusiasm, some help may be required, both in guiding these students towards the most supportive and sympathetic friends and ensuring that their initial approaches are socially acceptable (Adams et al., 2004; Gutstein & Sheely, 2002). For those students who prefer to withdraw from others, it may be most appropriate to teach social skills on a one-to-one basis, before introducing one or two sympathetic friends. Nearly all students will require some encouragement in even the most basic of friendship skills. Learning to share at school is a skill that may need to be taught, despite the fact that many will have already learned how to share with siblings at home. Depending on the individual, this may include being taught about sharing physical working space, materials, adult attention, friends, and time. With younger students, and with older ones in new situations and settings, it is reasonable to expect only a minimal amount of sharing to begin with. One way to teach about and encourage sharing is to point out to students when they are doing it, and reward them appropriately (see Smith et al., 2008). This is most easily done with the sharing of working materials and space, but may also include the sharing of other people. When "good sharing" is the focus of the teaching, it should be praised in as many situations and settings as possible. There are programs available to help teach sharing and friendship skills, though it is useful initially to prepare pupils for these by doing some individual work with them (see White, 2006). Because of their inability to generalize, students may need to be taught these skills both in and out of the classroom (Koegel, Camarata, Valdez-Menchaca, & Koegel, 1988). In some cases, staff may need to engineer some "real life" situations whereby students experience a degree of success in their use of sharing and friendship skills.

The classroom environment has to be nonthreatening. For instance, round games are nonthreatening, fun ways of teaching pupils how to share space, time, activity, and adult attention. For optimum results it is best to work in a small, manageable group of no more than three or four, supported by sympathetic peers. The verbal sharing of nursery rhymes, important or exciting happenings or particular worries regarding school can all be included in rounds. Depending on individual needs and the age group, other rounds might include suggestions of smart ways to ask for help, and the facial expression and body gesture that should be used when doing so. Some students may benefit from being taught how to play board games such as snakes and ladders, and draughts (see Hwang & Hughes, 2000; Searle & Streng, 1996). While younger pupils often use games for activities (see Moor, 2002), this may not be the case for older students, who may still benefit from the inclusion of board games and cards to encourage their skills in sharing. These sessions could be held during breaks or lunchtimes, or otherwise timetabled in, depending on the availability of staff, and parental agreement. Break and lunchtime sessions might include sharing of outdoor activities and playground apparatus. Once students have experienced and understood what good sharing is, and have been taught in a fun way how to share, they can be encouraged to adapt and use their knowledge and skills in the classroom.

A small group situation of any kind frequently provides an excellent opportunity for staff to teach and encourage physical sharing of working materials and space (Painter, 2006). Staff may need to perceive the teaching of sharing in the same way they would any other academic learning task, in that it needs to be rewarded with stickers. For some students, this may mean temporarily reducing or setting aside other work or behavioral expectations in order to focus fully on good sharing. For others, it may be taught alongside their individual curriculum. In all cases, as a student's confidence and understanding of what is good sharing, increase, so too can the expectations of staff.

Studies (see LeGoff, 2004; LeGoff & Sherman, 2006) involving the use of LEGO©s show considerable promise in social skills building. For example, LeGoff (2004) found that pairs of young boys with autism increased their social competence while building LEGO© projects, taking turns in the roles of builder and engineer. When LeGoff adapted this approach to groups of children with autism spectrum disorders, and this researcher consistently found increased cooperative play with appropriate strategies and structure.

These strategies included (a) having siblings attend as helpers, (b) including aides or graduate students (but not parents) as helpers, (c) allowing free play time using the sets to create new designs, (d) encouraging females to join groups, (e) opening the group with a short time for sharing recent personal experiences, (f) encouraging joint decision making regarding activities and organization of a the LEGO© club, (g) assigning mentors for new members, and (h) encouraging family members to form a support group (LeGoff). The value of the above findings were enhanced in a study by LeGoff and Sherman (2006) that found that interventions using LEGO© therapy outperformed comparable training methods, maintaining and generalizing social competence skills over a three year period.

The SCORE Skills Strategy program was developed by the University of Kansas Center for Research on Learning (Vernon, Schumaker, & Deshler, 1996). It includes instruction in five cooperative skill areas such as sharing, complimenting others, offering help or encouragement, recommending changes, and exercising self-control. These skills are presented with a series of concise steps that include modeling of the skill, verbal rehearsal of the skill, and practice using the skill in designed role-plays with a partner. Ratings of the level of competence using the skill include the body language (tone of voice, facial expression, and eye contact) accompanying the actions. A few years ago, Webb, Miller, Pierce, Strawser, and Jones (2004) used the SCORE Skills strategy to teach social skills to 10 high functioning adolescents with autism spectrum disorders during a 10-week program. All students showed substantial improvement in all cooperative skill areas.

Gagnon (2001) developed a power card strategy to help children with autism reduce problem behavior by preparing a script and pictures using an individual's hero to model desirable behaviors. The power card became a reminder of the story that was presented to cue the desired response. It was found that this shortened the intervention and also allowed an easy way to generalize the response in a variety of situations. Other strategies that have been found to improve social skills of autistic children include structured play (see Levine & Chedd, 2006; Schoen & Bullard, 2002), drama training (see Attwood, 2003; Schneider, 2006), and Social Use of Language Program (SULP) (Rinaldi, 1995).

THE NEED FOR A SOCIAL SKILLS THERAPIST

It is current knowledge that people with autistic spectrum disorders have difficulty in social interaction (see Asperger, 1997; Attwood, 2007; Gray &

White, 2002; Quill, 1997). This difficulty is, of course, made more significant by problems with speech and language. In addition, autism seems to create problems with "mind reading" (e.g., knowing what another person might be thinking) (see Barron-Cohen, 2007). Most people can observe others and guess, through a combination of tone and body language, what's "really" going on. Clearly, without help and training, autistic people cannot pick up social skills. "Mind blindness" can lead even the highest-functioning person on the autism spectrum to make social blunders that cause all kinds of problems. Without knowing why, a person on the autism spectrum can hurt feelings, ask inappropriate questions, act oddly and generally open themselves up to hostility, teasing, bullying, and isolation (see Caldwell, 2007). As a result, a social skills therapist is highly important. There is no such thing as an association of social skills therapists, nor is there an official certification in the field. Thus, social skills practitioners can come from a wide range of backgrounds and training. As it appears, social skills therapists can be a social worker, psychologist, occupational therapist, or speech/language therapist who specializes in working with autistic people. Over time, these professionals have developed or learned techniques to build social interaction skills ranging from basic skills (such as making eye contact) to complex and subtle skills (such as asking for a date). In recent years, "do it yourself" social skills teaching tools for parents and adults on the autism spectrum have hit the market (see Dixon, 2007; White, 2006). These generally take the form of books and videos modeling different types of interactions, along with hints and tips for "doing it right" (see Nikopoulos & Keenan, 2006) Drama therapists also work on social skills through literally scripting scenarios and/or improving and critiquing practice interactions.

Since there is no official certification for social skills therapists, techniques vary from professional to professional. In a school setting, social skills therapy may consist of group activities (usually games and conversation) with autistic and typically developing peers. Groups may be overseen by school psychologists, school counselors, or social workers, and may be held in the classroom, lunchroom, or playground. Generally, school social skills groups focus on game playing, sharing, and conversation (Painter, 2006). Out-of-school social skills groups are similar in style, but are paid for privately (medical insurance is unlikely to cover such programs). Children are grouped by age and ability, and may make use of specific social skills curricula as developed by well-established practitioners of social skills therapy.

In theory, social skills therapy provides people on the autism spectrum with the ability to converse, share, play, and work with typical peers. In an ideal world, such therapy allows people with autism to become almost indistinguishable from their typical peers. In fact, social skills therapy tends to be offered no more than an hour or two a week. While it may provide autistic learners with specific skills and techniques (e.g., "look at a person's face when you're conversing") it is unlikely to make an autistic person appear typical. A program most likely to have such an impact would be very intensive – unlike the vast majority of existing social skills programs.

It can be a challenge to find a qualified practitioner who can be a social skills therapist. Most of the best social skills therapists happen to be very talented therapists in their own field, with an innate understanding of how to help people with autism to think, feel, and act. Thus, the fact that someone has been trained in a particular social skills method does not necessarily make him/her an ideal therapist. Probably, the best way to decide if a therapist is right for the client or child is to attend a few sessions. Most school programs for children with autism do include social skills therapy. There is no guarantee that the person running those programs has specific training in or experience with running such programs, so it may be worth a parent's time to inquire into just who is offering such programs and why he/she is chosen to do so. It is not at all unusual for a school psychologist or social worker to run social skills programs with relatively little training or background.

CONCLUSION

Many strategies have been demonstrated to be effective in the development of social skills for children with autism. However, it is appropriate to reiterate that a diagnostic label of autism or Asperger syndrome does not point to some simple or unitary set of behaviors. Therefore, the selection of educational and behavioral strategies needs to take into account, as far as possible, the needs of the individual child. The child's age and level of development are important factors to consider before selecting an intervention. In addition, careful observation of the child and a clear understanding of his/her needs should guide the selection of an appropriate intervention. Clearly, some strategies may be impractical in the classroom setting due to the extensive training needed and/or the extensive time needed to implement the strategy. Therefore, to maximize gains of instruction, it may be necessary to consider repetition or modification of interventions that work in a variety of settings.

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ASSESSMENT OF AUTISM SPECTRUM DISORDERS

Marty Sapp

INTRODUCTION

According to the Diagnostic and Statistical Manual of Mental Disorders (DSM-IV-TR, American Psychiatric Association (APA), 2000), autistic spectrum disorders (ASD) are a collection of chronic conditions that include Autistic Disorder, Rett's Disorder, Childhood Disintegrative Disorder, Aspeger's Disorder, and Pervasive Developmental Disorder Not Otherwise Specified. Typically, ASD are often identified during infancy or the toddler years. Most individuals with ASD have some degree of mental retardation. According to Deisinger (2001), genetic factors, abnormalities in brain structure and biochemistry, and complications during pregnancy have been implicated as possible causes of these disorders. Generally, students with ASD have difficulties with daily activities such as language, self-care, mobility, and independent functioning. The focus of this chapter examines the many features that must be considered before diagnosing and classifying individuals with ASD.

Mental health professionals use the DSM-IV-TR (APA, 2000) to diagnose students with ASD. It allows one to make multiaxial diagnoses – one for each of five axes (DSM-IV-TR, 2000, pp. 27–38). Axis I is used to diagnose the presenting problem for a student such as anxiety and depression. Axis II is used to diagnose personality disorders and mental retardation. Axis III is

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employed for general medical conditions, diagnosed by a medical practitioner, that are related to a student's performance. Axis IV is used for psychosocial and environmental concerns that may influence diagnoses on Axis I and Axis II. Negative life events that can produce interpersonal stress are diagnosed on Axis IV. The following are some psychosocial and environmental concerns for students:

- Educational problems such as academic difficulties and negative school experiences.
- Problems with primary support group – divorce, death of a family member, sexual, and/or physical abuse.
- Problems related to the social environment such as death of a friend, relative, or someone in the community.

Axis V is used to diagnose a student's overall level of functioning, and it is called the Global Assessment of Functioning (GAF) scale. This scale has values ranging from 0, inadequate information; to 10, persistent danger to self and others; and from 50, moderate symptoms; to 100, superior functioning in a variety of areas.

The following case illustrates how a DSM-IV-TR (APA, 2000) is formulated: *Jackson Brown is a 14-year-old African American adolescent with multicultural special education needs. He lives with his African American foster parents. Recently, Jackson began having grand mal seizures. He shows the following in terms of impairment in social interaction:*

- *Marked impairment in the use of nonverbal behavior*,
- *Failure to develop peer relationships*,
- *Lack of social and emotional reciprocity.*

In terms of communication expressions, Jackson displays the following:

- *Delay in spoken language expressions*,
- *Impaired ability to converse with others*,
- *Stereotyped and repetitive use of language.*

A recent psychological evaluation reported that Jackson attained a Verbal IQ of 58 and a Performance IQ of 68, which yielded a Full Scale IQ of 60. His DSM-IV-TR multiaxial diagnosis is:

Axis I	*299.00*	*Autistic Disorder*
Axis II	*317*	*Mild Mental Retardation*
Axis III		*Epileptic Disorder*

Axis IV	*Significant social interaction problems,* *Extensive special education needs*
Axis V	*GAF = 60*

Clearly, Jackson has multicultural special education needs.

Diagnosis and Assessment: A Mutually Inclusive Relationship

Multimodal Behavior Assessment (MMBA) (see Sapp, 2004) is a method used within psychological assessment. It is a comprehensive intraindividually based assessment that can be adapted to assess students with ASD. The MMBA method assesses seven modalities in acronym form called the BASIC-ID or IB, and this acronym assesses the following modalities: behaviors, affect, sensation, imagery, cognition, interpersonal relationships, and drugs/biology.

- *Behaviors* are actions that students engage in, and they are observable. Students are assessed in terms of behaviors to decrease and increase.
- *Affects* are feelings such as test anxiety, school phobias, general anxiety, depression, and so on. Students are assessed in terms of emotions that need to be increased and decreased.
- *Sensations* are tactile sensations such as bodily tension, headaches, dizziness, abdominal pains, and so on. Students are assessed in terms of sensations to be increased and decreased.
- *Imagery* encompasses images that students have such as academic self-concepts, self-images, and the visual sense of self. Students' areas of strengths and weaknesses are assessed within this imagery modality.
- *Cognitions* encompass all cognitive functioning such as thoughts, beliefs, attitudes, and cognitive distortions. Students' rational and irrational cognitions are assessed.
- *Interpersonal relationships* is an assessment of all of students' relationships such as families, siblings, and friends.
- *Biology/drugs* is an assessment of students' physiological functioning and medication usage by a medical professional.

Applying the MMBA to the case study of Jackson could lead to IEP recommendations related to the following (e.g., increase: in spoken language expression; social interactions with others, especially students; adaptive behavioral functioning; and a decrease in the repetitive use of language). This application could also produce interpersonal relationships (e.g., an increase in social interactions; the use of reinforcement to increase social and emotional reciprocity; and reinforcement in conversations with others).

Lastly, a trial period of psychotropic medication to reduce the frequency of grand mal seizures could be tried.

Diagnosis and assessment is never perfect as it involves a collection of information on a student. For example, students will often fall within several diagnostic categories, and often students will have several comorbid factors that do not fit into clear categories. There are several factors to address when attempting to assess students with developmental delays (Sapp, 2006); however, the two most important factors are the reliability and validity of assessment procedures. Unfortunately, these factors are not adequately addressed within the profession of special education (see Sapp, 2006). Before students can be diagnosed and assessed with ASD, reliable and valid assessment measures must be employed. This can be problematic when testing African American and Hispanic students with ASD who may not be adequately represented in most testing standardizations. Realizing this, mental health professionals must take great care when attempting to diagnose and assess students with ASD who are culturally different.

Autistic Spectrum Disorders: Characteristics and Symptoms

The DSM-IV-TR (APA, 2000) specifies that ASD are characterized by severe and ongoing impairment in reciprocal social interactions, communication skills, and stereotyped behavior. Children with ASD may have impairment with eye-to-eye contact, facial expressions, body postures, and gestures. Essentially, with this condition, children can have impairment in many nonverbal behaviors. Because ASD is a developmental disorder, it has neurological origins that appear at birth or early development (see Akshoomoff, Pierce, & Courchesne, 2002; Chez, 2008; Dacey, Nelson, & Stoeckel, 1999; Filipek et al., 2000). The notion that ASD is a broad spectrum disorder suggests that the skills and deficits vary from child to child. For example, some children with ASD have normal or high IQs and others fall within the cognitive disability range. Moreover, some children with ASD are highly verbal, while others do not have functional speech.

Impairments in reciprocal social interaction, verbal and nonverbal communication, and restrictive, repetitive, and stereotyped behavior patterns are the major characteristics of ASD (Autism Society of America, 2004). For instance, stereotyped behaviors include rocking, dipping, swaying, and clapping. Even a behavior as benign as a child walking on his or her tiptoes may contribute to the diagnosis of ASD. The attachment to inanimate objects such as strings, rubber bands, and tin cans can be also indicators of this broad spectrum disorder. A range of cognitive disability from mild (50–55 to approximately 70 IQ) to profound (below 20 or 25 IQ) can exist with ASD. Diagnostically, cognitive disability can only be made with an IQ of about 70 and impairment in adaptive functioning.

The DSM-IV-TR (APA, 2000) defines adaptive functioning as the capacity a student has to cope with life demands and how well a student meets the standards of personal independence expected for his or her particular age group, sociocultural background, and community setting (Oakland & Houchins, 1985; Smalley, 1998). The DSM-IV-TR (APA, 2000) reported the median rate of ASD in epidemiological studies as 5 cases per 10,000 individuals and ranges from 2 to 20 cases per 10,000 individuals (Filipek et al., 1999; Garnett & Atwood, 1997). The rate of ASD is 4 to 5 times higher in males than females, and females with this disorder tend to have more severe cognitive disability than males (Chez, 2008).

Diagnostically, the onset of ASD is before the age of 3 years, and researchers are hoping to diagnose this spectrum disorder by 18 months so that interventions can occur which may decrease the lifetime impact of this disorder (see Brewer Mueller, 2008; Ozonoff, Rogers, & Hendren, 2003; Simpson & Myles, 2007; Wahlberg, Obiakor, Burkhardt, & Rotatori, 2001). Familial patterns suggest that the probability of ASD is increasing within families (Lord et al., 2000).

Autistic Disorder

The DSM-IV-TR (APA, 2000) diagnostic criteria for autistic disorder is a total of six or more items from categories (1), (2), and (3) below, but there has to be at least two items from (1), and one item each from (2) and (3):

1. Qualitative impairment in social interactions, as demonstrated by at least two of the following:
   a. Marked impairment in the use of nonverbal behaviors,
   b. Lack of peer relationships that are developmentally appropriate for one's age,
   c. Lack of spontaneous sharing of enjoyment and interests with others,
   d. Lack of social or emotional reciprocity.
2. Qualitative impairments in communication as manifested by at least one of the following:
   a. Delayed or lack of spoken language,
   b. Marked impairment in ability to initiate or sustain a conversation with others,

   c. Repetitive or stereotyped use of language,
   d. Lack of developmentally appropriate make-believe play.
3. Restrictive repetitive and stereotyped forms of behavior, as manifested by at least one of the following:
   a. Preoccupation with at least one stereotyped pattern of interest,
   b. Inflexible adherence to nonfunctional routines or rituals,
   c. Stereotypes and repetitive motor mannerisms,
   d. Persistent preoccupation with parts of objects.

Rett's Disorder

Children with Rett's disorder have normal prenatal and perinatal development. The DSM-IV-TR (APA, 2000) describes the diagnostic features of Rett's disorder as the development of multiple specific deficits shortly after birth following a period of normal psychomotor development. In fact, child development is normal through the first 5 months of life. Even though at birth head circumference is normal, somewhere between 5 and 48 months, head growth decelerates. Between 5 and 30 months, there is a loss of hand skills and subsequently stereotyped hand movements resembling hand-wringing or hand washing occurs. Another feature of Rett's disorder is a diminished interest in the social environment; and like autism disorder, there is impairment in expressive and receptive language. An associated feature of Rett's disorder is severe or profound cognitive disability. In terms of prevalence, this disorder has only been reported with females. The course of development of Rett's is an onset prior to the age of 4 years and the duration is persistent and progressive. In terms of differential diagnosis, autism disorder, childhood disintegrative disorder, and Asperger's disorder are more common with males, whereas Rett's disorder has only been diagnosed in females.

Childhood Disintegrative Disorder

Childhood disintegrative disorder is characterized by a period of at least 2 years of normal development after birth followed by marked clinically significant loss of age acquired communication, socialization, play, adaptive, motor skills, and bowel and bladder control skills. Also, between approximately 2 and 10 years, the child has abnormalities of functioning in two of the following areas: social interactions; communication; and restrictive, repetitive, and stereotyped patterns of behavior, interests and activities, including motor stereotypies and mannerisms (DSM-IV-TR, 2000). Like Rett's disorder, childhood disintegrative disorder is correlated with severe cognitive disability. Unlike autism, disintegrative disorder is a rare disorder and like autism more males appear to be affected.

Asperger Disorder

The DSM-V-TR (APA, 2000) defines Asperger's disorder as impairment in social, occupational, and other areas of functioning, and unlike autistic disorder, there are no significant deficits in language acquisition. Very similar to autistic disorder, Asperger's disorder is defined as lack of social reciprocity, and eccentric and one-sided social interaction with others. Like other pervasive developmental disorders, the disorder is diagnosed at least five times more in males than females. The diagnostic criteria for this disorder are the following:

A. Qualitative impairment in social interactions with at least two of the following:
   1. Marked impairment in the use of nonverbal behaviors such as eye-to-eye contact, facial expressions, body postures, and other social interactions,
   2. Failure to develop age appropriate peer relationships with others,
   3. Lack of spontaneous enjoyment seeking activities with others,
   4. Lack of social and emotional reciprocity.

B. Restrictive repetitive and stereotypes patterns of behavior with at least one of the following:
   1. Preoccupation with one or more stereotyped patterns of interest,
   2. Inflexible adherence to nonfunctional routines or rituals,
   3. Stereotyped and repetitive motor mannerisms. For example, hand, finger, or body flapping,
   4. Preoccupation with parts of objects.

C. Significant impairment in social, occupational, and other areas of functioning.

D. No significant delays in language. For example, the child is able to use single words by age 2 years and phrases by age 3 years.

E. No significant delays in cognitive development.

F. Criteria not met for another specific pervasive developmental disorder.

Pervasive Developmental Disorder not Otherwise Specified (Including Atypical Autism)

Pervasive developmental disorder not otherwise specified is severe impairment in reciprocal social interactions with impairments in verbal and nonverbal skills and the presence of stereotyped behaviors (DSM-IV-TR, 2000). This diagnostic category includes atypical autism. In summary, this diagnosis is made when a child does not meet the criteria for a specific diagnosis of autism, but there are impairments in behaviors that relate to autism (see Chez, 2008; Volkmar, 2000; Yeargin-Allsop et al., 2003).

Even though there are no cures for ASD, early assessment and intervention are critical for favorable outcomes (Anderson, 2007; Chez, 2008; Handleman & Harris, 2008; Prelock, 2007). Experts recommend that effective intervention may involve between 20 and 40 h of speech, occupational, and maladaptive behavioral reduction programming per week (see Kearney, 2007; Ortiz, 2007; Sturmey & Fitzer, 2007). Often, these interventions are not covered by private insurance and the cost can be as expensive as $100,000 a year (Courchesne, Carper, & Akshoomoff, 2003; Dunlap & Foxe, 1999).

ASSESSING AND DIAGNOSING ASD

Wahlberg, Rotatori, Deisinger, and Burkhardt (2003) state that diagnosing ASD in young children is very difficult because their autistic behaviors can be exhibited by other children, even normal youngsters. Additionally, Burkhardt (2008) emphasized that ASD can exist with related diagnoses to the point that these other diagnoses are the ones that are first diagnosed rather than ASD. For example, Fig. 1 depicts a number of diagnoses (attention-deficit hyperactivity with joint attention problems, depression, mental retardation, anxiety, obsessive compulsive, and Tourettes) that can occur with ASD (Burkhardt, 2008).

Burkhardt and Rotatori (2008) stress that mental health professions tend to initially diagnose some children with mild ASD as oppositional defiant or attention-deficit hyperactivity disordered when first treated. Later, a diagnosis of depression or obsessive compulsive is made and finally ASD is diagnosed. According to Burkhardt, a survey of mental health professionals in Illinois revealed that five referrals can occur before children with ASD are accurately diagnosed. During the process of being treated for other related diagnoses before being diagnosed with ASD, these

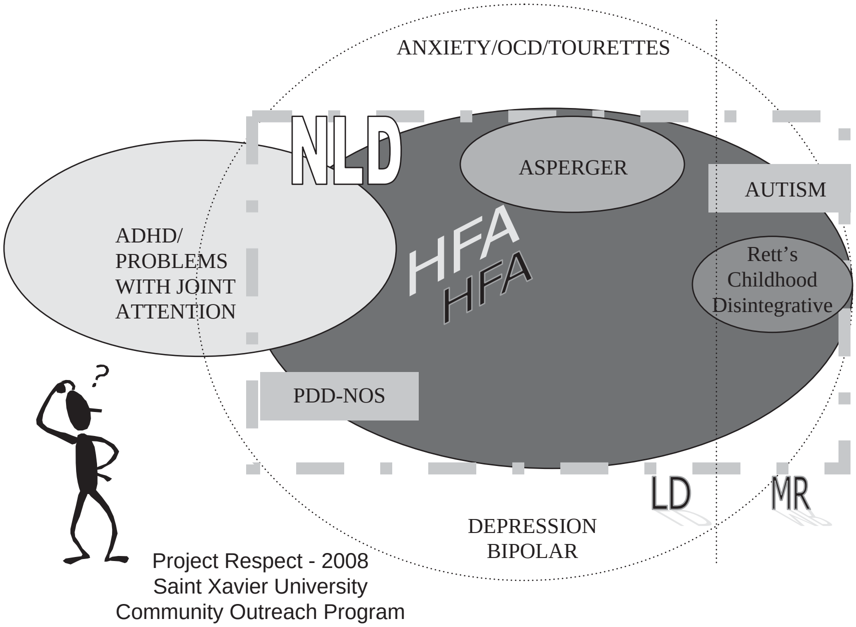

Fig. 1. Autism Spectrum Disorders and Related Diagnoses.

children may benefit from intervention practices and/or psychotropic medication, which reduce problematic symptoms (e.g., attention, hyperactivity, oppositional behavior, anxiety, and/or depression). With these related symptom reductions, the core symptoms of ASD may become more prominent, which leads to an accurate diagnosis of ASD (Burkhardt & Rotatori). Table 1 can be used by mental health professionals in the identification of ASD from other disorders beginning in childhood (Burkhardt, 2008). A review of the table indicates that the majority of children who are diagnosed with these childhood disorders exhibit social, affective, and sensory motor difficulties. The table also delineates the difference in language difficulties for those children diagnosed with ASD while emphasizing that the majority of children with other childhood disorders do not display language difficulties.

Assessment and diagnoses is typically carried out using procedures that include the following: screening, interviews, checklists and rating scales, profiles and observations (see Deisinger, 2001; Prelock, 2007; Wahlberg et al., 2001). In the section below a variety of these procedures is delineated.

Table 1. Comparison of Disorders Beginning in Childhood.

Condition	Areas of Developmental Difficulty		
	Language	Social-Emotional	Sensory-Motor
Autism[a]	Not before 2 years	Yes	Yes
High functioning autism (HFA)	Not before 2 years	Yes	Yes
Aspergers disorder[a]	Pragmatic	Yes	Yes
Pervasive developmental disorder-not otherwise specified (PDD-NOS)[a] (also atypical autism and nonverbal learning disability)	Pragmatic	Yes	Yes
Attention deficit hyperactivity disorder (ADHD)[a]		Yes	Hyper
Obsessive compulsive disorder (OCD)[a]		Yes	Repetitive
Tourette's[a]	Vocal tics		Motor tics

Source: Burkhardt (2008).
[a] A formal DSV-IV-TR diagnostic category.

Screening Procedures

Screening tests can be used to assess ASD. Instruments that have been developed for screening ASD include the following: Checklist of Autism in Toddlers (CHAT; Baird et al., 2000); the modified Checklist for Autism in Toddlers (M-CHAT; Robbins, Fein, Barton, & Green, 2001); the Screening Tool for Autism in Two-Year Olds (STAT; Stone, Coonrod, & Ousley, 2000); Evaluating Acquired Skills in Communication-Revised (EASIC-R; Riley, 1984); Pervasive Developmental Screening Test Stage-1 (PDDST; Siegel, 1998, cited in Filipek et al., 1999); Autism Screening Questionnaire (ASQ: Berument, Rutter, Lord, Rickles, & Bailey, 1999); High-Functioning Autism Spectrum Screening Questionnaire (ASSQ; Ehlers & Gillberg, 1993; Ehlers, Gillberg, & Wing, 1999); and the Australian Scale for Asperger's Syndrome (ASAS; Garnett & Attwood, 1997). Age ranges and evaluative areas of these instruments appear in Table 2.

A newly revised screening instrument is the Autism Screening Instrument for Educational Planning-Third Edition (ASIEP-3; Krug, Arick, & Almond, 2008). The ASIEP-3 is a valid and reliable measure to identify individuals

Table 2. Screening Devices for ASD.

Device	Age Areas	Range
Australian Scale for Asperger's Syndrome (ASAS; Garnett & Attwood, 1997)	6 to 11 years	Affect, social interactions, cognitive, and motor behaviors
Autism Screening Instrument For educational Planning-Third Edition (ASIEP-3; Krug, Arick, & Almond, 2008)	2–0 to13–11 years	Vocal behavior, social interaction, expressive, and receptive language
Autism Screening Questionnaire (ASQ; Berument, Rutter, Lord, Rickles, & Bailey, 1999)	up to 10 years	Reciprocal social interaction, communication, repetitive behaviors, play behaviors, behavioral problem
Checklist for Autism in Toddlers (CHAT; Baron-Cohen, Allen, & Gillberg, 1992)	18 to 30 months	Social play and interests, joint-attention, communicative pointing, and imitation
Evaluating Acquired Skills in Communication-Revised (EASIC-R; Riley, 1884)	3 to 30 months	Receptive and expressive language skills
High-Functioning Autism Spectrum Screening (ASSQ; Ehlers & Gillberg, 1993)	6 to 11 years	Literal interpretations of metaphors, restricted interests, social naivety, difficulties in peer relationships
Pervasive Developmental Screening Test-Stage-1 (PDDST; Siegel, 1998 cited in Filipek et al., 1999)	6 to 36 months	Behavioral regression, positive and negative ASD symptoms
Screening Test for Autism Two-Year-Olds (STAT; Stone, 1998 cited in Filipek et al., 1999)	24 to 30 months	Pretend and reciprocal play, imitation of movements, nonverbal communication

Source: Adapted and modified from Wahlberg, Rotatori, Deisinger, & Burkhardt (2003).

with autism as well as assist in planning appropriate educational programs for students with ASD. The manual provides instructional procedures for monitoring performance and progress as well as research endeavors. The ASIEP-3 has five assessment areas, namely Autism Behavior Checklist, Sample of Vocal Behavior, Interaction Assessment, Educational Assessment, and Prognosis of Learning Rate. This screening instrument covers normed data for individuals between the ages of 2-0 and 13-11 years. The normative data was collected from a demographic representative sample of the U.S. population. The ASIEP-3 provides standard and percentile ranks for the aged range 2-0 to 13-11 years.

Interview Procedures

If the screening evaluation reveals the need for further examination due to the presence of ASD characteristics as well as the documentation of the following red flags for ASD (see Ozonoff et al., 2003; Carter et al., 1998; Couper & Sampson, 2003; De Bildt, Kraijer, Systema, & Minderaa, 2005):

- Child does not respond to his or her name.
- Child acts as if he or she is deaf.
- Child does not smile at other children.
- Child does not use gestures such as point by 12 months.
- Child does not babble by 12 months or use words by 16 months.
- Child is able to talk, but does not communicate.
- Child loses social and communication skills.

a comprehensive structured interview should be carried out by a mental health professional. This interview should lead to information on the child's: prenatal and perinatal history; medical concerns during the first 24 months; the attainment of developmental milestones; occurrences of trauma, injuries, or accidents; any significant regression in attained verbal or motor skills; the presence of stereotypic behavior or unusual interests; and the identification of family members with ASD or mental retardation. There are two popular clinical-structured interview procedures that can assist a mental health professional in obtaining some of the above information, namely The Parent Interview for Autism (PIA; Stone & Hogan, 1993) and the Autism Diagnostic Interview-Revised (ADI-R; Lord, Rutter, & LeCouteur, 1994).

The PIA (Stone & Hogan, 1993) covers the following areas: social behaviors; communication abilities; and repetitive movements. It has 118 items that can be administered in 30–45 min. The PIA was not devised according to meet DSM-IV criteria but it is considered to have adequate psychometric properties (see Filipek et al., 1999).

The ADI-R (Lord et al., 1994) was constructed to meet DSM-IV criteria for ASD. It examines a child's characteristics in the following areas: communication abilities; social development; play behaviors; repetitive movements; and behavioral problems. The age range for the ADI-R is 18 months to adulthood. It takes more than an hour to administer. Special training in administration and scoring are needed to give this interview. The ADI-R is often used in research on ASD due to its good psychometric properties (see Filipek et al., 1999; McDougle, Stigler, & Posey, 2003; Ozonoff et al., 2003).

Checklists, Rating Scales, and Profiles

Since the 1980s, the number of checklists, rating scales, and profiles to identify symptoms of individuals with ASD has increased dramatically (see Deisinger, 2001; Ehlers et al., 1999; Ottenbacher et al., 1999; Scott, Baron-Cohen, Bolton, & Brayne, 2002; Tadevosyan-Leyter et al., 2003; Wahlberg et al., 2001). Table 3 delineates age ranges, content, and administration time for a variety of ASD checklists, ratings scales, and profiles. Three of these devices are discussed in more detail below.

The Gilliam Autism Rating Scale-Second Edition (GARS-2; Gilliam, 2006) is a norm-referenced device that can be used to identify and diagnose individuals with autism. The 42 test items were selected based on the definition of autism adopted by the Autism Society of America (2004) and the DSM-IV-R (APA, 2000). The items represent characteristic behaviors of persons with autism between the ages of 3-0 years and adulthood. The GARS-2 has three subscales, namely Stereotyped Behaviors, Communication and Social Interaction. It was normed on a representative sample of 1,107 persons with autism from 48 states keyed to the 2000 U.S. census data. The psychometric properties of the GARS-2 are strong and the manual reports a number of reliability and validity studies that demonstrate its effectiveness. Scoring of the GARS-2 leads to three subscale scores and an Autism Index score. A major feature of the GARS-2 is its ability to discriminate persons with autism from persons with other severe behavioral disorders, such as mental retardation. Another key feature of the GARS-2 is the reporting of multiple discrete target behaviors for each item. Each discrete behavior is operationally defined, and specific examples are provided for applied research projects and purposes. Lastly, the GARS-2 test kit includes a booklet that can be used to assist teachers and clinicians in the formulation of instructional goals and objectives based on the individual's subscale performances.

The Asperger Syndrome Diagnostic Scale (ASDS; Myles, Bock, & Simpson, 2001) can be used to identify whether an individual has Asperger Syndrome. This 50 yes/no item scale can be completed by parents, siblings, teachers, pareducators, clinicians, psychologists, and speech-language pathologists in 10–15 min. The ASDS has five major areas, namely, Cognitive, Maladaptive, Language, Social, and Sensorimotor. The items from each major area represent symptoms of Asperger Syndrome. It was normed on 115 individuals with Asperger Syndrome, autism, learning disabilities, behavior disorders, and attention-deficit/hyperactivity disorders from across the U.S. Scoring of the ASDS leads to percentile and standard scores in each major area as well as a total score or "AS Quotient". The AS Quotient has strong

Table 3. ASD Checklists, Rating Scales, and Profiles.

Device	Age Range	Content	Testing Time (Minutes)
Asperger Syndrome Diagnostic Scale (ASDS: Myles, Bock, & Simpson, 2001)	5 to 18 years	Social interactions, cognitive abilities, language, sensorimotor, maladaptive behaviors	10–15
Autism Behavior Checklists (ABC; Krug, Arick, & Almond, 1980, cited in Volkmar & Marans, 1999)	6 to 12 years	Sensory and relational symptoms, use of body and objects, language use, and self help abilities	15–25
Autism Diagnostic Observation Schedule (ADOS; Lord, Rutter, DiLavore, & Risi, 2002)	15 months to adults	Social interaction and communication	30–50
Autism Rating Scale (CARS; Schopler, Reichler, DeVellis, & Daly, 1988)	2 to adult	Social relationships, eye contact, stereotypic movements, resistance to change, echolalia, pronoun reversal	15
Children's Social Behavior Questionnaire (CSBQ; Luteijn, Luteijn, Jackson, Volkmar, & Minderaa, 2000)	6 to 12 years	Disruptive behaviors, social interactions problems, social cues, resistance to change, stereotypic behaviors	20–35
Gilliam Asperger Disorder Scale (GADS; Gilliam, 2001)	3 to 22 years	Developmental history, cognitive patterns, restricted behaviors, and pragmatic behaviors	5–10
Gilliam Autism Rating Scale-Second Edition (GARS-2; Gilliam, 2006)	3 to 22 years	Stereotyped behaviors, social interactions, communications, developmental disturbances	5–10
Asperger's Disorder Index (KADI; Krug, Arick, & Krug, 2003)	6 to 21 years	Distinguishes students with Asperger's disorder from students with high functioning autism	10–15
Revised Behavior Summarized Evaluation Scale (BSE-R; Barthelemy et al., 1997)	6 to 12 years	Social interactions, eye contact, communications, odd utterances and movements, resistance to change, mood difficulties, sleep disturbances	15–20
Psychoeducational Profile-Third Edition (Schopler, Lansing, & Reichler, 2005)	6 months to 7 years	Problem behaviors, personal self-care, adaptive behaviors, developing skills ASD behavior characteristic	45–90
TEACCH Transition Assessment Profile-Second Edition (TTAP-2; Mesibov, Thomas, Chapman, & Schopler, 2007)	8 to adult	Vocational skills, leisure skills, vocational behavior, independent functioning, functional communication, interpersonal behavior	180–210

Source: Adapted and modified from Wahlberg et al. (2003).

diagnostic meaning and is the one used by mental health professionals to determine the likelihood of the syndrome. A valid administration of the ASDS is based on the examiner knowing the examinee well based on regular, sustained contact with the examinee for at least 2 weeks.

The Psychoeducational Profile-Third Edition (PEP-3; Schopler, Lansing, & Reichler, 2005) can be used to assess the skills and behaviors of children with autism and communicative disabilities. Administration of the PEP-3 results in a profile of uneven and idiosyncratic development, emerging skills, and autistic behavioral characteristics.

According to the manual, normative data were collected from 2002 to 2003, with large national samples of children in the ASD and typical children ranging in age from 2 to 7.5 years. The PEP-3 scoring has been quantified as 0, 1, and 2 with each score clearly defined, which leads to more accurate statistical comparisons. The PEP-3 can be very helpful in assisting early childhood teaches in assessing adaptive, communication, and developing skills in youngsters 3–5 years of age as well as planning for older students' Individualized Education Programs (IEPS). Added to the third edition of the PEP is a "Caregiver Report" which provides teachers and parents with critical information on a child's current developmental levels, diagnostic categories, and degree of problems in three areas, namely problem behaviors, personal self-care, and adaptive behavior.

The Autism Diagnostic Observation Schedule (ADOS; Lord, Rutter, DiLavore, & Risi, 2002) is a standardized observational schedule that gathers information to assist mental health professionals in the diagnosis of autism. The ADOS is standardized by: tasks and activities; materials; behavior of the examiner; behaviors to be covered; how the individual's behavior are quantified; how diagnosis is achieved; training of examiner; and the standards for achieving and maintaining reliability (see Hanson, 2005). It has three major areas, namely social behavior, use of vocalizations/speech and gestures in social situations, and play/interests. The ADOS has four modules. Module One is used with nonverbal children while Module Two is used with children who have verbal skills, but are not verbally fluent to communicate with the examiner. Module Three is chosen when the child is verbally fluent to communicate well with the examiner. Lastly, Module Four is appropriate for verbally fluent adolescents and adults. Each module has a diagnostic algorithm which allows classification of participants as having the social and communicative deficits of ASD. According to Hanson, the ADOS targets tasks that differentiate behaviors associated with ASDs across developmental levels and ages, however, it does not provide information on cognitive ability and should be considered as one source of information for the diagnosis of ASD. A shortcoming of the ADOS is that it does not offer an adequate opportunity to measure restricted and repetitive behaviors, but these behaviors can be coded if they occur spontaneously during the observation period (Hanson). Another concern is that it does not include information about onset or early history of characteristics which is necessary for a DSM-IV-R (APA, 2000) diagnosis of ASD (Hanson). Lastly, while the ADOS was constructed to elicit behavior in a standardized context, it should not be used by mental health professionals to assess change over time or to document responses to treatment or developmental gains (Hanson).

CASE STUDY

Background Information

Willie is an 11-year-old African-American male who is small for his age. He was referred for evaluation due to school and home behavioral problems, which included impulsivity and temper tantrums. This junior high youngster lives with his parents and an 8-year-old brother. Willie's father is an accountant and his mother works part time as a librarian. According to his parents, Willie was born after a normal pregnancy, however, his mother did experience some bleeding at the beginning of her pregnancy but once she stopped working and took things easier, the bleeding stopped. His developmental milestones included the following: sat up at 7 months, walked at 13 months, said his first words at 10 months, finger feed himself at 24 months, talked in short sentences at 24 months, and was toilet trained at 36 months. The parents reported that Willie had a number of injuries, which required emergency room visits due to accidents (falling off a wagon, falling down the stairs). The accidents appeared to be related to Willie's lack of caution, impulsivity, and clumsiness. Presently, he is receiving medication (Concerta) for his hyperactivity and impulsivity. Willie has been on medication for the past 3 years. Willie is able to fed, toilet, dress, and bathe himself independently. His parents indicated that his adaptive skills are age appropriate except for socializing with children of his age.

Parent Interview

The major behavioral difficulty reported by his parents was Willie's temper tantrums. His temper tantrums occur when he does not get his way or when he plays with other children. According to his father, Willie has a hard time getting along with others and can become angry and explosive with frequent crying spells. His play with others is immature and he does not seem to realize what the children are interested in doing. He does not have any friends of his age. He prefers to play with younger children who he can direct and dominate in play. If challenged by peers, Willie becomes tense and angry. In general, his parents reported that Willie's socialization with others is poor as he tends to be very self-centered. Additionally, he may say things to others that are negative, insulting, or inappropriate. Also, Willie does not establish eye contact when he interacts with others. In fact, his mother stated that her son has rarely established eye contact with her or his dad.

His father reported that Willie has a history of engaging in impulsive actions which put him into harms way. These include the following: running out into the parking lot after leaving a restaurant at night, jumping down the basement stairs, climbing on furniture, throwing small toys into a moving fan, walking his bike down the basement stairs, opening the car door when it was moving, putting small objects up his nose, putting coins into his month and sucking on them, and climbing on chairs to reach objects in the cupboards. Additionally, Willie has the following peculiar behaviors: enjoys shredding papers, constantly asking for and removing band aids, becomes upset when liquids are spilled, does not like to see specks of dust on furniture or floor, arranges his model cars in a fixed order and becomes upset if his mother changes the order when she dusts, enjoys spinning himself around, when playing with toy cars he spins then around endlessly, twirls his fingers and steers at them, is obsessed with the "Star Wars" movies and the "Wheel of Fortune" television show, and frequently repeats lines from the Star Wars movies over and over again. Also, he is overly interested in fans, trains, and vacuum cleaners. In fact he will look at spinning fans for up to an hour or ask to go down to the train station to observe the commuter trains arriving and leaving. His parents related that Willie likes things to be the same and not change. For example, he has a certain routine that he sticks to. One is the type of food that he eats. He eats a very restricted diet and limits his food choices. In fact, he almost has a "food fetish" (e.g., tuna fish, pizza, tomato soup, chocolate milk, bagels and cream cheese, and oranges). In addition, he prefers to wear the same tennis shoes, only light blue jeans, Star Wars tee shirts, white loose fitting athletic socks, and a Mickey Mouse hat. Lastly, Willie experiences tension and stress when he has to make transitions even small ones such as going to church services earlier in the morning or having his tutor come later in the day.

