Reflections on the Autism Spectrum

Kimberly Gilbert

Assistant Professor, Department of Psychology
Director, Diagnostic and Research Institute
for Autism Spectrum Disorders at Hofstra University

Two-year-old boy with autism during a session with Dr. Gilbert at Hofstra University's Diagnostic and Research Institute for Autism Spectrum Disorders. *Photo by Steven DeClemente Photography.*

When my godson, Jackson, was diagnosed on the spectrum for autism, I can remember the struggle we had as a family as we each attempted to make our peace with this information. All the dreams and ideas we had for Jackson changed, and I found myself often reflecting, *What will Jackson's life be like as he grows? Will he have friends as he grows? Will he be able to sustain independent living as an adult? Will he find a career, and will he find meaning in his work?*

It was and continues to be a time of questions, and consequently, I have found a need to move toward empowered acceptance. Even with my extensive knowledge and experience in the area of Autism Spectrum Disorders (ASD), I was, and still am, left with questions about Jackson. Jackson's diagnosis along the spectrum has brought ASD even more to life for me, and in doing so, has kindled my passion to strive further to connect and influence families positively.

And so, as I began to work toward understanding ASD, I encountered an author, who himself was diagnosed as having an ASD, Asperger's Disorder, who seemed to capture the paradox inherent in Autism Spectrum Disorders. Stephen Shore (2003) is quoted, "When you have met one person on the Autism Spectrum, then you have met one person on the Autism Spectrum." As someone who has an ASD, Shore has provided such insight to the outsider looking within the complexities of the spectrum. This compelling quote sheds such light on the importance of treating the child/adult as an individual, and further dispels the notion of a cookie-cutter approach to treatment. At a time when heightened awareness is emerging regarding Autism Spectrum Disorders, it

is imperative that researchers, clinicians, parents, and family members who are touched by someone who struggles with an Autism Spectrum Disorder continue to strive toward early diagnosis and consequent implementation of the most efficacious treatments.

What Is an Autism Spectrum Disorder?

Autism is referred to as a Spectrum Disorder due to the high nature of variability among children and adults. Although a common thread unites the salient features of autism, variability in the presentation of symptoms exists. ASD is referred to as a triad disorder, meaning symptoms manifest in three areas: communication, impaired social interactions, and/or repetitive motor movements or stereotyped behaviors. Thus, each child presents *uniquely*; therefore, treatment plans must be addressed individually given that child's particular strengths and target areas.

There are *five* pervasive developmental disorders or categories under the umbrella of Autism Spectrum Disorders:

- Autistic Disorder
- Pervasive Developmental Disorder, Not Otherwise Specified (PDD-NOS)
- Asperger's Disorder
- Rett's Syndrome
- Childhood Disintegrative Disorder

Autistic Disorder

To further muddy the waters of understanding, Autistic Disorder is also called "early infantile autism," "childhood autism," "Kanner's syndrome" and "classical autism." Technically, the correct term is "autistic disorder," and it is classified as a pervasive developmental disorder in the *Diagnostic and Statistical Manual* (DSM-IV-TR) (APA, 2000). In summary, the behavioral characteristics associated with Autistic Disorder are:

- Significant difficulties with social interactions; the adult or child does not pay attention to other people; does not play or interact with others; and does not reciprocate.
- Significant difficulties in verbal and nonverbal communication; grabs what is wanted or leads to get what is wanted; copies or parrots words (echolalia) if the child or adult has words; and he/she does not converse back and forth.
- Significant difficulties in the development of play; he/she uses only parts of toys; lines up or stacks objects; and has no imaginative play.
- Highly restricted, repetitive and stereotyped patterns of behavior and interests; may talk continuously about one topic or repeat the same questions; may spin and stare at objects; may flap fingers or pieces of string; and may mouth or engage in self-injurious types of behaviors, such as hitting.
- Highly resistant to even slight changes in routines.

