

Identifying & Caring for Children with Autism

By Judith Bloch ACSW

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Autism, a spectrum disorder with symptoms from mild to severe, has become a developmental disability of national concern. The number of children with this diagnosis is rising sharply, and it is now estimated at 1 in 500 births. This number is compared to 1 in 10,000 only 10 years ago, and autism is three to four times more prevalent in boys than girls (National Institute of Child Health and Human Development, 2003). It is not known if these alarming statistics represent an actual increase, a growing awareness of the disorder, or an expansion of the defining criteria. In all likelihood, it is some combination of all three factors. This devastating disability is found in all socio-economic and racial/ethnic groups according to the Center for Disease Control and Prevention, the National Institute of Health, and the Autism Society of America. Due to these changing demographics, autism has become a major issue for millions of families, educators, and clinicians.

Prevalence of Autism

Worried parents often notice the characteristics that set children with autism apart from their peers by the time the children are 18 months old. Parental concerns should be taken seriously; their observations are usually reliable (Dinnebeil & Rule, 1994). In a 1997 report describing the experiences of almost 1300 families with children with autism, Howlin and Moore concluded that parents in the United Kingdom recognized the problem by the time the child was 18 months old and sought medical help by the time the child was two years of age. However, the report indicates that a diagnosis was not made until the child was six, too late for early educational intervention to be of any benefit. As a rule, a diagnosis can be reliably confirmed when a child is 18-24 months old (National Research Council, 2001; Olley & Gutentag, 1999).

Pervasive Development Disorder

An umbrella term, Pervasive Development Disorder (PDD) is "characterized by severe and pervasive impairment in several areas of development: reciprocal social interaction skills, communication skills, or the presence of stereotyped behavior, interests and activities. These disorders are usually evident in the first years of life and are often associated with some degree of mental retardation" (DSM-IV-TRTM, p. 69). Under this PDD umbrella, there is a continuum of three conditions that are of particular interest to educators: Autism, PDD Not Otherwise Specified (NOS), and Asperger's. The similarities and differences between two of these conditions, autism and PDD (NOS), and their impact on the child, family, and educational placement will be examined.

Autism

Autism is a neuro-biological disorder. "The essential features...are the presence of markedly abnormal or impaired development in social interaction and communication and a markedly restricted repertoire of activity and interests. In most cases, there is an associated diagnosis of mental retardation, which can range from mild to profound. Manifestations of the disorder vary greatly depending on the developmental level and chronological age of the individual" (DSM-IV-TRTM, p. 70-71). The age of onset, under 30 months, is a defining feature. PDD (NOS), also known as atypical autism, is used "when there is a severe and pervasive impairment in the development of reciprocal social interaction associated with impairment in either verbal or non-verbal communication skills or with the presence of stereotyped behavior, interests and activities, but the criteria are not met for an Autistic Disorder (DSM-IV-TRTM, p. 84).

Asperger's Syndrome

Listed under PDD and difficult to identify before the age of five, Asperger's is a related condition that exists "along a hypothetical spectrum bounded by severe autism at one end, and by a condition of nearly normal, save for a distinctive life-long social or empathic blindness at the other" (Wing, 1992). This child is likely to have normal or superior intelligence and age-appropriate language along with autistic-like social and emotional deficiencies.

Diagnosis

There are no laboratory procedures (e.g., x-rays, blood tests) that can help confirm the condition. Since autistic children are at risk for seizure disorders and other health problems, diagnosis is linked to observation of behavioral patterns that are characteristic of a medical evaluation. Even though children with autism vary greatly in the extent and severity of their disability, there are enough characteristic behaviors for early childhood educators to recognize the warning signs of this disorder as they observe the way children play and interact in their setting.

This disorder produces an enormous gap between the expectations of parents and teachers for age-appropriate behavior at home and in school. With rare exceptions, these children are part of families who initially do not have the knowledge, skills, or support systems to help them deal with this challenge (Moses, 1987). Teachers of typical children are often in a similar situation, inadequately informed and unprepared when faced with this child in the classroom (Handleman, 1999).

The Opportunity and the Challenge

The passage of IDEA (Individuals with Disabilities Education Act Amendments of 1997) by Congress created entitlements for children with disabilities and developmental delays and, indirectly, additional responsibilities for early childhood educators who are in a good position to identify children with suspected disabilities, inform parents of their concerns, and assist with evaluations that will help access services in a timely way. Since the behavior patterns of these children are so unusual, all programs have the capacity to identify a child with this type of disability, even if they do not have the ability or inclination to serve them. If teachers assume that children will outgrow their problems and do not discuss them with parents, the affected children may not receive the early care they need. Understanding the procedures for referring children appropriately and initiating a dialogue with parents will help prepare staff to deal with this important responsibility (Bloch, 2000).