Clinical Interview

Willie entered the interview room with some hesitation. He examined the room carefully and went over to the computer and then sat down. Willie answered correctly questions related to his age, address, home phone, school, current school subjects, daily activities, hobbies, and special interests, but his responses tended to be delayed and only occurred after he exhausted a topic of interest to him. On three occasions, Willie stood up and walked around and examined toys in the room. When asked about his favorite television shows or movies, Willie went into an in-depth description about the Star Wars movies, naming each one and the theme of each. When conversing with the clinician, he did not establish eye contact. Throughout, Willie appeared anxious and his affect was flat. He was guarded in his conversation. Willie became lively when he conversed about his toy car collection after looking at one in the examiner's toy area. At no time did Willie interact in a reciprocal social manner. Willie indicated that he has a difficult time getting along with children in his class. He stated he does not have school friends. Willie related that most of the kids in his class were "jerks". He informed me that he likes to stay at home and play video games by himself but sometimes he plays video games with an 8-year-old neighborhood boy. This youngster stated that he has difficulty getting along with his brother and brother's friends because they annoy me and "hog" my video games.

Academic History

School reports indicate that Willie has had behavioral difficulty in school from the beginning. For example, he experienced problems with attention, staying on task, and completing his work. Psychological testing in second grade indicated that Willie was achieving at a high average range in reading and spelling but at a low average grade in math. An adaptive behavior evaluation concluded that Willie rarely initiated social interaction with adults and his social interactions with peers tended to be immature, odd, and silly. Also, during group discussions, Willie tries to make funny comments but his teachers commented that his remarks were "off the wall". Lastly, Willie would get overly frustrated when his peers teased him, criticized his performance or did not include him in their play. These situations have led to "mini melt downs" (e.g., whining, crying, and expressions of sadness). Finally, with changes in school day routines, Willie has exhibited tenseness, increased off task behavior, and hyperactivity.

Intelligence

Willie was administered the Wechsler Intelligence Scale for Children-Fourth Edition (WISC-IV) to assess his present cognitive functioning level. This youngster attained a Verbal IQ of 110, a Performance IQ of 115, and a Full Scale IQ of 113. These score place Willie in the high average range of intelligence. His verbal subtests scaled scores were somewhat uneven as he had high subtest scaled scores on Vocabulary (15) and Similarities (14) and lower scores on Arithmetic (8) and Digit Span (8) In contrast, his subtest scaled scores on the Performance subtests were very even except for a lower subtest scaled score on Picture Arrangement (7). The lower scores on Arithmetic and Digit Span tends to be more common among students with attention and anxiety deficits. The Picture Arrangement subtest is considered a measure of ones ability to evaluate the social relevance of pictured situations and to anticipate the consequences of actions and to distinguish essential from irrelevant details. Furthermore, this subtest is sometimes considered a measure of ones planning ability.

ASD Test Evaluation

The examiner administered the Autism Diagnostic Observation Schedule Module 3 for Students who are verbally fluent. Willie's ratings follow:

Communication	Score
Stereotypic/Idiosyncratic use of words or phrases	1
Reporting of events	1
Conversation	1
Descriptive, conventional, instrumental, or informational gestures	2
Communication Total =	5[a]
Reciprocal Social Interaction	
Unusual eye contact	1
Facial expression directed to others	1
Insight	1
Quality of social overtures	2
Quality of social response	1
Amount of reciprocal social communication	1

Overall quality of rapport	1
Social Interaction Total = 8[a]	
Communication + Social Interaction Total = 13[a]	
Imagination/Creativity	1
Stereotyped Behaviors and Restricted Interests	
Unusual sensory interest in play materials/person	0
Hand and finger and other complex mannerisms	1
Excessive interest in unusual or highly specific topics or objects	1
Compulsion or rituals	2
Stereotyped Behaviors and Restricted Interests Total = 4	

[a] Meets Autism cut off.

Social-Emotional Status

Willie has difficulty understanding the social relevance and themes of common social encounters. Many times he takes a self-centered approach in his interactions with others. Willie will dominate the conversation with his interests while ignoring the topics or even questions of others. He prefers to direct the flow and topic of discussion but will address questions to him if required. However, his response to these questions may be delayed and typically occur after he has thoroughly covered a topic. Willie has a strong preference for routine and he will experience distress with deviations. Transitions even minor ones can be challenging and difficult for him to handle. Even when Willie meets routine daily challenges from classroom assignments, he is likely to experience stress and anxiety. When he is faced with new, unpredictable, or unexpected social challenges, Willie may be easily throw into "overload" which may lead to intense distraction, off task behavior, hyperactivity, "zoning out", and an "emotional melt down" (crying, outburst of anger, ruminating thoughts). Willie does not typically reveal his stress through voice tone or body posture. Thus, his level of agitation may go unnoticed by others and lead to a point of crisis and extreme emotional overload.

Willie has pragmatic language skills deficits. These deficits interfere in daily social interactions with peers and adults. His conversation with others tends to be one sided. At times his conversation may include "unusual response" such as playing off words from a Star Wars movie. He lacks awareness of social protocol, misinterprets social cues, and is emotionally blunt. Willie exhibits a lack of empathy with others and is primarily at the egocentric stage of social development.

Case Study Conclusion

Willie meets the DSM-IV-R Diagnostic Criteria for Asperger syndrome as he demonstrates: (a) significant social interactional impairment in – nonverbal behavior use (lack of social interactional gestures, eye contact), difficulty with social and emotional reciprocity, and an inability to form developmentally appropriate relationships with peers; (b) repetitive and restricted patterns of interest and routines – preoccupation with Star Wars, strict adherence to daily routines of living, has difficulties with transitions; (c) clinically significant social impairment in functioning; (d) absence of a clinically significant language delay; (e) absence of a clinically significant delay in cognitive development or age appropriate adaptive behavior (other than social interaction), self-help skills, and childhood curiosity about the environment; and (f) does not meet diagnostic criteria for schizophrenia or another pervasive developmental disorder.

SUMMARY

This chapter discussed the intricacies in assessing ASD. This can be especially intriguing within a multicultural context because minority students are seldom a part of standardization samples for educational tests (see Dyches, Wilder, Sudweeks, Obiakor, & Algozzine, 2004). As indicated, ASD are developmental disorders with neurological origins that are present at birth. These disorders tend to be life-long and affect one's social skills, communication skills, and repertoires of behaviors throughout life. Generally, mental health professionals are able to detect these disorders by age 3 years.

There are many instruments that can aid the assessment of ASD, and the number of new devices is increasing. The ADI-R (Lord et al., 1994) is the gold standard for assessing ASD, but it is a lengthy interview to administer. Learners with ASD tend to need very structured and specialized programs. It is critical to note that applied behavior analysis (ABA) (Lovaas, 1987) is an evidence-based treatment that has been recommended for ASD (Autism Society of America, 2004). ABA demonstrates the relationship between behavior and the environment (see Sturmey & Fitzer, 2007; Sapp, 2004). For example, how does a child with autism behavior change as a result of environmental events? Moreover, the term "applied" suggests that events can have social importance, and behaviors are the things that we do. To ameliorate problems associated with ASD, the Autism Society of American (2004) recommends intensive behavior therapy, one-on-one for at least 25–40 h a week, based on ABA principles (see McEachin, Smith, & Lovaas, 1993). Finally, ASD have to be assessed across a broad developmental perspective, and interventions must be adapted based on individual characteristics such as strengths, weaknesses, and culture.

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RECENT DEVELOPMENTS IN THE DIAGNOSIS AND ASSESSMENT OF AUTISM SPECTRUM DISORDERS

Julie A. Deisinger

INTRODUCTION

According to current estimates, the prevalence of autism spectrum disorders (ASDs) ranges from 1 in 500 children to 1 in 150 children (Centers for Disease Control and Prevention/CDC, 2007; Desmon, 2007). In the past such disorders usually were not identified until a child was school-aged, but these disorders are now more likely to be diagnosed in affected individuals during the preschool years (McConachie, Le Couteur, & Honey, 2005; Rutter, 2006). For example, Mandell, Novak, and Zubritsky (2005) surveyed over 900 caregivers of children with ASDs and learned that on an average, children with autistic disorder were diagnosed at 3.1 years of age. These researchers also reported that children who exhibited such characteristics as severe language impairment, toe walking, hand flapping, and sustained unusual play behaviors were diagnosed earlier than children without these features.

However, delays in the accurate diagnosis of ASDs still are common (Dosreis, Weiner, Johnson, & Newschaffer, 2006), particularly when there are no accompanying intellectual deficits (Rutter, 2006). A study by

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Wiggins, Baio, and Rice (2006) reported that children with more severe impairments (such as those with autistic disorder) tended to be evaluated sooner than children with milder deficits (such as those with Asperger's disorder). Another study (Mandell et al., 2005) found that among a sample of participants with ASDs, children with Pervasive Developmental Disorder Not Otherwise Specified (PDD-NOS) typically were not diagnosed until almost four years of age, and children with Asperger's disorder usually went undiagnosed until over seven years of age.

Beyond the type of ASD that a child may have, other factors that were associated with delayed diagnosis included living in a rural community, near-poor family income status, impaired hearing, oversensitivity to pain, and having many pediatric healthcare providers. Mandell and colleagues (2005) found that children with ASDs from low-income families tended to be diagnosed almost 11 months later than children from families with adequate financial resources. They speculated that this finding might have been due to inadequate health insurance coverage for near-poor families, which would limit their access to diagnostic services. Similarly, children living in rural areas might be diagnosed later because they have less access to both routine and specialized healthcare. The presence of hearing impairment delayed identification of ASDs by almost 10 months, due to the increased complexity of the diagnostic process in such cases. Children's oversensitivity to pain also impeded early diagnosis because such symptoms seem to suggest the presence of medical rather than developmental causes. In addition, children who were evaluated by four or more primary care physicians tended to be diagnosed six months later than children whose pediatricians referred them for specialized developmental evaluations (Mandell et al., 2005).

Additional variables that may affect the initial assignment of an ASD diagnosis are the evaluation site and the professional training of the evaluator. An investigation by Wiggins et al. (2006) involved a sample of 114 children in the Atlanta, Georgia metropolitan area. These researchers found that children with an ASD who were initially identified at a non-school source such as a hospital, clinic, or private practice were diagnosed significantly earlier than children whose initial diagnosis was made in a school setting. They also discovered that almost one-third of the initial ASD diagnoses in their sample were made by psychologists who held the Doctor of Philosophy (PhD) degree. Neurologists and developmental pediatricians were the professionals next most likely to make an initial ASD diagnosis. Psychiatrists accounted for approximately 12% of the initial diagnoses, and other professionals such as psychologists with the Doctor of Education

(EdD) degree accounted for roughly 10% of initial diagnoses (Wiggins et al., 2006).

Delayed identification of ASDs is a significant cause for concern due to the loss of time that could be spent on early intervention. Previously physicians often counseled parents to wait and see if children with developmental delays would outgrow their symptoms (Desmon, 2007); however, this approach is misguided because it delays the onset of treatment. Early treatment usually improves the long-term prognosis for a child with ASD, and treatment gains typically become smaller as the child's age increases (Mandell et al., 2005; Wiggins et al., 2006). For these reasons, researchers currently are seeking better methods for the early, accurate identification of ASDs. This chapter will describe recent innovations in the diagnosis and assessment of ASDs, including updates about established measures of ASDs, alternative diagnostic criteria for Asperger's disorder, the use of home movies and videotapes as diagnostic aids, and screening for ASD in adults using a personality self-report. New assessment instruments and medical tests that show promise as diagnostic tools also will be discussed.

UPDATES ABOUT ESTABLISHED ASD MEASURES

The Autism Diagnostic Interview-Revised (ADI-R; Rutter, LeCouteur, & Lord, 2003) and the Autism Diagnostic Observation Schedule (ADOS; Lord, Rutter, DiLavore, & Risi, 1999) are considered "the instruments of choice for the diagnosis of autism" (Tomanik, Pearson, Loveland, Lane, & Shaw, 2007, p. 922). The ADI-R consists of a parent interview to gather information about a child's developmental history with regard to communication, social interaction, and repetitive behaviors (Chawarska, Klin, Paul, & Volkmar, 2007; Tomanik et al., 2007). Its companion instrument, the ADOS, is an interactive test that provides opportunities to evaluate ASD symptoms related to communication, social interaction, play, repetitive behaviors, and unusual interests (Tomanik et al., 2007). The ADI-R and ADOS "are among the most reliable diagnostic instruments for autism available" (Tomanik et al., 2007, p. 926). However, several recent studies have recommended ways to improve the use of these measures.

A limitation of the ADOS is that it cannot be used with non-verbal adolescents and adults whose intellectual functioning falls within the range of severe to profound mental retardation (Berument et al., 2005). To address this problem, Berument and associates (2005) developed a modified form of the instrument called the Adapted Pre-linguistic Autism Diagnostic Observation Schedule (A-PL-ADOS). This revised measure incorporates activities similar to those currently found in modules 1 and 2 of the present ADOS, such as tasks to evaluate joint attention, imitation, and social interaction. However, it has eliminated tasks that involve language skills, as well as situations that pertain to preschoolers but not to teenagers and adults, such as snack time and an imaginary birthday party. Based on their pilot study, Berument et al. (2005) reported that the A-PL-ADOS shows potential as a method to distinguish cognitively impaired individuals with ASDs from those with mental retardation but no ASDs.

Mazefsky and Oswald (2006) identified a limitation common to both the ADOS and the ADI-R. These authors evaluated 78 youngsters with ASDs who ranged in age from 22 months to 8 years old and found that in comparison to clinical diagnoses, use of the ADI-R and ADOS tended to produce more diagnoses of autism, as opposed to other forms of ASD. They stated that further research on the ADI-R and the ADOS is needed concerning the ability of these instruments to differentiate children with ASDs other than autism.

Risi et al. (2006) also explored the utility of the ADI-R and ADOS for diagnosing autism and other ASDs. Upon examining ADI-R and ADOS data from over 1,500 participants, they reported sensitivities and specificities of 75%–80% or higher when data from both instruments were combined. The sensitivity of a test refers to its ability to detect actual cases of a disorder, while specificity reflects a test's ability to correctly identify individuals who are not at risk for having the disorder (Coonrod & Stone, 2005). Generally accepted levels of sensitivity are 80% or higher, and specificity should be in the range of 80% to over 90% (Coonrod & Stone, 2005). Risi and associates (2006) reported that specificity declined significantly when either the ADI-R or the ADOS was used by itself. These authors also stated that the specificity of these measures was poor when evaluating individuals with profound mental retardation, and that both sensitivity and specificity were lower when attempting to identify non-autism ASDs.

In still another investigation of these issues, Ventola et al. (2006) compared diagnoses obtained from the ADI-R and ADOS to diagnoses that were derived either on the basis of clinical judgment or through use of a screening instrument called the Childhood Autism Rating Scale (CARS; Schopler, Reichler, & Renner, 1980). They discovered that diagnoses from the ADOS, clinical judgment, and CARS were in agreement, but these differed from the diagnoses indicated by the ADI-R. As noted by Ventola and colleagues (2006), toddlers with ASDs often are misclassified by the ADI-R as not having autism, because young children with ASDs may not demonstrate restrictive interests and stereotyped behaviors. They suggested that the ADI-R should be revised to allow for a possible diagnosis of PDD-NOS, and stated that such a change would improve the ability of the ADI-R to properly identify toddlers with ASDs (Ventola et al., 2006).

A 2007 study by Chawarska et al. expressed concerns about the validity of the ADI-R for diagnosing children with a mental age of less than two years. These authors found that the ADI-R may over-diagnose non-verbal children who have deficits in social communication and mental ages of less than 18 months, while under-diagnosing children with better verbal and social skills. Chawarska et al. (2007) reported that the sensitivity of the ADI-R can be improved by lowering the cut-off score for Stereotyped Behaviors (ADI-SB); thus, the test will be more likely to detect children who are at risk for having ASDs (Coonrod & Stone, 2005). However, lowering the ADI-SB cut-off score has the unfortunate effect of reducing the specificity of the ADI-R (Chawarska et al., 2007), meaning that more individuals without ASDs will be mistakenly identified as at risk for having an ASD (Coonrod & Stone, 2005). Chawarska and colleagues (2007) recommended that the cut-off points for the ADI-R should be studied further and modified to make them more appropriate for use with younger children. They also stated that the ADOS is more sensitive than the ADI-R for detecting ASDs in infants.

Improving the sensitivity and specificity of the ADOS also was the focus of research by Gotham, Risi, Pickles, and Lord (2007). These authors sought to modify ADOS scoring algorithms, which combine scores from various testing tasks to determine whether or not children meet criteria for having an ASD. They revised their scoring procedures by adding new domains to measure social affect and repetitive behaviors. As a result of these changes, Gotham et al. (2007) were able to slightly increase the ADOS's ability to detect ASDs other than autism in non-verbal toddlers and in children with only phrase speech capabilities.

According to Tomanik et al. (2007), the reliability of ASD diagnoses obtained through the use of the ADI-R and ADOS can be enhanced by including data from the Vineland Adaptive Behavior Scales. In this study, 129 child and adolescent participants underwent evaluation with the ADI-R and the ADOS. Comparison of diagnostic information from these two measures revealed that 75% of participants received the same classification from both the ADI-R and the ADOS. Adding information from the Vineland scales to the classification process increased diagnostic accuracy by another 9% (i.e., up to 84%). Therefore, Tomanik et al. (2007) suggested that clinicians may wish to add the Vineland Scales as a component of an ASD evaluation, because doing so may improve diagnostic accuracy.

Finally, a 2007 study by Klein-Tasman, Risi, and Lord highlighted the importance of administering the correct module of the ADOS in order to increase diagnostic accuracy. Clinicians must select the appropriate module of the ADOS to administer, based on a client's level of expressive language. Module 1 is intended for individuals who are non-verbal or whose expressive abilities are limited to simple phrases. Module 2 is given when the test-taker's language ability ranges from three-word phrases to fluent speech, and Module 3 is administered to children with fluent speech (Klein-Tasman, Risi, & Lord, 2007). Results of this investigation showed that failure to administer the proper ADOS module produced classification errors. Administering a module that is too easy leads to under-classification of ASDs, while administering a module that is too difficult creates an impression of greater impairment than is actually the case. Klein-Tasman et al. (2007) suggested that when uncertainty exists about a child's level of expressive language, the clinician should administer both the easier and the more difficult ADOS module. Such a procedure should not be standard practice because it lengthens the time needed for test administration; however, it may lead to more accurate classification of an ASD (Klein-Tasman et al., 2007).

Recent investigations of the ADI-R and the ADOS have demonstrated that even when using well-designed instruments for the assessment of ASDs, diagnostic errors can occur. Therefore, these measures should be viewed as components of a multi-faceted evaluation. The diagnostic process should take findings from the ADI-R and the ADOS into consideration but also must include other sources of information such as parent reports, behavioral observations, and data from other assessment instruments (Klein-Tasman et al., 2007; Klin, Saulnier, Tsatsanis, & Volkmar, 2005).

ALTERNATIVE DIAGNOSTIC CRITERIA FOR ASPERGER'S DISORDER

Asperger's disorder is a relatively new addition to the group of pervasive developmental disorders listed in the *Diagnostic and Statistical Manual of Mental Disorders* (*DSM*), having been included in this classification system since 1994 (Klin, Pauls, Schultz, & Volkmar, 2005). As noted earlier, Asperger's disorder often is diagnosed several years later than other types of ASDs. According to McConachie et al. (2005), delays in the identification of Asperger's disorder may be partly a function of the diagnostic criteria used to define this condition. These criteria specify that language delays and cognitive deficits cannot be apparent, and they require the presence of age-appropriate adaptive skills and curiosity. Children who can use language to communicate, who have at least average intellectual ability, and who demonstrate self-help behaviors that are expected for their age level may not appear to have any disorders, particularly during the years before they are subjected to the social demands of a school setting. McConachie and colleagues (2005) hypothesized that parental reports of a child's repetitive behaviors and other problems such as hyperactivity and sleep disturbances may be more important as early markers for the identification of Asperger's disorder in toddlers.

The diagnostic criteria for Asperger's disorder that are most commonly used by mental health professionals in the United States are those originally published in the 4th edition of the *Diagnostic and Statistical Manual of Mental Disorders* (*DSM-IV*; American Psychiatric Association, 1994). However, three other sets of diagnostic criteria for Asperger's disorder also exist. One alternative set of criteria can be found in the 10th edition of the International Classification of Diseases (ICD-10; World Health Organization/WHO, 1993). The other two sets of diagnostic criteria were developed by researchers who have studied Asperger's disorder in depth: Gillberg and Gillberg (1989) and Szatmari, Bremner, and Nagy (1989).

A 2007 study by Mattila et al. compared these four sets of diagnostic criteria and identified similarities and differences among them. All four criterion sets included the presence of impaired social abilities and suggested that lack of empathy and lack of sharing could be indicators of Asperger's disorder. Mattila et al. (2007) also noted that none of the diagnostic criteria included mention of unusual responses to sensory stimuli, despite anecdotal information suggesting that sensory issues are associated with Asperger's disorders. In all other respects, however, these criterion sets differed. For example, only the Szatmari et al. (1989) criteria specified a lack of friendships as a criterion for Asperger's disorder. Also, both the ICD-10 and *DSM-IV* criteria stated that delays in cognitive development and adaptive behavior are not present among individuals with Asperger's disorder, whereas Gillberg and Gillberg (1989) and Szatmari et al. (1989) did not define criteria with regard to cognitive development or adaptive skills (Mattila et al., 2007).

Concerning language development, both the ICD-10 and *DSM-IV* criteria excluded speech delays. Gillberg and Gillberg (1989) did allow for the possible presence of speech delays, while Szatmari et al. (1989) did not include this criterion. Other differences among the four criterion sets with regard to speech involved pedantic language, unusual prosody, literal interpretations of language, repetitive speech, and unusual word usage. The ICD-10 and *DSM-IV* criteria did not include any of these characteristics as diagnostic indicators. However, both Gillberg and Gillberg (1989) and Szatmari et al. (1989) included odd prosody as a possible diagnostic criterion for Asperger's disorder. The criteria by Gillberg and Gillberg (1989) also allowed for the possible presence of excessively formal speech and misinterpreted language as diagnostic markers, while the Szatmari et al. (1989) criteria did not include these. Instead, Szatmari et al. (1989) included the use of repetitive speech and idiosyncratic words as diagnostic indicators (Mattila et al., 2007).

With regard to repetitive behaviors, all but the Szatmari et al. (1989) criteria included this feature as a diagnostic indicator of Asperger's disorder. Yet there were differences in the four criterion sets concerning the nature of the repetitive behavior. For example, both ICD-10 and the *DSM-IV-TR* allowed for the possible presence of unusually intense interests, behavioral rituals, repetitive mannerisms, and preoccupations with parts of objects, while none of these characteristics were included among the Szatmari et al. (1989) criteria. Repetitious mannerisms and preoccupations with parts of objects also were not mentioned by Gillberg and Gillberg (1989), but their criterion set stated that intense interests and behavioral routines were definite indicators of Asperger's disorder (Mattila et al., 2007).

Gillberg and Gillberg (1989) also were the only authors to include physical clumsiness as a diagnostic criterion for Asperger's disorder, although ICD-10 did allow this feature as a possible indicator. ICD-10 further stated that it is common for individuals with Asperger's disorder to have isolated special skills, while none of the other three criterion sets included this characteristic. Only the *DSM-IV* specified that symptoms of Asperger's disorder must result in clinically significant impairment in functioning. Finally, all of the criterion sets except for Gillberg and Gillberg (1989) specified that autistic disorder had to be excluded before a diagnosis of Asperger's disorder could be assigned (Mattila et al., 2007).

Mattila et al. (2007) employed these four criterion sets to conduct an epidemiological study of Asperger's disorder among school-aged children in Finland, using both parents and teachers as informants about the children's symptoms. They found differing prevalence rates depending on the set of diagnostic criteria used, with the ICD-10 criteria yielding the highest prevalence rate of 2.9 per 1,000. Prevalence rates based on the *DSM-IV* and Gillberg and Gillberg (1989) criteria were 2.5 per 1,000 and 2.7 per 1,000, respectively. The Szatmari et al. (1989) criteria produced the lowest prevalence rate of 1.6 per 1,000.

On the basis of their findings, Mattila et al. (2007) concluded that the diagnostic criteria for Asperger's disorder need to be re-evaluated due to inconsistencies among the four criterion sets concerning the types of symptoms required for diagnosis. The authors recommended that the *DSM-IV* criterion of clinically significant impairment in functioning should be retained in future revisions of the diagnostic criteria, and they highlighted the need for clinicians to obtain continuing education in order to increase the likelihood that cases of Asperger's disorder will be correctly identified. Mattila et al. (2007) also noted that females with Asperger's disorder may be under-diagnosed, and they emphasized that clinicians should seek information about a child's symptoms from teachers as well as parents. The importance of teacher input was based on teachers' interactions with large groups of children, thereby enabling them to notice abnormalities more easily than parents. Furthermore, because the etiology of Asperger's disorder is related to genetic makeup, the possibility exists that parents themselves may have characteristics of Asperger's disorder which may interfere with their ability to detect subtle peculiarities in their own children's behavior (Mattila et al., 2007).

HOME MOVIES AND VIDEOTAPES AS AIDS TO EARLY IDENTIFICATION OF ASD

Because ASDs often go undetected until a child is three years of age or older, and because early intervention tends to produce better outcomes for affected children, researchers are now seeking ways to identify ASD in early childhood (Werner, Dawson, Osterling, & Dinno, 2000). One potential way to achieve early identification of ASD is through the use of home movies and videotapes (Palomo, Belinchon, & Ozonoff, 2006; Volkmar, Chawarska, & Klin, 2005; Werner et al., 2000; Werner & Dawson, 2005).

Some types of diagnostic information may be difficult to obtain from home movies. As noted by Trillingsgaard, Sorensen, Nemec, and Jorgensen (2005), eye contact may be hard to assess in this manner, and episodes of challenging behavior are seldom captured on videotape. However, the analysis of behavioral data from videotapes and home movies also offers several advantages as a method for the early identification of ASDs. First, these sources provide information regarding children's early behavior that is independent of parental reports about ASD symptoms (Trillingsgaard et al. 2005). Retrospective information obtained from parent interviews may be adversely influenced by parents' knowledge of the diagnoses that their children later received (Palomo et al., 2006). Parental reports also might be compromised due to inadequate recall about their children's early behaviors, as well as parents' potential difficulties in noticing subtle symptoms that might be more readily apparent to clinicians (Palomo et al., 2006). The use of home movies and videotapes avoids these problems because symptoms that are observable on film or videotape can be coded by raters who are blind to the diagnoses of the children being rated (Werner et al., 2000). Another advantage of using home movies and videotapes to detect ASD in early childhood is that this method circumvents the need for large samples in which to find infants and toddlers with ASD characteristics. Still another benefit of this approach is that it can be used to study changes in behavior across time (Palomo et al., 2006).

According to an overview by Palomo et al. (2006), the use of home movies to study children with autism began during the 1970s and 1980s. These early studies were noteworthy because they supported a shift away from psychodynamic explanations of autism, focusing instead on cognitive and developmental perspectives. However, early studies often provided scant diagnostic information due to methodological limitations. To overcome these problems, Palomo and colleagues (2006) located eight well-designed research studies involving the use of home movies or videotapes. These eight studies, which were published between 1994 and 2005, included the use of comparison groups and behavioral coding systems as well as evidence of sufficient inter-rater reliability.

Palomo et al.'s (2006) review of these eight home movie analyses described behaviors that distinguished children with ASD from typically developing youngsters, and from children with other types of developmental delays such as mental retardation. According to their findings, one-year-old children with autism could be differentiated from both neurotypical children and children with mental retardation because children with autism showed less response to their own names and looked at other people less often. These behaviors could be seen in home movies when children with ASD were as young as 8–10 months old (Palomo et al., 2006). Other behaviors evident during the first two years of life which distinguished children with ASD from typically developing children included: lower rates of pointing to make a request or to share, less frequent babbling, less use of words, more frequent repetitive behaviors, and greater likelihood of unusual posture (Palomo et al., 2006). Video footage also revealed that children with ASDs were more likely than children with mental retardation to visually inspect objects, and they demonstrated less varied and less flexible play activities than children with mental retardation (Palomo et al., 2006).

In some recent studies, investigators have videotaped children at risk for the development of ASDs and have followed these children prospectively over time to determine which behaviors might serve as red flags for the later development of ASD. One such study by Loh et al. (2007) used videotaped footage of 18-month-old children who had siblings with ASD, and found that frequent arm-waving and placement of the hands over the ears were associated with an eventual diagnosis of ASD. Another study (Iverson & Wozniak, 2007) analyzed videotapes of at-risk youngsters that were made when the children were from 5 to 18 months old, and concluded that delays in babbling and in the attainment of motor developmental milestones signified the possible presence of ASD.

Yet another study (Werner & Dawson, 2005) used home videotapes to examine the issue of autistic regression. Some parents of children with ASDs have claimed that their children appeared to develop normally until 15–24 months, after which the children's abilities declined in the areas of social and communication skills. By analyzing home videotapes of children's first and second birthday parties, Werner and Dawson (2005) corroborated parents' reports that their children's behaviors regressed between ages 12–24 months. At 12 months of age, children who later regressed were observed to babble and use words more often than neurotypical one-year-olds. However, by 24 months of age, these children clearly demonstrated symptoms of ASD such as reductions in social gaze, less response to name, less pointing, and less vocalizing. Werner and Dawson (2005) also administered a standardized interview to parents to gather additional information about the children's early development. Interview data suggested that prior to age one, the children who eventually displayed regressive ASD had sleep problems and were overly sensitive to sensory stimulation, although such behaviors were not observed in home movies.

In summarizing their review about the use of home movies and videotapes as diagnostic tools, Palomo and colleagues (2006) stated that as of yet, no home movie studies indicate that ASDs can be diagnosed using this approach before a child reaches one year of age. These authors cautioned that some observable differences in social behaviors prior to 12 months of age might be transitory, or such differences might constitute evidence of a disorder other than ASD. However, they did note that abnormalities in social orienting might signify that an infant is at risk for developmental delays. Also, because this type of research can be limited by difficulties in obtaining heterogeneous research samples and uniform videotape content, Palomo et al. (2006) suggested that it would be advantageous for universities to establish a shared videotape database of home movies and videotapes depicting young children with ASDs.

AN ATYPICAL SCREENING TOOL FOR ASD IN ADULTS

As previously mentioned, the accurate identification of ASDs often is delayed. In fact, Ozonoff, Garcia, Clark, and Lainhart (2005a) reported that some individuals with ASDs may receive inaccurate diagnoses in childhood and may reach adulthood without having been correctly diagnosed: "Many of these individuals are seen by multiple providers who have little knowledge of ASD characteristics and little experience in screening for an ASD diagnosis" (Ozonoff et al., 2005a, p. 93). Therefore, they conducted a preliminary investigation with adults who have ASDs, using a commonly administered personality test called the Minnesota Multiphasic Personality Inventory-Second Edition (MMPI-2; Butcher et al., 2001). This questionnaire requires test-takers to rate each of its 567 items as either true or false about themselves. Responses to these items are combined to form various scales that indicate whether respondents answered the questions in a consistent manner and information about test-takers' personality characteristics and clinical symptoms.

Ozonoff and colleagues (2005a) administered the MMPI-2 to 20 young adults with high-functioning ASD and compared their MMPI-2 scores to scores obtained from a control group of 24 neurotypical adults who were matched to the ASD participants in terms of age, gender, and level of intelligence. Despite producing valid MMPI-2 profiles, the ASD group generated higher scores than the control group on four validity scales. In particular, 30% of the ASD respondents obtained elevated scores on the L scale, which is intended to detect whether respondents are trying to portray themselves in an overly positive way by denying minor personal failings. Ozonoff et al. (2005a) interpreted this finding as an indicator of ASD participants' limited self-awareness and lack of insight concerning the effects of their behavior on other people.

When examining scores for the MMPI-2 clinical scales, Ozonoff et al. (2005a) found that the ASD participants had much higher scores than the control group on scales that measure depression and social introversion. The adults with ASD also scored noticeably higher than control participants on an MMPI-2 content scale that measures social discomfort, and on MMPI-2 supplementary scales measuring repression and anxiety. In addition, adult respondents with ASD scored lower than the comparison group on supplementary scales measuring alcohol problems, addiction potential, and ego strength. Concerning the so-called PSY-5 scales of the MMPI-2, adult respondents with ASD scored higher than control respondents on an introversion scale and lower than controls on scales that assess aggressiveness and behavioral disconstraint.

The clinical features measured by MMPI-2 scales that yielded higher scores for adults with ASD are consistent with what is known about the characteristics and symptoms of ASDs (Ozonoff et al., 2005a). Often, individuals with ASDs do manifest difficulties with depressed mood, social discomfort, and anxiety. Consequently, these authors suggested that clinicians who are unfamiliar with ASDs should take note if a client obtains elevated scores on MMPI-2 scales that measure depression, introversion, and social anxiety. Should an adult client obtain a similar MMPI-2 profile, he or she may have an undiagnosed ASD and therefore might benefit from more in-depth evaluation to examine this possibility (Ozonoff et al., 2005a).

NEW MEASURES FOR ASD SCREENING AND ASSESSMENT

Investigators continue to develop new instruments to identify ASDs for both clinical and research purposes. One such measure is a questionnaire called the Early Screening of Autistic Traits (ESAT; Swinkels et al., 2006). It was designed to be used by primary healthcare personnel as a way to screen for ASDs in children who are 14–15 months old. This test contains 19 Yes/No items, for which a No response indicates a developmental abnormality. When creating the ESAT, Swinkels et al. (2006) included items to assess behaviors such as eye contact, interest in other people, non-verbal and verbal communication, joint attention, imaginative play, unusual reactions to sensory stimuli, and repetitive actions. They found that the ESAT did a good job of identifying young children with ASDs and was able to distinguish these children from neurotypical youngsters. Additionally, they discovered that a 4-item version of the ESAT correctly identified almost all of the children with ASD in their initial sample. Thus, Swinkels et al. (2006) suggested that the 4-item ESAT might be useful as a rapid prescreening measure.

The ESAT underwent further scrutiny in a follow-up study by Dietz, Swinkels, van Daalen, van Engeland, and Buitelaar (2006). They analyzed ESAT data from a random population of over 31,000 children who were 14–15 months of age. These children were prescreened by physicians at well-baby clinics, using the 4-item version of the ESAT. This brief prescreening procedure takes only three minutes to administer, and involves assessment of a child's interest in toys, play behavior, ability to read others' emotions, and reactivity to sensory stimuli. Infants who failed the prescreening then were further evaluated using the 14-item ESAT. If they obtained three or more negative scores, they were deemed to be at high risk for having an ASD and were referred for in-depth assessment. In cases where the ESAT screening yielded false positives for ASD, the children exhibited other problems such as mental retardation or a language disorder.

Dietz et al. (2006) reported that use of the 4-item ESAT produced a large number of false positive results, and noted that the prescreening version should be used with caution. However, they also found that the ESAT was capable of identifying children as young as 14 months who either had ASDs or were at risk for some other form of developmental delay. Thus, even if children identified by the ESAT do not have ASDs, they still may have other forms of developmental abnormality that may warrant further evaluation and intervention (Dietz et al., 2006).

Some researchers have tried to identify ASDs in early childhood using a method called the Face-to-Face/Still Face (FFSF) paradigm. During this procedure a parent plays with a baby for a few minutes, then stops playing for several minutes while maintaining an expressionless face, and finally resumes playing. Infants' reactions to this process can be videotaped and analyzed for the presence of either smiling or crying (Cassel et al., 2007).

Two recent studies employed the FFSF test to look for early warning signs of ASDs in young children who had brothers or sisters already diagnosed with an ASD. Cassel and associates (2007) reported that six-month-old siblings of children with ASDs smiled for significantly less time during the FFSF test than did the infants who had typically developing siblings. Visual tracking was the focus of a study by Merin, Young, Ozonoff, and Rogers (2007), who videotaped babies during the FFSF test using special cameras that could detect the position of the infants' gaze. Merin and colleagues discovered that infants with older ASD siblings seldom looked at their mothers' eyes. Although these studies are preliminary, they suggest the possibility that differences in facial expression and gaze direction might serve as early red flags for the presence of ASDs.

A newly developed instrument called the Early Development Questionnaire (EDQ; Ozonoff, Williams, & Landa, 2005c) seeks to identify children who exhibit regression in early life following an initial period of seemingly normal development. The first section of this 69-item questionnaire asks parents to indicate whether their child has manifested symptoms of autism such as social deficits, communication delays, or repetitive behaviors. In the second section, parents report whether their child has experienced observable losses in adaptive functioning or in communication, social, and motor skills. The third section of the EDQ is completed only by parents whose children have shown regression; it consists of open-ended questions to obtain information about the onset and course of the regression. Ozonoff et al. (2005c) stated that results of EDQ administrations provided support for the existence of autistic regression. These authors also found that approximately 50% of children who later regressed had shown signs of early social delays. They reported that seven social behaviors distinguished children with early onset autism from children who regressed. In comparison to children with early onset autism, children who regressed had initially oriented to their own names more frequently, looked at other people more often, shown objects to others more often, demonstrated joint attention more frequently, responded to someone else's pointing or looking behaviors more often, were more likely to start games, and were able to engage in pretend play (Ozonoff et al., 2005c).

Epidemiological studies may benefit from use of the Childhood Asperger Syndrome Test (CAST; Scott, Baron-Cohen, Bolton, & Brayne, 2002). This Yes/No questionnaire contains 39 items, 31 of which contribute to a total score; scores at or above 15 suggest the possibility of Asperger's disorder. The CAST can be completed by parents to screen for the presence of Asperger's disorder and other ASDs in children from ages 4 through 11 years. Questionnaire items were written to correspond to key features of Asperger's disorder as described by the ICD-10 and *DSM-IV* criteria. According to its authors, use of the CAST is preferable to other screening instruments because it can be used with a non-clinical population and because it focuses specifically on Asperger's disorder. Scott et al. (2002) observed that sometimes undiagnosed children with Asperger's disorder are viewed as disruptive or misbehaving; proper identification of children with Asperger's disorder helps to avoid inaccurate interpretations of these children's behavior.

The CAST underwent further investigation in 2007 when Allison et al. examined its test–retest reliability. Parents of children whose CAST score exceeded 15 were asked to complete the CAST again within two months of the initial administration. Statistical comparisons of the two CAST scores demonstrated moderate test–retest reliability, with almost 74% of children being classified the same way in both test administrations. However, Allison and colleagues (2007) cautioned that CAST scores around 15 tend to be unstable and may move downward over time (i.e., suggesting a decreased likelihood of ASD). They plan to conduct further studies to check whether children whose CAST scores moved down upon a second CAST administration eventually receive an ASD diagnosis.

Perhaps the most unusual new approach for diagnosing ASDs can be found in the social robotics laboratory at Yale University. The laboratory's director, Brian Scassellati, PhD, has been working in collaboration with psychologists from the Yale Developmental Disabilities Clinic to create robots that can provide diagnostic information about children with ASDs (Meyers, 2007; Scassellati, 2005). Scassellati recognized that the process of diagnosing ASDs involves observing social behaviors such as eye contact, gaze, and proxemics. He designed and built robots that can be programmed to produce standardized forms of interaction which allow for the measurement of social responses in children with ASDs. These robots also can be built to monitor and record clinically relevant variables such as interpersonal space and gaze tracking. One benefit of robotic assessment is that children with ASDs may be more interested in and willing to interact with robots than with people. Another advantage of using robots as assessment tools is that they are objective and precise, thereby reducing subjectivity and variability in clinical judgment from one evaluator to another (Meyers, 2007).

MEDICAL TESTS THAT MAY FACILITATE ASD DIAGNOSIS

In addition to psychological and behavioral assessment, a variety of medical tests may be helpful when diagnosing ASDs. For example, blood tests have shown that in roughly 33% of individuals with ASDs, elevated levels of serotonin are present in their blood (Burgess, Sweeten, McMahon, & Fujinami, 2006). Serotonin is one of the chemical messengers that allow brain cells to communicate (Halgin & Whitbourne, 2007). Burgess et al.

(2006) surmised that higher levels of serotonin in the blood might be associated with higher levels of this substance in the brains of individuals with ASDs. They indicated that the inclusion of testing for blood levels of serotonin might be important in future research, to examine the possible role of blood serotonin levels in the etiology of ASDs.

Blood tests also might eventually be used to screen for the presence of mitochondrial dysfunction as a medical condition linked with ASDs. Filipek (2005) wrote that heightened levels of lactic acid in the blood are associated with ASDs, and that lactic acidosis may be an indicator of mitochondrial dysfunction as a causal factor for autism. To explore this possibility, Oliveira et al. (2005) screened 120 children with autism and discovered that over 20% had higher than normal levels of plasma lactacte. They suggested that further study of this issue is warranted to determine whether evaluation of mitochondrial functioning might have clinical significance as an indicator of ASD.

Since genetic makeup appears to be strongly associated with the development of ASDs (Rutter, 2005), genetic testing also has been studied as a way to identify ASDs, their causes, and the risk of recurrence (Schaefer & Lutz, 2006). Testing for fragile X syndrome and tuberous sclerosis, as well as chromosomal karyotype studies, may pinpoint genetic causes of ASDs (Filipek et al., 1999; Rutter, 2005). However, the value of this information pertains less to individual diagnosis and more to genetic counseling for families, so that they may be aware of their risk for recurrence of ASDs (Filipek, 2005; Rutter, 2005).

At present, other types of medical tests may be more useful for diagnostic purposes. For example, several studies have reported that differences in head circumference may connote the presence of ASD (Filipek et al., 1999; Researchers study abnormal head growth, 2005). In one such investigation, Lainhart et al. (2006) obtained head circumference data from 338 people with ASDs and compared these to the head circumferences of participants' parents and siblings, as well as neurotypical controls. This study revealed that among persons with ASDs, head circumference often is large in relation to height and is associated with delayed onset of language and greater social impairment.

Sacco et al. (2007) measured head circumference in 241 individuals with autism who ranged in age from 3 to 16 years of age and found significantly larger head sizes among their participants. They reported that when head circumference exceeded the 75th percentile, it was associated with greater impairment in adaptive behavior. These researchers also discovered that larger head circumference was associated with a history of allergies and immune disorders in the participants and their first-degree relatives, leading to speculation that ASDs may be related to immune dysfunctions.

Fukumoto et al. (2008) also performed a study of head circumference, utilizing retrospective data from 85 infants. They learned that at birth, the head circumferences of these babies were similar to average head circumference. However, these infants with ASD later demonstrated a significant increase in head circumference, beginning at one-month-old and peaking at age six months.

Collectively, studies of head circumference suggest that individuals with ASDs display measureable differences in head size. Although prospective research is needed to shed further light on this finding, it appears that abnormalities in head circumference may potentially serve as an indication of risk for the development of ASDs (Researchers study abnormal head growth, 2005).

Minor differences in the facial features of persons with ASDs also may be indications of abnormalities in cranial and neurological development that occur during the first trimester of pregnancy (Hardan, Keshavan, Sreedhar, Vemulapalli, & Minshew, 2006). Hardan et al. (2006) performed magnetic resonance imaging (MRI) scans on 40 individuals with autism and 41 neurotypical controls, measuring the distance between the lenses of the eyes (interlens distance) and the distance between the orbit of each eye within the skull (interorbit distance). Results indicated that in comparison to controls, participants with ASDs had hypotelorism (i.e., eyes that are abnormally close together). Hardan et al. (2006) noted that these findings need to be replicated through future research, but they suggested that decreases in interorbit distances may be typical among a subgroup of individuals with autism.