Pervasive Developmental Disorder, Not Otherwise Specified ("PDD-NOS")

Pervasive Developmental Disorder, Not Otherwise Specified (PDD-NOS) is considered a "subthreshold" condition in which some, although not all, features of Autistic Disorder are present. PDD-NOS is often incorrectly referred to as simply "PDD." The term PDD refers to the class of conditions to which the categories on the Autistic Spectrum belong. PDD alone is not a diagnosis, whereas PDD-NOS is a diagnosis. The term Pervasive Developmental Disorder, Not Otherwise Specified (PDD-NOS) also has numerous interchangeable names, which can add to the confusion for parents and paraprofessionals alike, such as "atypical personality development," "atypical PDD" or "atypical autism." PDD-NOS is included as a diagnostic category to

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encompass cases where there is marked impairment of social interaction, communication, and/or stereotyped behavior patterns or interest, but when full features for autism or another explicitly defined PDD are not met (APA, 2000).

This "subthreshold" category includes patients in whom deficits in peer relations and unusual sensitivities are typically noted; however, social skills are less impaired than in Autistic Disorder. Due to the lack of a clear-cut definition within this category, there is limited research available regarding prevalence rates. As data is limited regarding children with PDD-NOS, a plausible explanation for this fact may be that these children, due to their lack of intellectual deficits, are referred to professionals at a later age (APA, 2000).

Asperger's Disorder

Asperger's Disorder differs from Autistic Disorder in that impairment is primarily within the domain of social interactions. Unlike Autistic Disorder, development of other adaptive behavior, cognition, and language skills is not significantly delayed, and sometimes can be quite advanced in certain individuals with verbal skills as a particular strength. Such children are often referred to as "little professors" when they speak, as they tend to have a monotone that varies little in terms of cadence or pitch, and they are typically extremely knowledgeable in one topic of interest (APA, 2000).

Repetitive patterns of behavior or rituals must also be present; however, a hallmark of Asperger's Disorder is within the area of pragmatics. These patients have difficulty in understanding the rules that govern typical social behavior. For example, a person with Asperger's Disorder might stand too close to the person speaking, and, therefore, misread cues to regulate his/her voice when speaking. Asperger's Disorder tends to be diagnosed later, usually after 3 years of age, when social interactions become more salient and deficits are more apparent. Idiosyncratic interests are common and may take the form of an unusual and/or highly circumscribed interest (e.g., such as train schedules, dinosaurs, weather, computers, or air conditioners). For example, when speaking about train schedules, a person with Asperger's Disorder can appear quite competent and knowledgeable; however, when the topic changes to one outside of that person's prescribed areas of interest, behaviors and dysfluency can become apparent. Prevalence data on Asperger's Disorder is inconsistent due to the variability in the manner in which the term has been used; however, there is some suggestion of an increased incidence of this condition in family members (Volkmar, Paul, Klin, & Cohen, 2005).

Rett's Disorder

Rett's Disorder differs from Autistic Disorder primarily in that it is associated with loss of previously acquired hand skills between ages 5 months and 30 months. In people with Rett's Disorder, very early development is normal. Head growth then decelerates, usually in the first months of life, and a loss of purposeful hand movements occurs. Motor skills are replaced with repetitive movement, such as characteristic hand washing or wringing, and profound mental retardation is typical. While the DSM-IV-TR does not list male sex in the exclusionary criteria, the existing literature on Rett's syndrome documents the condition *primarily in girls*. Since the discovery of the MECP2 gene, which is the marker for Rett's Disorder, variants of the syndrome have been reported in males who have mutations of MECP2, with some similar symptomatology observed in girls (Amir, Van de Veyver, Wan, Tran, Franke, & Zoghbi, 1999; APA, 2000; Schanen, Kurczynski, Brunelle, Woodcock, Dure, & Percy, 1998; Schwartzman, Zatz, Vasquez, Gomes, Koiffman, Fridman & Otto, 1999).

Childhood Disintegrative Disorder

Childhood Disintegrative Disorder (also known as Heller's syndrome) is another pervasive developmental disorder. CDD is diagnosed when a child shows significant losses in social behavior, language, play and adaptive behavior after development was apparently normal for at least the first 2 years and before 10 years of age. CDD occurs *more frequently in boys*, although both boys and girls can be affected. A distinct period of regression occurs for children with CDD, which may manifest quickly over a period of a few weeks, or may occur slowly over several months. Previously developed skills are lost, such as toilet training, language and social skills. The child may become essentially mute, lose the ability to play purposefully and develop autistic-like stereotypes. Prior to this period of marked deterioration, the child may exhibit periods of agitation. Differential diagnosis between Autistic Disorder and Childhood Disintegrative Disorder is made based on a detailed history of the child's development (APA, 2000; Volkmar et al., 2005).