With the goal of early identification in mind, an appreciation for both the central role of the family and the responsibility of the professional is important. Collaborative behavior observation in both the classroom and the home is more likely to promote appropriate evaluations, planning, and programming for the child and family.

Inclusion and LRE

The reauthorization of IDEA (Individuals with Disabilities Education Act for Children 3-21, 1997) continues to provide all children with disabilities the right to an appropriate education at no cost to parents. Federal and state legislation requires local education agencies (in some states this is the public school district) to conduct free, multi-disciplinary evaluations for all children with suspected disabilities. A child who is classified with a disability must receive special education and/or related services in the least restrictive environment (LRE). Federal legislation defines a least restrictive environment as follows: "To the maximum extent appropriate, children with disabilities...are educated with children who are not disabled...and special classes, separate schooling, or other removal of children with disabilities from the regular educational environment occur only when the nature or severity of the disability of a child is such that education in regular classes with the use of supplementary aids and services cannot be achieved satisfactorily" (University of the State of New York, 1997, p.15).

Inclusion, often considered the least restrictive environment, has both strong advocates and skeptics. Despite the federal legislation and the LRE emphasis, many schools and educators argue that profoundly impaired children will not receive the specialized services they require (Burack, Root, & Zigler, 1997). Parents may think that placement in preschool programs with trained and experienced staff may maximize the child's progress. In addition, strong differences remain amongst professionals and settings about the best ways to achieve the child's IEP goals. The debate serves the child best when the team (which should include parents) focuses on the practical, rather than the philosophical.

While inclusion is the ultimate goal for classified children, placement options remain a source of controversy. An inclusionary placement may not always meet the optimal needs of young autistic children and their families. The feasibility of an inclusionary setting is only partially determined by the severity of the child's disability. The school's capabilities and inclination to accommodate the child must also be considered. Interventionists need to have the understanding, skill, and ability to design and offer specialized services to both the child and family (Zager, Shamow, & Schneider, 1999).

The Teacher's Challenge

Since education is at this time the most effective intervention available for children on the autism spectrum, training of all the stakeholders, the children, their parents and teachers, is primary (National Research Council, 2001). Inappropriate or ineffective intervention is a serious matter that may compromise the child's later development. As a result, a number of assumptions need to be considered when placement and services are determined. There is general consensus that autistic children do best in a setting with the ability to implement the following:

- A child's IEP (Individualized Education Program)
- An individualized curriculum
- Functional goals
- Focus on multi-domain functioning (e.g., language, cognitive, social)
- A structured predictable schedule of daily routines
- Collaboration with parents
- Training and support for parents
- Interdisciplinary team work (that includes parents)

Early Childhood Programming criteria need to include:

- Understanding of the disorder
- Support, training, and consultation for all teachers
- Readiness to accept and include the child

- Appropriate modifications in the environment and physical setting
- Adaptation of curriculum and use of materials
- Extra time for planning, preparing, and collaborating
- Readiness to collaborate with related therapists (special education teacher, speech therapist, for example)

Attitudes about inclusion, access to specialists and collaborative planning, and curriculum are important factors influencing the success of inclusion (Bennett, Deluca, & Bruns, 1997; Dev & Morgan-Tanghal, 2002). In addition, research has indicated that staffing, class size, number of children with disabilities, and the nature and quality of a child's disability are significant factors in successful programs (MacMillan, Gresham & Forness, 1996; Sadler, 2003; Young, Marsland, & Zigler, 1997). A 1996 survey conducted by Scruggs & Mastropieri (Bennett et al., 1997) found that two-thirds of the teachers surveyed supported the concept of inclusion. However, only 25-33 percent said they had sufficient time, training, and resources to implement inclusive practices successfully; 30 percent thought that inclusion would disrupt the regular classroom.

The absence of full agreement about the efficacy of one kind of intervention over the other, or of the educational program of choice, heightens the tension level of the decision-makers and importance of a dialogue with parents. Familiarity with the autism syndrome and the panic it generates for families will assist staff to develop an approach to parents that helps them take advantage of legal entitlements and deal with the informing process and discussion that will follow (Bloch, 2000). Decision-makers will do best when they include parents in their deliberations as they evaluate the child's capabilities, (needs and behavioral patterns), community options, and the resources, which should consider the attitudes, skills, and readiness to collaborate that will be found in any proposed inclusionary setting.

Two Children: Martin and Paul

Two autistic children with different degrees of disability and strengths, will be discussed: Martin, a four-year-old with PDD (NOS) enrolled in an inclusionary class; and Paul, a three-year-old with a diagnosis of autism, enrolled in a special education self-contained class. A picture of each child's behaviors and level of functioning will serve to highlight the challenge involved in promoting their development and will also provide a framework for consideration of some of the major issues that programs need to address as they evaluate and make decisions about placement and intervention plans.