Hrdlicka et al. (2005) also employed structural MRI to identify different subgroups of ASDs. Using a complex statistical technique called cluster analysis, they examined MRI data from 64 children with autism and obtained four groupings that differed in terms of the sizes of brain structures such as the corpus callosum, amygdala, hippocampus, and caudate nucleus. Of the four clusters, the one that showed the least functional impairment was the group that had the largest amygdalas and hippocampi. According to Hrdlicka et al. (2005), these types of structural differences in the brain might confer some protective advantage.

Functional differences in the brains of people with ASDs were examined by Silk et al. (2006), utilizing functional MRI (fMRI) to study visuospatial information processing differences associated with autism. Participants in this study were seven adolescent males with autism and nine neurotypical males who were matched to the ASD males in terms of age and intellectual ability. These teens were asked to perform a mental rotation memory task, during which fMRI scans indicated the areas of their brains that were most active during the task. Results indicated that compared to the control group, the ASD participants showed significantly less brain activity in the cortical and subcortical regions of the frontal lobe (Silk et al., 2006).

Finally, brain wave studies may be yet another method that could contribute to the identification of ASDs. Two recent studies (Hoeksema, Kemner, Kenemans, & van Engeland, 2006; Kemner & van Engeland, 2006) have reported that both children and adults with ASDs have consistently been found to have abnormalities in a pattern of brain electrical activity called P3. This brain wave pattern occurs when an unexpected visual or auditory stimulus is noticed. People with ASDs emit smaller P3 waves than neurotypical individuals, suggesting that they process sensory information differently than neurotypical individuals (Kemner & van Engeland, 2006).

CONCLUSION

Most current instruments for the assessment of ASDs focus primarily on the identification of deficits. In contrast, Cosden, Koegel, Koegel, Greenwall, and Klein (2006), have advocated for a different type of assessment approach that seeks to identify strengths in children with ASDs. According to Cosden et al. (2006), examples of strength-based assessment for children with ASDs include such methods as functional analysis of behavior, preference assessments, goodness-of-fit evaluations, and identification of positive traits and behaviors. Functional analysis of behavior provides information about factors that may trigger challenging behaviors; once these triggers have been determined, positive behavioral supports can be implemented to reduce the frequency and severity of disruptive behaviors. Preference assessments can yield information about the likes and interests of people with ASDs, so that their preferences can be used to increase interest in tasks. Goodness-of-fit evaluations examine the relationships among the person with ASD, his or her treatment plan, and the person's daily environment. Such evaluations may suggest ways to modify the person's environment or intervention program to promote more optimal functioning. Lastly, Cosden et al. (2006) suggested that making note of a child's positive attributes (e.g., memorization skills, facility with computers, honesty, etc.) may have a beneficial impact on child outcomes by modifying parents' and teachers' attitudes about the child's capabilities.

This chapter has provided an overview about newer approaches for the diagnosis and assessment of ASDs, including information about the relative merits and drawbacks of the various measures. Future studies will elucidate which of these newer assessment techniques should be routinely included in a comprehensive diagnostic evaluation. As emphasized by Ozonoff, Goodlin-Jones, and Solomon (2005b), the assessment of ASDs should involve instruments and procedures that have been shown through previous research to have good psychometric properties as well as meaningful implications for treatment planning and outcome evaluation. Using evidence-based assessment may increase the likelihood of accurate classification, and avoids fruitless expenditures of time, effort, and money in the pursuit of diagnostic information that will enable access to treatment services for individuals with ASDs.

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ASPERGER SYNDROME IN THE AFRICAN AMERICAN COMMUNITY: BARRIERS TO DIAGNOSIS

Frederika C. Theus

More than 60 years have passed since Hans Asperger (Asperger, 1944), a Viennese pediatrician, described a group of children who displayed what he termed "autistic psychopathy." Asperger's work with these children was not widely known over the following decades. Nearly 40 years later, however, Lorna Wing (Wing, 1981) first used the term "Asperger Syndrome" (AS) to describe a group of children and adults with unusual speech and language, social behaviors, and cognition. Subsequently, in recent years, the publication of articles and books on AS for both professionals and the general public has escalated remarkably (Attwood, 2007; Gillberg, 2002; Grandin & Barron, 2005; Willey, 2001).

Despite the significantly increased awareness of AS, many issues continue to interfere with effective assessment and accurate diagnosis, including the lack of a universally accepted definition, and the relatively limited number of professionals adequately trained in diagnosing this syndrome. Further, despite recent increases in awareness, there remains a relatively limited understanding of the symptoms of AS, particularly during the early childhood stages. These factors are relevant for all children with potential diagnoses of AS. The unique experience of African Americans, however,

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contributes to distinct obstacles and barriers to the accurate diagnosis of AS in African American children.

PREVALENCE OF AS AMONG AFRICAN AMERICANS

Estimates of the prevalence of AS in children throughout the entire population of the United States are highly limited and greatly variable. Ozonoff, Dawson, and McPartland (2002) stated that estimates of AS range from 0.2 to 0.5% (or 2–5 individuals in 1,000), while Volkmar and Klin (2000) cited studies reporting rates of 36 in 1,000 to approximately 1 in 10,000. The Diagnostic and Statistical Manual of the American Psychiatric Association (2000), fourth edition (DSM-IV-TR), states that "definitive data about the prevalence of Asperger Syndrome does not exist."

While a highly significant increase in the prevalence of autism is documented in several studies (Croen, Grether, Hoogstrate, & Selvin, 2002; Laidler, 2005; Newschaffer, Falb, & Gurney, 2005), children with AS are not typically or clearly represented in these studies. Croen et al. (2002), for example, found a statistically significant increase in the prevalence of autism in California, ranging from 5.8 per 10,000 children born in 1987 to 14.9 per 10,000 for children born in 1994. Only children with diagnoses of autism "full syndrome" were eligible for inclusion in this study, however, while children with diagnoses of AS were not included. Newschaffer et al. (2005) used a national data source to compare the prevalence of autism with that of other disabilities among successive birth cohorts of school-aged children in the United States. It is not clear, however, how or if children with AS were represented. Similarly, Laidler (2005) examined the autism data collected by the United States Department of Education (USDE). It was concluded that "The USDE data of autism seem to indicate that there has been an exponential rise in autism prevalence between 1993 and 2003." The inclusion or exclusion of children with diagnoses of AS in the data examined was not discussed.

The study (see Centers for Disease Control and Prevention, 2000) of autism prevalence in Brick Township, New Jersey, included children with diagnoses of AS. Nevertheless, children with AS were categorized as "other spectrum diagnoses," and were considered only as grouped with children with diagnoses of Pervasive Developmental Disorder-Not Otherwise Specified (PDD-NOS) or as part of the entire autism spectrum (Centers for Disease Control and Prevention, 2000). Therefore, while this study found higher rates of both autism and autism spectrum disorders than previously published, little can be speculated about the prevalence rates for AS, specifically. Similarly, Yeargin-Allsopp et al. (2003) found higher rates of autism in children age 3–10 years in metropolitan Atlanta, Georgia. Children with AS, as well as those with PDD, NOS, or autistic disorder according to DSM-IV-TR criteria were included, but results were not reported by "autism subtype."

Ethnic/racial factors regarding autism spectrum disorders, particularly AS are rarely addressed in the literature, specifically. While the DSM-IV-TR provides information on cultural, gender, and age-related factors that may affect symptom presentation for many diagnoses, only gender and age factors are discussed regarding AS. Regarding the recent studies of autism spectrum prevalence, Croen et al. (2002) reported that Whites, Hispanics, Blacks, and Asians were included in the study of "full syndrome" autism prevalence in California, and that the pattern of increase in prevalence was essentially the same for these ethnic/racial groups. The ethnic/racial distribution of the Brick Township Report was reported to be comparable to the composition of Brick Township. The distribution was reported to be 89% white non-Hispanic, 4% Hispanic, 4% other races, and 3% unknown (Centers for Disease Control and Prevention, 2000). It is unclear, however, whether or not African Americans were incorporated into the 4% "other races" included in the study. Additionally, children with AS were not clearly represented.

Children with autism may come to the attention of professionals at an earlier age than children with AS. Children with autism present earlier with speech and language delays. In contrast, many children with AS may seem quite precocious to their parents, having learned to talk fluently or perhaps even read at an early age. It is often not until the child with AS begins attending school that the teacher recognizes patterns of unusual social and play behaviors and difficulties with the pragmatic aspects of language, such as conversation skills (Attwood, 1998). Volkmar and Klin (2000) stated that early social skills, including attachment, may not be drastically unusual in young children with AS. Further, the possible absence of delayed or deviant language, at least regarding formal language development (phonology, syntax, and semantics) compared to pragmatic language, may lead to a delay in the recognition of the symptoms as part of a meaningful developmental delay (Volkmar & Klin, 2000; Volkmar, Klin, & Pauls, 1998). Nevertheless, the degree of impairment regarding language functioning, social use of language, and overall social competence becomes more notable with age for children with AS and are generally consistent with the impairments observed in individuals diagnosed with high-functioning autism (Howlin, 2003; Macintosh & Dissanayake, 2004).

Overall, studies have documented a later age of diagnosis for children with AS in comparison to those with other autism spectrum disorders (Goin-Kochel, Mackintosh, & Myers, 2006; Rutter, 2006). Mandell, Novak, and Zubritsky (2005) found that the average age of diagnosis for children with AS was 7.2 years, in comparison to 3.1 years for children with autistic disorder, and 3.9 years for those with PDD-NOS. McConachie, Le Couteur, and Honey (2005) concluded that, regarding children with AS, the majority "will continue to come to attention once they are introduced to the demands of educational settings and have reached the age when lack of friendships, poor self-help skills, circumscribed interests, and inappropriate conversations skills are more evident through comparison with other children" (p. 175). In summary, the above literature indicates that current knowledge about the prevalence of AS is emerging, with data on the prevalence in African Americans compared to other racial groups essentially nonexistent.

BARRIERS TO HELP-SEEKING BEHAVIORS

There is important diversity within the African American community regarding factors such as socio-economic status (SES), religion, and cultural experiences. For example, African Americans have a highly unique history compared to that of White Americans, as well as other ethnic/racial groups in the United States because approximately 96% of African Americans are descendants of slaves (Arceneaux, 2005; Harrison, Wilson, Pine, Chan, & Buriel, 1990). As a result, contemporary African American culture is influenced by a multitude of factors, including "the African legacy, the experience of slavery, racism and discrimination, and the victim system" (Boyd-Franklin, 1989, 2006).

The above factors are associated with specific help-seeking behavior patterns that are rooted in African American sociocultural experiences. Help-seeking behavior for African Americans regarding AS may involve complex and multifaceted issues associated with both socioeconomic and sociocultural factors. These factors are likely to interfere with the development of trusting relationships with professionals from the multiple disciplines often involved in diagnosing AS, including neurodevelopmental pediatricians, psychologists/mental health professionals, and educators.

Socioeconomic Factors

According to Census 2000 (Grieco & Cassidy, 2001), 35 million people, or 12.3% of the total population reported their race as Black or African American. These numbers indicate a clear increase in the number of African Americans in the United States, with the African American population increasing faster than the total U.S. population between 1990 and 2000 (Grieco & Cassidy, 2001). Nevertheless, the African American community experiences shorter life spans and higher rates of poverty, which are well documented over time. The poverty rate for African American children in 1994, for example, was 43.3%, in comparison to 21.3% for the entire population of children (Allen & Majidi-Ahi, 1998). Many African Americans continue to live in deep poverty. More recently, the U.S. Census Bureau reported that in 2006 Black households had the lowest median annual income, (about $32,000) among race groups (DeNavas, Proctor, & Smith, 2007). The poverty rate for Blacks was reported to be 24.3%, in comparison to 10.3% for Asians, 20.6% for Hispanics, and 8.2% for non-Hispanic whites (DeNavas et al., 2007). Further, regarding health insurance coverage, the uninsured rate in 2006 was 20.5% for Blacks, in comparison to 10.8% for non-Hispanic whites, and 15.5% for Asians (DeNavas et al., 2007).

The continued high prevalence of poverty has a significant impact on the ability of African American families of children with AS to seek appropriate services. Clearly, issues such as limited income and lack of health insurance, for example, greatly hinder access to behavioral, clinical, and special education services. Brown and Rogers (2003) stated, for example, that "The autism-specific treatment and clinical services in outlying and rural areas, and those available in urban settings to persons of cultural diversity, are often limited, fragmented, costly, or inaccessible" (p. 220). Further, limited financial resources become a barrier to accessing essential support, such as educational parent workshops, support groups, and online information where many families gain knowledge about the characteristics of AS and explore options for assessment and intervention for their child.

Sociocultural Factors

Similarities and differences in the emotional reactions of parents to the diagnosis of a child's disability across cultures in the United States have not been widely explored. Mary (1990) compared the reactions of

Hispanic, White, and Black mothers to their child's disability. Although, this study involved only mothers of children with mild and severe mental retardation, the findings are perhaps applicable for parents of children with a range of disabilities, including AS. The findings suggested "common if not universal reactions of love and sorrow across cultures." While parents of different races may experience similar patterns and degrees of grief, sorrow, and shock, studies exploring help-seeking behaviors suggest that there may be significant differences in the patterns exhibited by African American parents, in comparison to other ethnic/racial groups (Bogart & Thorburn, 2006; Ross, Essien, & Torres, 2006; Schnittker, Pescosolido, & Croghan, 2005).

One of the most significant influences on help-seeking behavior is the overall historical and current social-cultural experience of African Americans. The historical legacy of slavery, including ongoing experiences of racism and discrimination, have contributed to feelings of fear and mistrust of general health care and mental health services. Historically relevant experiences, such as the Tuskegee experiment (Bates & Harris, 2004), are well known within the African American community. The Tuskegee experiment involved 399 African American men in the late stages of syphilis, who were never informed about the nature of their disease and who were denied appropriate treatment throughout the duration of the study (Bates & Harris, 2004; Brandon, Isaac, & LaVeist, 2005; Jones, 1992; Kirp, 1995).

More recently, research (Whetten et al., 2006) on responses to AIDS in the African American community provides a powerful example of the continued fear and mistrust in the health profession that exists among many African Americans. For examples, studies have indicated that many African Americans believe that AIDS is basically "another Tuskegee, another act of genocide" (Kirp, 1995). Such suspicions and beliefs of conspiracy, including the notion that AIDS was created by the government to kill people of color, have contributed to a notable distrust of the available preventive strategies and treatments (Bogart & Thorburn, 2006; Ross et al., 2006; Whetten et al., 2006).

Similar to experiences with the public health system, historical and current experiences with the mental health system have a strong negative influence on the help-seeking behaviors of African Americans. Regarding views on mental health research, Freimuth et al. (2001) stated that "it is necessary to acknowledge that many African Americans view research within the context of contemporary racism, urban legends, and mistrust in health care and the larger society, and that their concerns and fears have a legitimate basis in historical reality" (p. 807). Further, Schnittker et al.

(2005) indicated that evidence generally suggests that African Americans seek medical care, and particularly mental health care, less regularly than Whites, but that "evidence for disparities in rates of utilization is not as consistent as differences in quality."

Numerous studies (see Kilbourne, Haas, Mulsant, Bauer, & Pincus, 2004) have suggested a racially based diagnostic bias, particularly regarding the diagnosis of schizophrenia and affective disorders. Such studies have indicated that in both inpatient and outpatient settings, African Americans are more likely than Whites to be diagnosed as having schizophrenia, and less likely than Whites to be diagnosed as having affective disorders (Hu, Snowden, & Miller, 1997; Kilbourne et al., 2004; Lawson, Hepler, Holladay, & Cuffel, 1994). There is strong, longstanding evidence that the differences in diagnostic prevalence, as illustrated in these studies, are due to diagnostic bias, even when standardized criteria are used (Loring & Powell, 1988; Lu, Lim, & Mezzich, 1995; Mayo, 2004; Neighbors, Jackson, Campbell, & Williams, 1989; Neighbors, Trierweiler, Ford, & Muroff, 2003; Worthington, 1992).

Further, African Americans' attitudes toward the educational system are influenced by ongoing concerns about bias and discrimination regarding special education categorization and placement. Specifically, the well-documented overrepresentation of African Americans in special education classrooms, such as those for children with mental retardation, emotional or behavioral disorders, or learning disabilities, fuels mistrust in the educational system (Blanchett, 2006; Hosp & Reschly, 2004; Hunt & Marshall, 1994; O'Connor & Fernandez, 2006). For example, Chinn and Hughes (1987) analyzed data from surveys conducted by the Office of Civil Rights over several years from the late 1970s to the mid-1980s, and found that African American children were placed in classes for children with mild mental retardation at a rate twice what would be expected. Unfortunately, recent evidence (Blanchett, 2006; O'Connor & Fernandez, 2006) suggests that overrepresentation of African American children in special education programs is a continuing trend.

In light of fearful and negative beliefs, it is highly likely that many African American parents would be quite suspicious if school personnel raise concerns about their child displaying characteristics of AS. While a guarded parental response is understandable regarding the suggestion of any type of disorder for a child, such a response is perhaps most likely with a potential diagnosis of a disorder such as AS, with its significant social symptoms and discouraging prognosis. Furthermore, unlike parents of children with mental retardation who may have noticed and were concerned about development since an early age, many parents of children with AS, including African American parents, may have felt that their child was gifted, with concerns about learning and development being far from their thoughts. Therefore, when a teacher raises concerns about poor social adjustment or social skills deficit, a parent may be skeptical. When these types of behavioral concerns are raised, some African American parents may respond with a level of suspicion regarding a subtle form of institutional racism. In fact, a request for assessment initiated by a child's school may be viewed as an unwarranted attempt to label and place their child in the special education system; a system which most African American parents know is disproportionately populated with African American children.

The result of this socioculturally based mistrust in the healthcare, mental health, and educational systems leads African American families to depend on self-reliance and the community as alternatives to seeking help from systems outside the African American community. These alternatives include turning to spirituality, family, friends, and religious leaders, as well as neighborhood associations and civic groups for assistance (Gibbs, 2003; Johnson, Elbert-Avila, & Tulsky, 2005; MacMaster et al., 2007; Neighbors & Jackson, 1996; Snowden, 2001; Taylor, Lincoln, & Chatters, 2005). Unfortunately, this approach, which is so often adaptive and effective, may contribute to a significant delay in receiving formal diagnostic and treatment services for an African American family with a child who has AS.

BARRIERS TO REFERRAL OF AFRICAN AMERICAN CHILDREN

The early diagnosis of autism spectrum disorders is considered to be highly valuable for several reasons. Foremost is the importance of implementing early behavioral and educational intervention, such as Applied Behavioral Analysis (ABA) (Lovaas, 1977, 1987) which is widely believed to be associated with positive outcomes (Eikeseth, Smith, Jahr, & Eldevik, 2002; Smith, Groen, & Wynn, 2000). TEACCH-based structured teaching approaches (Schopler, Mesibov, & Hearsey, 1995) and relationship-based interventions, such as Developmental, Individual-Difference, Relationship-Based model (DIR) (Greenspan & Wieder, 1999) and Relationship Development Intervention (RDI) (Gutstein, 2000) are other popular and commonly used approaches to intervention. Further, the timely provision of genetic counseling to parents of children with autism spectrum disorders who are considering having additional children is often considered beneficial (Mandell, Listerud, Levy, & Pinto-Martin, 2002; Schaefer & Lutz, 2006). African American children, however, may be particularly vulnerable to factors interfering with the provision of appropriate referrals for evaluation, and subsequent intervention.

One factor that may interfere with referral services is within the professional community itself. Mandell et al. (2002) found that in a study of 406 Medicaid-eligible children, there were significant racial differences in the initial clinical identification and diagnosis of children with autism. Specifically, African American children first received the diagnosis of autism, on an average, a year and a half later than White children, with White children receiving the diagnosis at an average age of 6.3 years, compared with 7.9 years for African American children. Further, African American children entered specialty mental health services at an older age than White children, and required three times the number of visits over three times as long as White children before a diagnosis of autism was made. Specifically, 72% of White children were diagnosed with autism upon their first visit compared to 58% of African American children.

Mandell et al. (2002) indicated one reason for the disparity in age of referral and diagnosis between White children and African American children with autism is the differing expectations among clinicians about treatment and service needs. They stated that clinicians may "not screen for autism spectrum disorders in African American families as quickly as they would among white families" (p. 1452). Further, they proposed that "physicians may also more quickly discount the concerns of African American parents than they do concerns of white parents related to their children's developmental delays, or they may not elicit those concerns in the first place" (p. 1452). Evidence for this stance is suggested by Cooper-Patrick et al. (1999), who found that regardless of the race of the physician, African Americans rated their visits as "significantly less participatory" than did Whites.

Johnson, Roter, Powe, and Cooper (2004) found differences in physician–patient communication that reflected previous findings regarding differences in African American and White patients' views on their quality of health care. Specifically, they concluded that "Physicians were more verbally dominant and tended to be less patient centered in their approach with African American patients than with White patients" (p. 2087). Further, in addition to perceived disparities in health care treatment among the public, Wilson, Grumbach, Huebner, Agrawal, and Bindman (2004) found that medical students and physicians perceived unfairness, also.

While the diagnosis of AS was not addressed, specifically, the results of the above studies have important implications. Since AS is typically diagnosed at a significantly later age than autism, it appears that professionals who are in a position to recognize possible features of AS in young children and make referrals for evaluation, may be highly unaware or confused about early signs and symptoms. Further, they may be even less likely to elicit or to explore concerns suggestive of AS when expressed by parents of African American children.

BARRIERS TO ASSESSMENT

Typically, assessment of children with AS involves the administration of diagnostic interviews and instruments as well as differential diagnosis. Specific issues of assessment of African American children regarding a diagnosis of AS are discussed.

Diagnostic Interview

Assessment ordinarily begins with a diagnostic interview. While the administration and interpretation of standardized tests is often considered to be the more structured, objective and, therefore, reliable portion of an assessment, a thorough clinical interview is crucial to the general diagnostic process. Barkley (1998) stated that "An interview that uses highly specific questions about symptoms of psychopathology that have been empirically demonstrated to have a high degree of association with particular disorders greatly enhances diagnostic reliability" (p. 267). Regarding the diagnosis of autism spectrum disorders, specifically, Ozonoff et al. (2002) described a thorough developmental history as one of two "essential ingredients in a diagnostic evaluation," with observation being the other. Parents are likely to be the most complete source of information about the child's early history and daily functioning in a variety of settings. Therefore, parents are often able to provide invaluable insight into the child's strengths and difficulties that may not be clearly demonstrated in a clinical setting.

The Autism Diagnostic Interview-Revised (ADI-R) (Le Couteur, Lord, & Rutter, 2003) is a semi-structured interview designed to be administered to parents/caregivers. It is considered to be one of the most valuable tools in diagnosing autism spectrum disorders, particularly in regard to obtaining information on developmental history, as well as current symptoms

(Volkmar, 2005). Further, the ADI-R provides comprehensive information of both past and current functioning related to autism spectrum disorders. The Autism-Tics, ADHD and Other Comorbidities Inventory (A-TAC) (Hansson et al., 2005) and the Diagnostic Interview for Social and Communication Disorders (DISCO) (Wing, Leekam, Libby, Gould, & Larcombe, 2002) are two other standardized interviews that have been developed to facilitate and to enhance the assessment process. Regardless of standardization and well-developed administration guidelines, however, the accuracy and thoroughness of data obtained in any interview is largely dependent on the skill and expertise of the clinician, and is vulnerable to the clinician's biases, misconceptions, and skill in establishing good rapport.

The importance of understanding the "healthy cultural suspicion" or "healthy paranoia" that African Americans may bring to a clinical setting is often discussed (Bender, 2005; Sue, 2006). Regarding multicultural issues in the field of disabilities, Bryan (1999) emphasized the importance of clinicians understanding a family's views of causation and the helping-process. Further, the author stressed the importance of a clinician knowing the history of an individual's cultural group in this country to assist in understanding the individual's perceptions of his or her situation, as well as understanding factors contributing to current behaviors.

Takushi and Uomoto (2001) suggested that the clinician must be willing to consider the "multicultural perspective" of the client, in order to establish a comfortable relationship, while still being able to obtain valid information. Further, they emphasized the importance of maintaining "culturally congruent" communication that remains mindful not only of the meaning of the client's communication but the client's simultaneous interpretation of the clinician's behavior as well.

Gibbs (2003) emphasized that misunderstandings between clients and clinicians are often due to differences in communication style, such as the frequency with which verbal acknowledgment is given when engaged in a verbal exchange. They suggested that African Americans tend to give less verbal reinforcement to one another during a conversation. Further, the authors stated that there is a cultural pattern of "masking true feelings and concerns from whites and authority figures." Given the history of oppression and ongoing experiences of discrimination, it is often difficult for African American clients to trust White clinicians. Further, economically disadvantaged African Americans and/or those with limited education may have nearly as much difficulty in trusting middle-class African American clinicians, viewing them as part of "the system." A clinician who is unfamiliar with such patterns, as a result, may interpret these behaviors during a diagnostic interview as a sign that the parent is disinterested, not invested, and/or resistant to receiving assistance.

Overall, obtaining a thorough, accurate history is crucial to making a diagnosis of AS. An African American parent, however, due to feelings of mistrust, might be ambivalent about disclosing less positive aspects of the child's history, such as unusual interests, or odd social behaviors. Further, if a clinician is less likely to screen for autism in African American children, as Mandell et al. (2002) suggested, this tendency may be even more likely when AS is a possible diagnosis given the often relatively subtle nature of the symptoms. If important historical information and descriptions of current behavior are not elicited, are minimized, or are overlooked by the clinician during the parent interview, the possibility for misdiagnosis is enormous.

Diagnostic Instruments

Several instruments, in addition to diagnostic interviews, are available to aid in the diagnosis of AS. Rating scales, such as the Asperger Syndrome Diagnostic Scale (Myles, Bock, & Simpson, 2001), and the Gilliam Asperger Disorder Scale (Gilliam, 2001) are two rating scales that assist in obtaining data in a structured format from parents, teachers, or others who know the individual well. The Autism Diagnostic Observation Schedule (ADOS) (Lord, Rutter, DiLavore, & Risi, 2001) provides a standardized format for conducting structured observations of social and communication behaviors.

Similar to the ADI-R, the ADOS was developed, originally, as a tool to be used in research studies of autism. Both instruments, however, provide a measure of the severity of autism symptomatology and, therefore, are often used to assist in making a diagnosis of AS. While Klin, Sparrow, Marans, Carter, and Volkmar (2000) state that both the ADI-R and the ADOS are being used routinely by clinical researchers throughout North America, as well as Europe, Latin America, and Asia, comprehensive studies comparing the performance of African American children with other racial groups are not available.

One possible explanation offered for the overrepresentation of African American children in special education classrooms is that the assessment tools typically used by professionals may not provide valid or true representations of functioning when used with non-White, non-middle-class populations. Research on cross-cultural differences in the diagnosis of Attention Deficit Hyperactivity Disorder (ADHD) provides support for this hypothesis (Bauermeister, Berrios, Jiménez, & Gordon, 1990;

Mann et al., 1992; Sonuga-Barke, Minocha, Taylor, & Sandberg, 1993). Studies comparing the use of behavior ratings by Chinese, Indonesian, American, and Japanese professionals (Mann et al., 1992) and teacher ratings of Asian and English students (Sonuga-Barke et al., 1993) resulted in significant differences between cultural/racial groups. Regarding direct assessment, Bauermeister, Berrios, Jiménez, and Gordon (1990) examined the performance of Puerto Rican children on the Gordon Diagnostic System, and found that use of U.S. norms resulted in significant over-identification of Puerto Rican children.

These studies did not involve African American children. However, Reid et al. (1998) compared the teacher ratings of Caucasian male students and African American male students (ages 5–18) on the ADHD-IV Rating Scale (DuPaul, Power, Anastopoulos, & Reid, 1998). The authors found that, across all age groups, teachers rated African American students higher on all symptoms. Further, analysis of the data suggested a different relation between items for the African American students in comparison to the Caucasian students. The authors stated that, "the results suggest that the norms for the Caucasian group may not be appropriate for the African American group." Further, they stated that, the findings suggested that "there is the possibility that student ethnicity may affect the likelihood of a rater endorsing the presence of ADHD symptoms."

Similarly, Pierce and Reid (2004) concluded that "Children from diverse cultural groups may be over identified as having ADHD." Epstein et al. (2005) found higher ratings from teachers and higher levels of ADHD behaviors in the classroom for African American students in comparison to Caucasian students. They offered several possible reasons for these differences, including higher rates of ADHD behaviors in African American children than Caucasians or, conversely, a referral bias suggesting that African American children must exhibit higher levels of ADHD behaviors than Caucasian children before they are referred for assessment and intervention.

These findings suggest that, although the reasons appear complex, significant difficulties exist in the identification of ADHD in African American children. Such findings raise important issues for AS assessment. The symptom presentation for AS is generally believed to be universal across cultures. This is an assumption, however, based primarily on anecdotal evidence, with no clear data supporting this notion. Further, while the ADI-R and the ADOS-G are structured, standardized measures, they both require general skill in interviewing, observing, and interacting with individuals with autism spectrum disorders. Regardless of the high quality of these measures, like any measure, their validity is dependent, largely, on the skill and objectivity of the examiner. Therefore, the question remains as to whether African American children differ from other groups in their scores on these measures, as well as other assessment tools for AS, such as rating skills.

Differential Diagnosis

Currently, there is a notable lack of consensus among both clinicians and researchers regarding the central clinical features of AS. Much of our current knowledge of the unusual aspects of social behavior associated with AS that influence the diagnostic criteria is based on ‘‘clinical impressions rather than rigorous scientific study’’ (Attwood, 1998). Professionals in the United States are most likely to use the criteria established by the American Psychiatric Association in the DSM-IV, while professionals outside of the United States typically rely on the criteria provided by the World Health Organization in the ICD-10, criteria considered to be rather restrictive. Clinicians and researches include other diagnostic criteria, such as speech and language peculiarities, narrow interests, nonverbal communication problems, and motor clumsiness, highlighting features strongly believed to be important to the diagnosis of AS (Gillberg & Gillberg, 1989; Klin, 2005; Szatmari, 2000; Szatmari, Brenner, & Nagy, 1989). The lack of universally accepted diagnostic criteria may contribute greatly to difficulties with the early referral of children with potential diagnoses of AS.

There are several diagnoses that share some common features with AS, including attention deficit hyperactivity disorder (ADHD), obsessive-compulsive disorder (OCD), and schizophrenia. It is possible for these diagnoses to occur as co-morbid conditions with AS. Because of the symptom overlap and similarities in some aspects of functioning, however, it is not unusual for individuals receiving a diagnosis of AS later in childhood or even in adulthood to have received a diagnosis of ADHD or OCD, previously, although sometimes inappropriately. Eisenmajer et al. (1996) found that one in six children with AS also exhibited clear signs of ADHD. Martin, Patzer, and Volkmar (2000), however, suggested that ‘‘Individuals with higher-functioning social disabilities, given that their social and communicative dysfunctions are less obvious, are often first diagnosed with ADHD’’ (p. 218).

Children with ADHD and those with AS may share symptoms such as poor attention span, excessive talking, and difficulty waiting their turn, and problems with play with peers. The causes of such difficulties, however, are often quite distinct. Children with AS often have difficulties with taking turns, excessive talking, and interrupting others, for example. These behaviors are primarily related to deficits in social behaviors, rather than problems with impulse control and attention, as are typical for children with ADHD. Further, Attwood (1998) emphasized that while children with ADHD and those with AS may both have difficulty playing cooperatively and constructively with other children, those with ADHD tend to understand how to play and want to play, but do so badly.

Ozonoff et al. (2002) suggested that the reasons for an early diagnosis of ADHD in children who are later diagnosed as having AS appear related to symptom overlap and the greater familiarity and training among clinicians regarding diagnosing ADHD, as opposed to AS. Further, Stein, Klin, and Miller (2004) stated that "Although children with ADHD may exhibit social and learning vulnerabilities, the early onset, nature, and magnitude of the social disabilities encountered in autism and AS are critical in differential diagnosis." He emphasized, however, that ADHD can be a co-morbid condition with Asperger's.

Regarding OCD, Attwood (1998) suggested that individuals with AS are susceptible to anxiety, due to the combined effects of stress related to managing social demands, dealing with changes in routine, and certain sensory experiences. He proposed that long-term experiences of severe anxiety may lead to the development of secondary psychiatric conditions, including OCD.

Similar to the relationship between ADHD and AS, there is some overlap in the symptoms of OCD and those of AS. Russell and Sofronoff (2005) found that parents of children with AS reported significantly more obsessive-compulsive symptoms than parents of children considered to be clinically anxious. They stated that "The higher levels of OCD could be interpreted as a reflection of the general characteristics of the syndrome (i.e., unusual and repetitive routines or behaviours)" (p. 637). Further, the authors noted previous findings indicating that children with AS may engage in repetitive and ritualistic behaviors as a means of reducing their anxiety.

Specifically, the unusual rituals sometimes observed in children with OCD, may appear quite similar to the repetitive behaviors exhibited by children with AS, often leading to the misdiagnosis or incomplete diagnosis of OCD. The circumscribed range of interests and intense focus on certain topics and activities often observed in children with AS, however, tend to be quite pleasurable and anxiety reducing. Conversely, most individuals with

OCD recognize that their obsessions and compulsions are unusual and try to suppress them and/or hide them from others although children with OCD do not always have the level of awareness that adults have regarding the unusual nature of their obsessions and compulsions. OCD and AS are further distinguished, typically, by the lack of developmental difficulties and deficits in reciprocal social interactions in OCD that are characteristic of AS (Szatmari, 1998).

Schizophrenia is perhaps the most controversial diagnosis often discussed in relation to AS, given schizophrenia's historical association with poor prognosis and institutionalization, as well as its prior hypothesized association with AS. Berney (2004) notes that, despite Hans Asperger's original intent to distinguish the "innate social distance of 'autistic psychopathy,'" from that which develops into schizophrenia, autism was not distinguished from schizophrenia until 1971. Unfortunately, many lay people and clinicians still retain some degree of misconception, however, that individuals with AS are at high risk of developing schizophrenia.

Further, clinicians inexperienced with AS may easily mistake the characteristics of AS for those of schizophrenia, as the symptoms may be superficially similar. Restricted and repetitive behaviors, for example, are considered to be a core feature of autism spectrum disorders, including AS. Hand and body mannerisms, however, are observed often in children and adolescents with schizophrenia, as well as other psychiatric disorders (Richler, Bishop, Kleinke, & Lord, 2007). The unusual usage of language and pragmatic difficulties that are often observed in individuals with AS may be confused with the disordered language patterns characteristic of schizophrenia, and the odd mechanical speech quality often associated with AS may appear similar to the flattening of affect observed frequently in schizophrenia. Further, the unusual thoughts and preoccupations common in individuals with AS may be mistaken for delusions and unusual sensory experiences may be mistaken for hallucinations.

Perlman (2000) noted observations of adults in a psychiatric setting who appeared to have the negative symptoms of schizophrenia, such as "social withdrawal, apathy, lack of ambition, and communication difficulties." Their histories revealed, however, "a lifelong pattern of relational problems, without psychotic episodes or acute exacerbation," suggestive of AS.

Overall, there is limited evidence in the literature indicating that schizophrenia is any more common in individuals with AS than in the general population (Attwood, 1998; Tantum, 1991, 2003). Klin (2003) found no support for the notion that schizophrenia was more common in people with AS than in other populations. Further, it is important to note that only two of the 200 individuals Asperger studied developed schizophrenia later in life (Wolff, 1998).

Psychiatric diagnoses, such as OCD and schizophrenia, have the potential to be highly debilitating. It is important to note that AS may, indeed, co-occur with other disorders, and that the provision of appropriate treatment for both disorders, if present, is essential (Klin, 2003). Berney, (2004) stressed that if true psychotic symptoms are present in an individual with AS, then treatment should not be delayed by diagnostic doubts, as early treatment of psychosis is extremely important to prognosis. The author added, however, that "once a patient has been established on neuroleptics, it can be difficult to disentangle the two disorders."

Given the limited number of professionals trained in diagnosing AS and the lack of a universally accepted diagnosis, the risk of misdiagnosis or incomplete diagnosis of another disorder, such as ADHD, OCD, or schizophrenia, is high for all children with AS. Is the risk, however, greater for African American children? Are African American children with AS more likely to be misdiagnosed or incompletely diagnosed as having ADHD, schizophrenia, OCD, or other diagnoses, such as conduct disorder? There is a definite concern that ADHD, as previously discussed, may be overly diagnosed or poorly diagnosed in African American children. Further, evidence that schizophrenia is misdiagnosed in African Americans is well documented (Loring & Powell, 1988; Lu et al., 1995; Mayo, 2004; Neighbors et al., 1989; Neighbors et al., 2003; Worthington, 1992). Therefore, there appears to be at least cause to question, seriously, whether this diagnostic bias extends to AS, as well.

SUMMARY AND IMPLICATIONS

Understanding of the clinical presentation of AS has advanced greatly over the last several years. Knowledge of the features of AS in early childhood, however, remains relatively limited. Further, the limited number of clinicians who are knowledgeable about diagnosing AS and the lack of a universally accepted diagnosis continue to interfere with the accurate and timely diagnosis of children. The historical and ongoing experiences of racism and oppression in the African American community contribute to significant differences in help-seeking behaviors. Particularly, there is decreased trust in the health care, mental health, and educational systems, resulting in a reliance on community support that is quite likely to be insufficient for accessing services related to AS.

Further, although additional study is needed, research suggests a bias in diagnosing autism, leading to a later age of diagnosis and a slower process in diagnosing African American children. Research on the diagnosis of both ADHD and schizophrenia suggests a significant racial bias. Given the relatively more subtle and complex symptoms of AS, in comparison to autism, there is cause for concern that similar bias exists in diagnosing AS, perhaps with diagnoses such as ADHD, OCD, and schizophrenia being applied inappropriately. Further, research on diagnostic instruments designed to assess autism spectrum disorders, including AS, does not address whether there are differences in performance and/or in the manner in which clinicians rate children related to ethnicity.

The potential consequences of misdiagnosis are highly significant. First, and perhaps, foremost is that a delay in diagnosis is highly likely to impede the receipt of appropriate intervention. Perlman (2000) emphasized that "Contrary to popular opinion, many examples have been reported of autistic persons improving their social skills with age and making adequate social and vocational adjustments." The provision of appropriate intervention, however, is essential to such progress. The interventions for ADHD and OCD, for example, are clearly not sufficient for addressing the social and communication deficits related to AS. Regarding OCD and schizophrenia, in particular, maintenance on neuroleptic medication may be highly inappropriate, with potentially harmful side effects. Further, misdiagnosis or incomplete diagnoses are likely to result in inaccurate and inappropriate treatment planning and medication management, as well as inappropriate expectations and planning for future supportive needs. Some children with AS who receive misdiagnoses or incomplete diagnoses of other disorders, actually, may never receive appropriate therapeutic or educational interventions.

It bears mentioning that debates continue within the research and clinical communities about whether or not AS and High-Functioning Autism (HFA) qualify as separate and distinct diagnoses (Ghaziuddin & Mountain-Kimchi, 2004; Howlin, 2003). A review of this question is beyond the scope of this chapter. The issue raises additional questions for research and clinical practice, however, regarding the prevalence of the diagnosis of AS, in comparison to HFA, across racial groups. Regarding PDD-NOS, it appears likely children who receive a diagnosis of PDD-NOS, when AS would better describe their functioning and behaviors, may still be at a significant disadvantage. While interventions that are useful for PDD-NOS will often benefit children with AS, the criteria for PDD-NOS is, by design, quite mixed and the ways in which clinicians use the diagnosis are highly varied. Parents of a child with AS who is inappropriately diagnosed with PDD-NOS may have difficulty achieving a thorough and clear understanding of their child's disorder, which, in turn, may significantly interfere with planning effectively for their needs.

Second, the misdiagnosis of children may subtly influence both public and professional perceptions of the diagnostic category of AS, in regard to race. If African American children are diagnosed with AS less frequently than are children from other racial groups, they are less likely to be pictorially represented in parent and professional resource materials about AS, such as educational videos, books, and organizational brochures. Qualitative observations suggest that this is often the case. Similarly, support groups for parents of children with AS may be located primarily in predominately White areas of a city, perhaps contributing to increased discomfort among African American parents about attending such a group. Both clinicians and parents may, essentially, view AS as a "White" disorder. Whether or not such a belief system is in conscious awareness is inconsequential, as it may ultimately lead to decreased openness in clinicians to exploring symptoms of AS when they are presented in African American children, as well as to parents' decreased openness to accepting the diagnosis.

Third, an obvious, but not insignificant, consequence of African American children being less likely to receive a diagnosis of AS is that they would be then less likely to be included in research studies, thereby, perpetuating the lack of knowledge about AS across ethnic/racial groups. A vicious cycle is created in that significant changes in diagnostic practices, if needed, are unlikely to occur without supportive research data.

Research on AS has expanded tremendously in recent years. Areas of continued need include the establishment of more widely accepted diagnostic criteria, which is crucial to beginning to obtain more definitive prevalence data. Further, there is significant need for developing effective ways of training clinicians to recognize the symptoms of AS, and to diagnosis accurately, including effective methods of interviewing families of varied ethnic/racial groups. An exploration of ethnic/racial issues, including prevalence, may seem premature given the many questions about AS, in general, that remain unanswered. Nevertheless, there appears to be considerable cause for concern about possible bias in the diagnosis of AS in African Americans, and a great need for research exploring these issues, and those involving other ethnic/racial groups, as well.

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ISSUES PERTAINING TO SIBLINGS OF INDIVIDUALS WITH AUTISM SPECTRUM DISORDERS

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Many articles and books have highlighted the problems and worries that affect parents of individuals with autism spectrum disorders (ASDs) (e.g., Bashe & Kirby, 2005; McMahon, Malesa, Yoder, & Stone, 2007; Orsmond, Lin, & Seltzer, 2007; Ozonoff, Dawson, & McPartland, 2002; Royko, 2007; Stillman, 2005). However, because bonds between brothers and sisters tend to be the long-lasting relationships in most people's lives (Meyer & Vadasy, 1994; Orsmond & Seltzer, 2007; Papalia, Sterns, Feldman, & Camp, 2007), siblings of people with ASDs comprise another group with needs and concerns due to living with an immediate family member who has a pervasive developmental disorder (Feiges & Weiss, 2004; Harris & Glasberg, 2003; Ozonoff et al., 2002; Stillman, 2005). The purpose of this chapter is to provide an overview of issues that are relevant to the experience of having a brother or sister with an ASD. Information will be presented about the possibility that siblings of already diagnosed individuals may themselves have some characteristics of ASDs. Psychosocial issues that pertain to brothers and sisters of people with ASDs also will be discussed.

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SIBLINGS' SUSCEPTIBILITY TO ASDs

The heritability of ASDs reportedly exceeds 90% (Halgin & Whitbourne, 2007; Rutter, 2005), indicating that genetic endowment strongly influences the etiology of these disorders (Halgin & Whitbourne, 2007). Research to date has suggested chromosomes 2, 7, and 15 as possible sites for genetic abnormalities associated with ASDs (Filipek et al., 1999; Halgin & Whitbourne, 2007; Muhle, Trentacoste, & Rapin, 2004; Yonan et al., 2003). However, the genetics of autism is complex and is not yet fully known (Chuthapisith, Ruangdaraganon, Sombuntham, & Roongpraiwan, 2007; Goldberg et al., 2005; Muhle et al., 2004; Ozonoff, South, & Provencal, 2005; Rutter, 2005; Szatmari, Zwaigenbaum, & Bryson, 2004).