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What Do Prevalence Rates of Autism Spectrum Disorders Tell Us?

Much information exists through research, possibly indicating a rise in prevalence regarding ASD. The question then becomes, *Are prevalence rates for Autism Spectrum Disorders truly on the rise, or are we simply becoming better at identifying ASD?* Some prevalence rates for ASD have been estimated as high as 1 in 166, which is the current estimate from the Centers for Disease Control, whereas other rates appear to be lower. It is clear as our definitions become more refined and inclusive/exclusive of salient behaviors, that prevalence data will become more reliable. Currently, researchers are attempting to understand the factors that may be contributing to this apparent rise in identification. We do know that we have much better objective measures for diagnosing ASD, and most trained clinicians will utilize a variety of measures to determine a convergence of validity when evaluating. Additionally, we do know there is about a 5 percent increase in the likelihood that biological parents with one autistic child will have another child on the Autism Spectrum. Again, this percentage might be an underestimate, as many families decide not to have another child given their stress about the possibility of having two children with the disorder (Volkmar et al., 2005).

Causes of ASD

Researchers are working diligently to determine the causes of ASD so that we can work toward decreasing the number of individuals and families affected by this disorder. Still, there are many questions researchers continue to ponder. For example, are multiple factors involved in the development of Autism Spectrum Disorders, or is the disorder the result of genetics alone? Some researchers are examining the possibility of causative agents, such as toxins in the environment, the exposure of higher than normal levels of testosterone in utero, or the exposure of toxins such as mercury-based products as contributing factors in the rise in ASD. To date, no one contributing factor has been identified as the single cause of ASD. Clearly, given the variety of results, continued research is necessary to determine which factors are the determinants of ASD. At the present time, there are no genetic, neurological or other physical markers that can be used to distinguish a person with autism from persons with similar behavioral characteristics. Instead, a diagnosis along the Autism Spectrum is applied to persons who meet specified behavioral criteria (Volkmar et al., 2005).

Diagnostic and Research Institute for Autism Spectrum Disorders at Hofstra

Our mission at the Diagnostic and Research Institute for Autism Spectrum Disorders at Hofstra University, a subspecialty clinic of the Psychological Evaluation, Research and Counseling Clinic at the Joan and Arnold Saltzman Community Services Center, is to provide families with thorough evaluations utilizing the premier objective measures, the Autism Diagnostic Observation Schedule (ADOS) and the Autism Diagnostic Inventory (ADI-R).

The Autism Diagnostic Observation Schedule (Lord, Rutter, DiLavore, & Risi, 2002) is a standardized observation designed to assess behaviors related to autism or Autism

Spectrum Disorders. The ADOS consists of a semi-structured play session with a child using standard toys. This particular measure was created by Catherine Lord, Ph.D., an internationally renowned researcher at the University of Michigan Center for Communication Disorders. The ADOS is the first objective measure that is widely used in the diagnostic process for ASD, and is designed to create situations in which the child is pressed to communicate, such as turn-taking in conversation, sharing a common interest, and making eye contact, which can be difficult for a child on the Autism Spectrum. The ADOS can be used to evaluate individuals at different developmental levels and chronological ages, from toddlers to adults, and from individuals with no speech to those who are verbally fluent (Lord et al., 2002).

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The goal of this assessment is to provide standardized information concerning the diagnosis of autism in the areas of social behavior, use of vocalizations/speech and gesture in social situations, and within play. Structured activities and materials provide standard contexts in which social interactions, communication and other behaviors relevant to autism spectrum disorders might be observed (Lord et al., 2002).

The counterpart to the ADOS is the Autism Diagnostic Interview-Revised (ADI-R), a semi-structured diagnostic interview with parents to assess behaviors related to Autism Spectrum Disorders (Lord, Rutter, & Le Couteur, 1994). The ADI-R contains questions about children's early development, communication, social interaction, prevalence of sensory issues, and patterns of behavior. Parents are asked in-depth questions regarding every facet of their child's growth to date. The ADI-R yields scores for current behaviors and history, and results in cutoff scores indicating presence of autism (Rutter, Le Couteur, & Lord, 2003).

One of the primary interests at the Diagnostic and Research Institute for Autism Spectrum Disorders is evaluation and accurate diagnosis. Comprehensive evaluations are completed by a licensed clinical psychologist and psychology interns who are under the direct supervision of a licensed clinical psychologist. Evaluations include a standardized parent interview, a standardized observation measure, cognitive or developmental assessment, and speech/language tests. In addition, records are reviewed and a report is written with recommendations for the child's caregivers. Additionally, an extensive conference follows all evaluations so family members may understand the evaluation process and ask any questions as they arise. The primary goals of the comprehensive evaluation are to determine diagnosis, determine developmental skills, and obtain a thorough understanding of the child in order to delineate appropriate follow-up services.

Research and Training at Hofstra University

At Hofstra University, research and training initiatives strengthen clinical services by incorporating the latest research findings and sharing this information with families. At the same time, families have the opportunity to be a part of the research studies and

help expand scientific knowledge through their participation. Hofstra University is a doctoral training site where future school psychologists learn to design and implement various interventions with children manifesting an ASD. Further, doctoral students learn about the function of various behaviors as they learn to identify antecedents (what happens before the behavior), reinforcers and consequences to exhibited behaviors. Such training is essential in our view, as we learn from research the best practices for treating children with ASD.

Research clearly supports the importance of early identification and implementation of behavior and language interventions. If we identify children along the spectrum earlier, we can begin to implement the interventions that research indicates have the best efficacy. As a result, researchers are working toward developing a better understanding of how these children present in development in the first two years. Some of the communicative issues that serve as red flags for clinicians are a lack of meaningful gestures, such as pointing and reaching, a lack of reciprocity in communicative moments, and limited eye contact. Given these early indicators and what we now understand about the importance of early intervention, we must work toward understanding further the salient symptoms that might indicate an ASD diagnosis. Research indicates that the earlier we begin behavioral and language interventions, the better the prognosis for a child on the Autism spectrum. At Hofstra, we are now in the process of recruiting even younger participants, ages 12 to 24 months, to further explore these early signs.

Interventions for Children and Adults With ASD

Although there is no cure, children and adults with ASD typically respond well to behavioral and language interventions. Research suggests that early intervention is especially effective in achieving growth in cognitive and communication skills, and research supports intensive intervention with children who have an ASD. Due to the variety of interventions available, it is important for families to understand that there is no single intervention that will manifest the most growth. Some children respond well to social stories, whereas others may need interventions such as prelinguistic milieu training, which is described below; discrete trial training; or Greenspan Floor Time. And the list goes on. Therefore, careful consideration must be given to the type and variety of the intervention.

As all children differ, so do children along the spectrum. Therefore, programs should be individually tailored to facilitate the child's academic gains. Typically, programs that are behavioral in nature and provide immediate reinforcement for the child are successful in helping a child with an ASD enhance communication. However, it is important to add supplemental programs that build on acquired skills by offering teaching moments to ensure such skills generalize to the natural environment. Programs that have found the most success typically involve a blend of highly structured learning tasks coupled with more naturalistic learning to foster this generalization. According to Volkmar et al. (2005), a common denominator in such programs should include:

- Individualized treatment plans.
- Specialized curriculum for children with ASD.
- Strong communication component.
- Family training and involvement.
- Systematic, structured teaching.
- Intensity of engagement (at least 20 hours/week).
- Developmentally appropriate practice.
- Social skills with typical peers.

At Hofstra University, we are currently researching some of the most effective treatments for children and adults with ASD.

Prelinguistic Milieu Intervention

Prelinguistic milieu intervention is important as children on the spectrum typically are lacking in such skills as pointing, gesturing, and use of eye contact to communicate. Such skills are modeled and acquired in a natural play environment that incorporates routine building as the interventionist follows the child's lead. Research indicates that intervention at the prelinguistic level is important as such behaviors serve as building blocks for functional, incorporated communication. At the Diagnostic and Research Institute for Autism Spectrum Disorders at Hofstra, we will soon begin to recruit children ages 1 to 3 to further explore the nature of prelinguistic gesture in children with ASD.