Despite the current lack of definite information about the locations of genes that cause autism, abundant evidence demonstrates that ASDs run in families (Toth, Dawson, Meltzoff, Greenson, & Fein, 2007). Findings of both family studies and twin studies reveal that genetic factors contribute to the development of ASDs (Connors et al., 2005; Gillberg & Cederlund, 2005; Filipek et al., 1999; Micali, Chakrabarti, & Fombonne, 2004; Muhle et al., 2004; Rutter, 2005; Szatmari et al., 2004; Toth et al., 2007; Yonan et al., 2003; Zwaigenbaum et al., 2002). For example, twin studies have examined identical twin pairs to learn the frequency with which both twins in a pair have an ASD. These studies indicated that when one identical twin had an ASD, the other twin also had an ASD from 36% to 95% of the time (Cassel et al., 2007; Micali et al., 2004; Zwaigenbaum et al., 2002). This rate of agreement (i.e., concordance) among identical twin pairs contrasts sharply with rates of concordance for fraternal twins. When one fraternal twin has an ASD, the frequency with which the other twin also has an ASD is in the range of only 0–23% (Zwaigenbaum et al., 2002). Since identical twins have exactly the same genes, the high rate of concordance for ASDs among identical twins points to genetic factors as a prominent underlying cause.

According to Rutter (2005), "… the absolute likelihood of autism being present in a second child in the same family is quite low" (p. 441). Studies have found that among families in which one child has been diagnosed with an ASD, only 2–10% of siblings also will have an ASD (Filipek et al., 1999; McMahon et al., 2007; Merin, Young, Ozonoff, & Rogers, 2007; Micali et al., 2004; Muhle et al., 2004; Rutter, 2005). In spite of the low absolute likelihood, however, this rate of recurrence is roughly equivalent to a 1 in 20 to 1 in 10 chance of having another child with an ASD (Filipek et al., 1999). This level of risk is anywhere from 20 to 50 times higher than the risk level in the general population, which has only a 1 in 500 chance of having a child with an ASD (Filipek et al., 1999; Rutter, 2005). Therefore, siblings of people with ASDs comprise an at-risk group for having ASDs themselves (Blacher & Hastings, 2005; Filipek et al., 1999; Goldberg et al., 2005; Harvard Mental Health Letter, 2007; Loh et al., 2007; McMahon et al., 2007; Merin et al., 2007; Micali et al., 2004; Sullivan et al., 2007; Toth et al., 2007; Volkmar, Chawarska, & Klin, 2005).

SIBLING STUDIES TO FIND EARLY MARKERS OF ASDs

Since at least some siblings of children diagnosed with ASDs may themselves develop similar conditions, researchers are conducting studies of siblings to learn more about symptoms that might allow for earlier identification of these disorders. Early detection could lead to earlier intervention, thereby contributing to better outcomes for affected individuals (Cassel et al., 2007; Gamliel, Yirmiya, & Sigman, 2007; Merin et al., 2007).

When searching for diagnostic markers, the use of a group that is known to be at increased risk for ASDs is important because these conditions "... occur in approximately one in every 150–250 pre-school children, making the disorder too rare to study prospectively in the general population" (Cassel et al., 2007, p. 123). Scientific investigations focusing on siblings of children with ASDs have examined a variety of characteristics that could signal the presence of an ASD. These attributes include theory-of-mind ability, facial expressions, visual tracking and fixation patterns, bodily movements, language ability, cognitive functioning, social communication skills, and capacity for joint attention.

In one such study, Shaked, Gamliel, and Yirmiya (2006) examined theory-of-mind abilities in siblings of children with ASDs. The term "theory of mind" refers to the ability to recognize the mental states of others, such as their thoughts and beliefs; deficiencies in this ability are assumed to underlie the social deficits of children with ASDs. Shaked et al. (2006) sought to learn whether siblings of children with ASDs also might manifest problems in theory-of-mind abilities. They compared 24 siblings of children with ASDs and 24 typically developing children, all of whom were about four and half years old. Both groups were comparable in terms of expressive and receptive language proficiency, cognitive ability, and daily living skills, as measured by mean standardized test scores. These participants were asked to solve a false belief task, presented to them in the form of a story. In the story, a girl placed a ball in a basket and left; during her absence, a boy moved her ball from the basket to another location. The participants were asked where the girl would look for the ball when she returns. Next, they were presented with three different vignettes in which people said things that were not intended to be taken literally. The participants were asked questions to check whether they understood the figurative expressions used in the vignettes. Analyses of the findings from both of these tasks revealed no between-group differences, suggesting that siblings of children with ASDs performed no worse than typically developing children with regard to theory-of-mind ability.

However, other investigations examining siblings of children with ASDs have identified several behaviors that show greater promise as ASD markers. For example, Cassel and colleagues (2007) compared 12 six-month-old infants who had older siblings with an ASD and 19 six-month-old infants who had typically developing older siblings with regard to the babies' emotional expressivity. To study the babies' facial expressions, Cassel et al. (2007) employed a procedure called the ''face-to-face/still-face'' (FFSF) protocol. This method required a parent to play with the child for a few minutes, then to stop playing for a few minutes while keeping an expressionless face, and finally to resume play. Infant participants' responses to this sequence were videotaped and then coded for the presence of either smiling or crying. Results indicated that infant siblings of children with ASDs smiled for significantly less time during the FFSF test than did the infants who had typically developing siblings.

Participants with ASD siblings in the Cassel et al. (2007) study were re-evaluated at either 15 or 18 months of age, using an instrument called the Early Social Communication Scale (ESCS). This instrument examines a preverbal child's ability to use gazes and gestures to direct other people's attention to events or objects, and to engage in shared attention when other people point out objects or events. It also measures a child's ability to make eye contact or use gestures to ask for help or to request objects. Behavioral ratings from the ESCS revealed that 15-month-old siblings of ASD children demonstrated less interest in and enjoyment of toys than similarly aged children in the comparison group. Also, 18-month-old siblings of ASD children were significantly less likely than siblings of typically developing children to respond to an examiner's attempts to get the child to look at a toy across the room. Cassel et al. (2007) concluded that young siblings of children with ASDs manifest problems with emotional expression and communication that may signify the need for early intervention.

Merin et al. (2007) also used a form of the still-face technique to compare visual fixation patterns in infant siblings of older children who did or did not have autism. Each participant's mother played with the child for one minute, shifted to a still face for a minute, and then resumed play with the baby for a minute. During this sequence of events, each of the infant participants was videotaped by specialized cameras that tracked the baby's gaze position. Using data derived from the videotapes, Merin et al. (2007) calculated an index score to represent the percentage of time that each child looked at its mother's eyes and mouth. Through a cluster analysis of these scores, they identified a subgroup of 11 infants who seldom looked at their mothers' eyes. Ten of these 11 infants had an older sibling with autism (Merin et al., 2007). On the basis of these findings, Merin and colleagues suggested that abnormal face scanning in infancy might be a trait that denotes susceptibility to ASDs.

Another group of investigators (Loh et al., 2007) used videotapes of high- and low-risk infants to study whether unusual bodily movements might serve as early markers of ASDs. They coded videotapes of both groups of infants to check for the presence of repetitive movements that did not appear to be communicative. Loh and colleagues discovered that among 12- and 18-month-old children, arm waving was noticed more often among infants who were eventually diagnosed with an ASD themselves. Also, placing the hands near the ears occurred with higher frequency among 18-month-olds who had an ASD sibling than among children in the comparison group. The authors noted that their study needs to be replicated but they indicated that these findings might represent a first step toward the identification of behaviors that could lead to earlier detection of ASDs (Loh et al., 2007).

Because cognitive and language abilities often are impaired in children with ASDs, these two domains were examined prospectively by Gamliel et al. (2007) to check for differences in siblings of children with ASDs as compared to siblings of neurotypical children. Among a group of 39 ASD siblings, 12 demonstrated delays in cognitive and language abilities; in contrast, only 2 participants among a group of 39 children with neurotypical siblings showed similar developmental delays. Although group differences in cognitive functioning disappeared by the time that the participants reached the age of 54 months, some differences in both expressive and receptive language ability still were evident among the siblings of children with ASDs (Gamliel et al., 2007).

A study conducted in Thailand (Chuthapisith et al., 2007) also examined language and cognitive abilities among siblings of children with ASDs. When 32 pre-school-aged siblings of ASD children were compared with a group of 28 pre-schoolers who had no ASD siblings, it was found that 8 of the high-risk siblings exhibited delays in use of oral language. However, similar to the findings of Gamliel et al. (2007), the two groups in this study produced no significant differences on mean scores for verbal, nonverbal, and composite IQs as measured by the fourth edition of the Stanford-Binet Intelligence Test.

Iverson and Wozniak (2007) investigated the relationship between motor abilities and vocalization skills among infant siblings of children with ASDs. From ages 5 months to 14 months, and again at 18 months, these babies and a no-risk comparison group of infants were videotaped with their caregivers on a monthly basis. The videotaped observations captured information about the babies' natural postures, play behaviors, and attainment of developmental milestones. Participants' videotaped movements then were coded by raters who were unaware of the group membership of each infant. Results found that high-risk infants reached developmental milestones (such as sitting, babbling, showing something to someone else, and saying the first word) significantly later than no-risk infants. Infants with ASD siblings also demonstrated significantly less stable posture than babies in the no-risk group, showed fewer rhythmic arm movements from pre-babbling to the onset of babbling, and manifested delays in language comprehension and vocabulary production at age 18 months. On the basis of these findings, Iverson and Wozniak (2007) recommended that delays in babbling and in the attainment of motor development milestones should be considered as non-specific indicators of risk for possible ASDs.

In addition to cognition and language, social communication in siblings of children with ASDs served as a variable of interest in a study conducted by Toth and colleagues (2007). These researchers compared 42 toddlers who had ASD siblings against 20 toddlers with no family history of ASDs, and learned that the sibling group demonstrated a lower IQ score and lesser abilities for both expressive and receptive language. Furthermore, the siblings of children with ASDs scored lower on measures of adaptive behavior and social communication. Toth et al. (2007) also stated that siblings of children with ASDs were less likely than children in the comparison group to produce social smiles, and used fewer words and gestures. Parents of the toddlers with ASD siblings in this study reported that they noticed social impairments in their undiagnosed children by as early as 13 months of age. Therefore, Toth and colleagues (2007) recommended that young siblings of children with ASDs should be monitored carefully to detect developmental delays and to provide intervention if necessary.

Capacity for joint attention is yet another behavior that has been studied as a potential early marker for ASDs. Sullivan et al. (2007) evaluated joint attention abilities of 51 toddlers who had siblings diagnosed with autism. As one way of testing the participants' joint attention abilities, the examiner made a sound to express excitement, turned his or her head, looked at an object positioned on a wall at a 45° angle to the side, and checked to see if the toddler looked at the same object. Another test involved the examiner pointing to an object placed at either 90° or 180° from the child and saying, "Look." A third measure of joint attention was taken from an item in a commercially available test called the Autism Diagnostic Observations Schedule (ADOS; Lord, Rutter, DiLavore, & Risi, 1999). This measure involved the activation of a switch-operated toy while calling the child's name and telling the child to look at the toy. These three tests were administered when the participants were 14 months old and were repeated when they were 24 months of age. When the participants reached 30 or 36 months of age, they were assessed using the ADOS and the Mullen Scales of Early Learning (MSEL; Mullen, 1995). On the basis of results from the ADOS and the MSEL, participants were assigned to one of three groups: ASD, broader autism phenotype, and neurotypical. Sullivan et al. (2007) reported that problems with joint attention at 14 months of age predicted eventual problems with expressive and receptive language, in addition to predicting a later diagnosis of ASD. In contrast, the ability to demonstrate joint attention at 14 months was related to a non-ASD outcome.

Collectively, the studies described above suggest that siblings of children with ASDs often lag behind children with no family history of ASDs in terms of motor, language, and social development. These investigations point to a need for parental awareness that siblings of children who have already been diagnosed with an ASD constitute a group that also may struggle due to developmental delays. The early development of undiagnosed siblings needs to be monitored so that early indicators of ASD will be recognized and will lead to remedial actions such as in-depth evaluation and intervention if warranted.

Even if siblings of people with ASDs do not meet full criteria themselves for a diagnosable ASD, they may exhibit features of the so-called "broader autism phenotype" or BAP (Bashe & Kirby, 2005; Bishop, Mayberry, Wong, Maley, & Hallmeyer, 2006; Cassel et al., 2007; Filipek et al., 1999; Micali et al., 2004; Ozonoff & Rogers, 2003; Ozonoff et al., 2005; Rutter, 2005; Toth et al., 2007; Volkmar & Klin, 2005). BAP characteristics include social impairment and slower language development in childhood, anxiety or other psychiatric conditions in adulthood, and problems with executive functions of the brain such as difficulties with planning, self-monitoring, and cognitive flexibility (Micali et al., 2004; Ozonoff & Rogers, 2003; Ozonoff et al., 2005; Presmanes, Walden, Stone, & Yoder, 2007).

Some parents reportedly do notice differences in the development of siblings of children with ASDs, possibly because they have greater familiarity with characteristics that may be indicative of ASDs (McMahon et al., 2007). Unfortunately, other parents sometimes might fail to recognize mild social and communication impairments in siblings of children with ASDs, because the symptoms manifested by the siblings may be less severe than those of the child who already has been diagnosed with an ASD (Filipek et al., 1999; McMahon et al., 2007). Given the possibility that brothers and sisters of people with ASDs also may have an ASD themselves, these siblings should be screened for the presence of such disorders (Filipek et al., 1999; Harvard Mental Health Letter, 2007). Screening improves the chances of identifying ASDs in less obviously affected siblings, which in turn increases the likelihood that they will receive whatever supports might be necessary to help them thrive (Filipek et al., 1999).

COMMON EXPERIENCES OF INDIVIDUALS WHO HAVE SIBLINGS WITH ASDs

The family experiences of individuals whose siblings have ASDs often include certain types of situations and emotions. One commonality among neurotypical individuals who have ASD siblings is that they frequently lack sufficient information about the nature of their brother's or sister's disorder (Glasberg, 2000; Marcus, Kunce, & Schopler, 2005; Meyer & Vadasy, 1994). Without such information, neurotypical children may harbor misconceptions about the causes of ASDs and may be fearful of developing problems similar to those of their siblings (Marcus et al., 2005; Meyer & Vadasy, 1994). For example, some youngsters might worry that autism is a contagious condition that they might contract from their ASD siblings (Harris & Glasberg, 2003). Some neurotypical children also might mistakenly believe that they caused a sibling's ASD through a show of anger or physical aggression toward the sibling (Feiges & Weiss, 2004).

In a study conducted by Glasberg (2000), 63 neurotypical youngsters who ranged in age from 5 to 17 years of age were interviewed to determine how well they understood the nature of their siblings' ASDs. Results revealed that even the teen-aged participants in this investigation lacked an adequate understanding about the causes of autism and the effects of autism on the lives of their disabled siblings. Yet participants' parents mistakenly believed that their neurotypical children understood autism and its life implications better than the participants actually did. For example, more than 90% of the parents in the Glasberg (2000) study expected that their neurotypical children knew the name of their brother's or sister's diagnosis, yet 20% of these participants claimed that they did not know the name of their sibling's disorder. On the basis of these findings, it appears likely that most neurotypical youngsters would benefit from being given more detailed information about the characteristics and effects of ASDs. Receiving age-appropriate explanations about the symptoms and causes of ASD could help to reduce neurotypical siblings' stress due to a lack of understanding about the etiology of these conditions (Feiges & Weiss, 2004; Glasberg, 2000).

Another reality for many children who have siblings with ASDs is a reduction in the amount of time and attention that their parents can give to them (Bashe & Kirby, 2005; Bittner, 2006; Bleach, 2001; Feiges & Weiss, 2004; Marcus et al., 2005; Meyer & Vadasy, 1994; Ozonoff et al., 2002). Out of necessity, parents usually must allocate more of their time and energy to caring for a child with an ASD. However, because pre-adolescent children tend to think and interpret events concretely (Papalia, Olds, & Feldman, 2006), a neurotypical youngster may not grasp the reasons for such parenting behavior and may misinterpret such actions to mean that the brother or sister with an ASD is loved more than the neurotypical child (Harris & Glasberg, 2003; Meyer & Vadasy, 1994). This circumstance also may lead the neurotypical child to feel resentful of the sibling with ASD (Feiges & Weiss, 2004; Stillman, 2005). For example, an 11-year-old girl wrote a poem titled "Dad Hogger" to express her frustration about the way that her older brother with autism monopolized their father's attention (Naseef, 2006, p. 160). Children who have siblings with ASDs occasionally should be allowed to spend special time with one or both parents, away from their brother or sister with ASD (Harris & Glasberg, 2003). Providing opportunities for individualized time and attention can alleviate neurotypical children's perceptions of parental favoritism toward their siblings with ASDs.

Because parents' time and energy is limited, many neurotypical children are expected to assume significant responsibility for the care of a brother or sister with an ASD. This situation has been referred to as parentification (Feiges & Weiss, 2004; Siegel & Silverstein, 2001). Some typically developing siblings may become angry or feel abandoned by their parents for being placed in such a position, whereas others may feel comfortable and take pride in holding an adult-like position within the family (Feiges & Weiss, 2004). Some neurotypical siblings may voluntarily adopt a parentified role because caring for their developmentally disabled brothers or sisters earns the approval of their parents (Siegel & Silverstein, 2001).

Another experience that is common among neurotypical children who have siblings with ASDs is difficulty in playing with their developmentally disabled siblings (Harris & Glasberg, 2003; Marcus et al., 2005; Siegel & Silverstein, 2001; Tsao & Odom, 2006). Because many children with ASDs lack play skills such as sharing and turn-taking (Beyer & Gammeltoft, 1998), neurotypical siblings may lose interest in attempting to engage their brother or sister with ASD in play activities (Harris & Glasberg, 2003; Ozonoff et al., 2002). Parents may need to teach their typically developing children how to use behavioral techniques such as making eye contact, providing prompts, and giving praise as positive reinforcement to promote more interactive play with siblings who have ASDs (Harris & Glasberg, 2003; Tsao & Odom, 2006).

Having a brother or sister with an ASD also may evoke a variety of negative emotions. These may include jealousy, resentment, frustration, anger, embarrassment, guilt, sadness, loneliness, and perfectionism (cf. Bittner, 2006; Bleach, 2001; Coyle, 2006; Feiges & Weiss, 2004; Fisher, n.d.; Frender & Schiffmiller, 2007; Harris & Glasberg, 2003; Liang, 2006; Royko, 2007; Siegel & Silverstein, 2001). In addition to jealousy about the amount of time and attention that parents give to siblings with ASDs, neurotypical siblings may feel jealous or resentful about being held to a higher standard with regard to self-sufficiency, chores, or household rules (Bleach, 2001; Feiges & Weiss, 2004; Flaschen, 2006; Meyer & Vadasy, 1994; Siegel & Silverstein, 2001). They may feel frustrated about a developmentally disabled sibling's behavioral rituals, about the ASD sibling's slow progress in attaining self-care skills, about disruptions in daily routines such as family meals or watching television, or about having to cope with a sibling's ASD symptoms even while on family vacations (Band & Hecht, 2001; Buschbacher, Fox, & Clarke, 2004; Feiges & Weiss, 2004; Frender & Schiffmiller, 2007; Liang, 2006; Konidaris, 2005).

Anger is a feeling that is difficult to acknowledge and express for many individuals who have siblings with ASDs (Feiges & Weiss, 2004; Siegel & Silverstein, 2001; Strohm, 2005). Neurotypical children may feel angry at their parents for giving more attention to siblings with ASDs, or at their siblings for requiring special accommodations and disrupting daily activities (Feiges & Weiss, 2004; McHugh, 2003). They also may feel angry about the unfairness of having an unusual family life that is fraught with difficulties which most other families do not experience (Feiges & Weiss, 2004; McHugh, 2003). Yet many neurotypical siblings deny that they feel angry about their circumstances and do not recognize or admit to such feelings until they are much older (Feiges & Weiss, 2004;

Siegel & Silverstein, 2001). In some families, parents may directly forbid expressions of anger toward the disabled sibling or toward them (Strohm, 2005). In others, neurotypical children may suppress anger because they perceive that expressing such feelings would only impose a greater burden on a family that is already struggling to make the best of a difficult situation (Feiges & Weiss, 2004).

Embarrassment is another uncomfortable emotion that many neurotypical youngsters experience in response to inappropriate behaviors of their siblings with ASDs (Feiges & Weiss, 2004; Fisher, n.d.; Harris & Glasberg, 2003; Meyer & Vadasy, 1994; Orsmond & Seltzer, 2007; Siegel & Silverstein, 2001). For example, 10-year-old Emily Hecht (Band & Hecht, 2001) expressed embarrassment when her older brother laughed too loudly in movie theaters, and 11-year-old Zoe Naseef (2006) indicated that she was embarrassed about being afraid of her older brother who has autism. Another author, Stephanie Coyle (2006), wrote that she felt so embarrassed about her brother with ASD that she kept his existence a secret from many of her friends and concocted fictitious excuses to explain why her friends should not come to her house to socialize. It may be difficult and uncomfortable for neurotypical siblings to explain the nature of a brother's or sister's disorder to typically developing peers, and worries about being rejected by peers are common (Feiges & Weiss, 2004). Feelings of embarrassment about ASD siblings may be especially pronounced during adolescence, when typically developing teens may be particularly concerned about the opinions of peers who may not understand the characteristics of ASDs (McHugh, 2003; Siegel & Silverstein, 2001; Strohm, 2005).

Negative emotions such as jealousy, anger, and embarrassment often lead to feelings of guilt among individuals who have siblings with ASDs, because they are aware that such feelings are not viewed as acceptable given the circumstances (Bittner, 2006; Feiges & Weiss, 2004; McHugh, 2003). In some instances, typically developing individuals may experience a sense of survivor guilt for having been born without developmental disabilities (Siegel & Silverstein, 2001; Strohm, 2005). In other cases, guilt may be a by-product of believing that more should be done to help the ASD sibling, or conversely it may result from a lack of involvement with the brother or sister who has ASD (Feiges & Weiss, 2004).

Another feeling that is common among siblings of individuals with ASDs is sadness. Neurotypical siblings often feel sad that life is hard for their developmentally disabled brother or sister. In addition, they are sorrowful about the emotional pain that their parents endure, and they mourn the loss of normalcy in their own lives (Feiges & Weiss, 2004).

Yet another frequent emotion for neurotypical siblings is loneliness. People who have brothers or sisters with ASDs may feel lonely when their parents or other family members cannot spend time with them due to caregiving responsibilities (e.g., Fisher, n.d.). They also may feel socially and emotionally isolated from peers whose family circumstances bear little resemblance to their own (Feiges & Weiss, 2004; Meyer & Vadasy, 1994; Orsmond & Seltzer, 2007).

Some neurotypical children may respond to having a sibling with an ASD by striving to be perfect in all that they do. They may be trying to lighten their parents' burden by being self-sufficient, or they may hope to garner positive attention for themselves by maintaining high levels of achievement. However, by appearing to be highly capable, they may unwittingly contribute to their own isolation because their parents consequently may not notice their loneliness and need for emotional support (Feiges & Weiss, 2004). Additionally, the success of high achievers may elicit feelings of sorrow or guilt due to the contrast between their own good fortunes and the lives of their siblings with ASDs (Feiges & Weiss, 2004).

ADJUSTMENT OF NEUROTYPICAL CHILDREN TO HAVING ASD SIBLINGS

Studies investigating the issue of adjustment to having a sibling with an ASD have produced mixed findings. Some research suggests that siblings of children with ASDs are more likely than siblings of children with no disability to manifest adjustment problems (Orsmond & Seltzer, 2007). For example, Hastings (2003) reported that siblings of children with autism appeared to have significantly more problems in peer relationships, significantly lower levels of pro-social behavior, and overall poorer adjustment when compared with a normative sample of other community-dwelling children. However, other studies have shown no greater risk for either internalizing or externalizing behavior problems (Orsmond & Seltzer, 2007). Orsmond and Seltzer (2007) attributed this lack of consistency to variations in research methodology, such as differences in the sizes of participant samples and in the types of instruments that were used to measure adjustment. These authors also noted that siblings of ASD children tend to score as well as or better than other children with regard to positive self-concept and self-competence.

One factor that may impact how well or poorly a person adjusts to having a sibling with ASD is the severity of the sibling's developmental disability.

The better the functioning of the child with ASD, the better the adjustment of his or her neurotypical sibling tends to be (Feiges & Weiss, 2004).

Other variables also may influence how someone adjusts to having a sibling with an ASD. For example, gender may affect the relationships of neurotypical individuals and their ASD siblings (Hastings, 2003; Orsmond & Seltzer, 2007). Past research has found that among typically developing children, sibling bonds tend to be stronger between same-sex siblings than between opposite-sex siblings (Feiges & Weiss, 2004; Harris & Glasberg, 2003). A similar pattern may hold true regarding how neurotypical children relate to their siblings who have ASDs (Orsmond & Seltzer, 2007). For example, a 24-year-old man wrote the following about his older brother with autism: "I felt a very strong emotional connection to him and wanted the luxury of continuing to participate in his development" (Konidaris, 2005, p. 1272). Another author (Royko, 2007) described his neurotypical son Jake as "a devoted, protective brother" (p. 14) of Jake's twin Ben, who has autism. Typically developing sisters also may feel especially fond of their sisters with ASD, as exemplified in this passage: "Outside of school, Kristy was my friend. Besides, I thought the other kids at school would not understand Kristy or accept her complex needs like I could" (Bittner, 2006, p. 142).

Perhaps due to her sense of closeness to her sister, Kimberly Bittner (2006) also wrote that she "became like a second mommy to Kristy … I didn't always grasp it so much then, but as I grew up I realized I gave up a lot to play such a large part in Kristy's upbringing" (p. 142). Bittner's statement may reflect the experiences of many sisters of individuals with ASDs. Sisters are more likely than brothers to assume a care-giving role in relation to a sibling with an ASD, and they may be less shielded from the negative effects of the developmental disorder (Feiges & Weiss, 2004; Fisher, n.d.; McHugh, 2003; Meyer & Vadasy, 1994; Orsmond & Seltzer, 2007; Siegel & Silverstein, 2001; Stevens, 2007). For example, an 11-year-old girl wrote the following:

> Sometimes it's kind of hard having Daniel as my brother. There have been times when he has embarrassed me, made me really mad, or when I've felt worried about him. Even though I am actually two years younger than he is, there are times that I feel kind of responsible for Daniel … . (Band & Hecht, 2001, p. 41)

Boys may feel the impact of having a sibling with an ASD less intensely because they may be more likely than girls to participate in activities outside the home, and therefore less involved in care-giving (Blacher & Hastings, 2005; Feiges & Weiss, 2004). Alternatively, parents and other family members may tacitly assume that sisters should be more involved than brothers in caring for a sibling with ASD (e.g., Fisher, n.d.), since care-giving behavior is consistent with gender role norms for females (Papalia et al., 2006).

Age also affects a neurotypical individual's reaction to having an ASD sibling, due to differences in the ability to understand and cope with the sibling's disorder (Feiges & Weiss, 2004; Orsmond & Seltzer, 2007). Younger children tend to be less able to comprehend the nature of ASDs but their level of understanding improves as they get older (Feiges & Weiss, 2004; Glasberg, 2000). Age similarity among siblings also may be a relevant factor. Because children who are similar in age must compete more directly for their parents' time and attention, typically developing children who are close in age to ASD siblings may exhibit adjustment problems such as jealousy (Feiges & Weiss, 2004). On the other hand, a neurotypical sibling might experience more empathy for an ASD sibling who is close in age to him- or herself (Strohm, 2005).

Another pertinent individual difference is birth order (Feiges & Weiss, 2004; Harris & Glasberg, 2003; Orsmond & Seltzer, 2007; Strohm, 2005). Older siblings have experienced a normal quality of family life prior to a birth of the child with ASD. Therefore, they may be more aware of parental stress and may more keenly feel the loss of parental attention (Strohm, 2005). In contrast, younger siblings of ASD children may take longer to realize that their families' circumstances are different from those of families with typically developing children. Also, if they have no typically developing siblings, younger siblings of ASD children may be somewhat disadvantaged in terms of learning social skills that are usually acquired through interactions with siblings, such as sharing. It is also possible that as they grow older, younger siblings eventually will exceed the abilities of older siblings with ASDs, which may engender feelings of confusion, resentment, or survivor guilt (McHugh, 2003).

Past studies have reported poorer adjustment in older sisters and younger brothers of ASD siblings (Feiges & Weiss, 2004; Harris & Glasberg, 2003). Older sisters may fare worse as a result of their gender rather than their age; as mentioned earlier, sisters may be expected to perform many care-giving duties for siblings with ASDs (McHugh, 2003). The poorer psychological adjustment of younger boys may be due to their parents' difficulties in giving them sufficient time and attention while caring for their children with ASDs (McHugh, 2003).

Family size also may influence adjustment to having a sibling with an ASD (Orsmond & Seltzer, 2007). Feiges and Weiss (2004) wrote that adjustment often is better when there is more than one typically developing sibling, since these siblings can share care-giving duties and provide each other with emotional support. Other family-related variables that may influence adjustment to having a developmentally disabled sibling include the parents' emotional health, the quality of parents' marital relationships, and families' socioeconomic status (Feiges & Weiss, 2004; Orsmond & Seltzer, 2007).

At various times in their lives, typically developing individuals may benefit from the support of professional mental health service providers who understand their circumstances and needs. Individual counseling and support groups are two interventions that can assist neurotypical siblings by giving them information, allowing them to voice distressing emotions, and teaching them coping skills (Siegel & Silverstein, 2001; Strohm, 2005).

ISSUES PERTAINING TO ADULTS WITH ASD SIBLINGS

Once a typically developing sibling reaches adulthood, new concerns may emerge. Having a sibling with an ASD may influence a person's career path, place of residence, and personal relationships (Strohm, 2005). Frequently, siblings of people with ASDs enter helping professions such as education, medicine, and mental health care (Feiges & Weiss, 2004; Harris & Glasberg, 2003; Meyer & Vadasy, 1994; Siegel & Silverstein, 2001; Strohm, 2005). Neurotypical siblings may gravitate toward caring professions because their childhood experiences have heightened their awareness of diversity and social justice issues. Also, as a result of living with a brother or sister with special needs, they may have acquired care-giving skills that they can put to use in the helping professions (Strohm, 2005).

Deciding where to live may prompt feelings of divided loyalties for adults whose siblings have ASDs. A sense of responsibility may lead some adult siblings to stay close to their families of origin. Those who opt to move away in pursuit of educational or career opportunities may experience guilt about leaving, possibly accompanied by resentment over the fact that most adults can choose to relocate without being troubled by guilt (Strohm, 2005).

Dating and marriage may be complicated by the presence of a sibling who has an ASD. An adult whose brother or sister has an ASD may be extremely cautious about forming intimate relationships, due to uncertainties about how potential partners might react to the developmentally disabled sibling (Feiges & Weiss, 2004; Strohm, 2005). Choosing a compassionate and understanding life partner becomes even more important in situations where the adult sibling lives with and provides daily care-giving for a brother or sister with an ASD (Harris & Glasberg, 2003). Among families where the quality of the parents' marital relationship was strained by the demands of caring for a developmentally disabled child, adult siblings may be disenchanted with the idea of getting married themselves (Feiges & Weiss, 2004).

Whether or not to have children is another issue with which many adult siblings grapple (Feiges & Weiss, 2004; Harris & Glasberg, 2003; Strohm, 2005). Knowing that they could themselves become parents of children with ASDs may trigger feelings of fear, even prompting some adult siblings to forego having children. In other cases, adult siblings will consider the low level of absolute risk for having a child with an ASD and pursue their desires for a family of their own (Feiges & Weiss, 2004). Also, due to their familiarity with the characteristics of ASDs, they may feel prepared to accept and care for a developmentally disabled child in the event that they have one (Strohm, 2005). Should they have children of their own, adult siblings eventually will be required to explain the nature of their ASD siblings' disorder to their own offspring (Harris & Glasberg, 2003).

Yet another important consideration facing many adult siblings is the possibility of assuming financial and/or legal responsibility for their brothers or sisters with ASDs. Such actions may be precipitated by the illness or death of one or both parents (Harris & Glasberg, 2003). Adult siblings should obtain the guidance of attorneys who are familiar with disability law so that they can make appropriate decisions concerning living arrangements, financial planning, medical care, and other needs of their ASD siblings (Feiges & Weiss, 2004; Harris & Glasberg, 2003; Strohm, 2005).

POSITIVE EFFECTS OF HAVING AN ASD SIBLING

Although having a sibling with an ASD presents many challenges, this situation also may promote the development of positive qualities and emotions. Individuals whose brothers or sisters have ASDs often indicate that they have learned to be kinder, more patient, more persistent, and more open-minded as a result of living with their ASD siblings. They discover that the experience of having an ASD sibling has imbued them with strength and wisdom when facing other difficult life circumstances (Feiges & Weiss, 2004). Beneficial outcomes also may include increased emotional awareness and greater appreciation for life's joys and blessings (Bleach, 2001; Feiges & Weiss, 2004).

Siblings of individuals with ASDs take pride in the accomplishments of their brothers and sisters, knowing how hard-won these may be (Feiges & Weiss, 2004). Finally, they report feelings of caring and love for their ASD brothers and sisters. Jason Konidaris (2005) eloquently conveyed these emotions when he wrote

> I am not a martyr. I have gained infinitely from the relationship I have with my brother. To him I owe my character. I am a better person, a more complete person, one that achieves the daunting balance between compassion, discipline, and understanding. I carry this benefit, which my brother has fostered within me, to all other aspects of my life. (pp. 1274–1275)

NOTE

1. Julie Deisinger is the sister of an individual with an autism spectrum disorder.

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REFLECTIONS ON THE SCHOOL EXPERIENCES OF A STUDENT WITH AUTISM SPECTRUM DISORDERS

John Markley

Mr. Markley is an adult with Autism Spectrum Disorder (ASD) who was invited by the editors to share his recollections of attending school as a student with a developmental disorder that affected his social, emotional, and physical developmental while leaving intact his superior cognitive capabilities. Mr. Markley successfully completed an undergraduate degree, wrote for the campus newspaper, and is a freelance writer.

My first major exposure to other kids outside the family was a preschool I attended at a local church. The teachers and other students terrified me, and the experience went badly. I could handle structured activities, barely, but the free play periods were intolerable – the noise of the other children playing was upsetting and even physically painful, and the lack of order confused and frightened me. I would suffer overwhelming fits of fear and anger, and even became violent on one occasion. Unfortunately, my parents were not told about these episodes by the school, and I was too afraid to admit them myself.

Luckily, the next year I went to a different preschool, and the difference was like night and day. The class had a much smaller group of kids, which made things less intimidating, and the whole atmosphere was calm, peaceful,

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and orderly. I promptly became a model student. I did not like talking to the other kids, but I could handle being around them.

Kindergarten went relatively well. Things were calm, and I was well behaved as a result. I did not talk to the other kids very much, but they did not bother me very much either. The class was strictly supervised, so the other kids did not have much opportunity to bother me.

Things changed in the next year. I was teased and bullied relentlessly from 1st grade onward. My abnormality was easy for the other kids to see: I shook and blinked constantly, I walked and moved awkwardly, and I had a speech impediment. Teachers did not care, and I quickly gave up telling them when I was bullied, since it did no good. I did not try telling my parents; I did not think they would care either. I remained a very well-behaved student, mostly because I dreaded doing anything that might draw attention to me. My desk was very messy, due to my extreme reluctance to throw anything away, on the chance that it might turn out to be useful, which eventually resulted in the teacher bringing me in front of the class to publicly berate me at great length. Being yelled at and told how rotten I was was not new to me – I got it all the time at home – but being made the center of the class's attention was extremely upsetting.

Once I learned to read in 1st grade, school bored me intensely. I would read all my textbooks in advance, often months before we had reached that unit in class. I would also read all the history, geography, and science books I could get at home or from my grandfather, and what we learned in school was very dull by comparison. I coped with this through fantasy; almost all my time in school was spent in my imagination. During recess, rather than participate in any games, I would isolate myself from the other children to avoid harassment and continue with whatever I had been imagining. There would be no overt sign that I was doing anything imaginative or creative; I would simply stand in place, or at most pace back and forth.

Making friends was very difficult; I was too afraid of other kids to approach them. Until her death when I was seven, my best friend was my paternal grandmother. Spending time with her was ideal for me – she was very calm, gentle, and quiet. Her death hit me very hard, but fortunately not long after her death I started to make a few friends. They were, like me, outcasts, but I was fine with that; I had no interest in sports and thus had little in common with popular boys, who despised me in any case. By the end of third grade, I had a few friends I would see with some regularity.

Academically, I had extremely high scores on standardized tests, and my reading and vocabulary scores tested at college level by 6th grade, but I had only moderately above-average grades. Teachers frequently complained to my parents that I was not performing to my potential. I dreaded and hated school, and felt no motivation to put significant effort into assignments. I did what seemed necessary to get by, which was still enough to get grades that were fairly good.

Lunch was the worst part of the day. It was a relentless assault on the senses: the roar of conversation, the smell of other people's food, the sight of other people eating, and the pressure of other people on the lunch bench pushing against me.

My problems with motor control caused problems at school in several ways. Gym class was a nightmare. It was here that my lack of coordination and oddness of movement became most obvious to other children. There was virtually nothing I could do correctly or normally, which invariably made me the butt of ridicule. Art class was almost as bad. The art teacher at my elementary school was very rigid and demanding, and my poor motor skills meant I was totally incapable of doing anything right.

Written assignments were extremely difficult, especially once we learned cursive and were no longer allowed to print. My writing was virtually illegible, and writing for any extended period, especially in cursive, was physically painful. Any essay I had to write was very short as a result, and the disparity between my very brief essays and my very good skills during class discussion led my teachers to believe I had some sort of mental problem with translating thoughts into written format.

In 6th grade, teachers went to my parents with their suspicions that I had some sort of disorder or learning disability. As a result, I was placed in special education in junior high. This barred me from being in honors classes, even though my grades and test scores qualified me.

Junior high school was a disaster. I was harassed and taunted nonstop before and after school, during lunch, at recess, in the halls, and whenever the teacher's back was turned during class. Teachers and administrator's were completely indifferent. The harassment only started to diminish when I started getting into fights with my tormentors near the end of 8th grade.

One major change from elementary school was the fact that we no longer spent the day in one classroom; we had to move from class to class after each period. This was awful for me. In addition to giving the school bullies access to me, the noise, the chaotic rushing about, and the sensory overload of bodies pushing against me as I went from class to class was unbearable.

High school was an improvement in some ways. I was allowed to take honors classes, though I still found most of school unstimulating. Most of the principal bullies from junior high went to different schools, and relatively few new bullies sprang up. I did well academically, and liked most of my teachers. Most things were not any easier, though – walking through halls was still a miserable experience.

I was placed in the high school's special education program, which excused me from gym classes and allowed me to spend lunch and study hall periods in the special education room. The woman in charge of special education was extremely helpful, and I received far more effective assistance with my problems in high school than I had in junior high. When she was present, she was extremely effective. Unfortunately, she was often called out of the room to deal with some crisis elsewhere in the school. The special education room usually held a broad mixture of kids; some had learning disabilities, some were mentally retarded, some were autistic, and some were just too ill behaved or hostile to be in regular class. When she left, it was often every man for himself, with the nastier kids amusing themselves by tormenting the more vulnerable students. As time passed I eventually took on a sort of leadership role, trying to keep some sort of peace. I did this partly of concern for the people being bullied – seeing people with mental problems being harassed and belittled struck close to home, obviously – but also partly because the noise and disorder drove me nuts. I succeeded some of the time.

I took very little interest in girls; I had sexual feelings but no interest in acting on them. The whole social ritual of dating seemed boring and somewhat silly. I found the idea of sexual contact horrifying; reading physical descriptions of sex in health class or seeing diagrams made me physically ill. I found the behavior of other boys in this regard baffling and somewhat repulsive. I had female friends, but I never dated.

I began to find some social groups. The drama club, which I joined in my sophomore year, was one of the few places where people who were different were readily accepted. Many of the most popular kids in the club were shunned elsewhere. No one in the club knew I was autistic, but it was fairly obvious I was not normal. No one had any problem with that fact.

Despite my shyness, acting came surprisingly easy to me – being watched by a crowd while I was on stage was not significantly more frightening than normal conversation or a typical trip down the school hallways. In addition, acting was in some ways an extension of normal life – my natural tendency is to show little emotion in my voice, face, or body language, and so I had learned over the years to consciously "put on" facial expressions or changes in my tone of voice, according to the situation, in order to fit in and communicate better.

Due to extreme depression, I missed most of my senior year of high school and was put on what was called the homebound program. I did attend economics and government classes. The economics class was especially nice for me; I had been reading economists heavily in my free time anyway, and the coldly rational, unsentimental nature of economic reasoning was fun for me.

The government class was a semester long, and one of our activities was a weekly debate between two students on some subject. I disliked standing in front of people, since a small classroom is much more intimate than a big theater, but it was manageable.

The debating turned out to be a big success for me. I spent weeks researching my position and planning arguments and counterarguments, and ended up crushing my opponent. The second semester class was much smaller than the first semester class I was in, about half the size, which would have left them with only half as many debates. The teacher's solution was to have me debate everyone, once a week. I agreed, on the condition that I pick which side of each debate I would take. (I find it very unpleasant to argue in favor of a point I disagree with, even as an academic exercise. I was encouraged to join the debate team in both high school and college, but I declined because I could not imagine being able to treat public argument, especially argument over something with moral relevance such as politics, as a sort of intellectual game, as they do; to me it is always deadly serious.)

I ended up overwhelming every opponent, partly because of skill and partly because I took it very seriously and did much more to prepare. Once I got over the need to stand in front of people, I really liked it. I usually feel uncomfortable displeasing or disagreeing with people. I got around this by thinking of myself as arguing solely against ideas; I pushed to the back of my mind the fact that a person a few feet away from me was delivering those ideas, and imagined that I was alone, thinking of a response to a book or editorial I had read. It was easier than a normal conversation, in a way, since I cannot really detach a person from their words that way, and thus control my fear of them, in other contexts.

EDITORS COMMENTS ON MR. MARKLEY'S REFLECTIONS

Mr. Markley's personal reflections mirror the characteristics and social experiences of students with ASD that have been delineated in previous chapters of this book. Similar to high functioning students with ASD, his *diagnosis came later and even though he became eligible for special education services, the breath of the services were insufficient to address his social skills needs. Fortunately, Mr. Markley had superior intellectual capabilities that allowed him to channel his interests into academics that he enjoyed. This adjustment strategy worked most of the time but as Mr. Markley emphasized, he still was challenged by his ASD characteristics which lead at times to discomfort and distress.*

It is hoped that Mr. Markley's reflections provide educators, clinicians, and mental health professionals with insight into the thinking and emotional workings of students with ASD so that they can more effectively educate and treat these students. Fortunately, more and more individuals with ASD are putting their experiences and thoughts related to ASD diagnosis into words (see Birch, 2003; Hale; 2005; Hammerschmidt, 2008; Jackson, 2003; Miller, 2003*). One of the first to do this was Temple* Grandin (1986) *in her book "Emergence: Labeled Autistic". In this book and another by* Grandin (1996) *entitled "Thinking in Pictures and Other Reports from My Life with Autism"; she describes the struggles, challenges and adjustments in her life with an emotional commentary that allows the reader insight into the affect and thinking parameters of a person with ASD. Lastly, a book by* Jackson (2003) *provides the reader with similar insightful commentary from a teenager who wants parents to know what it feels like having ASD as well as letting other teenagers know they are not alone.*

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INFANT MENTAL HEALTH: AN EMERGING FIELD FOR CHILDREN WITH DEVELOPMENTAL DISABILITIES

Casey A. Holtz and Robert A. Fox

Since 1986, the federal government has recognized the importance of identifying children with developmental disabilities as early as possible and providing appropriate services to help these children reach their potential, to provide their families with training and support, and to prevent new problems from emerging (Hallahan & Kauffman, 2006). This commitment to serving our youngest children, from birth to three years of age, was buttressed in 2004 with the passage of Part C of the *Individuals with Disabilities Education Improvement Act*. This law provides federal funds to states for early intervention services for infants and toddlers with disabilities. Historically, the bulk of these services have been provided to address delays in the areas of cognition, speech and language, gross and fine motor, and self-care. Relatively less attention has been devoted to the social and emotional development of these children. In a U.S. Department of Education survey (2002) of children enrolled in early intervention programs in 2000, less than 3% received any mental health services. Yet we now know that significant behavioral and emotional problems are common in very young children with developmental disabilities (Baker, Blacher, Crnic, & Edelbrock, 2002), they can persist over time (Sigafoos, 2000), and they may

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interfere with the child's responsiveness to therapies that address other areas of delay (Fox, Keller, Grede, & Bartosz, 2007).