Social Skills Groups

Doctoral students at Hofstra University learn about children and adults on the Autism Spectrum as they work toward teaching building skills, such as turn-taking in conversation, perspective-taking and sharing interests. Social

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group meetings combine brief skill learning and practice with activities of interest, in which participants are encouraged to use their social skills. Group leaders provide positive reinforcement and feedback to participants throughout the structured activities to further emphasize social interaction skills. As children on the spectrum sometimes evidence remarkable memories and can recall scripts from movies verbatim, such memory skills are emphasized as social skills are taught and practiced within a script of a social story.

Parent Support Groups

Parent support groups are an essential piece of our community outreach. We hope to provide families with the opportunity to gain understanding and exchange ideas, as doctoral students learn to provide a forum to help facilitate this understanding. A future study for which we are recruiting participants involves examining the relationships and feelings among various extended family members regarding ASD.

Sibling Workshops

Sibling workshops are an important part of treating the family as a system, and are a future focus for the clinic at Hofstra University. Siblings have much to share about their experiences, and we hope to provide a forum for this to happen.

Individual Therapy

Individual therapy for children, parents and families is critical as they understand and acknowledge feelings. At Hofstra University, we provide sessions in which we work with parents as they process through a myriad of feelings.

Future for Children and Adults With ASD

Our goal within the Diagnostic and Research Institute for Autism Spectrum Disorders is to improve the lives of individuals with Autism Spectrum Disorders and their families in a variety of ways, such as through the education of future doctoral students in school psychology, through research that enhances the understanding of interventions and emphasizes the importance of early diagnosis, and through the provision of clinical services to individuals and families in our surrounding community. Further, as we continue to learn from research the best treatment practices for children and adults with ASD, we will strive to continue to provide our doctoral students in school psychology with training, so they, in turn, might impact positively children and families within our community.

As I reflect upon Autism, I am reminded of the wonderful families who have touched and continue to touch my professional life, and to each I am grateful. I look to the future of Autism with hope and optimism as my family rises to the challenges and celebrates the joys my godson, Jackson, brings to our daily lives.

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Kimberly Gilbert

Kimberly Gilbert is an assistant professor in the Department of Psychology. She is also the director of the Diagnostic and Research Institute for Autism Spectrum Disorders, a specialty clinic of the Psychological Evaluation Research and Counseling Clinic at Hofstra University. Currently, she supervises doctoral students in the techniques of Applied Behavior Analysis as well as in objective diagnostic assessments, such as the Autism Diagnostic Observation Schedule (ADOS) for diagnosis along the Autism Spectrum.

Dr. Gilbert is a New York state-licensed clinical psychologist and certified school psychologist. She has held positions such as assistant professor in the Child Development Center at Vanderbilt University and school psychologist in New York elementary and high school settings. Currently, Dr. Gilbert serves as a behavioral consultant with the Greenwich Autism Program in Connecticut, where she conducts functional behavioral assessments, develops functional behavioral plans, and provides supervision for various home programs. Utilizing cognitive behavioral techniques, Dr. Gilbert also maintains a private practice in Manhattan at which she treats patients with various clinical needs, such as anxiety disorders, depression and stress management.

Dr. Gilbert's current research interests include exploration of the phenotypic expression of children along the Autism Spectrum to further delineate early onset predictive behaviors of Autism Spectrum Disorder. She has explored the efficacy of behavior and language interventions for children with special needs through support from the National Institute of Mental Health at Vanderbilt University. Additionally, her research interests include prelinguistic interventions, social skills training, behavior and language interventions, parent training, stress management, and academic integrity. Dr. Gilbert has presented her work at annual meetings of the American Psychological Association, and her research has been published in the *Bulletin of the Psychonomic Society*. Her professional affiliations include the American Psychological Association and the Association for the Advancement of Behavior Therapy.

At Hofstra, Dr. Gilbert teaches doctoral courses such as Psychopathology of the Emotionally Disturbed Child, Advanced Development, Exceptional Child, and Cognition and Perception, as well as undergraduate courses such as Child Development, Developmental Research Seminar, and Clinical Research Seminar. She currently supervises doctoral dissertation students in the Psy.D. Program, and serves on numerous dissertation committees in both the Psy.D. and Ph.D. programs.