This failure to address mental health needs is not limited to only young children with developmental delays. Tolan and Dodge (2005) reviewed a number of national reports on mental health needs of children from all ages and concluded that there was a significant gap between their needs and the availability of mental health services to address them. This current gap is tragic, not only due to the significant emotional toll it takes on these untreated children and their families, but also because of the potential cost savings lost to society by not addressing these issues at their genesis (Weissberg, Kumpfer, & Seligman, 2003). Fortunately, there are signs that this current situation may be gradually changing, even for our youngest children. One sign has been the emergence of the new field of infant mental health (Zeanah, 2000). This development reflects the growing consensus across professional disciplines of the importance of recognizing and addressing mental health issues in children as soon as possible. Another positive sign has been a parallel increase in research devoted to mental health problems in young children (Luby, 2006). This chapter will review what we have learned from this research regarding the nature, prevalence, and course of mental health problems in young children, the contributing factors to these early social and emotional difficulties, useful assessment tools, and treatment strategies that have shown promise (Strain & Timm, 2001).

BEHAVIOR PROBLEMS: NATURE, PREVALENCE, AND COURSE

Behavior problems are common in toddlers and preschoolers. Richman, Stevenson, and Graham (1975) identified difficulties with eating, sleeping, toileting, temper, fears, peer relations, and activity as typical in this young population. While all young children should be expected to experience behavior problems as part of their normal development, an ongoing challenge in the field has been to determine when these "normal" developmental problems rise to the level of being considered "clinical" behavior problems (Keenan & Wakschlag, 2000). For example, when does a two-year-old child's tantrum behavior, a three-year-old's urinary accidents, and a four-year-old's defiance become clinically significant? To answer these questions, clinicians must examine the frequency, intensity, and durability of these difficulties, their potential to cause injury to the child or others, the extent to which they interfere with the child development, and the degree to which they disrupt the lives of their siblings, caregivers, peers, teachers, and others.

Campbell (1995) provided a comprehensive and frequently cited review of the literature on behavior problems in preschool children. She reported that between 10% and 15% of preschool-aged children have mild to moderate behavior problems, with about half of these children having problems persisting well into their formal school years. The prevalence rate may be even higher among children living in poverty. In their review of the literature, Qi and Kaiser (2003) reported that up to 30% of these children had behavior problems.

A number and variety of behavior and emotional difficulties emerge in the early childhood period that are sufficiently severe to warrant psychiatric diagnoses. The *Diagnostic and Statistical Manual of Mental Disorders* (*DSM-IV*; APA, 2000) has inherent limitations when applied to young children and an alternative diagnostic system has been developed (Zero to Three, 2005). However, the DSM-IV remains the standard reference work in the field. Also, Keenan and Wakschlag (2002) have demonstrated that the *DSM-IV* can be successfully adapted to accurately diagnose psychiatric disorders in young children, particularly those with disruptive behavior problems. Of the numerous psychiatric diagnoses presented in the *DSM-IV*, the following have been used with very young children: attention-deficit/hyperactivity disorder, oppositional defiant disorder, eating and sleeping problems, anxiety, mood and attachment disorders, posttraumatic stress disorder, and autism (Luby, 2006).

While there is some consensus that the prevalence of psychiatric disorders in children is 10–15% (Wicks-Nelson & Israel, 2006), currently we do not have similar data available for toddlers and preschoolers. Even less is known about the occurrence of significant mental health problems in children with developmental disabilities. Feldman, Hancock, Rielly, Minnes, and Cairns (2000) found that children as young as two years of age with developmental disabilities showed an increased risk for behavior problems compared to peers without developmental delays. Baker et al. (2002) reported that children with delays were three to four times more likely to obtain clinically significant scores on a child behavior scale than their non-disabled peers. Finally, psychiatric disorders are believed to occur three to six times more often in children with developmental disabilities than in normally developing children (Matson & Barrett, 1993; Tonge, 1999) and are likely to persist over time (Green, O'Reilly, Itchon, & Sigafoos, 2004). What is clear from the limited database on behavior problems in young children is that they are common, they can persist over time, they interfere with the child's overall development, and they may escalate into diagnosable psychiatric disorders.

CONTRIBUTING FACTORS

The theoretical work of Maccoby (1992) and Belsky (1984) provided useful conceptual models for stimulating research and helping us better understand the complexity of issues that contribute to the development and maintenance of behavior problems in young children. Maccoby stressed the importance of studying children within the context of the reciprocal parent–child relationship. Simply stated, not only will a child's severe temper tantrums affect his parents (how they think, feel, and behave), but the parent's response to this challenging behavior will also impact the child (his aggressive behavior may reduce, increase, or stay about the same). In describing how parents and other caregivers are going to respond to children's behavior problems, Belsky suggested that there may be multiple determinants including the child's health and temperament, and the caregiver's age, education, marital and socioeconomic status, level of social support, and mental health.

Child Factors

Almost any characteristic of children that makes them more difficult to care for can affect how their caregivers respond to them (Belsky, 1984). These characteristics include a difficult temperament and poor infant attachment (Qi & Kaiser, 2003), prematurity and other serious health conditions (Minde, 2000), genetic and other biologically based disorders (Rockhill, Collett, McClellan, & Spelz, 2006), and communication deficits (Sigafoos, 2000).

One of the many important child factors that contribute to potential behavior problems is their cognitive level of functioning. Lavigne et al. (1996) found a relationship between a child's IQ and behavior problems; lower IQs were associated with more behavior problems. In one study of 92 delayed and 133 non-delayed three-year-old children, Baker et al. (2002) reported that approximately 25% of their delayed sample met the cutoff score for clinically significant behavior problems compared to about 7% for the non-delayed sample, with boys in the delayed sample receiving the highest behavior problem scores. In a related study, Baker et al. (2003) reported similar findings with delayed three-year-old children receiving higher behavior problems scores than non-delayed children based on parent ratings on the *Child Behavior Checklist* (Achenbach & Rescorla, 2000); these children's level of behavior problems also remained stable from three to four years of age. Sigafoos (2000) studied 13 preschool children with developmental disabilities and found a strong inverse relationship between their communication ability and the severity of their aberrant behavior with receptive vocabulary deficits having a stronger relationship than expressive deficits.

Clearly, a number of child factors play a contributing role to the development of behavior problems. However, these important child factors do not exist in a vacuum, nor do they necessarily result in behavior problems in a cause and effect manner. Consequently, to obtain a fuller view of factors contributing to behavior problems in children, it is important to consider how caregivers respond to their children.

Caregiver and Contextual Factors

The seminal work of Baumrind (1966, 1991) identified four styles of parenting including authoritarian, permissive, neglecting, and authoritative, with the authoritative parenting style producing the best outcomes for children (Steinberg, Lamborn, Darling, Mounts, & Dornbusch, 1994). Brenner and Fox (1999) applied Baumrind's parenting style taxonomy using the *Parent Behavior Checklist*, which measures parents' development expectations, nurturing, and their use of corporal and verbal punishment with children less than five years of age, in a diverse sample of over 1,000 mothers from a large urban area. Important findings for the subgroup of mothers described as authoritarian (high on controlling and low on nurturing) were that they: (a) frequently disciplined their children for misbehavior using verbal and corporal punishment; (b) had a tendency to expect more from their children than they were developmentally capable of doing; and (c) spent relatively less time engaged in positive nurturing activities with their children. These mothers, who tended to be younger, single, and less educated, were also the most likely to report more behavior problems in their young children. In a related study, Brenner and Fox (1998) reported that the best predictor of behavior problems in young children was parental use of verbal and corporal punishment. The relationship between behavior problems in children and harsh parenting practices has also been found in other research (Baker & Heller, 1996; Nix et al., 1999).

As shown, some parents respond to challenging behaviors in children with harsh responses that, while intended to stop these behaviors, may just have the opposite effect. Which characteristics of caregivers make them more prone to respond negatively to challenging behaviors in young children? Parents, who are single, younger, less educated, from lower socioeconomic levels, and have more than one child under five years of age, are at at-risk for using harsh discipline (Fox, Platz, & Bentley, 1995). A number of other factors have been associated with behavior problems in children including maternal depression, low social support, family instability, family conflict, and community violence (Qi & Kaiser, 2003). In a more positive vein, Koblinsky, Kuvalanka, and Randolph (2006) reported that positive parenting practices within the context of predictable family routines were associated with higher levels of pro-social behaviors and fewer behavior and emotional problems in young children.

One common factor that captures the reciprocal nature of early parent–child relationships relative to behavior problems in young children is parental stress. While parental stress has been associated with children's behavior problems for some time (Eyberg, Boggs, & Rodriguez, 1992), this stress is likely exacerbated when children have developmental disabilities. For example, Baker et al. (2003) studied 205 preschool children with and without developmental delays and found that high parenting stress increased child behavior problems over time with these behavior problems in turn also increasing parenting stress. This reciprocal relationship between child behavior problems and parenting stress is important to understand within assessment and treatment practices, particularly for parents of children with developmental disabilities, who may be at increased risk for child abuse (Rodriguez & Murphy, 1997).

ASSESSMENT

Assessment in childhood is defined as an exploratory process in which a range of evaluation procedures are used to help conceptualize children's challenging behaviors and formulate effective treatment programs (Ollendick & Hersen, 1993). This definition delineates two important aspects of assessment during the early childhood years. First, assessment is best viewed as a complex, multimodal, and multi-informant process where information about the child's behavior is collected in a variety of contexts (Johnston & Murray, 2003). That is, to gain an accurate picture of a child's behavior problems, it is important to use a variety of assessment procedures with the child and with a number of persons who know the child well across the different settings that the child encounters. One also must consider this information within the context of the child's unique history, present environment, and current developmental level. Second, assessment is an ongoing process of collecting and gathering information to refine how we conceptualize children's behaviors and to fine-tune our treatment programs to better meet their needs.

Various assessment methods are available to assist practitioners working with young children with challenging behaviors and their parents, including parent and teacher-report surveys (Achenbach, 1992; Eyberg & Pincus, 1999; Reynolds & Kamphaus, 2004), behavioral observation (Neilsen & McEvoy, 2004), and functional behavioral assessment (Reitman, 2006). A comprehensive understanding of a child's behavior problems is more likely to occur when information is gathered using a multi-method, multi-informant, and multi-setting approach (Copeland, Landry, Stanger, & Hudziak, 2004). Unfortunately, such comprehensive evaluations can be quite time consuming and costly. Therefore, a step-wise approach has been recommended as more efficient and cost-effective strategy (Reitman, 2006). In a step-wise approach, parent interviews and rating scales are used first to screen all children referred for challenging behaviors. As a second step, more time-consuming procedures such as direct observation and functional behavioral assessment can be implemented for those children identified to need a more comprehensive evaluation. The following section will provide an overview of each major form of behavioral assessment for young children as well as a summary of the frequently used measures within each category.

Parent/Teacher Surveys

Very young children do not make good informants about their own behaviors. As a result, mental health professionals often rely on parental report to assess the frequency and severity of a child's behavior problems (Doctoroff & Arnold, 2004). Parent surveys can be accurate predictors of behavior problems in children (Reitman, 2006). In a study designed to examine whether parent ratings at the beginning of a school year would predict externalizing ratings at the end of school year, Doctoroff and Arnold found that children with more frequent behavior problems at the beginning of the year also exhibited higher year-end ratings.

Children often exhibit behaviors that are qualitatively and quantitatively different depending on the setting they are in Merrell (2000). Further complicating the picture is that different informants may have differing views of the same child's behaviors (Achenbach, McConaughy, & Howell, 1987; De Los Reyes & Kazdin, 2005). As a result, most researchers and clinicians support the use of a variety of measures rated by a number of different informants. Other than parent report, the most common alternative survey instruments used to assess childhood behaviors are teacher-report measures (Mash & Wolfe, 2005). Because parents and teachers are likely to see different aspects of a child, information from both sources is needed to obtain a comprehensive picture of the child (Copeland et al., 2004). Parents are better able to rate behaviors that occur primarily at home (eating, sleeping, sibling interactions, family relations), whereas teachers are more qualified to rate behaviors that occur primarily at school (peer relations, attention, following directions).

A description of popular assessment instruments for use with young children follows; a summary of each measure including its psychometric properties is included in Table 1.

Behavioral Assessment System for Children, Second Edition (BASC-2; Reynolds & Kamphaus, 2004) The BASC-2 rating scales measure internalizing and externalizing behaviors such as hyperactivity, aggression, conduct problems, anxiety, depression, withdrawal, and attention problems. The BASC-2's parent and teacher rating scales can be used individually or in combination to assess and identify toddlers and preschoolers (ages 2–5) with behavioral and emotional disorders. The parent rating scale contains 134 items and the teacher rating scale contains 100 items that are rated using a four-point frequency scale (never, sometimes, often, or almost always). For example, the BASC-2 includes items that ask the parent/teacher to indicate how frequently the child pays attention, bullies others, wets the bed, and breaks the rules. Each scale takes approximately 15–25 min to complete. Both the parent and teacher rating forms, which can be completed with self-scoring carbonless answer sheets or by computer, yield four composite scores (internalizing problems, externalizing problems, adaptive skills, and the behavioral symptoms index) and 10-scale scores (aggression, hyperactivity, anxiety, depression, somatization, attention problems, atypicality, withdrawal, adaptability, and social skills). All raw scores are converted to *t*-scores (*t*-scores have a mean of 50 and standard deviation of 10); children with *t*-scores in the 60 through 69 range are considered at-risk and those with scores 70 or higher are considered to have clinically significant social, emotional, or behavior problems. The BASC-2 also includes a validity index that assesses the possibility that a teacher or parent rated a child in an inordinately negative way. The validity index consists of items that represent

Table 1. Summary of Assessment Measures for Use with Young Children and their Caregivers.

Behavioral Rating Measure	Scales	Age (Years)	Informant Options	Reliability	Standardization Sample	Time to Complete (Minutes)
Behavioral Assessment System for Children -2 (BASC -2; Reynolds & Kamphaus, 2004)	Primary (e.g., adaptability, aggression, attention problems, conduct problems, depression, social skills); content (e.g., anger control, developmental social disability, bullying); composite (i.e., adaptive skills, behavioral symptoms, externalizing problems, internalizing problems)	2–11	Parent, teacher, self	Internal consistency (.70-.97); test–retest (.65–.92); interrater (.23–.71)	1,050 children 2–5, 1,800 children 6–11; closely matched 2001 U.S. Census Data	20–30
Child Behavior Checklist 1 1/2–5 (CBCL 1 1/2–5; Achenbach & Rescorla, 2000)	Internalizing behaviors (e.g., withdrawal, depression, social problems, anxiety), externalizing behaviors (e.g., attention problems, rule-breaking behavior, aggressive behavior), pervasive developmental problems	1 1/2–5	Parent	Internal consistency (.66–.92); test–retest (.68–.92); interrater (.51–.67)	Parents of 700 children, considered representative of 1999 U.S. Sample	25–30
Caregiver-Teacher Report Form (C-TRF; Achenbach & Rescorla, 2000)	Same as CBCL 1 1/2–5	1 1/2–5	Teacher, daycare provider	Internal consistency (.68–.93); test–retest (.57–.87); interrater (.30–.58)	1,192 children; considered representative of 1999	25–30

Table 1. (*Continued*)

Behavioral Rating Measure	Scales	Age (Years)	Informant Options	Reliability	Standardization Sample	Time to Complete (Minutes)
Connor's Rating Scales- Revised (CRS-R; Conners, 1997)	Short form: Oppositional, cognitive problems, hyperactivity, ADHD; Long form: Oppositional, cognitive problems, hyperactivity, anxiety, perfectionism, psychosomatic, ADHD	3–17	Parent, teacher	Internal consistency (.73–.96); test–retest (.47–.86)	Over 8,000 children, higher proportion of European American children than in general population	10–20
Eyberg Child Behavior Inventory (ECBI; Eyberg & Pincus, 1999)	Intensity and problem of child behaviors	2–16	Parent	Internal consistency (.93–.95); test–retest (.86–.88)	798 children; ethnic distribution of 1992 U.S. Census Data	10–15
Infant-Toddler Social and Emotional Assessment (ITSEA; Briggs-Gowan & Carter, 2005)	Externalizing behaviors (e.g., impulsivity, aggression), internalizing behaviors (e.g., depression, separation anxiety), dysregulation (e.g., negative affect, eating problems, sensory problems), competence (e.g., compliance, attention, play, empathy)	1–3	Parent, childcare provider	Internal consistency (domains = .85–.90; subscales = .66–.79); test–retest (.76–.91); interrater (.72–.79)	1,235 parents; representative of 2002 U.S. Census Data	30

Parent Behavior Checklist (PBC; Fox, 1994)	Parent expectations, discipline, and nurturing	1–5	Parent	Internal consistency (.82 –.97); test–retest (.81–.98)	1,040 mothers	Short form: 10; long form: 20
Parent Child Relationship Inventory (PCRI; Gerard, 1994)	Parental support, satisfaction with parenting, involvement, communication, limit setting, autonomy, and role orientation	1–15	Parent	Internal consistency (.76–.88); test–retest (.81)	1,100 parents; not representative of U.S. Census Data	15
Parenting Stress Index-Short Form (PSI-SF; Abidin, 1995)	Defensive responding, parental distress, parent–child dysfunctional interaction, difficult child, total stress	1–16	Parent	Internal consistency (.85–.91)	800 mothers; not representative of U.S. Census Data	15–20
Sutter-Eyberg Student Behavior Inventory-R (SESBI-R; Eyberg & Pincus, 1999)	Intensity and problem of child behaviors	2–16	Teacher	Internal consistency (.96–.98); test–retest (.87–.93)	Not clearly described	10–15

maladaptive behaviors, to which the respondent answered *almost always*, and adaptive behaviors, to which the respondent answered *never*. Using a table in the BASC-2 manual, raw scores on the validity index are placed in one of three categories: acceptable, caution, extreme caution. Validity scores in the caution or extreme caution category indicate that the parent or teacher may be rating the child in an overly negative manner.

The BASC-2 is one of the few available measures that allows for an integrated approach to the assessment of young children across multiple informants (Kamphaus, VanDeventer, Brueggemann, & Barry, 2007). It was standardized on a large, nationally representative sample and is technically sound. The BASC-2 rating scales distinguish between children with conduct and internalizing disorders and can be used at the preschool level to help develop Individual Family Service Plans (IDEA, 2004) for four- and five-year-old children with disabilities. Regarding limitations, the current edition of this measure is relatively new and the empirical base of literature supporting its use is only emerging (DiPerna, 2004). Additionally, it has not been validated on children below the age of two even though it has been demonstrated that significant behavior problems do occur before two years (Keenan & Wakschlag, 2000). Finally, although this measure can be self-scored, the scoring procedures are somewhat complex.

Child Behavior Checklist (CBCL; Achenbach, 1991, 1992). The CBCL is often considered the gold standard for screening behavior problems in children. Besides being one of the most researched assessment instruments, other measures of child behavior problems are often compared to it in order to demonstrate their own validity. The CBCL was initially developed for children ages 6–18, and then a downward extension was developed for children ages 1.5–5 years of age (CBCL/1.5–5; Achenbach & Rescorla, 2000). Achenbach also developed the CBCL-Teacher Report Form/1.5–5 (C-TRF) which was designed to be completed by day-care providers and preschool teachers who see the child in a group of at least four children. Both forms measure internalizing behaviors (anxiety, depression, withdrawal) and externalizing behaviors (attention problems, rule-breaking behavior, and aggressive behavior). They also can be used to support DSM-IV-TR diagnostic criteria (APA, 2000; oppositional defiance, pervasive developmental disorders, ADHD). Both the parent and teacher versions of the CBCL/1.5–5 collect information about the child's demographic characteristics, strengths (at home or at school), and interests. Parents and teachers rate the child on 120 questions (e.g., how often does the child act mean to others) based on a three-point scale of 0 = not true, 1 = somewhat true or sometimes true, or 2 = very true or often true.

Scoring templates, scanned answer sheets, and computer scoring are available. Hand scoring takes approximately 15–20 min for trained professionals (Watson, 2004). Total raw scores are computed for total behavior problems, an internalizing factor score, an externalizing factor score, and the six subscales. The computed raw scores are converted to gender- and age-standardized scores so that they can be compared with scores obtained from normative samples of children. For the six syndrome scales, *t*-scores less than 67 are considered in the normal range, *t*-scores ranging from 67–70 are considered to be borderline clinical, and *t*-scores above 70 are in the clinical range. For total problem scores, externalizing and internalizing problem scores, *t*-scores less than 60 are considered in the normal range, 60–63 represent borderline scores, and scores greater than 63 are in the clinical range (Achenbach, 1992; Carter, Briggs-Gowan, & Davis, 2004).

Similar to some other measures discussed in this chapter, the CBCL system supports cross-informant assessment of children. The CBCL/1.5–5 was standardized on a smaller sample ($N = 700$) than the earlier version of the CBCL, but is still considered to be representative (Achenbach, 1992; Flanagan, 2004). The C-TRF was standardized on a nationally representative sample of caregivers who rated 1,192 children ages 1.5–5 (Achenbach, 1992). Internal consistency and test–retest reliability properties are adequate on both the CBCL/1.5–5 and C-TRF (Flanagan, 2004; Watson, 2004). Although reliabilities for the total problem scores and internalizing and externalizing scales are very good, some of the subscales (i.e., somatic problems, anxiety problems) have relatively low reliabilities and therefore should be used with caution for diagnostic decision making (Flanagan, 2004; Sattler & Hoge, 2006). Validity-based correlations with other measures of challenging behavior were satisfactory (Watson, 2004). Researchers have also demonstrated the measure's specificity; using a 90th percentile cutoff, the CBCL correctly classified 82.6% of clinically referred and non-referred children (Achenbach, 1992). Although administration takes approximately 20–30 min, with the additional time needed for scoring, some professionals consider it to be too cumbersome and time consuming to be used as a brief screening tool (Simonian, 2006).

Overall, the CBCL/1.5–5 and C-TRF are well-researched, empirically derived measures that allow professionals to assess a wide range of behaviors across a variety of settings and informants (Watson, 2004). The scales are supported by an extensive research base and are technically sound (Flanagan, 2004). The CBCL has been used in a wide range of outcome studies for in-home and school treatment of behavior problems

(Hofstra, van der Ende, & Verhulst, 2002; Rescorla et al., 2007). The CBCL has also been demonstrated to be an accurate predictor of treatment success (Kendall, Marrs-Garcia, Nath, & Sheldrick, 1999; Kroes et al., 2002) and later behavior problems (Ferdinand et al., 2003; Shaw, Owens, Giovannelli, & Winslow, 2001).

Conners' Rating Scales-Revised (CRS-R; Conners, 1997). The CRS-R provides for cross-informant assessment of behavior problems in children, with a primary emphasis on externalizing behaviors. The parent and teacher rating scales assess a variety of childhood disorders including: oppositional behavior, hyperactivity, anxiety, perfectionism, social problems, attention-deficit hyperactivity disorder (ADHD), and others. There are four different forms available: parent long form (80 items), parent short form (27 items), teacher long form (57 items), and teacher short form (28 items). With the exception of the psychosomatic subscale, which is only on the parent long form, the teacher and parent long forms contain the same subscales. The parent and teacher short forms also share the same subscales (i.e., oppositional, cognitive problems/inattention, hyperactivity, and ADHD index). Completion of the short forms takes 10–15 min, where the parent or teacher rates each item (e.g., my child is easily distracted) using a four-point rating scale: 0 (not true at all), 1 (just a little true), 2 (pretty much true), 3 (very much true). The long forms typically take two to three times longer to complete; therefore, the short form is often preferred within educational settings (Todd & Thyer, 2002).

The CRS-R forms are well designed for easy scoring. The teacher or parent responses on the rating form transfer through to a scoring form that the practitioner uses for computing and profiling the results. Subscale total raw scores are converted to *t*-scores. *T*-scores of 65 and above indicate a clinically significant problem. However, a *t*-score of 65 should not be considered an absolute rule, so teachers and clinicians should reflect on each case individually and use the cutoff score of 65 as a general guideline (Conners, 1997). The CRS-R scales show good reliability and adequate validity (Knoff, 2004), with the parent and teacher forms particularly effective for evaluating externalizing behaviors, specifically those associated with ADHD. The CRS-R is well aligned with the ADHD criteria in the DSM-IV-TR (Hess, 2004) and studies have shown that the CRS-R scales consistently distinguish between children with and without ADHD (Gianarris, Golden, & Greene, 2001; Miller, Koplewicz, & Klein, 1997). The CRS-R standardization sample consisted of over 8,000 individuals and norms are provided separately for males and females by age level, which is important for accurate interpretation of behavior (Conners, 1997).

Although the sample is quite large, there are a higher proportion of European American children in the standardization sample than in the 1997 U.S. census general population (Knoff, 2004). Clinicians and educators should be aware of possible cultural differences in both response patterns and culturally normative behavior (Hess, 2004; Todd & Thyer, 2002). Research on the CRS-R teacher rating form has demonstrated its ability to identify conduct problems and ADHD in African American preschoolers (Fantuzzo et al., 2001).

Overall, the CRS-R is a well-crafted and important tool for the assessment of externalizing behaviors in young children. The CRS-R also is useful for monitoring treatment outcome. Well-controlled studies have shown the Conners' Scales to be sensitive to a wide array of treatments (e.g., pharmacological, behavioral) among varied populations (Conners, Sitarenios, & Epstein, 1998; Gianarris et al., 2001). In addition to teacher preference, empirical literature points to the short forms as the ideal choice for measuring treatment outcome (Gianarris et al.). Within schools, the CRS-R teacher rating form has been found to be suitable for single-subject evaluation of children (Todd & Thyer, 2002). School-based professionals can confidently use this measure to identify problem behaviors in young children and to evaluate the effectiveness of school-based interventions (Fantuzzo et al., 2001; Todd & Thyer, 2002).

Eyberg Child Behavior Inventory and Sutter-Eyberg Student Behavior Inventory. The Eyberg Child Behavior Inventory (ECBI) and the Sutter-Eyberg Student Behavior Inventory-Revised (SESBI-R; Eyberg & Pincus, 1999) assess conduct problems in children ages 2–16 years old. The ECBI, a 36-item measure, includes items about common behavior problems in children and adolescents such as non-compliance, defiance, aggression, whining, and destructiveness. The ECBI asks parents to rate their child's behavior on an intensity scale and a problem scale. The intensity scale uses a seven-point Likert rating scale to indicate the frequency with which the behavior occurs (1 = never, 2–3 = seldom, 4 = sometimes, 5–6 = often, 7 = always). Scores on the ECBI intensity rating scale range from 36 to 252. The problem scale uses a simple yes or no response format to indicate whether the parent considers each behavior issue to be a problem for a particular child. Problem scores on the ECBI can range from 0 to 36. Higher scores on either scale reflect higher levels of perceived behavior problems.

The SESBI-R, which is designed to be filled out by a teacher or day-care provider, is a modified version of the ECBI that includes items applied specifically to school settings. For the SESBI-R, 13 items were removed from the ECBI and replaced with items more relevant to educational settings. These new items were the result of a review of problem behaviors most frequently reported by teachers of children referred for treatment of behavior problems. For example, added items were about school-related behaviors such as obeying school rules, bossiness with other students, and distractible behavior. The SESBI-R is rated on the same intensity and problem scale as the ECBI. SESBI-R scores on the intensity scale range from 38 to 266 and problem scores range from 0 to 38. Like the ECBI, higher scores on either scale reflect higher levels of perceived behavior problems.

ECBI and SESBI-R total raw scores can be quickly and easily computed by hand (Whiston & Bouwkamp, 2004). Raw scores on both scales are converted to *t*-scores; a *t*-score above 60 is considered the cutoff score for clinical significance and indicates the need for further assessment.

The ECBI and SESBI-R assess a broad spectrum of behavior problems common among children across home and school settings. The scales are quickly administered and scored and both scales have good evidence of reliability and validity (Eyberg & Pincus, 1999; La Paro & Pianta, 2000; Sattler & Hoge, 2006). Scores on these scales have been shown to successfully discriminate between children with normal behavior problems and conduct disorders (Weis, Lovejoy, & Lundahl, 2004). The ECBI and SESBI-R standardization norms are representative of the general child and adolescent population from the 1992 U.S. Census data (Burns & Patterson, 2001; Eyberg & Pincus, 1999). However, the norms are not stratified by age or gender. This limitation is important to recognize due to the wide range of behavior problems observed in children and adolescents, ranging from wetting the bed to stealing (Collett, Ohan, & Myers, 2003; Whiston & Bouwkamp, 2004). Although the scales have been normed on youths up to 17 years old, their item content may make them more suitable for younger children presenting with oppositional defiant behaviors (Collett et al., 2003). Other limitations are the wording of some items, which may be unfamiliar to parents (e.g., "dawdles"), and the seven-point rating scale that can be challenging for respondents with lower educational levels.

The ECBI and SESBI-R have received widespread use as outcome measures in studies of interventions for disruptive youth. The ECBI has demonstrated sensitivity to behavior change from pre- to posttest in studies on behavioral interventions with high-risk families enrolled in the Head Start program (Webster-Stratton, 1990, 1994; Webster-Stratton, Reid, & Hammond, 2001) and with clinically referred children receiving Parent–Child Interaction Therapy (PCIT; Eyberg, 1988; Eyberg et al., 2001). The SESBI-R has received less use as an outcome tool, but the original version has been used to detect treatment effects from Parent–Child Interaction Therapy as well as generalization of these effects from home to school (McNeil, Eyberg, Eisenstadt, Newcomb, & Funderburk, 1991).

Infant-Toddler Social and Emotional Assessment (ITSEA; Briggs-Gowan & Carter, 2005; Carter, Briggs-Gowan, Jones, & Little, 2003). The ITSEA is a 169-item questionnaire designed to identify social–emotional problems in 1–3 year old children. The ITSEA was developed as a comprehensive tool to profile children's strengths and weaknesses in the social–emotional domain (Carter & Briggs-Gowan, 2000). The ITSEA measures four broad domains: Internalizing (e.g., depression, anxiety, separation anxiety), externalizing (e.g., impulsivity, aggression), dysregulation (e.g., negative affect, eating problems, sensory problems), and competence (e.g., compliance, attention, empathy). In addition to the domains, the ITSEA contains three scales that consist of low base rate behaviors (e.g., stereotypy, lack of eye contact, social isolation) and other behaviors that are never considered developmentally appropriate. Parents, parental guardians, and/or childcare providers/teachers of the child are asked to rate the items using a four-point scale: (0) = not true/rarely, (1) = somewhat true/sometimes, (2) = very true/often or (N) = no opportunity to observe. To score, mean raw scores are computed (by hand or computer) within each domain and are converted to *t*-scores; *t*-scores of 65 and above in the problem domains indicate the child is at risk for deviant behavior and may have difficulty regulating their behaviors and emotions. *T*-scores of 35 or below in the competence domains indicate that the child is at risk for delayed development of social–emotional competencies.

The ITSEA is a comprehensive measure of social–emotional problems in young children (Briggs-Gowan & Carter, 2005). It contains developmentally appropriate items and is one of the few measures designed to assess strengths and competencies, which can be very useful in treatment planning and educational placement (Irwin, Carter, & Briggs-Gowan, 2002). The ITSEA was standardized on a large sample representative of the 2002 U.S. census, which was stratified by age and gender. It has acceptable internal consistency and test–retest reliability (Briggs-Gowan & Carter, 2005; Carter & Briggs-Gowan, 2000; Carter et al., 2003). The ITSEA has also demonstrated the ability to distinguish between children with internalizing and externalizing behaviors and those with no behavior problems (Carter, Little, Briggs-Gowan, & Kogan, 1999).

The ITSEA is utilized in treatment planning and early identification of behavior problems (Carter, 2001; Carter et al., 1999), but there is currently limited evidence of its applicability as a measure of treatment efficacy.

Additionally, due to the length of time needed to administer the ITSEA, it may be more difficult to use within school and day-care settings (Carter et al., 2004).

For preliminary screening and identification of problems, the developers suggest that teachers and day-care providers use the Brief Infant-Toddler Social and Emotional Assessment (BITSEA; Briggs-Gowan & Carter, 2005). The BITSEA has 49 items and has demonstrated adequate reliability and validity, along with concurrent validity with the ITSEA (Briggs-Gowan, Carter, Irwin, Wachtel, & Cicchetti, 2004). The BITSEA has not been empirically evaluated for use on individuals with autism or other severe developmental delays (Briggs-Gowan et al., 2004).

Assessing Caregivers

Parents and other caregivers play a significant role in the development and maintenance of behavioral and emotional problems in young children. Therefore, as part of a comprehensive evaluation of a young child for the purpose of formulating an intervention plan, it is important to gather assessment information about the parent's behaviors, the parent–child relationship, and parent stress levels.

The Parent Behavior Checklist (PBC; Fox, 1994). The PBC is a 100-item parent self-report measure designed to assess the behaviors and expectations of parents of young children between the ages of 1 year and 4 years, 11 months. The PBC consists of three empirically derived scales: Expectations – 50 items that measure parents' developmental expectations ("My child should be able to feed him/herself"); Discipline – 30 items that assess punitive parental responses to children's problem behaviors ("I yell at my child for spilling food"); and Nurturing – 20 items that measure specific parent behaviors that promote a child's psychological growth ("I read to my child at bedtime") (Fox, 1992). Items are rated using a four-point frequency scale (4 = almost always/always, 3 = frequently, 2 = sometimes, and 1 = almost never/never). PBC raw scores for each subscale are converted to normalized *t*-scores based on a representative sample of 1,140 mothers. Interpretation of the PBC subscales is straightforward with high and low scores on the Expectations subscale, high scores on the Discipline subscale, and low scores on the Nurturing subscale suggesting that further assessment is warranted. For example, a high Discipline score should lead to further inquiring regarding how and when parents use corporal and verbal punishment with their young children.

In order to make the PBC more efficient for practitioners to use, a short form of the scale was developed. This short form includes 32 items and has demonstrated good reliability for the three subscales: Expectations = .93, Discipline = .85, and Nurturing = .73. A Spanish version of the PBC long and short forms also is available. The PBC successfully discriminates between parents of children of different chronological ages (Fox & Bentley, 1992) and in one study, the PBC was shown to not be related to a social desirable response set (Peters & Fox, 1993). The PBC has been shown to be an effective measure of parenting practices for parents living in America (Fox et al., 1995) and Mexico (Solis-Camara & Fox, 1996), and Latino families in the United States (Cardona, Nicholson, & Fox, 2000). It also has been successfully used with families of children with disabilities (Tucker & Fox, 1995; Keller & Fox, in press), congenital heart disease (Carey, Nicholson, & Fox, 2002), and significant emotional and behavioral problems (Nicholson, Fox, & Johnson, 2005). Finally, the PBC also has been used as an outcome measure for treatment programs involving parents of young children (Nicholson, Anderson, Fox, & Brenner, 2002; Nicholson, Brenner, & Fox, 1999) and for training programs for professional who work with parents of young children (Fox, Duffy, & Keller, 2006; Fox & Parroni Hennick, 1996). A limitation of the PBC is that it has not been normed on fathers of young children, who may differ in their parenting practices from mothers (Platz, Pupp, & Fox, 1994). However, it has been successfully used to study parenting practices of fathers (Burbach, Fox, & Nicholson, 2004; Fox & Solis-Camara, 1997).

Parent–Child Relationship Inventory (PCRI; Gerard, 1994). The PCRI is a 78-item measure that assesses parental attitudes about parenting and their relationship with their child. It was designed to supplement other assessment tools as a way to identify factors that contribute to normal and problematic parenting of children. Five of the subscales directly assess the parent–child relationship through statements that look at satisfaction with parenting ("having a child was a good decision"), involvement with the child ("my child and I spend time together"), communication ("I talk with and listen to my child"), limit setting ("it is not easy to discipline my child"), and autonomy ("parents should monitor their child's friendships"). The PCRI also measures parental support and parental role orientation, and includes social desirability and inconsistent response items to identify invalid protocols. Parents respond to all of the statements on a four-point Likert scale ranging from 1 (strongly agree) to 4 (strongly disagree). Scaled scores (*t*-scores and percentiles) are based on a sample of 1,139 parents with higher scores indicating "good parenting attitudes." *T*-scores less than 40 (one standard deviation below the mean) are indicative of possible problematic parenting and scores falling below 30 (two standard deviation below the mean) are indicative of more serious potential problems.

In general, the PCRI, like the PBC, fills an important and often neglected role in both research and clinical assessment. A focus on the role of parenting in any type of family assessment has historically been missing (Merchant & Paulson, 1998). The PCRI has good psychometric properties (Coffman, Guerin, & Gottfried, 2006; Gerard, 1994) and it has been demonstrated to be useful as a predictive and outcome measure in clinical settings (Coffman et al., 2006; Heinze & Grisso, 1996; Reitman et al., 2001). Although the PCRI was developed using a relatively large sample, norms for parents of children from differing ethnic or cultural groups are not available (Boothroyd, 1998). Certain dimensions of parenting (e.g., limit setting, autonomy) may differ between cultural groups. Also, the PCRI measures parenting attitudes and not behaviors. Each of these two constructs, while related, have different implications for interpretation and treatment planning.

The Parenting Stress Index, Third Edition (PSI; Abidin, 1995). The PSI is a 120-item scale used to measure stress in the parent–child system and to identify dysfunctional or at-risk parenting by assessing the behavioral characteristics of the child, the parents' sense of their own parenting competence, the quality of the marital relationship, and the availability of social support. The author designed this measure with hopes of identifying a diverse range of potential influences on parenting practices (Reitman, Currier, & Stickle, 2002). The initial 120-item scale was normed on a variety of parents of children ranging in age from 1 month to 12 years. Percentile rankings were derived for the total PSI and each PSI subscale and were based on the raw score frequency distributions of responses from mothers ($N = 800$) in the normative sample. Clinicians often use the PSI Short Form (PSI-SF), an abbreviated 36-item scale derived from the full-length PSI, to reduce the response burden on the parent (Reitman et al., 2002). This time-efficient tool takes approximately 15 min for the parent to complete and is often preferred by researchers to reduce assessment time (Keefe, Karlsen, Lobo, Kotzer, & Dudley, 2006). The PSI-SF contains the following three subscales: difficult child (DC), parental distress (PD), and parent–child dysfunctional interaction (P-CDI). Each of the three subscales contains 12 items, which are rated on a Likert scale from 1 (strongly disagree) to 5 (strongly agree); a score of 3 indicates not sure. The PSI-SF also includes a defensive responding scale that allows for identification of parents who may be answering in an overly positive or defensive manner. PSI-SF subscale scores (DC, PD, P-CDI) range from 12 to 60; the total score ranges from 36 to 180. Similar to the PSI, the PSI-SF subscales are converted to percentile rankings based on the normative sample. Percentiles above 85 warrant concern and further assessment.

Reliability properties for the three PSI-SF scales are good and correlations of the *PSI*-SF with the *PSI* show a strong relationship between the total stress scores, between the PD and Parent Domain scores, and between the DC and Child Domain scores (Allison, 2004). The *PSI*-SF has a well-defined factor structure supporting the scales, which was replicated in a second sample (Keefe et al., 2006). The PSI-SF is frequently used in research and clinical evaluations (Keefe et al., 2006; Thomas, Renaud, & DePaul, 2004; Uzark & Jones, 2003; Youngblut et al., 2001), but it is still unclear whether the scale primarily measures parental-related stress or other factors which may contribute to parent stress (Allison, 2004; e.g., depression, developmentally delayed children). Examination of the Parental Distress subscale shows that seven of the 12 items are descriptive of general maladjustment/depression (Reitman et al., 2002). The Parent–Child Dysfunctional Interaction subscale includes items suggestive of internalizing difficulties or developmental delays on the part of the child, rather than disturbed interaction between the parent and child (Allison, 2004). The Difficult Child subscale does seem to measure this construct, with many of the items descriptive of externalizing difficulties of childhood (Keefe et al., 2006).

Functional Behavior Assessment

Functional behavior assessment (FBA) is a targeted approach based on direct observation for understanding the behavior of young children. Since the reauthorization of the Individuals with Disabilities Education Act (IDEA) in 2004, functional assessment for students with disabilities has received considerable attention from practitioners, administrators, policy makers, and researchers. When a teacher or clinician is concerned with the purpose, cause, or function of a behavior, FBA may be the most appropriate means of assessment (Reitman, 2006). FBA is a systematic process used to identify the conditions that motivate the child to engage in problem behavior, the events that occur before and possibly trigger the behavior, and the consequences of the child's behavior that may reinforce their actions (Kazdin, 2001). The task of this assessment is to identify a functional relationship between the child's behavior and environment that is both authentic and that occurs in a variety of contexts (and times) beyond where the assessment occurred (Neilsen & McEvoy, 2004). FBA begins with an assessment of what the challenging behavior looks like according to parents and teachers who frequently interact with the child. Unlike the self-report measures described previously, FBA requires direct observation of the child's behavior to determine where and when it occurs, what antecedents predict behavior, and what consequences in the environment are maintaining the behavior (Neilsen & McEvoy, 2004). Whenever possible, children should be observed in their natural environment as part of a comprehensive evaluation of their behavior (Sasso, Conroy, Stichter, & Fox, 2001). In fact, some professionals feel the best way to learn about a child's behavior is to observe it and collect data on it (Benham, 2000). There are a large number of systems designed for observation of behaviors in clinical, home, and school settings. It is important to observe parent–child interactions as well as other interactions (e.g., with teachers, siblings) in order to gain full understanding of a child's behavior. Parent–child interactions are the typical focus before the child enters school, but teacher–child and peer–child interactions are very important when considering a child who attends a day care or preschool.

There are three major reasons to directly observe and measure challenging behavior. First, collecting data before an intervention allows for accurate assessment of the initial level of severity of the behavior problem. Direct observation can be used to confirm or disconfirm initial reactions. For example, a student may be reported to be aggressive all day long, but upon observation, one may find that it only occurs a few times a day and that they typically happen during times of transition. The second reason is to allow for observation of the relationship between the environment and the challenging behavior more directly (Kaiser & Rasminsky, 2007), that is to see what triggers the behavior, what consequences seem to be maintaining it, and what the child is getting as a result. The third reason is to track the progress made by classroom or in-home interventions. For instance, one could monitor the effectiveness of a reinforcement program by observing the child's behavior over time, along with the child's ability to adapt to the structure of the program.

Approaches to conducting observations with young children include activities ranging from free-play to parent-directed situations, such as listening to simple requests (Neilsen & McEvoy, 2004). In all situations, the mental health provider presents the child and parent with age appropriate toys and uses direct behavior measures (anecdotal records, frequency counts) or a behavior coding system to rate the interactions based on a predetermined list of child and adult behaviors (e.g., child affect, child compliance, parent sensitivity to the child's needs, aggression).

Using parent/teacher measures and direct observation, clinicians and educators can design comprehensive, individualized interventions that specifically address the antecedents and consequences involved with the target behavior (Sasso et al., 2001). Research has demonstrated the usefulness of FBA within schools (Boyajian, DuPaul, Handler, Eckert, & McGoey, 2001; Umbreit & Blair, 1997; VanDerHeyden, Witt, & Gatti, 2001). Boyajian et al. (2001) used FBA to identify relevant variables for three preschool boys with aggressive and noncompliant behaviors. The researchers identified a few specific teacher reminders and requests as antecedents to the behaviors. FBA also identified that the boys' aggressive and noncompliant behaviors led to an escape from compliance with teacher requests, the provision of teacher attention, and access to preferred toys and activities. Appropriate manipulation of these variables resulted in behavioral improvement for all three children. In a community setting, Newcomer and Lewis (2004) investigated the efficacy of using FBA in order to determine treatment for young children with behavior problems. Using a multiple-baseline approach to examine the impact of treatment based on FBA, the researchers found that FBA-based intervention had a greater impact on behavior than baseline and non-FBA based intervention.

TREATMENT

Once significant behavior and emotional problems are identified, research suggests that early intervention is essential (Stormont, 2002; Weisz, Sandler, Durlak, & Anton, 2005). Without treatment, early behavior problems can develop into more severe and resistant behaviors (Webster-Stratton & Taylor, 2001; Qi & Kaiser, 2003). Researchers and clinicians recommend that treatment should be comprehensive including prevention and intervention efforts in both home (Kumpfer & Alvarado, 2003) and school settings (Stormont, 2002). Early intervention also should include a component that addresses the development and strengthening of a nurturing relationship between the caregiver and the child. This supportive bond with caretakers is critical for proper childhood development and affects the effectiveness of behavior management strategies (Kaiser & Rasminsky, 2007). Nurturing relationships and supportive educational environments are especially important for young children living in high-risk circumstances (Bagdi & Vacca, 2005), some of whom may not have developed strong relationships with adult caregivers. Because adult–child relationships are a resource for development, strengthening these relationships with non-risk children can have benefits for development as well (Pianta, 1999).

Early intervention and prevention programs have demonstrated success in reducing early conduct problems (Nation et al., 2005; Webster-Stratton, Reid, & Hammond, 2004). Therefore, educators and clinicians are encouraged to use empirically validated treatment strategies (Weisz et al., 2005). The next section will examine a number of common elements to effective intervention programs and conclude with a description of some specific empirically supported programs developed for home and school interventions of early behavior problems in young children.

Common Elements in Prevention and Treatment Programs

There is great variability in treatment programs available for young children, but many of them employ similar techniques designed to prevent or decrease challenging behaviors while increasing pro-social behaviors. Some of the basic approaches to challenging behavior include using consistent positive reinforcement, establishing predictable routines, using clear and appropriate communication, maintaining reasonable expectations based on the child's developmental level, setting rules and limits, and using age appropriate discipline.

Positive Reinforcement of Pro-social Behaviors

Possibly the most important part of any behavior management program is positive reinforcement for pro-social behaviors. Positive reinforcement, the best approach to improving behavior, comes from social learning theory. It entails providing an immediate reward following a behavior, particularly behaviors that are incompatible with problem behaviors (Neilsen, Olive, Donovan, & McEvoy, 1999). Positive reinforcement can include verbal encouragement and praise ("way to go!"), physical contact (pat on the back or hug), and/or social or tangible rewards (a smile or a sticker). Along with being effective for behavior change, positive reinforcement also helps teachers and parents build a warm and trusting relationship with the child.

Routines

An important framework for any type of intervention within a school or home setting is a predictable routine. In all settings, it is vital to establish a daily schedule to provide young children with the comfort of predictability

(Lawry, Danko, & Strain, 2000). Inconsistency in daily routines at home, day care, or school can contribute to disruptive and aggressive behavior in young children (Bell, Clancy, & Gaddes, 2004). Structure and routine within a classroom prepare students for changing activities and limits student anxiety and frustration (Walker, Colvin, & Ramsey, 1995). Schedules specifically designed to meet the needs of an individual child can also be developed to increase independence in following classroom or home routines and to ease behavior problems during transitions (Mesibov, Browder, & Kirkland, 2002). Transitions between activities are often difficult for children with behavior problems. Incorporating a clear signal (or warning) at the beginning of a transition (e.g., flickering of lights, singing a song, clapping of hands) can improve the smoothness of the transition (Lawry et al., 2000). In addition, daily home routines (getting ready for day care or bed time) help limit problem behaviors during important daily transitions and also help increase compliance (Forehand & McMahon, 2003).

Setting Rules and Limits

Because it is easier for children to behave when they know what parents, teachers, and day-care providers expect of them, one of the most important components of preventing and managing behavior problems is the development of clear rules and limits (Stormont, 2002). These rules, which clearly communicate to the children what behaviors are expected, should be few in number and worded positively (keep your hands to yourself; always do your best; follow the direction of your teachers; always walk in the hallway; stay seated when the teacher is reading). Once rules and limits are established (considering the children's age and developmental level), they should be taught, reviewed, and enforced consistently (Gimpel & Holland, 2003). The establishment of firm and consistent limits and consequences for violations of rules has been associated with decreased levels of misbehavior (Hallahan & Kauffman, 2006).

Children's Compliance

One important strategy that will help increase young children's compliance with rules and will assist in decreasing challenging behaviors is giving effective requests (Forehand & McMahon, 2003). Teachers and parents often give children instructions in ways that make it difficult for them to comply (providing multiple requests simultaneously without giving the child an opportunity to comply, giving vague requests, giving inappropriate requests without considering the child's developmental level). In addition, when giving requests, teachers and parents may forget to follow through with a consequence for non-compliance. Parents and teachers should only give requests when they plan to follow through with an appropriate consequence for non-compliance. After reviewing the empirical literature on compliance, Gimpel & Holland (2003) provided these guidelines for effective communication with young children: (1) save requests for times you can follow through; (2) get the child's attention using their name and eye contact; (3) only give commands the child is capable of completing; (4) commands should be clear, direct, and simple in a matter of fact tone of voice; (5) give only one command at a time; and (6) phrase commands positively ("please stop running" instead of "no running"; "let me help you pick up your toys"). Using these simple techniques during interactions with challenging children will maximize the child's level of compliance.

Consequences

When a child breaks a rule, has significant tantrums or other behavior problems, or does not comply, it is essential that teachers and parents provide an immediate and appropriate consequence. In order to maintain classroom management, teachers must know how to use effective strategies to handle misbehavior. The discipline of choice for many caretakers and teachers of preschoolers and toddlers is time-out (Gimpel & Holland, 2003). Although controversial in some settings, time-out is a highly effective intervention strategy when used appropriately (Sterling-Turner, & Watson, 1999). Time-out involves removing the child from all reinforcing activities or events for a brief period time immediately following inappropriate or undesired behaviors. For example, when a young child hits someone during reading time, the time-out would include removal from the reinforcing environment (the reading carpet) and placement into a boring and non-stimulating time-out location (chair in the back of the classroom). Time-out should be very brief, a minute or two for every year of age, and works best when the activities and events from which the child is being removed are highly reinforcing. When the child is in the time-out location, all of the child's verbalizations and activities are ignored. Miltenberger (2001) provided the following as questions that teachers should ask to determine the appropriateness of time-out as an intervention choice:

- Does the child use time-out to escape a disliked classroom activity?
- Is adequate staffing available to implement the time-out? Is the child supervised during time-out?

- Does the time-out area provide additional opportunities for reinforcement of the disruptive behavior (attention from the teacher)?
- Is the use of time-out acceptable to teachers, staff, and parents?

Many other discipline strategies are highly effective with young children with behavior problems including ignoring and natural consequences. Ignoring is based on the concept of extinction – removal of intrinsic and extrinsic rewards for negative behaviors to reduce their frequency. If parents/teachers can ignore attention-seeking behaviors, the behaviors will soon weaken and eventually stop. There are times, however, when ignoring is not appropriate (the child throws a toy or colors on the wall). In these situations, clinicians and teachers should use natural consequences to teach children to become responsible for their own behavior (Fox & Nicholson, 2003). When teachers use natural consequences as a discipline technique, children learn by experiencing the consequences of their own behavior (Kaiser & Rasminsky, 2007). For example, a young boy will quickly learn the consequences of his action when his teacher takes away his toy immediately after he throws it at another child.

These techniques are important and effective elements that are commonly included in empirically validated home and school-based interventions designed to decrease challenging behaviors of young children. While these elements can be useful when used in one setting only, Webster-Stratton, Reid, and Hammond (2004) found that empirically supported teacher and parent therapy in combination create the most significant improvement in reports of behavior problems. The following section will provide a brief description of home- and school-based intervention programs along with evidence of their efficacy with young children. A summary of these programs is included in Table 2.

Parent–Child Interaction Therapy

Parent–Child Interaction Therapy (PCIT) is an evidence-based treatment program designed for preschool children with disruptive behaviors and their parents (Eyberg, Boggs, & Algina, 1995). PCIT is an integration of traditional play therapy principles and techniques with behavioral parent training (Werba, Eyberg, Boggs, & Algina, 2006). PCIT, which entails weekly one-hour sessions, changes dysfunctional parent–child interactions through direct coaching of authoritative parenting skills during play and task situations within the clinic setting (Boggs et al., 2004). PCIT therapists

Table 2. Summary of Intervention Programs for Use in Home and School.

Program	Description	Population	Empirical Evidence
Parent–Child Interaction Therapy (PCIT; Eyberg, 1992)	Parent training program: Child play; parenting skills – using praise, giving effective commands, discipline strategies	Parents; children 3–6 years old	↓ challenging behaviors & ↑ positive parenting practices (Eyberg, 1992; McNeil, Capage, Bahl, & Blanc, 1999)
Stepping Stones-Positive Parenting Program (SSTP; Sanders et al., 2003)	10-session parenting program: Strategies for encouraging child development, strategies for managing challenging behavior.	Parents; children 4–17 years old	↓ child behavior problems in children with DD (Roberts et al., 2006); ↓ conduct problems (Connell, Sanders, & Markie-Dadds, 1997; Sanders & Markie-Dadds, 1992)
Incredible Years Parenting Series (Webster-Stratton, 1992)	12–14 session group parent training: positive discipline strategies, parenting skills, (stress) coping strategies, social skills training for the children	Parents; children 2–8 years old	↓ conduct problems in children in a Head Start setting (Webster-Stratton et al., 2001); ↓ conduct problems (Webster-Stratton, 1998)
Parenting Young Children (formerly STAR Parenting; Fox & Nicholson, 2003)	10-session parent education program: Anger management, developmentally appropriate expectations, nurturing, and appropriate discipline	Parents; children 1–5 years old	↓ child behavior problems in low-income families and ↓ parent reliance of corporal punishment for discipline; ↓ parent anger and ↑ parenting confidence (Brenner et al., 1999; Nicholson et al., 1999; Nicholson et al., 2002)

Nurse–Family Partnership (NFP; Olds et al., 2002)	Nursing program offers prenatal education and healthcare. Seeks to modify specific risks that are associated with negative outcomes. Includes parent training and problem solving.	First time mothers; Prenatal – children two years old	↓child injuries and abuse; ↓parenting stress; ↑ parenting skills (Olds, 2006; Olds et al., 2002; Olds et al., 1986; Kintzman et al., 1997)
Parent Teacher Action Research (PTAR; Kay & Fitzgerald, 1997)	School-based intervention. Whole-class social skills instruction; customized individual plan based on child's needs	Preschool – 3rd grade	↓ internalizing and externalizing problems, ↑ on-task behavior, social skills, cooperation (McConaughy, Kay, & Fitzgerald, 1998; McConaughy, Kay, & Fitzgerald, 1999; McConaughy, Kay, & Fitzgerald, 2000)
First Step to Success (Walker et al., 1998a, 1998b)	School-based intervention. 1:1 and group work to train at-risk children to interact appropriately with peers and adults at school	Preschool through 3rd grade	↓ maladaptive behaviors, ↑ adaptive behaviors (Golly et al., 1998; Overton, McKenzie, King, & Osborne, 2002; Walker et al., 1998a, 1998b)

then work to generalize the skills into the family's daily life. A major focus of this therapy is the development of child-directed play skills where the child leads the play and the parent serves as more of a commentator and participant in the play under the child's directions. This non-directive form of play improves the child's tolerance to frustration, reduces anger levels of oppositional children, and offers an increased opportunity for pro-social behavior to occur. Parents also are taught how to incorporate appropriate consequences for the child's behavior (Bell & Eyberg, 2002). Problem solving skills are taught throughout all stages of therapy to help parents prepare for new problems that arise after treatment is completed.

In the first phase of therapy, *Child-Directed Interaction* (CDI), parents learn child-directed interaction skills in order to strengthen the parent–child relationship (Boggs et al., 2004). In this phase, parents are taught how to use praise, behavioral descriptions and reflection following their child's appropriate behavior, and they learn how to ignore any negative child behavior. Within CDI, parents are instructed to avoid using questions, commands and criticisms during play in order to reduce the demands placed on children and to increase the likelihood of positive interactions. CDI is also designed to give the child control of the play situation while still enforcing rules and teaching them desired behaviors. Parents first practice these relationship-enhancing skills with their child in play situations at the clinic while being coached by a therapist through an ear radio transmitter device (Werba et al., 2006). Parents are then asked to practice the skills during daily five-minute home sessions with their child.

After CDI, the focus of therapy moves to *Parent-Directed Interactions* (PDI), which center on using clear, direct commands and imposing consistent consequences for behavior. This phase helps parents establish control over disruptive child behaviors that were not changed by differential attention (e.g., ignoring aggression) through the use of clearly communicated, age appropriate instructions and consistent positive (praise) and negative consequences (time-out) for compliance and non-compliance, respectively. Discipline and praise techniques are taught and practiced in-session and are carried out at home. When both CDI and PDI are established, parents are asked to continue to practice all aspects of therapy at home with the child in gradually expanding situations.

Numerous studies have demonstrated statistically and clinically significant improvement in children's behavior by the end of PCIT. Eisenstadt, Eyberg, McNeil, Newcomb, and Funderburk (1993) evaluated the effectiveness of PCIT for 24 mother–child dyads. Families participated in

14 weekly sessions of PCIT; one-half received CDI training first and the other half received PDI training first. The PDI-First group showed more improvement on parent report of conduct problems, and mothers were more satisfied with therapy. When the groups were combined for a subsequent analysis, families moved from clinical levels to within normal limits on compliance, conduct problems, activity level, and maternal stress and showed improvement in internalizing problems and child self-esteem; gains were maintained at six-week follow-up. McNeil et al. (1991) found that PCIT, provided to 10, 2–7 year-old children, also resulted in improved behavior at school.

Brinkmeyer & Eyberg (2003) reviewed the effectiveness of PCIT on young children (3–8 years old). In their review of empirical literature, children who completed treatment experienced statistical and clinically significant improvements in child behavior problems upon completion of PCIT. Similarly, Boggs et al. (2004) found significant improvements for 23 parent–child dyads of treatment completers on parent ratings of child behavior and parent tolerance for child's behavior as well as parent stress levels. That change continued to be significant in a follow-up study 10–30 months following treatment completion; there were no significant changes for those who dropped out of treatment. Since its development, PCIT has been adapted and evaluated on children with ADHD, language delays, chronic illness, neglected children, physically abusive families, children at risk for abuse, and children with separation anxiety (Pincus, Eyberg, & Choate, 2005). PCIT has also been adapted for use in schools with young children and their teachers (McIntosh, Rizza, & Bliss, 2000). Through a case study design, McIntosh et al. (2000) found that PCIT used with a teacher and preschooler resulted in increased positive interactions, decreased challenging behaviors, and increased compliance.

Although there has been no empirical investigation of PCIT's effectiveness with young children with developmental delays, McDiarmid & Bagner (2005) supported its potential use with this population through a clinical case description. In this case, PCIT demonstrated significant improvement in compliance and challenging behaviors in a three-year-old boy with moderate mental retardation, language delays, and oppositional defiant disorder. There are a few important caveats in the use of PCIT with developmentally delayed children. Behavioral principles work well with children with developmental disabilities (Weisz et al., 2005), but parents must be taught how to give developmentally appropriate commands that are short, concrete, and repetitive. The easier the command is to understand, the more effective it will be in improving the child's behavior. Parents should also use concrete and descriptive comments on their child's behavior ("You are putting the pink pig in the blue car.") to facilitate the child's understanding, reduce frustration, and increase the enjoyment of the interaction.

According to these investigations, following completion of PCIT, parents change their interaction style with their child, child compliance and disruptive behaviors improve, and parent level of distress and family functioning improve. In addition, this effective intervention has been adapted and evaluated in school settings and with children at various developmental levels. PCIT is one of the most empirically supported interventions and its versatility makes it a useful intervention in community and school settings. More research is needed with children with developmental disabilities and children from low socioeconomic status families. Case studies have been used to demonstrate its utility with these populations, but more rigorous research is required to determine the program's effectiveness with these specific populations.

Stepping Stones Triple P: Positive Parenting Program

Stepping Stones (SSTP; Sanders, Mazzucchelli, & Studman, 2003), a recently developed and specialized version of the *Triple P: Positive Parenting Program* (Sanders, 1999), was specifically designed for parents with young children with developmental disabilities. SSTP utilizes the parenting principles established in the Triple P program including creating an interesting, safe, and positive learning environment, using assertive discipline, having realistic expectations, and monitoring parent self-care. SSTP also educates parents on how to adapt to living with a child with a disability and how to develop support within the community.

Based on social learning theory, SSTP stresses the importance of parent–child interactions for the proper development of the child. SSTP provides a system of behavioral family interventions to promote positive and caring relationships between parents and their children and to help parents develop effective management strategies for dealing with a variety of childhood behavior problems and common developmental issues. Through individually tailored sessions, therapists create a supportive learning environment and give parents practical information about parenting, one-on-one feedback on their use of parenting strategies, and assistance on personal issues. These therapeutic strategies are designed to increase parental competence in behavior management, to assist in managing developmental issues often found among children with developmental disabilities, to reduce parent use of coercive and punitive discipline methods, to improve parental communication, and to develop parents' independent problem-skills.

SSTP is delivered through 10 sessions where parents are taught strategies to encourage child development and to manage behavior. Families also receive an SSTP family workbook and watch video demonstrations of positive parenting skills (Sanders, 2003). Parents select goals and strategies to practice in the clinic appointments and home observation sessions based on the initial assessment and discussion with the therapists. In session, clinicians often teach parents to identify the functionality of the child's behavior and to select management strategies accordingly. They then develop a treatment plan with pre-selected management strategies designed to optimally influence the challenging behaviors of the child. Specific strategies included: (a) increasing quality time with the child; (b) improving communication; (c) showing affection; (d) using descriptive praise; (e) giving attention; (f) establishing rules; (g) giving clear instructions; and (h) using appropriate discipline techniques. Following the implementation of the plan, subsequent sessions include discussions of difficulties with the plan along with possible changes and adaptations necessary to improve the plan's effectiveness. Upon completion of the program, booster sessions are available to further foster parent coping skills and use of support systems (Roberts, Mazzucchelli, Studman, & Sanders, 2006).

Before SSTP was formally established, Sanders & Plant (1989) investigated the effect of a preliminary version of the SSTP presented to parents of children with developmental disabilities and behavior problems. Five families were included in this study. Families assigned to the intervention group successfully implemented the program and experienced a decrease in behavioral problems. Sanders, Mazzucchelli, and Studman (2004) conducted a randomized clinical trial with 78 families of preschool children with developmental disabilities and behavior problems. The researchers found significant improvements in behavior problems, parenting style, and the parents' adjustment to their children's disabilities when comparing pre- and posttest assessments. In addition, many children (30%) in the treatment group experienced a clinically significant decrease in symptoms. In the most recent study, which included 47 families (27 received SSTP and 20 were placed in a wait-list condition), researchers demonstrated that SSTP reduced child behavior problems, decreased parental stress, and improved parenting styles in parents of children with developmental disabilities and significant behavior problems (Roberts et al., 2006). The results were maintained six months following treatment.

SSTP is a useful clinical program that can be directly applied to very young children (ages 2–6) with developmental disabilities. It is designed to be flexible in order to meet the needs and goals of each individual family. Along with the effective strategies taught in this program, parents also develop problem-solving skills to help them independently manage future behavior problems. This program has not been extended to preschool or day-care settings. In addition, it appears that this program may require relatively high levels of clinical skills to implement effectively.

The Incredible Years Parenting Program

The *Incredible Years Parenting Series* is a group-training program designed for parents of children ages 2–8 years old. Webster-Stratton (1990) developed this program based on social learning and relational theories that promote healthy attachment and nurturing parent–child relationships. The relational framework provides parents with group support and allows for a collaborative relationship to develop between parents and the group leaders. *The Incredible Years Parenting Series*, which is led by one or two group leaders (therapists or teachers) with 10–14 parents per group, uses videotape examples to foster group discussion about important components of effective parenting including playing with children using "child-directed play" approaches, strategic use of differential attention (ignoring negative behaviors and praising positive actions), encouragement, praise, and effective commands, as well as nonviolent discipline concepts (time-out, logical, and natural consequences). This collaborative discussion process with parents encourages problem solving, self-management, and parent empowerment (Webster-Stratton & Taylor, 2001). Topics also cover general information such as helping children learn, effective limit setting, teaching children problem solving, and getting support from family, friends, and the community. Each parent involved in the program reads a copy of the parenting book *The Incredible Years: A Trouble Shooting Guide for Parents* (Webster-Stratton, 1992). Groups of parents then watch videos of parents interacting with their children, stopping between each vignette to discuss what happened, what was done well, and what alternative strategies could have been used to manage the child's behavior. Treatment typically lasts for 12–14 weeks; including one 2–2 1/2 h session every week.

The program developer has conducted a number of randomized trials (e.g., Webster-Stratton, 1981, 1982), which all demonstrated the program's efficacy with children ages 2–8 who have previously experienced conduct and behavior problems. In one large study, Webster-Stratton, Hollinsworth, & Kolpacoff (1989) studied 194 parents with clinic referred young children (3–8 years old) enrolled in the program at pre-test, post-test, and one-year follow-up. They found a significant pre- to post-test improvement in parental report of behavior problems as well as improvements in parent self-efficacy and decreases in parent distress; these findings were maintained at follow-up. Through the observation of 78 young children (3–8 years old) referred due to clinically significant behavior problems, Webster-Stratton (1994) found that the *Incredible Years Parenting Program* improved utilization of effective parenting strategies to manage child behavior. Clinicians within other mental health clinics have replicated this program with children with conduct problems (Taylor, Schmidt, Pepler, & Hodgins, 1998).

This program also has application to low-income children within educational settings (Webster-Stratton, 1998; Webster-Stratton, Reid, & Hammond, 2001). In an investigation of 426 parents with children in Head Start, Webster-Stratton (1998) found that children and parents involved in the program experienced significant improvement in the children's pro-social behaviors, a significant decrease in challenging behavior, and a decrease in parent level of distress. In addition, teachers involved in the children's care rated parents who had completed the program as more involved in their child's education and more nurturing. In a more recent study (Webster-Stratton et al., 2001), the *Incredible Years Parenting Program* was evaluated in a randomized clinical trial as a selective prevention program with Head Start families ($n = 328$). In this study, they extended their previous research by including an extensive teacher-training program with the traditional parent-training program. Using the 12-week program, both teachers and parents received training on positive management and discipline strategies that promote social competence at home and in the classroom in hopes of strengthening protective factors and reducing risk factors in children and families. This study demonstrated that children, parents, and teachers in the treatment group experienced significant improvements on measures of child behavior, parental stress, and management of challenging behaviors.

The *Incredible Years Parenting Series* is one of the most rigorously researched interventions for young children with behavior problems. Originally designed for children with oppositional defiant disorder (ODD) and conduct disorder (CD), the program also was extended to very young children with behavior problems. Community-based research suggested that it has potential as a prevention program to prevent and reduce the development of ODD/CD in Head Start children. In addition, the program has parent and teacher training programs to assist with the implementation of a comprehensive treatment program. The program requirements of 2 1/2 h sessions every week for 12–14 weeks in a clinic setting may impede some low-SES families from participating. In fact, the developers reported that of those low-income families who did participate in the program, 25–30% dropped out before completing the program.

Parenting Young Children Program

The *Parenting Young Children Program* (*PYC*; Fox & Nicholson, 2003), formerly called the *STAR Parenting Program*, is a psychoeducational program that was specifically developed for parents of 1- to 5-year-old children. There are four major components to the program. The first component addresses how young children's behavior influences their parents' thoughts and feelings ("When my child sasses me I feel angry and worry that my child will not learn to respect others"), and how these internal events may produce undesirable parent reactions (yelling, slapping). Parents are taught to adopt a more thoughtful parenting style through the use of cognitive-behavioral theory and anger management strategies. Using a familiar stop-and-go traffic light with an imbedded STAR acronym, parents are taught to *Stop* (red light) and *Think* (yellow light) about the thoughts and feelings that resulted from their child's behavior. The goal is to provide parents ample time to regain emotional control through various techniques (breathing exercises, counting to ten, listening to music) before responding to their child. Parents are provided a brightly colored card displaying the STAR cognitive strategy to place somewhere in their home to provide them a mnemonic cue. The second segment of the program teaches parents to monitor and, if necessary, alter their developmental expectations for their children based on normative information provided from the child development literature. While continuing to practice stopping and thinking, parents are taught to add the term *Ask* to the STAR strategy to check on the appropriateness of their expectations for their child's behavior and to alter them if needed. The final two components of the *PYC* program emphasize new ways to *Respond* (green light) to their children. First, parents are taught strategies to strengthen their children's prosocial behaviors including positive reinforcement, establishing routines, and giving good instructions. Second, parents are taught how to provide developmentally appropriate consequences for their children's challenging behaviors including redirection, ignoring (extinction), natural consequences, and quiet time (time-out). The *PYC Program* was developed to be delivered in different formats but generally comprises a minimum of 10–15 h of instruction as well as daily in-home practice.

The first pilot study of the *PYC Program* demonstrated that it significantly reduced anxiety and improved confidence of 12 married parents of young children (Peters, Platz, & Fox, 1989). An abbreviated version of the program was offered to 37 university employees over four lunch periods and resulted in a 90% attendance rate with 87% of the participants rating the program content as excellent and 91% indicating that it had changed their parenting practices (Anderson & Fox, 1990); this same parenting-at-work model was later replicated in a business setting with similar results (Platz, 1995). Extending this early work to the community, Fox, Anderson, Fox, and Rodriguez (1991) offered 10 hours of instruction to 75 mostly married, middle class parents in five settings. Most parents were interested in learning how to more effectively discipline their young children. A posttest evaluation indicated that parents enjoyed hearing that other parents were struggling with raising their young children and that learning to slow down their parenting, being positive, and providing consistent consequences for challenging behaviors were the most important outcomes for them.

In the first study to use a pre-posttest design and follow-up condition with 35 parents, Fox, Fox, and Anderson (1991) reported significant improvements in parental anxiety and confidence, reduction in emotional reacting to children's challenging behaviors, and increased use of positive reinforcement and time-out. These results were maintained at a six-week follow-up. In the first controlled study of the *PYC Program* (Nicholson, Janz, & Fox, 1998), 20 parents (14 mothers, 6 fathers) began the program immediately and 20 additional parents (15 mothers, 5 fathers) were placed in a wait-list control group. The program was provided in a 4-session, 2 1/2 hour per session format. Results indicated that compared to the control group, parents receiving the parenting program significantly: (a) reduced their use of verbal and corporal punishment; (b) decreased their child's challenging behaviors; and (c) improved their parenting attitudes. These changes were maintained at six-weeks follow-up.

These initial positive results led to the expansion of the program into large community-based field trials. In a diverse sample of 149 parents from lower to middle socioeconomic, provided the *PYC Program* through nine community-based agencies, Brenner, Nicholson, and Fox (1999) reported significant pre-post changes with parents using less verbal and corporal punishment and more nurturing. Also, their young children's challenging behaviors reduced significantly by the end of the program. Nicholson et al. (1999) extended this program to 143 low-income mothers of young children who were taught the program over 10 weeks in 12 community agencies. For program completers (50%), results similar to the previous study were found with decreased punishment, increased nurturing, and improvements in their children's challenging behaviors. The *PYC Program* also was extended to parents living in Mexico (Solis-Camara, Fox, & Nicholson, 2000) with similar pre-post changes found. In a carefully controlled study of parents who were defined as at risk based on their reported high frequency use of corporal and verbal punishment with their young children (Nicholson et al., 2002), 26 parents were assigned to an experimental or wait-list control conditions. Results showed that compared to the control group, parents participating in the 10-session program significantly decreased their levels of verbal and corporal punishment, anger, stress, and child behavior problems with results maintained at one-month follow-up.

In addition to providing the program directly to parents, care also has been taken to ensure that professionals offering this program are competent to do so. Fox and Parroni Hennick (1996) trained eight professionals to lead parenting classes based on the *PYC Program*. Results showed that following the training program, participants increased their knowledge and comfort level in the program and were able to obtain results similar to previous studies when leading actual parenting classes on their own. In a similar training program offered at three community sites for 43 professionals representing 14 community-based agencies, Fox et al. (2006) reported that 23 successfully completed the program and then offered the *PYC Program* individually to 28 low-income families. Their pre-post results for families completing the program were similar to those found in previous research.

The *PYC Program* has been demonstrated to be an effective intervention program for parents of young children across cultures and ethnic groups who live in very low to upper middle class circumstances. The strengths of the program include: (a) it is grounded in good theory; (b) the program is practical and down-to-earth; (c) it can be easily understood and successfully implemented by parents with varying levels of education; and (d) it leads to significant changes in parenting practices and improves the behavior of young children. Limitations include its reliance of parental report as a measure of effectiveness and a drop out rate that approaches 50% for families living in poverty.

The *PYC* Program was recently adapted for use with low-income families of children with developmental disabilities (Fox & Holtz, 2008). Adaptations included the addition of a non-directive play component and the provision of the program in the homes of the children's families by trained graduate students. Of the 161 children who were referred, 49 completed the treatment program with an additional 30 continuing to participate in the program (drop out rate = 51%). Approximately 70% of the young children had a significant delay in one or more areas of development. Parents were provided an average of 13 sessions (range = 6–34) with attendance averaging 77%. Direct observation of the parent–child interactions showed both children and parents significantly improved on a number of coded dimensions (e.g., child – positive affect, responsiveness; parent – allowing child to lead play, expectations). Pre-post program measures showed that children's challenging behavior reduced significantly in intensity and frequency, and parents' expectations increased and their reliance on corporal and verbal punishment for discipline decreased. At intake, 80% of the children met the criteria for a formal *DSM-IV* diagnosis with Oppositional Defiant Disorder being the most common. At program completion, 84% of these children lost their diagnosis. A family satisfaction survey completed at program completion showed high satisfaction scores (mean = 44.3 out of a possible score of 49).

Nurse Family Partnership

The Nurse Family Partnership (NFP) is a preventative program designed for low-income mothers who have had no previous live births (Olds, Henderson, Chamberlin, & Tatelbaum, 1986). Mothers begin NFP prenatally and can continue with the program until their children are two years old. NFP is based on a combination of human ecology, self-efficacy, social learning, and attachment theories (Olds, 2006). These theories form a framework that emphasizes the importance of social context and the children's experience of their unique environments for the development of their behavior. This program has three major goals: (1) improve outcomes of pregnancy by helping improve prenatal health, (2) improve child's health and development by helping parents be more sensitive and competent, and (3) improve parental life by helping parents plan future pregnancies, complete school, and find jobs. To reach these goals, NFP seeks to modify specific risks that are associated with negative outcomes (e.g., poor birth outcomes, child abuse and neglect, injuries, and compromised parental life course). Prenatally, NFP attempts to reduce maternal use of harmful substances, help women build supportive relationships with family members and friends, and link women with other needed health and human services (Kintzman et al., 1997). Following birth, nurses teach mothers and caregivers how to improve the physical and emotional development of the child. This includes teaching caregivers to increase their observation of childhood illnesses (e.g., how to properly take a temperature), enhance the parent's observation of their child's communication signals, increase the parent's interest in play with the child, and to make the home a safe and stable place for the child (Olds et al., 2002). In addition, NFP helps caregivers clarify their goals and solve problems that may interfere with future education plans, finding work, and planning their next pregnancies.

There have been three large-scale empirical investigations of this program. The first study was conducted to examine differences between the NFP program and typical health services (Olds et al., 1986). The 400 participants who received NFP services were primarily Caucasian. They averaged nine visits (range 0–16) during pregnancy and 23 visits (range 0–59) from birth to the child's second birthday; visits lasted approximately 75–90 min. Caretakers who utilized the NFP services reported higher levels of support from the community and fewer parent and child illnesses. According to the HOME inventory, designed to evaluate the structure and quality of the child's environment, families in NFP provided environments that were more conducive to the emotional and cognitive development of their children. Parents also reported less irritable and fussy children compared to the control group. Finally, the NFP group had 80% fewer verified cases of child abuse and neglect when compared to the control group.

Kintzman et al. (1997) conducted a similar study with 1,138 mothers for the pregnancy stage and 743 mothers for the infancy stage of the program. This sample was primarily African American and recruitment was heavily focused on including unmarried mothers and low-income families. These families averaged seven visits (range 0–18) during pregnancy and 26 visits (range 0–71) following birth; visits lasted approximately 75–90 min. Similar to the previous study, mothers in the NFP group were more nurturing and provided a healthier environment for their children when compared to controls.

The most recent study (Olds et al., 2002) also focused on examining the effects of the program on unmarried and low-income families. This sample ($n = 735$) primarily consisted of Latino families. This study found similar results as the two previously cited studies. In addition, the researchers looked for differences in treatment results when the NFP program was delivered by a trained paraprofessional rather than a licensed nurse;

no therapist/nurse effects were found. This finding suggests that NFP can successfully help families through properly trained paraprofessionals.

NFP has been demonstrated to be an effective treatment program and is one of the few empirically supported interventions designed for prenatal mothers (Olds, 2006). After being implemented for nearly 30 years, the program has been effective in helping mothers from different ethnicities and socioeconomic levels provide a better home environment to help their children get off to a good start.

Parent Teacher Action Research (PTAR)

Parent Teacher Action Research (PTAR; Kay & Fitzgerald, 1997) is a school-based prevention program for children at-risk for antisocial behaviors. The program includes assessment and intervention components that address all children in a classroom, not just those identified as at-risk. These components include a universal behavior screening and social skill training (McConaughy, Kay, & Fitzgerald, 1998).

PTAR employs a multi-step screening process to identify students who would benefit from additional support and intervention. Once target students are identified, teachers, parents, and other members of the team work together to identify the behavior of concern and the possible contributing factors through the use of direct observation and parent- and teacher-report measures (McConaughy et al., 1998). After collecting data to direct the team's intervention, the action plan is developed. The aim of each plan is to use the identified strengths of the child and additional new skills to reach parent and teacher goals for the child. Goals are set based on parent and teacher expectations as well as developmental norms (McConaughy, Kay, & Fitzgerald, 1999). Observable indicators of the goals are established to assist in an objective evaluation of the child's progress. To reach the plan's goals, parents and teachers generate an action plan that will target the specific risk behaviors that may include home visits, provision of community resources, weekly counseling sessions at school, and reinforcement programs. Continuous assessment of the child's progress through the plan drives further intervention and indicates when the treatment goals have been met (Kay & Fitzgerald, 1997).

A number of studies provide empirical support for the use of PTAR with young children. McConaughy et al. (1998) compared the effectiveness of PTAR versus general whole-class social skills training with 36 first grade students at risk for emotional and behavioral disorders (EBD). Using a matched control group, results revealed PTAR contributed to significant reductions in both externalizing and internalizing problems compared to the control group. Additionally, independent observers stated that PTAR was more effective as demonstrated by decreased hyperactivity in classes and reduced aggression during recess. Teachers in the treatment group also reported improvements in on-task behavior, social skills, cooperation, assertion, and self-control. In a replication study, McConaughy et al. (1999) randomly assigned 82 first and second grade students at risk for EBD to PTAR or a control group where the students received regular social skills training from the teacher. At the end of two years, PTAR children exhibited a significant reduction in teacher reported internalizing and delinquent behavior and parent-reported behavior problems compared to the control group. Parents also reported improvements in children's cooperation, self-control, and competence.

McConaughy, Kay, and Fitzgerald (2000) reanalyzed two separate cohorts of PTAR students (i.e., one-year vs. two-year outcome data) to compare the long-term benefits of PTAR as well as to gauge the proper dosage of the program. Eighty-two children were randomly assigned to the 1-year program, 2-year program, or a control group. Results revealed that treatment in both programs had a significant effect when compared to controls, but even more main effects were found at the end of year two than year one. These findings supported the overall effectiveness of the program, but also indicated that improvements may increase with longer implementation.

PTAR is an effective model for fostering home and school collaboration (Kay & Fitzgerald, 1997; McConaughy et al., 2000). It is designed to reach all students and to provide individualized treatment for children identified as at-risk for behavior problems. Because the program targets at-risk students, children with developmental disabilities are often included. The individualized treatment design allows for developmentally appropriate treatment approaches. Although the programs collaborative approach is an important strength, it also means that implementation of the program is not possible for parents who cannot or will not actively participate in the program (Reddy & Richardson, 2006). The program also requires a committed school staff for successful implementation.

First Step to Success (FSS)

First Step to Success (FSS; Walker et al., 1998a) is a home and school prevention program for at-risk kindergarteners with early signs of antisocial behaviors such as aggression and withdrawal from classroom activities. The primary objective of the program is to train at-risk children (preschool–third grade) to interact appropriately with peers and adults at school and to prevent the development of serious and long-term antisocial behavior problems (Walker, Severson, Feil, Stiller, & Golly, 1998b). FSS includes three modules: (1) universal screening, (2) school-based intervention, and (3) home-based parent-training intervention (Golly, Stiller, & Walker, 1998). Although designed to be applied in combination, the program developers state that the modules can be applied independently to achieve specific screening or intervention goals.

The proactive universal screening process begins with teacher nominations of 10 students who may need further evaluation for behavior problems (five internalizing, five externalizing). The top three students on the teacher's list are then evaluated using parent ratings, teacher ratings, and direct observation in order to identify the children who would benefit from targeted in school and home intervention (Beard & Sugai, 2004). Children identified as at-risk then move into the next module, school-based intervention. This module is consultation-based and includes intervention with the child, peers, and the teacher. Each target child's behavior is closely monitored for 30 days. During this time, the teacher praises the child for pro-social behaviors (attending to the teacher, sharing) and gives negative feedback such as verbal reprimands for inappropriate behaviors (yelling, getting out of their seat). Besides the close monitoring of the child's behavior, each day of the program involves two 20–30 min sessions where a FSS trained professional (e.g., school counselor, school psychologists, special education teacher, or social worker) works 1:1 with the child. During this time, the professional provides continuous feedback on the child's behavior through a flash of a red card for negative behavior and a green card for positive behavior. Consumables and picture aids are integrated into the program for cognitively delayed children who may not understand the pairing of behavior and the color of the card (Beard & Sugai, 2004). Throughout this module, home rewards (e.g., games, 1:1 time with parent) and individual school privileges (e.g., book reading time, computer time, 1:1 time with teacher) are given for extended periods of positive behavior. The program is repeated if the child does not meet the pre-set goals by the end of the 30 days (i.e., appropriate behavior for more than three days in a row). On average, students take two months to complete the program (Overton, McKenzie, King, & Osborne, 2002). The intensive parent-training module, which typically begins after the child has finished day 10 of the school program, is focused on improving academic achievement and school adjustment. It includes six one-hour sessions that instruct parents how to teach their child key school-related skills, such as communication and sharing, cooperation, limit setting, problem solving, and friendship making. Following instruction, parents are asked to practice these skills with their children 10–15 min every day.

Several outcomes studies have demonstrated the efficacy of FSS (Reddy & Richardson, 2006). Results from a four-year randomized wait-list control group study found that FSS produced significant improvements in adaptive and maladaptive behaviors across grade levels and home and school settings in a sample of 46 kindergarteners (Walker et al., 1998b). Compared to wait-list, significant differences in favor of FSS were found on teacher and parent ratings of externalizing behaviors; however, no differences were found for internalizing behaviors. In a replication study with 20 kindergarteners, Golly et al. (1998) found similar results. In addition, they found that teachers and parents involved in the treatment group reported high levels of satisfaction with the program. Another replication study, which implemented the same research design but included more families from communities with high rates of poverty, found significant differences between treatment and control groups at posttest and one-year follow-up (Overton et al., 2002). Again, the researchers only found reduction in externalizing behaviors. In the most recent study, Beard and Sugai (2004) compared the effectiveness of the teacher component versus the combined teacher and parent components on reducing antisocial behavior in the classroom. Six students were randomly assigned one of the two interventions. Results revealed that child problem behaviors reduced to almost zero in both groups; which suggests that the both treatment conditions were effective in improving problem behaviors in the classroom. However, this study did not investigate if the children's behaviors also improved at home.

FSS is a promising empirically supported intervention for young children (Reddy & Richardson, 2006). The comprehensive, collaborative approach is a positive feature of the program. The screening process is thorough, but the intervention component of the program may be difficult for schools with limited resources (Kaiser & Rasminsky, 2007). Although the empirical evidence strongly supports FSS's efficacy with young children and externalizing behaviors, the program has not shown an ability to decrease internalizing distress. This program has some adaptations that increase its utility with children who have developmental delays, but the developers indicated that it is not designed for children with autism or severe language problems. Further research with developmentally delayed children is needed.

CONCLUSIONS AND FUTURE DIRECTIONS

This chapter reviewed the emerging field of infant mental health. Behavior and emotional problems in young children are common and for many toddlers and preschoolers, these challenging behaviors do not just disappear with the passage of time. Children with developmental delays are even more at-risk for developing significant and persistent mental health difficulties. While the development of these behavior problems in early childhood is a complex issue, we now have sufficiently developed theories, assessment methods, and tools to untangle the contributing factors to a young child's presenting problems. Moreover, we also have the treatment technology to effectively address these challenging behaviors and to prevent them from gaining in strength that will make later intervention efforts more difficult. We also know that for maximum effectiveness, these treatment strategies should be implemented in all significant settings that the young child experiences, including home and school (child care, preschool).

One future challenge for researchers and clinicians is to determine how we can gain the cooperation of parents, teachers, and other caregivers to implement what we already know works. Of families who begin treatment for their children, 40–60% will terminate prematurely (Kazdin, 1996; Wierzbicki & Pekarik, 1993). Promising literature is emerging to help us begin to identify those barriers that lead to unsatisfactory family attendance and adherence in child therapy (Nock & Ferriter, 2005). These barriers include a myriad of factors such as conflict with a significant other about coming to treatment, lack of parent motivation to consistently implement treatment strategies, the quality of the relationship between the caregiver and therapist, parent perceptions regarding the effectiveness of the treatment program, illness in a family member, and distance to the clinic, to name a few (Kazdin, Holland, & Crowley, 1997). The findings generated from this research should lead to the fine-tuning of our treatment programs by incorporating components that address these barriers early in our treatment work with families and their young children.

A larger future goal in this field will be to continue to impress upon policy makers the importance of addressing mental health issues at their beginning, rather than allowing them to become more intractable when they are much more difficult and costly to manage.

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SELF-DETERMINATION AND PERSONS WITH DEVELOPMENTAL DISABILITIES

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In today's society, students with developmental disabilities are increasingly expected to meet more rigorous academic expectations. The No Child Left Behind Act of 2001 (P.L. 107–110), in particular, has placed great pressure on public schools to ensure that all children participate in and succeed in the general education curriculum. Ideally, such "success" for these students would include the development of skills needed for successful adult participation in society (e.g., employment, transportation and living in the community, and post-secondary education). This success assumes that students become empowered during the education process to the greatest extent possible, enabling them to participate in educational decision-making, evaluate options, and advocate for themselves (Abery, 1994; Mithaug, Wehmeyer, Agran, Martin, & Palmer, 1998). Such educational *self-determination* or empowerment is the "ultimate goal of education" (Halloran, 1993, p. 214).

As it appears, self-determination is more than increasing the capacity of the individual to participate solely in educational decision-making. Self-determination is a cadre of skills, knowledge, and beliefs enabling a person with developmental disabilities to engage in autonomous, self-regulated behavior that is goal-directed over time (Algozzine, Browder, Karvonen, Test, & Wood, 2001). From an awareness of personal needs, self-determined

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individuals choose goals and persistently pursue those goals; this involves asserting their presence, making their needs known, evaluating progress toward meeting their goals, adjusting their performance, and creating unique approaches to solve problems (Agran, Martin, & Mithaug, 1989). An underlying assumption of self-determination is that the individual understands his or her strengths *and* limitations, coupled with a belief in oneself as being capable and effective. Having such a personal foundation enables the person with a developmental disability to have greater ability to assume control of his or her life and participate as successful adults in the community (Field, Martin, Miller, Ward, & Wehmeyer, 1998b). Arguably, then, the assumption of roles of successful adults is essential to a definition of self-determination (Wehmeyer, Agran, & Hughes, 2000a).

Many people in American society might easily argue that independence and individualism are highly regarded values for all citizens (Hanson, 1997; Harry, 1994). These values assume self-determination and self-reliance. Interestingly, even though self-determination is a philosophical organizing concept in special education policy and practice (Algozzine et al., 2001), and has been highlighted in legislative, funding, and policy initiatives (cf. IDEA, 2004; National Council on Disability, 2004; President's Commission on Excellence in Special Education, 2002), persons with developmental disabilities often still do not experience the same level of personal choice and control over their lives as that demonstrated by their peers, presenting great challenges to the education community. In this chapter, we focus on how self-determination can be infused in educational programming to support persons with developmental disabilities.

INTEGRATING SELF-DETERMINATION IN THE ACADEMIC CURRICULUM

If students with developmental disabilities are to develop self-determination skills, instruction in targeted competencies must, of necessity, begin in the public schools. Wehmeyer, Field, Doren, Jones, and Mason (2004) have noted that "promoting access to the general education curriculum provides the chance to *more fully infuse* efforts to promote self-determination and student involvement actually provides a means to promote the participation of students with disabilities in the general curriculum" (p. 417). Teachers working with students with disabilities thus can (a) facilitate progress in the general education curriculum by teaching standards-based skills and knowledge associated with elements of self-determination (that are typically reflected in state and local standards); and (b) teaching specific self-determination skills, including self-regulation, self-management, goal setting, decision-making, and problem-solving (see Wehmeyer et al., 2004).

Although many teachers agree that it is important to teach self-determination, a relatively low percentage of special education teachers actually implement a self-determination program or include goals and objectives related to self-determination on student IEPS (Grigal, Neubert, Moon, & Graham, 2003; Wehmeyer et al., 2000a). The development of self-determination competencies implies students becoming actively involved in the IEP planning process, yet most education professionals do not know how comfortable students and families are with these concepts. Clearly, self-determination and overall student empowerment improve the quality of students' adult lives; and increasing students' self-determination may increase their success in moving from high school to adult living (Wehmeyer, 1995). Research findings demonstrate that (a) self-determined adolescents with cognitive disabilities leave school and demonstrate more positive adult outcomes than do their peers with cognitive disabilities who are less self-determined (Wehmeyer & Schwartz, 1997); and (b) adults with mental retardation who are self-determined experience a higher quality of life (Wehmeyer & Schwartz, 1997). Unfortunately, the frequency of self-determination goals being reflected in IEP development nationally is less than desirable. For example, Wehmeyer et al. (2000a) reported that (a) 22% of teachers include self-determination goals for all students with disabilities, (b) 47% of teachers include such goals for some students, and (c) 31% of teachers report no goals for their students with disabilities. Such lack of attention to the development of self-determination by the education community is puzzling, given the strongly held cultural values in the society regarding independence, self-sufficiency, productivity, and participation in the community. It is even more disconcerting when considering that many special education professionals report insufficient training in or information about self-determination (Wehmeyer et al., 2000a).

Algozzine et al. (2001), in a comprehensive examination of practices that promote self-determination, noted that both self-determination and advocacy skills can be successfully taught to students with developmental disabilities. Earlier, Wehmeyer et al. (2004) presented very specific recommendations regarding strategies for teaching a range of important skills related to self-determination, including the promotion of (a) autonomous behavior, (b) self-regulated behavior, (c) self-advocacy and leadership, and (d) self-realization and psychological empowerment. More recently, these strategies have been presented in the context of teaching pedagogy focusing on how to teach self-determined learning (Mithaug, Mithaug, Agran, Martin, & Wehmeyer, 2007). Empirically validated models for teaching self-determination and student self-regulation to adolescents (Wehmeyer, Palmer, Agran, Mithaug, & Martin, 2000b) and elementary age children (Palmer & Wehmeyer, 2003) have also been reported.

Integrating self-determination training in transition planning is especially important. Morgan, Ellerd, Gerity, and Blair (2000) observed that two key components must be in place for successful transition to occur: (a) coordinated services that are both accessible to students and which are assessed on a regular basis; and (b) student involvement characterized by awareness of needs, self-advocacy, and involvement in setting and working towards targeted goals. In both instances, all persons involved in planning – students, family members, and education professionals – must have sufficient information to make appropriate decisions. Clearly, student involvement must be infused in the transition planning stage whenever possible (Szymanski, 1994; Wehmeyer & Ward, 1995). Students, when appropriate, should be key players in the transition process. Students must be prepared to make a plan of action that will help them achieve the goals they desire by taking what they know about themselves and valuing it (Field, Hoffman, & Spezia, 1998a). To be successful, students must take long-term goals and break them into a series of short-term goals that build upon each other to lead them towards success. They must learn that they have choices they are going to make and that all choices have some sort of consequence. With that in mind, students must know they are responsible for their own actions and choices. Empowerment is necessary for students to make good choices; and prejudicial actions can impede such an empowerment process.

For students to become involved in the transition process, they must be empowered. They must be taught about their own disabilities and what they are capable of doing presently and in the future. There are four premises underlying the process toward student empowerment. The first premise is that students with disabilities are able to gain knowledge about their abilities, their IEPs, the IEP process, and why they receive services (Jones, 2006). It must be ensured that they understand what their disabilities mean and be able to talk about it to others. They must be encouraged to become comfortable stating what they need and what they do not need (Werger & Burnette, 2000). The second key premise is that no student is too young to learn about himself/herself or too young to become involved in decision making about his/her education. The third premise learned is that student empowerment promotes learning as students are encouraged to engage in inquiry, develop leadership skills, and make decisions that affect their own lives. The fourth premise is that student empowerment is contagious (see Jones, 2006). The more students are involved and empowered, the more they become involved in the process. Key components to empowering professionals to work with students in this manner requires that professionals acquire a firm foundation of what self-determination is, become familiar with possible activities for teaching self-determination skills, and then receive encouragement to embark on this adventure with the students (see Jones, 2006). In the same dimension, families must also be involved. It is of paramount importance that education professionals communicate their intentions with families. For example, one frequently used best practice strategy is to invite families to a convenient meeting site where the approach can be explained and questions answered (Werger & Burnette, 2000). Students also need to be a part of the process to be successful. For example, successful employment of adults with learning disabilities has been attributed to their personal quests for control of their lives and for choosing careers in their areas of strength (Cohen & Spenciner, 2005).

TEACHING SELF-DETERMINATION

Given the argument that students with developmental disabilities ages 18–21 years should be involved in all aspects of education program development and implementation (Wehmeyer, Garner, Yeager, Lawrence, & Davis, 2006), strategies for effectively teaching self-determination have been reported by numerous authorities (Algozzine et al., 2001; Field et al., 1998a; Mithaug et al., 2007; Wehmeyer et al., 2000b). These strategies, however, have tended to focus on older versus younger students with developmental disabilities (see Algozzine et al., 2001) and more recent work has emphasized the importance of infusing self-determination instruction into the general education curriculum (Wehmeyer et al., 2004). Generally, such infusion would require (a) curricula adaptations such as modifications to engage students in learning (Wehmeyer et al., 2004); or (b) curricula augmentation which supplement or expand the curriculum with strategies designed to help students succeed (Knowlton, 1998; 2008; Wehmeyer, Sands, Knowlton, & Kozleski, 2002). For example, as Knowlton (2008) observed, augmentation would promote long-term progress ranging along a continuum of self-determination activities from *simple choice-making* (e.g., use of vocabulary software programs to practice community-reference words) through *exploration and autonomy* (e.g., providing the student with supports leading to decisions and steps in obtaining a driver's license) to *self-sufficiency* (e.g., monitoring completion of state and federal income tax forms).

Using Students' Experiences to Teach Self-Determination

Experiences that students have frequently impact their self-determination abilities. Education professionals and others involved in the transition process must examine not only the types of high school experiences most likely to foster self-determination, but the processes by which students' self-determination interacts with high school experiences and the variation in their experiences (Eisenman, 2001). Students, when appropriate, should be key players in the transition process. They must make plans of action to help them achieve the goals they desire by taking what they know about themselves and valuing it (Field et al., 1998a). To be successful, they must take long-term goals and be able to break them into a series of short-term goals that build upon each other to lead them towards success. In addition, they must learn that they have choices to make and that all choices have consequences. With that in mind, they must know they are responsible for their own actions and choices. This learning should, however, be a gradual process where the student is guided at first with his/her responsibility by the education professional and/or parent and gradually he/she assumes personal responsibility. Getting students to predict or think of potential negative effects of certain choices is a goal that allows them to think about all options and outcomes before making a decision that will, hopefully, be as positive and beneficial as possible.

Using Assistive Technology to Support Self-Determination

To ensure that all students with developmental disabilities acquire needed self-determination skills to confront challenges of life, they must learn to advocate for their assistive technology (AT) needs (Bowser & Reed, 2001; Castellani & Bowser, 2006). The importance of AT in the lives of students with developmental disabilities has been noted by the Division on Developmental Disabilities of the Council for Exceptional Children (Parette, 1997). Specifically, the Division noted that

> a wide range of ATDs (assistive technology devices, emphasis added), ranging from "low-tech" to "high tech" in design, is currently available that can enable persons

> with mental retardation and developmental disabilities to acquire important skills that contribute to an enhanced quality of life and greater independence. (Parette, 1996, p. 9)

Numerous studies have been conducted in recent years supporting the use of AT with students with disabilities, with particular emphasis on the benefits for increased independence and participation in community life (Davies, Stock, & Wehmeyer, 2001, 2002; Wehmeyer, Smith, & Davies, 2005; Sturmey, 2003). A wide array of commercially available technologies (e.g., cell phones, computers, digital cameras, Palmtop PCs, and global positioning systems) hold immense potential to (a) support students in navigating in community settings, and (b) provide self-directed prompts for performing important functional tasks (Wehmeyer et al., 2005).

In addition to contributing to increased performance in academic tasks (Peterson-Karlan, Wojcik, & Parette, 2006; Strangman & Dalton, 2005), AT may be especially important for students in transition planning given that an array of devices and services can provide supports across school, community, and work settings. For example, Parette, Crowley, and Wojcik (2006) identified four specific types of AT tools that can assist students with monitoring their own behavior. These tools include (a) stop watches, (b) hand-held counters, (c) Palm devices, and (d) software spreadsheets. Stopwatches can minimize the burden of time-management by allowing the student with a developmental disability to focus more directly on a specific academic task at hand. Hand-held counters provide supports to (a) the cognitive tasks of counting words, paragraphs, math problems, and other tasks related to academic assignments; and (b) students with memory problems or difficulties tracking/counting in a cumulative manner, enabling them to focus on other aspects of an academic assignment, while providing an ongoing tally of specific student task achievements. Palm devices can be programmed with a series of questions related to the performance of a specific academic task, coupled with feedback to the student who responds to the question. Finally, spreadsheet applications, such as Microsoft® Excel, allow teachers to create spreadsheets that enable students to enter performance data as it is obtained, and have charts or graphs displayed immediately so that student progress can be visually presented (Parette et al., 2006). Many students with developmental disabilities have difficulties related to self-regulation of their behaviors during academic task performance (Kern-Dunlap et al., 1992; Wehmeyer et al., 2005). However, teachers can use a number of strategies and tools with these students and allow them to assume responsibility for managing their own behaviors (Alberto & Troutman, 2006). Computer-based visual/auditory prompting devices, particularly those that are electronic (Kimball, Kinney, Taylor, & Stromer, 2003), can be used to provide students with message prompts about steps to be completed in academic task, following rules, and other important sequences (Parette et al., 2006). For example, StepPad (Attainment Company, Inc., 2004) is a small hand-held device that works like a tape recorder – it allows the student to record and play step-by-step instructions. The TalkTrac™ Plus (Ablenet, n.d.) is a four-message communication aid that fits easily on the student's wrist and allows the student to record up to four steps in a sequence and change the messages as needed for different tasks. Time Pad (Attainment Company, Inc., 2004) is another hand-held device that allows the student to record up to five timer-activated messages (e.g., steps to a math problem).

On the whole, for appropriate AT devices to "considered" by IEP teams, Castellani and Bowser (2006) suggested that three important questions should be considered when developing transition plans for children with developmental disabilities. These include (a) Can the student describe his/her strengths and challenges? (b) What "opportunities" are needed to assist the student to develop self-advocacy and communication skills in community settings? and (c) What skills are needed for the student to communicate his/her AT set-up, maintenance, and breakdown needs?

Using Out-of-School Experiences to Generalize Self-Determination Skills

For the most part, when efforts to plan for a student's future have been made, they have traditionally focused on further education or employment, ignoring other key areas in which competence will be needed (e.g., daily and community living skills; Sitlington, 1996). In order to prepare young people for life after high school, community or daily living skills instruction (which includes self-determination training) must begin early in their school careers. This instruction should take place early and often and continue through high school to prepare students with developmental disabilities for life after high school.

The process of teaching self-determination, as noted previously, is a gradual process moving from education professional or family guidance to student assumption of responsibility. Getting students to predict or think of potential negative effects of certain choices is a goal that allows them to think about all options and outcomes before making a decision that will, hopefully, be as positive and beneficial as possible. To most effectively help students with developmental disabilities generalize their self-determination learning, direct instruction will need to be used. With direct instruction the student gets much needed practice as well as immediate and corrective feedback on his/her performance and continues working on needed skills until mastery is achieved. Once the student has acquired the needed skills, he/she can then practice these skills through role-playing. Such role-playing can be practiced in the special education classroom followed by a transition into practicing in other mainstream/regular classrooms and finally practicing in the home and community. Overall, the goal for students with developmental disabilities is to become independent decision makers.

Involving Families and the Community in Self-Determination

Without question, it is critical to have involvement of family members and parental support of school efforts to develop self-determination competencies among students with developmental disabilities (Abery, 1994; Carter, Lane, Pierson, & Glaeser, 2006; Grigal et al., 2003; Zhang, Wehmeyer, & Chen, 2005). Self-determination is a cornerstone for transition planning (Algozzine et al., 2001; Cohen & Spenciner, 2005; Westling & Fox, 2004). Wehmeyer et al. (2006) observed that active student involvement is a "hallmark of quality transition services" (p. 11), though families and members of the community must also be involved to the greatest extent possible. Grigal et al. (2003) noted that "the success of self-determination depends on parents' views of its appropriateness and desirability" (p. 98). When family members believe self-determination is important for their children, and thus is an important part of the school curriculum, there is a greater likelihood that self-determination will be embedded in the curriculum. In a study of 234 parents/caregivers perceptions of the role of self-determination in school curricula, Grigal et al. found that families (a) were supportive of the teaching of self-determination skills; (b) felt their children should attend and be taught to participate in IEP meetings; and (c) agreed that their children's schools supported the development of important self-determination skills (e.g., goal setting, opportunities for decision-making, and expressing interests and desires). Unfortunately, only 78% of the families who participated in this study felt that such skills were actually being taught to their children with disabilities.

On the basis of the overall points made above, it is important to note self-determination is an integral part of educational programming for

Table 1. Indicators of Quality Educational Services for Students with Developmental Disabilities Ages 18–21 Years.

Quality educational services are characterized by:

- Being delivered in age-appropriate environments with opportunities for social interaction and promote inclusion in the community,
- Having ecological validity and being community-based,
- Having an "outcomes" orientation,
- Academic instruction that is outcomes-focused and functional,
- An emphasis on person-centered planning and active involvement of families,
- Planning and implementation with active participation of adult service providers,
- Employing best practices in transitions,
- Active student participation and the promotion of self-determination.

Source: Adapted with permission from Wehmeyer et al. (2006).

students with developmental disabilities. It involves quality educational services for all students, especially for those who are ready to participate in the workforce. Table 1 lists important indicators of quality educational services.

To accomplish the goal of quality educational services, resources must be available. See Table 2 for self-determination resources for educational professionals.

CONCLUSION

In this chapter, self-determination was presented as an important value in American society that should be developed and instilled in persons with developmental disabilities. In the broadest sense, it is critical that persons with developmental disabilities both develop and exercise self-determination skills to participate more meaningfully in their daily lives. Education professionals in partnership with families play crucial roles in helping these individuals achieve meaningful levels of participation. While there are challenges and issues related to teaching self-determination skills in educational programs for learners with developmental disabilities, educators and service providers must know that many resources are available to help them make curricula decisions as well as understand the conceptual foundation for self-determination. The more we prepare people with developmental disabilities to be self-determined in dealing with problems, the better off our society is as a whole.

Table 2. Self-Determination Resources for Education Professionals.

Source	Address	Description
Center for Self-Determination	http://www.self-determination.com/	Provides guidebooks and other publications organized by topical areas.
Self-Determination Theory. An Approach to Human Motivation and Personality	http://www.psych.rochester.edu/SDT/index.html	Publications, theoretical information, and other resources evolving from 30 years of work at the University of Rochester and other partners.
Self-Determination Synthesis Project	http://www.uncc.edu/sdsp/home.asp	On the basis of a knowledge base and best practices related to self-determination (SD) and self-advocacy (SA) interventions, this site presents lesson plans based on research in the field. Information regarding five state transition technical assistance centers is also available.
Self-Determination for Persons With Disabilities: A Position Statement of the Division on Career Development and Transition	http://www.dcdt.org/pdf/self_deter.pdf	A comprehensive document on self-determination providing information about a range of issues, including historical perspective, educational practices, role of students and families, policy implications, and other topics of interest.
Beach Center on Disability	http://www.beachcenter.org/research/default.asp	Provides an array of self-determination research publications related to projects conducted at the University of Kansas.

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POST-SECONDARY PLANNING FOR STUDENTS WITH DEVELOPMENTAL DISABILITIES

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Colleges and universities are experiencing a dramatic increase in the number of students with developmental disabilities being admitted; and more and more institutions are establishing special programs and services for these students (see Dolyniuk et al., 2002; Hart, Grigal, Sax, Martinez, & Will, 2006). In the 1990s, for example, the percentage of college students with disabilities entering first-year nearly tripled from 1.2 percent to 3.5 percent (Henderson, 1999). This growth fueled the need for post-secondary personnel who work to ensure that these students are provided equal educational opportunity (Duke & Shaw, 1999). This increase in enrollment has been attributed to some important factors. At one time, college or university education was out of the question for many students with developmental disabilities. Beginning in the mid-1970s, the passage of Section 504 of the Vocational Rehabilitation Act (Public Law 93-112) prohibited institutions from discriminating against students with disabilities. After the passage of this law, colleges and universities did not suddenly open their doors to students with disabilities. Over time, as the courts helped to define the parameters of the law and public opinion about persons with disabilities improved, many became more comfortable with the idea of admitting and accommodating students with disabilities (Grigal, Neubert, & Moon, 2001, 2002; Hall, Kleinert, & Kearns, 2000). Many institutions now

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have full-time faculty or staff persons who direct programs for these students (Stodden, Conway, & Chang, 2003; Weir, 2004). In fact, some have gained reputations as good places for these students because of the level of support offered (Bender, 2008).

Apparently, Section 504 of the Rehabilitation Act of 1973, the Education of All Handicapped Children Act of 1975 (PL 94-142) and its amendments and the American with Disabilities Act (ADA) of 1990 (PL 101-336) have all contributed to the increase in enrollment of students with disabilities in post-secondary programs. These students, like others, have aspirations of entering professions or occupations that require post-secondary education (Brown, Gerber, & Dowdy, 1992; Henderson, 2001 as cited in Hitchings et al., 2001). As it stands, many of these students are receiving better academic preparation in high school (Bender, 2008). In other words, secondary-school teachers are preparing their students in making the right choices of colleges as well as helping them in delineating what accommodations they will need in their programs. Students and their families can now take advantage of published guides to college programs (Cobb, 2003; Peterson, 2008; Wax & Kravets, 2005). In addition, they can now avail themselves of special accommodations when they take the Scholastic Aptitude Test (SAT) and the American College Test (ACT) (Hallahan & Kauffman, forthcoming). Clearly, there are a great number of students with disabilities continuing their education requirements for emerging jobs as the national economy shifts from a manufacturing base to a services and technology base (Acne & Kroger, 1997). Despite these laws and the efforts of educational profession, these students continue to face challenges. The purpose of this chapter is to discuss post-secondary planning to support students with developmental disabilities. Embedded in this discussion are issues and challenges that hamper their success.

POST-SECONDARY EDUCATION FOR STUDENTS WITH DEVELOPMENTAL DISABILITIES: ISSUES AND CHALLENGES

The transition from school to work or to post-secondary training is a critical period for all students (Gilmore, Bose, & Hart, 2001; Zaft, Hart, & Zimbrich, 2004). Thus, a challenge for educators is to develop educational programs and services that embrace the characteristics that is prevalent in highly successful adults with and without disabilities. For years, adolescents and adults with development disabilities did not receive much attention from general or special educators. Fortunately, special educators now are reorganizing the complex needs of these older individuals and are making progress in designing interventions to meet their diverse needs. However, they alone cannot ensure the success of these students in secondary and post-secondary situations (see Hart, Mele-McCarthy, Pasternack, Zimbrich, & Parker, 2004). Legislators and policymakers must consider the special needs of this population in reforming secondary education; and general and special educators must share the responsibility of preparing them for graduation and post-secondary planning (see Bailey, Hughes, & Karp, 2004). In addition, community services must join forces with educators and employers to provide individuals with developmental disabilities with a continuum of services throughout their life span. Many students with developmental disabilities find themselves unprepared at college entry in a number of areas including inadequate knowledge of subject content, underachieving in academic skills, poor organizational skills (e.g., time management and study skills), poor test taking skills, lack of assertiveness, and low self-esteem (Dalke & Schmitt, 1987; Mull, Sitlington, & Alper, 2001; Stodden & Whelley, 2004).

To adequately prepare students with disabilities for post-secondary education, secondary education programs must reflect those skills and competencies that are important for coping with academic and social demands found in a college setting (Sharpe & Johnson, 2001). The content of the secondary program must provide these learners with the skills necessary to succeed in post-secondary programs. Their effective inclusion into college preparatory programs require that both regular and special educators contribute to the process. Therefore, the extent to which each group provides these students with preparatory skills needed to meet the demands of college setting is important. These students must receive a fair share of special education services. For example, the majority of these students seem to be graded on the same standards set for their non-disabled classmates, and they generally are not provided with tutoring services or other assistance outside of their classes. Moreover, many regular education teachers tend to receive little support in instructing these students. Wagner (1990) observed that "encouraging greater instruction of students with disabilities into regular education classes, without serious attention to the instruction that goes on in these classes, would seem simply to encourage greater rates of academic failure" (p. 28). The consequences of failing courses are serious, particularly those courses needed for graduation. Students who fail to accumulate sufficient numbers of required credit hours to pass 9th grade frequently drop out of high school before graduation. Although passing 9th grade does not guarantee successful completion of high school or transitioning into post-secondary education, failure at this grade level increases the likelihood of dropping out; and by leaving school early, these students may miss educational experiences most important for transition to adulthood.

It seems clear that teaching students who are not succeeding academically and those with developmental disabilities requires changing instructional patterns and classroom procedures to facilitate academic success (Grant & Sleeter, 2006). Obiakor and Utley (1997) called upon teachers to rethink their practices, revamp their strategies, and shift their paradigms as they provide services for students with disabilities. Although the existing body of knowledge in the area of post-secondary planning is extensive and spans nearly a quarter of a century of scholarly endeavor (see Neubert, Moon, & Grigal, 2004; Neubert, Moon, Grigal, & Redd, 2000; Stodden & Whelley, 2001, 2004), effective transition planning for student with developmental disabilities remains elusive. Fundamental changes must take place in schools to address the needs of these students. Schools should be about enhancing the quality of life for people and about creating better communities. General and special education instructors are consistently confronted with change while trying to maintain their traditional obligations. However, they seem to be poorly prepared to handle the changing demography. Similarly, delivering quality educational programming to students with disabilities has always posed particular challenges to students, families, and service providers. Support services for these students are one of the most vital of all college services and are primarily the responsibility of administrators to deliver (see Grigal, Dwyre, & Davis, 2006). The importance of this responsibility creates controversy on how support services should be implemented and about policy directions taken by administrators and higher institutions of learning (see Hart, Zimbrich, & Ghiloni, 2001). Economic and social difficulties, such as lack of financial resources and social injustices, make service delivery issues particularly problematic in colleges. In addition, the lack of adequate facilities and available technology make implementing comprehensive support services in colleges difficult. Given the present climate of fiscal austerity in higher education, colleges and universities may want to develop a core of support services for students with developmental disabilities until long-term institutional support is ensured. One cost-effective approach is to designate a staff person who has already shown an interest in students with disabilities as the campus contact person for individuals with special needs. Individuals who are given the responsibility for providing disability support services often come from a variety of different fields, including psychology, special education, counseling, social work, curriculum and instruction, rehabilitation, and allied health areas. Frequently, their job duties are expanded to encompass college students with disabilities. Within a year or two part-time duties often evolve into full-time "learning specialist" positions. The newly appointed learning specialist often looks for additional resources and contact persons who can assist in the development and refinement of the service delivery model (Gerber & Reiff, 1994). Developing post-secondary disability services can be a challenging opportunity as well as a lonely and frustrating undertaking. College and university administrators understand the benefits of educating a diverse student body (see Harvey, 2001). Students with developmental disabilities represent a significant segment of the group. As these students pursue not only undergraduate education but also graduate and professional education, it becomes increasingly critical for institutions to review both their mission and philosophies as they work toward an integrated model of service provision. On the basis of the Rehabilitation Act of 1973 and the Americans with Disabilities Act of 1990, post-secondary institutions must provide equal access to programs and services for these students. It is essential that institutions provide policies that ensure that students with disabilities receive the same high-quality education as their peers. These policies should address issues of admission, documentation of disability, accommodation, and curriculum modifications. Students are made aware of the existence of an appeal process, which is set forth in writing. In addition, they should have easy access to all written policies and procedures including the appeal process. Such documents should be available in a variety of formats, in all appropriate campus literature, and through available technology, such as a website, which all students can access (National Joint Commission on Learning Disability, 1996).

PROGRAMMATIC HEADWAYS FOR STUDENTS WITH DEVELOPMENTAL DISABILITIES

Of the numerous developmental programs across the nation, several can be identified as exemplars in terms of their success for students with developmental disabilities. However, many programs as indicated earlier, including those considered successful, frequently encounter a variety of problems. The continuous burdens that programs face include problems of funding, staff recruitment and retention, admission and placement standards, student enrollment, the relativity of curriculum, the quality of tests, and perceptions of the program. There are other problems that affect the implementation of developmental programs. Many of these problems are contingent upon each other such that one tends to exacerbate the other and, thereby, thwart the effective delivery of services to possibly larger numbers of students. Any of these problems or a combination of them can be identified in programs that are considered successful (Tomlinson, 1989). Apparently, it is not enough to merely place students with disabilities in supportive developmental programs without providing appropriate training, materials, and support to them and their professors. If these students are to be effectively assisted in supportive programs, critical issues and problems surrounding these programs must be addressed. Clearly, every successful program needs someone (e.g., a full-time staff member) to champion its cause. This also applies to programs for students with developmental disabilities. It is upon this person's shoulders that responsibility falls for initiating the steps to bring disability programs to fruition at an institution. Support services are typically coordinated by this staff member who is responsible for providing a variety of "academic adjustments" that are mandated under law. Again, these laws require that post-secondary institutions make modifications to their academic requirements to ensure that they do not discriminate against a qualified student with a disability (Frank & Wade, 1993). These modifications may include the provision of course substitutions, adaptation of instruction methods, and modifications in the length of time for the completion of requirements; or the provision of auxiliary aids such as taped texts, sign language interpreters, guide dogs, tape recorders, readers or writers, and access to adaptive or assistive technology. The individual who provides these core supports is often instrumental in linking students with disabilities with other support services on campus such as writing laboratory, math tutorial, and academic development center (Smith, 2007).

Although legislation now entitles all American youth to financial assistance for post-secondary education if they fall within the designated limit on household income, the unreliable funding of some developmental programs leads to a path of tenuous existence. In many instances, impressive sums of money are designated for developmental programs at the system-wide level, but the allocation of such funds to the various schools within the system does not necessarily coincide with the particular needs of each institution. Where funds are said to be distributed equally, some recipient institutions must make more intensive use of faculty, staff, equipment, and facilities in order to meet the special demands of its disadvantage students (Tomlinson, 1989). The most common problem related to funding has been threats of cancellation of grant funding.

Recruitment of programs staff continues to be a problem for most colleges and universities due to staff turnover. Instructors for many programs are hired as non-tenure track and/or temporary faculty and, thus, job insecurity is heightened. Reasonably competent individuals are reluctant to pursue such positions, and incentives for scholarly contributions in curriculum development, research, or service are scarce. Poor staff morale and faculty burnout frequently exacerbate the problem of recruitment and retention of individuals who are needed for the successful delivery of developmental services (Scott & Gregg, 2000). In addition, salaries that are not competitive, cut backs in travel reimbursement, few opportunities for upward mobility within universities, and a shift toward more stringent tenure and promotional requirements have created obstacles to the successful operation of developmental programs.

Varying systemic standards at certain institutional levels could create programmatic inconsistencies and instability. Sometimes there is no consistent indicator of what is held to be the threshold of preparedness or under-preparedness. Within an institutional level, minimum admission criteria vary across categories of entering freshmen. Students are also accepted with minimal entrance scores and then deemed by faculty as too deficient to be taught effectively. Whereas systems allow each institution to determine its own admission standards by a combination of high school grade point average and SAT or ACT scores that is said to predict success or failure, there is cause to consider whether the process is adequate – whether all who are accepted or rejected are accurately predicted for success or failure (Tomlinson, 1989). Although many developmental programs were instituted, as a part of the movement toward desegregation, there is often a pervasive misconception that affirmative action is the sole purpose of such programs. At most institutions where desegregation has been an issue, students with developmental disabilities within developmental programs are a small percentage of the program's enrollment. Another misconception is that the developmental program exists solely for the purpose of serving those who are under-prepared as a result of disadvantages. At many institutions, the student population of developmental programs includes individuals from affluent and middle-class homes. In some instances, foreign students speaking English as a second language have been enrolled in developmental programs because there are no other services to assist them in overcoming language barriers. Despite such an enrollment mix, many developmental programs continue to suffer the stigma of being perceived primarily as a vehicle for affirmative action, particularly for desegregation. This misconception was born of an age of accountability in which, to a considerable extent, desegregation orders have periodically driven developmental program policies and procedures as well as institutional policies system-wide.

At the same time that various institutions are attempting to serve the diversified learning needs of increasing numbers of individuals who do not meet regular admissions criteria but who wish to pursue the benefits of higher education, various factions within the public sector have questioned the efficacy, relevance, feasibility, and academic status of such programs within their respective institutions and among the larger educational community (Evans, Assadi, & Herriott, 2005). It is not enough to merely place students with developmental disabilities in supportive developmental programs without providing appropriate training, materials, and support to them and their professors. To do so certainly calls for their failures! As Wagner (1990) observed, "encouraging greater instruction of students with disabilities in regular education classes, without serious attention to the instruction that goes on in these classes, would seem simply to encourage greater rates of academic failure" (p. 28). Also, if students with developmental disabilities are to be effectively assisted in supportive program, issues and challenges surrounding these programs must be addressed.

FUTURE CONSIDERATION FOR STUDENTS WITH DEVELOPMENTAL DISABILITIES

Students with developmental disabilities entering post-secondary schools are rapidly growing, and with that growth come increasing needs for post-secondary planning that is effective and efficient to serve the needs of this population (Belch, 2000). Put another way, enhancing post-secondary planning to benefit this population requires a process of system change, as opposed to isolated programs and invalidated instructional practices often common with programming. A useful process for improving post-secondary planning is by reviewing the various concerns of scholars, researchers, and advocates who are interested in how colleges and universities provide supportive services.

Some critical questions seem to have emerged of late regarding services for students with developmental disabilities. What documentation is necessary to determine eligibility for which services? What are the institution's responsibilities to modify a curriculum? What constitutes true access to education? Kroeger and Schuck (1993) gave specific directives for creating a responsive environment and called for (a) organizing and structuring services; (b) further defining access to higher education; (c) clarifying available sources and allocations of funding services; and (d) consistently evaluating services and models for collaborating with faculty. Following are recommendations for building a responsive campus community to provide appropriate services to students with developmental disabilities:

1. Reviewing the institutional structure involves:
    - Ensuring that written college and university policy statements regarding services for students with developmental disabilities are consistent with the mission of the institution.
    - Reviewing all campus literature for statements of equal access and the procedures students with developmental disabilities must follow to request services.
    - Considering housing the office for disability services in academic affairs or a similar administrative office for effective reporting and support.
2. Establishing policies involves:
    - Ensuring confidentiality of student information.
    - Developing written policies and procedures, including the appeal processes regarding students with developmental disabilities in the areas of admission, documentation, academic accommodations, and curriculum adjustments.
    - Making policies and procedures available to the entire campus community via student handbook catalogs and course schedules in alternative formats.
3. Promoting awareness involves:
    - Establishing mechanism for dissemination of information about developmental disabilities to students, administration, faculty, and service professionals.
    - Disseminating information to the campus community about available services.
    - Familiarizing faculty, staff, administration, and students with laws governing accommodations for students with developmental disabilities.

- Designating individuals who make the decision regarding accommodation so that intra faculty or staff disputes are minimized.

4. Collaborating involves:
   - Building campus expertize through collaboration and consultation.
   - Establishing a team of service providers and faculty members for decision-making in regard to admission, documentation, academic adjustments, and program accommodations for students with developmental disabilities.
   - Remaining up to date regarding disability issues.
   - Providing cost-effective, reasonable accommodations for students with developmental disabilities.

Because of their frequent experiences with failure, many students with developmental disabilities do not aspire to be educated beyond high school. The emphasis should be on preparing students to make the right choices of colleges as well as on delineating what accommodations they will need in their programs (see Grigal et al., 2001). Choosing a college for any student is difficult. Reputation, academic rigor, location, types of majors offered, extra curricular activities, and costs are just a few of the many variables that parents and students consider in selecting a college. In the case of students with developmental disabilities, the choice can be even more difficult. In addition to the above factors, students and their parents will want to consider the level of support offered (see Weir, 2004). For example, special accommodations must be available for students with developmental disabilities when they take the SAT and the ACT. Following are several questions that can serve as guidelines for choosing a college (see Michaels, 1987):

1. *Does the college provide services?* To address this question, institutions should provide:
   - A full-time or part-time coordinator of services for student with developmental disabilities.
   - Preliminary diagnostic services to determine student abilities to work at a college level.
   - Pre-admission advisement.
   - Short-term and long-term student counseling.
   - Study skills course work.
   - Remedial and basic skills classes.
   - Feedback systems from professors to coordinators of services for students with disabilities.

  - Termination services (e.g., employment counseling and vocational testing) for those students with developmental disabilities who leave college.
2. *Does the college furnish services?* To address this question, institutions should provide:
   - Access to required course syllabi.
   - Access to tutors, readers, and note takers.
   - Computers for student use.
   - Taped textbooks and recorded lectures.
3. *Does the college allow services?* To address this question, institutions should provide:
   - Modified college admission procedures.
   - Student visits college classrooms in advance of enrolling in the college.
   - Untimed exams.
   - Varied testing options.
   - Advanced acquisition of required reading assignments.
4. *Does the college allow services?* To address this question, institutions should provide:
   - Full-time or part-time educators to assist with the needs of students with developmental disabilities.
   - Guidance in structuring the student workday.
   - Student groups that facilitate making friends.
   - Access to early registration procedures.
5. *Does the college give services?* To address this question, the institution should provide:
   - Assistance with the class scheduling.
   - Listing of outside services and support groups in the college community for use by students with developmental disabilities.

As indicated above, Section 504 of the Vocational Rehabilitation Act of 1973 requires that colleges make reasonable accommodations for student with developmental disabilities. These accommodations are of three general types:

- The way in which specific courses are taught, giving extra time on exams, allowing students to take exams in a distraction-free room, and allowing students to take exams in a different format (e.g., substituting an oral exam for a written one).
- Modifications in program requirements, and waiving or substituting certain requirements (e.g., foreign languages or allowing the student to take lighter academic loads each semester).

- Providing auxiliary aids, and providing tape recordings of textbooks or access to a Kurzweil Reading Machine (a computer that scans text and converts it into an auditory output), and recruiting and assigning note takers for lectures.

Although there are no simple solutions to meeting the educational needs of college-bound students with developmental disabilities, research and experiences show that the educator has a significant impact on the success of college-bound students with developmental disabilities (see Zaft, Hart, & Zimbrich, 2004). To facilitate continuing academic success for these students, colleges and universities need to have an understanding and awareness of the classroom changes that can make a difference. Colleges and universities need to institute strong policies and procedures aimed at helping to incorporate these changes into both their everyday teaching plans as well as their classroom management techniques (see Neubert et al., 2004). One of the classroom changes that can greatly benefit college-bound students with developmental disabilities is infusion of study skills into the teaching of content material.

Study skills are a very broad term that encompasses a multitude of skills that enhance the effectiveness and efficiency of learning. They are often considered to be mainly instructional strategies such as note-taking skills, memory techniques, or test-taking procedures. Just as important to learning, however, are organizational strategies, time management skills, and self awareness skills (see Janigo & Castenbader, 2002). The purpose of study skills must be to teach students how to learn. It is essential that these skills be transferable to all academic areas makes the teaching of study skills indispensable in education (Schumaker & Deshler, 1998). Many college students use different strategies to compensate for their learning problems in college work. Should educators and specialists have to assist students with developmental disabilities in selecting a college program; the following strategies can be used as rough indicators of the quality of the college program for the student. Bender (2008) noted that the college disabilities professors must:

- Arrange alternative times and modes of presentation.
- Arrange to tape-record lectures.
- Obtain copies of class notes from others for study.
- Arrange assistance in time planning for big projects during the semester and for smaller weekly assignments.
- Schedule an appropriate load of courses or a lighter load.
- Offer assistance in completing homework and daily assignments.

- Arrange for the use of highlighted or taped books.
- Offer no cost tutoring assistance on a daily, biweekly, or weekly basis.
- Arrange for use of word-processing/editing programs and computer time.
- Identify college faculty who are willing to assist students with developmental disabilities in their classes.
- Instruct the student in using learning strategies that promote metacognitive understanding of the material to be learned.

Furthermore, the 2004 Individual with Disabilities of Education Improvement Act (IDEIA) mandated the use of Universal Design Learning (UDL), a new model in the effective use of technology for students with disabilities. The UDL is designed to increase access for students with special needs to the general curriculum. In its purest form, UDL materials and instructions are designed to meet the learning needs of individuals with varying levels of ability. UDL requires curricular design that accommodates student abilities in various domains, such as vision and hearing, motor coordination, academic level, language, and attentional and organizational capabilities. The Teaching Every Student Website (CAST, 2006) offers real-life examples of the application of UDL for all grade levels and subjects. Colleges and universities must incorporate these innovative recommendations into their daily instructional plans. In addition, access to information, communication, and production through the Internet has become a preferred mode for students (DeBell & Chapman, 2004; Kruger, 2006). Informational literacy can be enhanced via teacher-created Webquests and Class Act Portals that provide the scaffolding that students need to develop higher-order thinking skills (March, 2006). Additionally, blogs, wikis, and pod casts can provide students with powerful methods of communication directed toward authentic audiences (Stahl & Aronica, 2002). These plans will inevitably enhance post-secondary planning for students with developmental disabilities (SETDA, 2003).

CONCLUSION

In this chapter, the authors have addressed the issues and challenges surrounding the delivery of support services, learning strategies, accommodations and modifications, and exemplary programs to enhance the full participation of college-bound students with developmental disabilities. Again, for many students with developmental disabilities, participation in post-secondary education is not far-fetched. However, to achieve this goal, comprehensive post-secondary planning is inevitable; and the primary objective of this planning should be to help students select access and succeed in a post-secondary education program. Legal mandates ensure that equal opportunities are provided to all individuals with developmental disabilities. Unfortunately, increased knowledge of legal rights has not materialized egalitarian educational access and accommodations at college levels. It behooves administrators, teachers, parents, and advocates to ensure that students with developmental disabilities receive appropriate accommodations and curricular modifications that are needed to succeed in post-secondary programs. Our belief is that as legal rights and protections are implemented and realized fully, college-bound students with developmental disabilities will have equal access and appropriate opportunities to maximize their academic potential. That is to say, legislators must realize that special education will continue to exist. This existence will be solidified when educators and administrators come to the realization that all students deserve equitable educational opportunities that respond to individual differences.

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EMPLOYMENT AND RETIREMENT CONCERNS FOR PERSONS WITH DEVELOPMENTAL DISABILITIES

Amanda Dykema-Engblade and Sarah Stawiski

OVERVIEW

People with developmental disabilities have persistent levels of low employment and employment rates among the working-aged disabled are declining (see Bound & Waidmann, 2002). For example, the average employment rate of those graduating with a four-year degree is just under 90% while employment rates for those graduates with a disability hover around 50% (The Center for an Accessible Society, n.d.). Subsequently, people with disabilities often have a difficult time becoming economically self-sufficient (see National Council on Disability, 2000; Sowers, McLean, & Owens, 2002). The Americans with Disability Act (ADA) is one notable attempt to help provide those with a disability to employment access. While the ADA has been a champion of the cause, people with developmental disabilities still face a host of employment-related barriers (e.g., biases associated with the disability) (see DiLeo, 2007; Luecking & Mooney, 2002). Furthermore, while most people have concerns over retirement (e.g., social isolation) those concerns are exacerbated for people with developmental disabilities (see Hodges & Luken, 2006).

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IMPORTANCE OF WORK

Aside from the obvious financial implications of being unemployed, work is often considered a major contributor to an individual's self-concept (see Wehman, 2006a). When people are asked to describe themselves, they often respond with their work title or work role (for a discussion on work centrality, see England & Misumi, 1986; MOW-International Research Team, 1987). Thus, it is not particularly surprising to learn that those individuals who have difficulty with employment-related issues face problems with respect to self-confidence, isolation, and marginalization (Stuart, 2006). Finding, maintaining, and succeeding in employment situations can result in a number of positive outcomes such as a sense of purpose and accomplishment, opportunities for new friendships, and greater financial independence (see Blanck, 1998; Kober & Eggleton, 2005; Test, Carver, Ewers, Haddad, & Person, 2000). Indeed, Test, Hinson, Solow, and Keul (1993) interviewed people with developmental disabilities who were employed in "mainstream" or integrated environments. Those interviewed all indicated that they had made friends at work and were satisfied with their work setting.

Social interaction is important for all people in employment situations. Friendships formed within the workplace have been linked to numerous benefits including job satisfaction, work performance, and job retention (Parent, Kregel, Metzler, & Twardzik, 1992). However, many people with developmental disabilities may be at a disadvantage for a number of reasons. One reason may be that in some cases, people with developmental disabilities lack social skills that are necessary for positive social interaction. For example, Gumpel, Tappe, and Araki (2000) found that participants with developmental disabilities found it much more difficult to solve vocational-based social problems than their non-developmentally disabled counterparts. Social skills have long been considered a predictor of quality of life (Gumpel et al., 2000). Research that has studied employment success in people with disabilities has consistently shown a relationship between social/interpersonal skills and better employment outcomes (Foss, Auty, & Irvin, 1989).

Parent et al. (1992) have found that workers with developmental disabilities engaged in more inappropriate social interactions than those workers without a developmental disability. Basic insights into the challenges of social interaction for people with developmental disabilities in the workplace can be found by looking at studies which have investigated interability communication patterns (i.e., communication between disabled and non-disabled individuals). Examining non-verbal communication alone, there are a number of findings worth noting. For example, when interacting with people with a disability, non-disabled individuals' communication patterns include less smiling (Comer & Piliavin, 1972), less eye contact, and greater physiological arousal (Kleck et al., 1968).

Research that has examined verbal behavior has also found that interability communication is sometimes strained (see Fox, Giles, Orbe, & Bourhis, 2000). For example, people without disabilities tend to pay less attention to people with disabilities (Grove & Werkman, 1991). Further, research on "baby-talk" has found that speech addressed to adults with developmental disabilities is often the same as speech addressed to six-year-olds (DePaulo & Coleman, 1987). Even highly skilled workers with a developmental disability often have difficulty with the "small talk" that is needed to maintain collegiality at work (Holmes, 2003).

LEGISLATIVE ACTS TO IMPROVE WORK OPPORTUNITIES

The United States has witnessed dramatic improvement in legislation on behalf of those with developmental disabilities in the past few decades (Migliore, Mank, Grossi, & Rogan, 2007). However, as pointed out by Brooke (1999), public attitudes and opinions cannot be legislated. Furthermore, as the Sociologist William Graham Sumner was quoted as saying "stateways don't change folkways" (as cited in Aronson, 2008, p. 338). It is important that advocacy groups continue to work on changing the general negative attitudes toward those with developmental disabilities (see Brostrand, 2006; Hernandez, 2000). Cultural attitudes have the potential to create change. A recent telephone survey conducted by Siperstein, Romano, Mohler, and Parker (2005) found that the general public thinks more favorably of companies that hire people with disabilities. However, whether this general attitude translates into a greater willingness, as consumers, to support those companies is another question (see Gilbride, Stensrud, Ehlers, Evans, & Peterson, 2000; Unger, 2002). Indeed, social psychologists have consistently shown a weak link between attitudes and subsequent behavior. For example, seminal work by LaPiere (1934) reported that hotel managers' attitudes toward Chinese guests did not match their behavior in response to a Chinese couple who asked to rent a room. Managers reported that they would not allow a Chinese couple to rent a room, but when a Chinese couple appeared at the hotel, they were almost always allowed to rent a room. Additional research (e.g., Fishbein & Ajzen, 1974) supports the finding that attitudes do a poor job predicting behavior. In other words, a favorable attitude toward an organization that routinely hires individuals with a disability may not necessarily translate into consumer support for the organization.

Obviously, some employers have positive attitudes toward hiring and promoting individuals with a developmental disability (see Siperstein, Romano, Mohler, & Parker, 2005). Simply put, employers are interested in hiring the best and most qualified person for a position based on job-relevant characteristics. However, not all employers are inclined to hire the best person based on relevant knowledge, skills, and abilities. As a result, several acts have been signed into law in an effort to help those people with disabilities achieve employment. Below is a summary of some of the most relevant policies/laws that impact the employment outlook for people with developmental disabilities.

Americans with Disability Act

The Americans with Disability Act (ADA) was enacted in response to the unique challenges faced by those individuals with disabilities (developmental and otherwise) when attempting to gain employment. The ADA stipulates that accommodations should be made to certain policies, practices, and work environments so that all those seeking employment have equal access to positions. Employers are expected (in accordance with the ADA) to make reasonable accommodations for a person with a disability as long as the person is still able to perform the essential functions of the job (see Gilbride, Stensrud, Vandergoot, & Golden, 2003). Essential functions are key or important parts of the job. Reasonable accommodations necessitate that organizations make allowances for an individual that will make it possible for her or him to perform the job (see Loprest & Maag, 2003). For example, if someone has a physical disability such as poor eyesight, a reasonable accommodation might include purchasing a computer screen that is capable of displaying extra-large font. Data suggest that most accommodations (71%) cost 500 dollars or less with 20% costing nothing (Job Accommodation network, n.d.).

The Equal Employment Opportunity Commission (EEOC, n.d.) maintains a website that provides information regarding the ADA. One of the areas that the EEOC provides information about is the kind of reasonable accommodations that applicants with a developmental disability should be provided during the application process. Some suggestions include replacing an application test with an expanded interview. The intention of an expanded interview is to allow applicants to demonstrate their skills and abilities relevant to the work environment (rather than just describing them). Another suggestion is to provide an aid for the applicant who can help him or her interpret application materials (especially if they are complex). However, the only way for an individual to receive the benefit of reasonable accommodations is if she or he discloses the disability. Interestingly, Thompson and Dickey (1994) found that college students with a disability were unable to articulate how the ADA protects them in an employment setting and they expressed serious reservations regarding their confidence in disclosing their disability to a future employer.

Although the ADA has certainly made great strides in protecting those with a disability from employment-related discrimination (see Kennedy & Olney, 2001), the Act is not without its critics. Undoubtedly it is thought by some to be creating a backlash of negative attitudes toward people with disabilities because businesses are resentful that they need to spend time and money meeting the needs of individuals with disabilities (Fowler & Wadsworth, 1991). Despite the efforts of the ADA, employees who were surveyed regarding the challenges of the workers with disabilities indicated that changing the attitudes toward those with a disability is still one of the biggest challenges being faced (Fox & Giles, 1996).

Ticket-to-Work Program

On December 17, 1999, President Clinton signed the Ticket to Work and Work Incentives Improvement Act of 1999 (TWWIIA) in order to provide people with disabilities greater access to employment services. This law included several important new opportunities for people who receive social security disability benefits and who want to go to work (National Center on Workforce and Disability, n.d.). This Act was implemented to give options to people with disabilities to be able to work if they choose to do so (see Rupp & Bell, 2003). Individuals can get a "ticket" which they can use to purchase employment services from a local employment network (EN). The EN may assist them in gaining employment directly, or providing relevant skills training that may assist them. In fall of 2004, it was estimated that 1,206,780 of the 10,000,000 tickets (approximately 12%) were distributed to people with developmental disabilities (Reading Room, n.d.). However, the outcomes for people with developmental disabilities are not always positive and consequently there is some disapproval surrounding this Act. The major downfall associated with the Act is that people in the program can expect to earn a very limited wage (see Henn & Henn, 2007) and that most participants in the program would be in a financially better situation by continuing to receive their monthly social security payment (The Rural Institute, n.d.).

Workforce Investment Act

The Workforce Investment Act was signed into law by President Clinton in 1998 and required states to streamline the provision of services to clients by integrating multiple employment and training services through the use of "One-Stop" centers. They are identified by the Social Security Administration (SSA) as being important to implementing the initiatives set forth in the Ticket-To-Work and Workforce Investment Act. Benefits of this collaborative approach to service provision include an increase in customer base and improved access to services (National Center on Workforce and Disability, n.d.).

Rehabilitation Act

The middle of the 20th century has been referred to as the "Golden Era of Rehabilitation" (Brooke, 1999). However, while funding was increasing during this time for vocational rehabilitation programs, there was still a lack of programs and policies in place that would assist people with developmental disabilities in finding and succeeding in meaningful employment in the competitive workforce.

The Rehabilitation Act of 1973 was an important milestone in the arena of employment for people with developmental disabilities. Specifically, it emphasized the need for employment services for all people with disabilities, even those with severe disabilities. Subsequently, several amendments of this Act led to improvements in the employment prospects of people with developmental disabilities. For example, amendments passed in 1986 and in 1992 led to a greater push for integrated employment after the realization was made that too many people with developmental disabilities were getting "stuck" in more sheltered workshop or isolated workplace environments (Rusch & Braddock, 2004). In the 1992 amendments, the notion of "presumption of employability" was introduced which sent the message that it was not a matter of if a person with a disability could work, but rather a question of how to help ensure success (see Wehman, 2006b).

INTEGRATING PERSONS WITH DEVELOPMENTAL DISABILITIES INTO THE WORKFORCE: SUPPORTED EMPLOYMENT

The use of supported employment programs has been one method utilized to integrate employees into the workplace (see Luecking & Certo, 2003; Storey, Bates, & Hunley, 2000). Under supported employment programs, people with disabilities work in a setting that integrates them with people without disabilities (see Metzel, Boeltzig, Butterworth, Sulewski, & Gilmore, 2007; Vila, Pallisera, & Fullana, 2007). This is a different approach than the use of "sheltered workshops" which in essence exist only to provide employment to people with disabilities. In addition, they are generally working very closely with an "employment specialist" who can assist them in their day-to-day duties. The primary goal of these programs is to increase the total integration of those with a disability into the workplace. Several studies have been conducted to evaluate these programs (see Blanck, Schartz, & Schartz, 2003; Cimera, 2007). One of the more consistent findings has been that while physical integration has been relatively easy to achieve, many supported employees are still socially isolated (Storey, 2002).

SOCIAL BARRIERS FOR PEOPLE WITH DEVELOPMENTAL DISABILITIES IN EMPLOYMENT SETTINGS

Several researchers have examined attitudes and beliefs about people with disabilities. For example, people report that those with developmental disabilities are different, often helpless, and that they deserve pity (Hazzard, 1983). Other common stereotypes include the notion that those with a developmental disability are dependent, socially introverted, emotionally unstable, hypersensitive, and easily offended (Emry & Wiseman, 1987). In general, it is difficult to challenge people's views toward those with a disability because there is a lack of positive representation (or any representation for that matter) of those with a disability in the media.

For instance, Parashar and Devanathan (2006) found in a content analysis of magazine advertisements, that less than 1% contained any textual and/or visual depiction of disability. Further, children often learn negative attitudes toward people with disabilities early in life, either through the media and/or school influences (Wahl, 1995) and these attitudes set the foundation for later prejudicial views toward those with a disability.

Another pervasive stereotype that has been documented about people with disabilities is that they are "eternal children" (Fox & Giles, 1996, p. 219). Obviously, employed people with disabilities are adults; however, we may see them as, and subsequently treat them like children. Clearly, children would generally not receive the same level of respect as adults in the workplace.

While there are apparent consequences associated with negative stereotyping, there are also implications of more "benevolent" prejudice as well. Some people perceive people with disabilities as objects of pity and treat them with a great deal of compassion. A more extreme example is that some would go so far as to label people with disabilities as "holy innocents" (Fox & Giles, 1996, p. 218). However, even benevolent prejudice can limit our expectations of social groups. When we perceive people with disabilities as needy or requiring extra compassion and care, we are limiting our expectations of what they can do in the workplace. Sanders (2006) has shown that lowered expectations and/or the protection of those with a disability seem to be a precursor to lower levels of self-esteem and lower levels of achievement. When individuals with a disability start to believe and act on these lowered expectations (known as the self-fulfilling prophecy) (Snyder & Stukas, 2000) they start to believe that she or he is indeed less capable than someone without a disability.

Some research has also specifically investigated the beliefs and attitudes of *employers* toward employing people with developmental disabilities (see Hernandez, Keys, & Balcazar, 2000). Some employers identify benefits of hiring employees with developmental disabilities including lower turnover, greater attendance, and the assistance of a job coach (Graffam, Smith, Shinkfield, & Polzin, 2002; Nietupski, Hamre-Nietupski, Vanderhart, & Fishback, 1996). In particular, research has shown that employers who have prior experience in hiring people with developmental disabilities cite more examples of benefits than those with no experience (Morgan & Alexander, 2005). However, there are still many attitudes and beliefs on the part of the employer that become obstacles for people with developmental disorders seeking employment (see Harter, Scott, Novak, Leeman, & Morris, 2006). For example, Peck and Kirkbride (2001) describe employers' concerns about increased costs, loss of productivity, and performance deficits.

Intriguingly, Grand, Bernier, and Strohmer (1982) found that people responded more positively toward working with a person with a disability than toward dating or marrying someone with a disability. This finding is consistent with the social psychological notion that prejudice is most apparent at the intimate level (e.g., I'll sit next to someone of the bus who is part of the "out-group" but I will not dance with a member of the "out-group"; Myers, 2008).

In summary, both hostile (e.g., "different" or "helpless") and benevolent (e.g., "they should be pitied") prejudices influence our expectations toward people with developmental disabilities in the workforce. Even people who report favorable attitudes toward those with a developmental disability are not that interested in knowing the person at a more personal level (see Brostrand, 2006).

SOCIAL PSYCHOLOGICAL BIASES AND THE APPLICATION TO EMPLOYMENT SETTINGS

The roles of biases in employment-related decisions have enjoyed a considerable amount of attention from social and industrial/organizational psychologists (see Dobbins, Cardy, & Truxillo, 1986). Some of the areas that have received the most attention are the similar-to-me, halo, first impression, and frame of reference biases. The role of expectations also plays a critical role when evaluating candidates for a job. There has not been a great deal of research conducted on disabilities specific to the above biases discussed but we can learn and borrow from research on other stigmatized groups. These biases and expectancy effects will be discussed as additional hurdles that those individuals with developmental disabilities must jump.

Research has demonstrated a similar-to-me effect, such that raters favor (i.e., are biased toward) applicants who are similar to them on certain dimensions (attitudinal, race, etc.) (see Sears, & Rowe, 2003). For example, some evidence suggests that when an applicant is of the same race as the evaluator, the evaluation is more favorable (Lin, Dobbins, & Farh, 1992; Waldman & Avolio, 1991). Likewise, when raters and applicants share similar attitudes (e.g., attitude toward presidential candidates) the subsequent evaluation is more positive (Baskett, 1973). In fact, there is some data showing that something as trivial as sharing a birthdate results in more favorable evaluations (Finch & Cialdini, 1989). *Inter*ability interviewers and interviewees are far less likely to share similarities than are *intra*bility interviewers and interviewees. Disabled job applicants are likely to differ from the interviewer in terms of marital status. For example, about 60% of the general population and only 14% of adults identified with a developmental disability are currently married (National Health Interview Survey, 1994–1995). There is also a difference in employment history with non-developmentally disabled persons employed in traditional settings at a far greater rate than those with developmental disabilities (Edgerton & Gaston, 1991). In brief, the evidence shows that we "like those who are like us." For this reason, persons with a developmental disability are far less likely to establish common ground with the interviewee and consequently may be given lower than deserved ratings.

A halo error is another bias that has consistently been shown to influence applicant ratings (see Lance, LaPointe, & Stewart, 1994). A halo error occurs when the evaluator rates an applicant based on her or his overall impression of the applicant and the subsequent rating is higher than expected. Halo errors usually result from schemas or prototypes of the "best" person for a job and the person who fits this schema receives higher than expected ratings while those individuals who do not fit the schema are not afforded the same inflated ratings (see Jackson & Furnham, 2001). Individuals with a disability are rarely the prototypical employee. Media portrayals of those with a disability only serve to reinforce people's misconceptions about those with a disability. Bogdan, Biklen, Shapiro, and Spelkoman (1982) argued that most often those with a disability are used in the media to represent negative people (e.g., the "bad guy" in horror films) and/or acts (e.g., violence and murder).

A frame of reference bias occurs when an employer uses information outside the scope of the job (e.g., gender, age, HIV status) in determining whether an applicant is qualified for a position (see Dobbins et al., 1986 for an empirical investigation of frame of reference errors). In this bias, employers who know about an applicant's disability might let it (unfairly) influence their evaluation of the candidate. As discussed earlier, if a person with a disability can perform the essential functions of a job, the disability cannot be used (legally) in hiring-related decisions.

Social psychologists have long known about the powerful effects of expectations (see Olson, Roese, & Zanna, 1996). Once we categorize someone using a term (e.g., "slow") we base our expectations about future encounters in light of the stereotype. If you are expecting to interact with someone labeled as "slow" your approach to the conversation will likely be very different than if you were expecting to interact with someone who is "sharp." Darley and Gross (1983) conducted an interesting experiment to demonstrate the potent effects of expectations. Participants either watched a video of a girl playing in either a low or a high socio-economic (SE) neighborhood. Next, they watched a video of her answering some questions for an academic achievement test. The researchers found that those who had viewed the low SE condition video rated the girl's ability lower than the participants who had viewed the high SE condition video. In other words, participants' expectations about the achievement ability of a person from a high SE area were higher than their expectations for a person from a low SE neighborhood. Again an employer's stereotypes about developmental disabilities may shape her or his expectations about the applicant.

OTHER SOCIAL PSYCHOLOGICAL CONCEPTS THAT MAY INFLUENCE RATINGS OF APPLICANTS IN EMPLOYMENT SETTINGS

Primacy effect in impression formation. Asch (1946), in a now classic study demonstrating the primacy effect, showed that information about a person obtained early in a conversation influences the evaluation to a greater degree than the exact same piece of information that is discovered later in a conversation. In Asch's study one group of participants were given traits about an individual in the following order: *intelligent, industrious, impulsive, critical, stubborn, and envious*, while another group of participants were given the exact same list but in the opposite order. Logically, participants should have rated the person the same, after all it was the same list; however, what Asch found was that participants who received the "favorable list" first (i.e., intelligent was listed first) gave the person far more favorable ratings than participants who received the "unfavorable list" first (i.e., envious was listed first). It is a logical leap to assume that finding out about an applicant's developmental disability early in the application process may color subsequent ratings of the applicant. This likely occurs because evaluators use early information to form an impression (e.g., intelligent) and the first impression shapes the interpretation of subsequent behaviors or attributes. For example, stubborn might be perceived in a more positive light if one already believes a person is intelligent (versus envious). Therefore, if an applicant with a developmental disability displayed any behavior or characteristic early on that was considered “strange” or that was classified as “unintelligent” by the interviewer, this may lead to more harsh subsequent judgment.

Confirmation bias. Once people have accepted an attitude, they tend to only pay attention to information that confirms their attitude and ignore or discount information that sheds doubt on the attitude. Confirmation bias seems to play an especially large role when it comes to issue of prejudice or stereotypes. For example, if a person holds a stereotypical view (i.e., a (usually) negative belief) about a group of people she or he might only seek out and/or remember instances that confirm the stereotype. Apparently, people engage in selective recall and processing of stereotypical behavior. The confirmation bias is able to explain, in part, why stereotypes persist even in the face of contradictory evidence (i.e., people do not pay attention or remember the discounting information, Ross, Lepper, & Hubbard, 1975). Related to confirmation bias, is a concept known as an illusory correlation; or a belief in a relationship that does not exist (see Hamilton & Gifford, 1976). In other words, people believe that there is a correlation between two events when in fact the events are unrelated. An employer, for example, might believe in an illusory correlation if in the past they hired an unsuccessful worker who had a developmental disability and then erroneously conclude that all workers with a developmental disability will prove to be unsuccessful on the job.

Contact hypothesis. There is a long history of negative societal attitudes and misconceptions about people with developmental disabilities. They have been viewed as incapable of making decisions and the development and care for them typically focused on the provision of basic needs only. Wolfensberger (1969) argued that the institutionalization of people with developmental disabilities ignores the basic potential positive contributions that people can make to society. More recently, policy makers and disability advocates have also supported the idea that institutionalization may be a determinant to the well-being of people with developmental disabilities. For example, Representative George Miller (Democrat, California) stated in a congressional debate that society made disabled people “invisible by shutting them away in segregated facilities” (The Center for an Accessible Society, n.d.). While it has been the unfortunate tradition to “shelter away” people with developmental disabilities, psychologists have ample evidence to suggest that this tradition is an ineffective way to change attitudes toward this group. Indeed, there is some evidence to suggest that contact (i.e., seeing and interacting with members of a group) increases positive attitudes toward those with disabilities in some situations (see Gillies & Shackley, 1988).

Jigsaw classroom. Aronson, Stephan, Sikes, Blaney, and Snapp (1978) were challenged with the task of finding a solution to the heightened racial tension prevalent in a school that was recently desegregated. The researchers noted that across the board, the classroom situation emphasized competition and rarely encouraged cooperation amongst the students. Thus, the goal was to find a way to encourage cooperation among the students. The result was the jigsaw classroom. In a jigsaw classroom, each member of a group is responsible for a piece of the puzzle and the only way for the group to successfully complete a task is for each member to contribute her or his piece of the puzzle. Thus, members of the group are interdependent and any given member has something to lose (i.e., their grade) by not paying attention or discouraging their group members. Jigsaw classroom (as the name suggests) has primarily been applied to classroom settings. The results suggest that students who were part of a jigsaw classroom liked school more and developed more positive attitudes toward members of another (i.e., ethnic) group than students who were part of a traditional classroom environment. Researchers have also successfully applied the jigsaw method to alleviate prejudices people hold toward those with a disability (Desforges et al., 1991).

Rather than institutionalizing or "sheltering away" people with developmental disabilities, the evidence suggests that a far better approach is to allow those with a disability to regularly come in contact with those without a disability. Further, allowing members from both "groups" to come together to complete a task, in which each member is responsible for a particular element, should assuage stereotypical beliefs.

RETIREMENT CONCERNS FOR THOSE WITH DEVELOPMENTAL DISABILITIES

Certainly, the aging population, in general, thinks of retirement with some degree of trepidation; however, concerns that most retiring adults have about retirement seem to be exacerbated for those with a developmental disability (see Cordes & Howard, 2005). Mahon, Solomondson, Isfeld, and Goatcher (1997) conducted a series of focus groups with people who have a developmental disability and found that many people fear losing their friends and income when they retire. This fear seems to be grounded in reality. For example, Mahon and Mactavish (2000) have shown that paid staff may be the primary system of social support for persons with developmental disabilities. Further, disabled employees rarely have contact with peers without disabilities outside of the work environment (see Mahon & Goatcher, 1999; Mahon, et al., 1997).

More recently, people with developmental disabilities have been facing challenges associated with *leaving* the workforce in retirement. Fewer than three decades ago, persons with developmental disabilities rarely survived into later life (Doka & Lavin, 2003). Several factors have contributed to longer life expectancies for this population, including improved healthcare, better medical treatments, and deinstititutionalization. In fact, with the exception of individuals with Trisomy 21 (Down syndrome), people with developmental disabilities have life spans similar to people without disabilities (Doka & Lavin, 2003). Therefore, people with developmental disabilities who enter the workforce may very well be able to work until retirement age.

There are many potential benefits (discussed earlier in the chapter) associated with working for people with developmental disabilities. For this reason, employers and caregivers are apprehensive of plans to take work away from this population (Hodges & Luken, 2006). What are the specific challenges associated with retirement for this population? First, aging in general is associated with health problems, and the need for greater care. However, research has shown that people with developmental disabilities tend to show more serious health problems and display these problems at any earlier age than their non-disabled counterparts (Doka & Lavin, 2003). These health concerns may force a person with a developmental disability to retire before they would like to. A second problem associated to retirement is the loss of a social network. Again, this is not necessarily unique to people with developmental disabilities; however for people with developmental disabilities this may especially be problematic if their primary caregiver and source of social support has been a parent, who may be deceased or will at least be ageing themselves. For many people without disabilities, spouses and adult children can provide this support. Siblings are also possible sources of support and benefit for people with developmental disabilities (Edgerton & Gaston, 1991).

Apart from the various forms of social support that come from family, friends can also provide support. Research, however, has shown that people with developmental disabilities are likely to have limited friends. For example, O'Brien and O'Brien (1993) found that more than 42% of people with mental retardation living in group homes reported having no friends. This is consistent with the idea that prejudice is most apparent at the intimate level (discussed earlier in the chapter). Therefore, the loss of the social networks from the place of employment, coupled with the limited social support they may receive outside of work presents an exceptional challenge to this population.

One solution to some of these programs has been to utilize post-retirement programming options for people with developmental disabilities. However, these programs are still not able to overcome all obstacles. For example, in a study conducted by Bigby, Balandin, Fyffe, McCubbery, and Gordon (2004) service providers in Australia cited numerous barriers to service provision including forming compatible groupings of peoples, increased levels of required support, and prohibitive transportation costs.

SUMMARY

Copious evidence highlights the numerous benefits associated with employment for individuals with developmental disabilities. Ironically, however, this very same group often faces difficulty in employment-related settings ranging from ignorance of the law to biases held by a potential employer. Further, there is evidence that suggest that interability contact may be the most beneficial at reducing negative stereotypes toward people with developmental disabilities; but interability communication is often strained and interability contact is inconsistent with the practice of "sheltering away" people with developmental disabilities. Finally, people with developmental disabilities are met with more obstacles in the age of retirement than most retirement-age individuals who do not have a developmental disability.

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USING ASSISTIVE TECHNOLOGY TO EDUCATE STUDENTS WITH DEVELOPMENTAL DISABILITIES AND AUTISM

Zandile P. Nkabinde

When children have developmental disabilities (DD) and autism, assistive technology can give them a voice to control their environment. In a classroom setting, technology can provide them with opportunities to actively engage in group activities, increased communication, and independence in their daily lives (Stokes, 2007). DD and autism can cause a person to be limited in communication and social skills. Positively, the limitation in communication for individuals with DD and autism can be managed with assistive technology (AT) communicative devices. The application of AT will allow these individuals to have some control over their social environments. However, to be truly effective, students will have to be trained on how to use such devices in all settings. While applied behavior analysis (ABA) has been used to modify aberrant (e.g., echolalia, hand banging) and socially significant behaviors of students with DD and autism (see Anderson, 2007; Cooper, Heron, & Heward, 2007; Kearney, 2007; Keenan, Henderson, Kerr, & Dillenburger, 2006; Nikopoulos & Keenan, 2006), it is not likely to improve their community integration when their

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communication skills remain socially deficit (see Simpson, 2005; Stokes, 2007). However, the improvement of communication skills for individuals with DD and autism can eliminate negative social isolation; make their needs and wants known which will allow them to integrate more successfully into their community environments. Communication skill development can be enhanced by using AT.

DEFINITION AND MEANING OF ASSISTIVE TECHNOLOGY

According to Alper and Raharinirina (2006), the passage of the Technology-Related Assistance for Individuals with Disabilities Act (Tech Act) of 1988 has contributed to the increased attention on the role that AT can have in improving the functional needs of individuals with DD and autism. AT can improve the quality of life for individuals with DD and autism by allowing these individuals to have their needs and wants in school, work, and community settings met. The Tech Act of 1988 and its 1994 amendments as cited by Alper and Raharinirina states:

1. The term "assistive technology device" means any item, piece of equipment, or product system, whether acquired commercially, modified, or customized, that is used to increase, maintain, or improve functional capabilities of individuals with disabilities.
2. The term "assistive technology service" means any service that directly assists an individual with a disability in the selection, acquisition, or use of an AT device (p. 47).

The Tech Act was further reinforced in 1998 with the passage of the Assistive Technology Act (ATA, 1998) which had the following goals:

1. Supported states in sustaining and strengthening their capacity to address the AT needs of individuals with disabilities.
2. Supported the investment in technology across federal agencies and departments that could benefit individuals with disabilities.
3. Supported micro-loan programs to individuals working to purchase AT devices and services.

Smith, Murphy-Herd, Alvarado, and Glennon (2005) stated that there are three components of the definition of an AT device, namely, *what it is,* *how it is made, and its use*. Smith et al. described the three components as follows:

- "What" refers to the device and what it actually is (e.g., an alternative communication device, a word processing application, and a text-to-speech application).
- "How" refers to how one acquires the device. Was it purchased at the local computer store? Was an existing device modified? Or, was it customized to meet the specific needs (e.g., language and social skill development) of the individual?
- "Use" refers to the actual purpose of the device specifically for the user. For a device to be applicable, it must sustain a functioning level or enhance the person's current functioning. For example, a personal digital assistant (PDA) may help a student get better grades because she can record her homework on the device and subsequently complete it.

ASSISTIVE TECHNOLOGY FOR STUDENTS WITH DEVELOPMENTAL DISABILITIES AND AUTISM

Children with DD and autism differ from one another and have different traits like any other group of children (see Chez, 2008; Miller, 2007; Heflin & Alaimo, 2007). An AT device that suits one child will not necessarily work for another. Thus, a match between an assistive device and a child's characteristics is necessary to ensure success. Students with DD and autism might benefit through assistive software with a speech element that may facilitate communication by providing information with accuracy and at an accelerated rate, which might not normally occur without the support of the technology. One major advantage of AT is its compatibility with the solitary engagement traits of children with DD and autism. Because children with DD and autism have impaired communication and social interaction abilities (see Zeedyk, 2008), AT can provide them with an avenue to improve their functional communication and social interactions. Another advantage of AT for students with DD and autism is that it supports their strongest processing modality, namely, visual instructional (see MacKenzie, 2008; Pierangelo & Giuliari, 2008). However, AT might not work for all children with DD and autism due to the nature of their disorder. For example, some children with DD and autism have a heightened sensitivity to sound which might interfere with their use of computers while others have object fixation behaviors (attraction to a number or symbol) which might also be problematic. Smith et al. (2005) recommended that teachers consider the following to create a good match between AT devices and the unique characteristics of students with DD and autism:

- Functional evaluation of the person in his/her customary environment
- Purchasing or leasing
- Selecting, designing, and fitting
- Coordinating and using of other therapies or interventions
- Training or technical assistance for an individual with disabilities or the family
- Training or technical assistance for a professional.

Simpson (2005) reported that although children with DD and autism can benefit from the use of AT, the potential for use of this medium by this population remains largely unexplored. According to Simpson, AT may be an effective intervention to address student needs in: (a) communication, (b) matching, (c) spelling, (d) problem solving, (e) alertness, (f) motivation and behavior, (g) task completion, and (h) self-help. In addition, AT may be effective with students with DD and autism because these students love playing with a computer due to the predictability of its activities (see Thorp, 2007). Furthermore, computers provide stimulating visual images that children with DD and autism crave.

Clearly, AT can help individuals with DD and autism communicate more effectively and increase their level of independence and social integration experiences. Increased communication gives them greater freedom to control their environments. AT devices which allow individuals with DD and autism to communicate more effectively include: a communication board (a device with pictures and words that can be carried around), a speech talker, and computer-assisted communication gadgets. These devices are popular with children and adults with DD and autism because these individuals will frequently tolerate one-on-one instruction via a computer but they will not engage in a human one-on-one interaction (Adams, 1997).

AT has great potential for high functioning verbally limited individuals with DD and autism because it allows them to communicate nonverbally, thus compensating for their lack of language. The benefits of AT are great in cases where the tools are matched with individual needs. Language skills of individuals with DD and autism have been noted to improve through computer-assisted instruction when all other traditional methodologies have failed (Adams, 1997). Furthermore, AT can be used to complement and support students' communication development across settings. Also, it can be used to improve functional communication skills needed to understand and express the language necessary to perform everyday activities (see Calculator, 1988; Smith, Polloway, Patton, & Dowdy, 2007).

ASSESSING ASSISTIVE TECHNOLOGY FOR STUDENTS WITH DEVELOPMENTAL DISABILITIES AND AUTISM

AT assessment is necessary to ensure that individual needs of each child are met. This assessment needs to include the family's perspectives on device selection and training (Brotherson & Cook, 1996). The Family Guide to Assistive Technology (2006) can be used for this purpose. The guide recommends that the following questions be considered:

- What tasks does the student need to perform?
- Is there a low-tech device which will address the student's need satisfactorily?
- What types of high tech assistive devices may help the student?
- Will AT help the student to perform the task in the least restrictive environment?
- Is the device being considered suited to the student's educational needs/abilities?
- Will the assistive technology device remain suitable over time?

It is common knowledge that AT devices for students with DD and autism can be effective, practical, and uncomplicated (see Appendix A). More importantly, these students must be able to use these devices in multiple settings and areas of development. The devices used must enable the students to actively control their environments which will free them from being dependent on their parents, teachers, and/or care providers to meet their needs. Devices that have been selected with care will empower students with DD and autism to apply newly acquired skills in various natural and least restrictive settings. The ultimate aim of AT must be the improvement of quality of life for individuals with DD and autism. Clearly, the use of AT in multiple settings will allow students with DD and autism to improve their: (a) overall understanding of their environment; (b) expressive communication skills; (c) attention skills; (d) motivation skills; (e) academic skills; (f) self-help skills; and (g) overall independent daily living skills (Stokes, 2007).

ASSISTIVE TECHNOLOGY STRATEGIES TO BE USED FOR STUDENTS WITH DEVELOPMENTAL DISABILITIES AND AUTISM

Three main types of technology strategies are used with children with DD and autism. These strategies are "low" technology, "mid" technology, and "high" technology. Low technology involves strategies/interventions that are not battery powered or electronically operated. It is usually less expensive and preferred for easy operation. Examples of low technology include:

(a) Picture exchange communication systems, such as Boardmaker a program for children with DD and autism. The program has a 30,000 Picture Communication Symbol Library in either black/white or color and can be used with any written word/message. The symbols can be customized into any size to suit the individual child's needs.
(b) Dry erase boards.
(c) Laminated photographs.
(d) Manipulatives/objects (Stokes, 2007).

"Low" technology strategies can be used with children with DD and autism to enhance their expressive and receptive communication skills. The use of picture prompts reduces stress in children who are nonverbal and cannot express their needs. Once children are able to recognize picture prompts, actual words will then be used to match visuals with words.

"Mid" technology strategies require the use of batteries or basic electronic devices to primarily support expressive communication (Stokes, 2007). Examples of mid technology include the following:

- Voice Output Communication Aids – Equipment that records voice and can be activated by touch. The voice is often paired with a picture clue.
- Big Mac – A single switch/button communication device which allows students to record messages for easy access.
- Talk Pad – A 4-message/battery operated device, which allows for 15 s of record per button.
- Voice in the Box – A multi-message battery operated communication device available in 16, 24, or 40 messages/buttons (Assistive Technology for Children with Autism, 2008).
- Language Master and Cards with Recordable Strips – Programmable cards that run through a machine to produce sounds. Students have the option of adding pictures to the cards.

- Tape Recorders – A teacher or parent records information into a tape recorder. The audio can be used by a child with DD and autism to help reduce the problem of background noise. The child can also listen to an audio at her/his own pace.

"Mid" technology strategies can be used to increase classroom participation, focus attention on various skill areas, and assist in the development of social skills.

"High" technology strategies are usually the most expensive and complex to use. They are highly motivating to children with DD and autism. A variety of AT devices are used to compensate for expressive communication deficits (Simpson, 2005). For example, video taping helps to teach children with DD and autism how to model adaptive behaviors and language skills. Adaptive hardware and software such as computers, scanners, communication books, and voice output communication aids are all used to enhance speech (Simpson, 2005). For some children with DD and autism, they may need to access the computer with an adapted device (Stokes, 2007). The following access devices can be used with students who have DD and autism:

- *Touch Window*: This device allows the child to navigate and interact with the computer by touching the screen, rather than operating the mouse.
- *Intellikeys*: This is a commonly used alternative keyboard that easily connects to a computer. In order to operate the computer, the child simply pushes various locations on an overlay that is placed in the Intellikeys. In addition to acting as an alternative keyboard, the Intellikeys has four switch jacks located on the side of the keyboard, so that a single switch or multiple switches can be connected to the computer through the Intellikeys for children to access via a single switch hit. This would allow limited fine motor control to access the computer.
- *Big Keys and Big Keys Plus*: This is an alternative alphabet keyboard that has been specifically designed for young children. The keys are large (1 in^2), with the various alphabet letters color coded to help children more readily find specific keys (i.e., vowels in one color, consonants in a different color). The keyboard is also arranged in ABC order for easy access for younger children.
- *Trackball*: Trackball comes in various sizes and shapes, and allow the child to move the mouse around the screen by rolling a stationary "ball" around with either his fingertips or hand. Some children with DD and autism can master the mouse operations with a trackball, and eventually transfer to use of a standard mouse.

Overall, Schultz and Tanaka as cited in Kalb (2005) stated that there is hope in using computer games to help students with DD and autism learn how to engage with human faces and identify emotions. High functioning children with DD and autism who have difficulty with reading or writing might benefit from using voice output systems and/or synthesized speech. Also, digital cameras can be helpful in making two-dimensional visual presentation systems for children with DD and autism who have a strong preference for visually presented information (Stokes, 2007).

Students with DD and autism can be encouraged to take notes using PDAs and can complete assignments using modified keyboards to eliminate sensory overload from talking word processors and voice recognition systems (Salend, 2005). At other times, these students can use selective programs such as screen reading programs with audio prompting to eliminate sensory processing overload.

Adapted books, picture and communication boards, and vocal output devices can be used to improve communication skills of children with DD and autism (see Dixon, 2007). Picture boards are described by Skau and Cascella (2006) as visual representations of words. Teachers and parents can use picture boards to highlight key vocabularies of the student's home and school routines (see Skau & Cascella). Song and storyboards can be used for story retelling activities. Vocal output devices can be used by teachers and parents to produce a prerecorded message that students with DD and autism can listen to later by pressing a button.

LIMITATIONS OF ASSISTIVE TECHNOLOGY

The lack of knowledge about AT can increase the frustration level for individuals with DD and autism. Complicated design factors of AT devices such as setup, programming, and portability can constitute barriers for persons with DD and autism. Additionally, the need to have a technical support person available for assistance can be a huge disadvantage. The effective instructional use of AT needs to be family centered because without the family's participation the intervention will fail. However, family involvement in the use of AT can present many challenges such as the time and effort required to learn how to use the different devices effectively. These challenges may increase substantially the stress and time management demands on families to the point that the use of AT becomes disadvantageous. When implementing AT in the home it is important to consider the following: values of the family; interaction patterns of the family; family resources; physical environment; and family culture (see Brotherson & Cook, 1996).

Students with DD and autism have characteristics such as distractibility which may interfere with their learning of an AT device. Distractibility takes many forms in the classroom such as reacting to outside car noises, visually following movements in the classroom, or obsessing about a teacher's pencil on her desk instead of completing required classroom assignments (see Dyrbjerg & Vedel, 2007; Mackenzie, 2008; Magnusen, 2005). Although most students with DD and autism are distracted by something, the specific distractions differ considerably from student to student. Thus, when teaching a student how to use AT devices, the teacher needs to reduce the student's idiosyncratic distractions.

Ritualistic behaviors of students with DD and autism such as obsessive-compulsive behaviors can present instructional problems. For example, the students may be unable to generalize what they have learned in one situation to other similar settings. Cooper et al. (2007) contended that appropriate generalization requires an understanding of the central principles in learned sequences and the subtle ways in which they are applicable to other situations. Clearly, focusing on specific details might prevent students with DD and autism from getting the central principles of an AT device.

It is important to note that AT equipment might draw negative attention to an individual (Alper & Raharinirina, 2006). Furthermore, there might be difficulty in identifying appropriate AT devices that can address specific needs of individuals with DD and autism. Lastly, specialized AT devices for students with DD and autism can be very expensive but their generic technology applications for use with other students may be limited (see Alper & Raharinirina, 2006). In general when selecting AT devices, it is best to: try less expensive low technology strategies first; ensure that the AT devices match the needs and abilities of the individual child; and analyze the environment to determine what types of AT devices will most support the child's participation (see Hitchcock & Stahl, 2003).

CONCLUSION

DD and autism are lifelong afflictions that need to be managed systematically. Persons with DD and autism who receive meaningful and enriched support can have a higher quality of life despite their affliction. Since there is no cure for autism, this support requires lifelong planning. Simpson (2005) concluded that students with DD and autism present educators with complex communicative situations that require flexibility and creative interventions. As a result, general and special educators must do whatever they can to help students with DD and autism maximize their potential in and outside the school. The use of AT can be extremely helpful in allowing general and special educators to assist students with DD and autism to reach their potential. However, to achieve their pedagogical goals, general and special educators must be well trained and well prepared in the instructional use of AT devices. Appendix B provides a number of websites that can be utilized by general and special educators to assist them with this endeavor.

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APPENDIX A. ASSISTIVE TECHNOLOGY ARTICLES ON STUDENTS WITH DISABILITIES

- Assistive technology: Becoming an informed consumer – NICHCY
  http://www.nichcy.org/pubs/outprintnd13.txt.htm
  Provides information for parents and professionals about critically examining assistive technology for use with young children with special needs. The article discusses laws pertaining to technology and provides a list of reading suggestions and organizations that add information on integrating assistive technology in the home
- Assistive Technology for Children with Autism
  http://www.cesa7.k12wi.us/sped/autism/assist/asst10.htm
  Provides the reader with information on various modes of technology for use with children with autism that can facilitate their communication, social and activities of daily living skills
- Computer access program – From the TRACE Center
  http://trace.wisc.edu/world/computer_access/
  Provides comprehensive information by many of the major computer and software developers regarding the educational uses of computers and software
- Technology in Early Childhood Programs
  http://www.naeyc.org/resourcea/eyly/1996/09a.htm
  Assists professionals in assessing computer programs for utilization with young children in developmentally meaningful ways
- Assistive technology legislation
  http://atto.buffalo.edu/registered/ATBasics/Foundation/Laws/atlegislation.php
  Lists critical assistive technology legislation and highlights important aspects
- The Public School's Special Education System as an Assistive Technology Funding *Source*: The Cutting Edge
  http://www.nls.org/specedat.htm
  Discusses the public school's role in providing assistive technology in the educational programming of students with disabilities
- Simplified Technology for Children with Disabilities
  http://www.2.edu.org/NCIP/library/ec/Burkhart.htm
  Provides an educational rationale for the use of assistive technology with young children with special needs

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Source: Retrieved from http://www.familyvillage.wisc.edu/education/at.html

APPENDIX B. ASSISTIVE TECHNOLOGY WEBSITES FOR EDUCATORS OF STUDENTS WITH DISABILITIES

- Alliance for Technology Access (ATA)
  http://www.ataccess.org/
  ATA is a national network of technology resource centers to assist persons working with children and adults with disabilities in closing computer systems, adaptive devices and software.
- Center for Electronic Studying
  http://ces.uoregon.edu/
  Provides ways that computer technology can be used to assist students with disabilities in studying and learning instructional material
- Closing The Gap
  http://www.closingthegap.cpm/
  This organization provides information on computer technology for persons with special needs via a bi-monthly newspaper, annual conference, and website postings
- Disability and Technology: A resource Collection
  http://home.nas.net/~galaambos/tech.htm
  Provides a list of websites that focus on disability and technological aspects. The sites listed provide information on assistive/adaptive devices and computer-based and/or related computer access
- DREAMMS for Kids, Inc.
  http://www.dreams.org
  This nonprofit agency provides information on assistive technology research, development, and information dissemination for use with students with special needs
- EASI-Equal Access to software and Information – K12 Connection
  http://www.rit.edu/~easi/
  Advocates that students and professionals with disabilities have equal access to assistive technology

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Source: Retrieved from http://www.familyvillage.wisc.edu/education/at.html