Paul

First, let's look at Paul, the more impaired child. Diagnosed with classic autism in the profoundly mentally retarded range at age two years, he had already received a number of individual services under the early intervention program. When, at age three, he began in a self-contained preschool class, his behavior was still markedly delayed and deviant. He did not use any words to communicate and did not seem to understand the everyday, simple words and directions that are part of life at home and school. He tended to make a few needs known by taking the adult by the hand (usually the wrist) and bringing her to an object of interest. At times he would cover his ears as though the usual classroom sounds were distressing.

At home, loud noises seemed to upset him. He also did not come to greet his mother when she returned from an outing and did not turn to her for comfort when he was hurt or upset. His play was solitary, limited, and repetitious. He preferred to line up small cars in the same way, day after day, and could not tolerate any changes in the patterns he created. Adult efforts to redirect his play or engage him in a small group with other children were disregarded or likely to exacerbate the problem and lead to an extended crying episode. He resisted any change in any of his basic daily routines (e.g., eating only from a very limited menu, and insisting on wearing only one of two sets of clothing). When left to his own devices, he scrutinized objects by passing them back and forth in front of his eyes or engaged in self-stimulating behavior. He would sit on the floor and rock, or tap a surface near him with his fingernail. These repetitive, ritualistic behaviors seemed to increase when he was distressed.

Paul was more than just a creature of habit with a preference for order and patterns. It was clear that this self-

Paul was more than just a creature of habit with a preference for order and pattern. It was clear that the son directed child had almost no ability to take advantage of play activities in the usual way, or to end one activity (deal with the transition) and move on to the next, or to self regulate or comfort himself. His parents had a hard time understanding his lack of curiosity in the toys and play things they provided for him and were distressed by their inability to get him to imitate anything or anyone.

The frequency, intensity, and duration of Paul's worrisome behavioral patterns shaped the team's recommendation. It was clear that he required a great deal of attention from a skilled and experienced staff as well as input from occupational and speech therapists. Paul was placed in a self-contained class (only classified children) of nine children that had a special education teacher and two assistants. A social worker provided support and training to his parents who were eager to acquire skills that would help them deal with problematic behaviors at home.

Martin

In contrast was Martin, a four-year-old child with PDD (NOS), not accompanied by any mental retardation. An inclusionary placement decision, insisted upon by Martin's mother, was approved and hesitantly accepted by the private preschool's interdisciplinary team. The decision-makers agreed that inclusion would not mean a reduction in services, but, instead, another way of providing them in a regular classroom. The expectation was that the theory and ideal of inclusion would not break down in its application. This class was larger than Paul's and had a less experienced staff, but the team thought that placement with typical children was an advantage. With the promise of administrative support, the teacher accepted the child and agreed to schedule regular meetings with his special education teacher and therapists. Martin's IEP provided him with a part-time special education teacher and aide, as well as individual time for Applied Behavioral Analysis (ABA) intervention, a speech therapist, plus consultations with an occupational therapist. When the interdisciplinary team met to set IEP goals and priorities, they quickly concurred that Martin would need help developing more appropriate language and play skills so that he could benefit from and tolerate the classroom.

While Martin demonstrated the characteristics of autism, he was also a compliant child who showed a capacity to learn. Even though his language skills were delayed and impaired, he was sometimes echolalic and would repeat exactly what he had just heard (e.g., when prompted to greet a friend, Martin would echo the teacher's words, "Say hello to Mary"), there was evidence that he understood directions and could use words and even some phrases appropriately. While his play was limited and lacking in imagination, the teacher could entice him on occasion to sit with the group during circle time. He also showed an unusual interest in letters and an ability to read some simple words. It was noted that even though he did not seem to pay attention in the same way as his classmates, he appeared to take in information peripherally, and most importantly, he was learning.

An adapted curriculum, with appropriate supports and a behavioral orientation, created opportunities for him to participate in a structured set of activities during the course of the day. Interventions were embedded within the context of regular classroom routines. For instance, the teacher built upon Martin's enormous interest in small trains (similar to Paul's preoccupation) by preparing a train station for him, adding small dolls, and expanding on the materials and equipment. Additionally, a reading program was developed using sight words of high interest, e.g., train, caboose, etc. Since Martin was not the only boy who loved trains, it attracted another interested child. This created an opportunity for peer interaction during free playtime, which had already been identified as a problem time.

Planning Implementation in the Inclusionary Setting

The ecological model proposed by Thurman & Widerstrom (1990) is a useful classroom guide. It builds on Bronfenbrenner's earlier work (1979) and highlights the concept of adaptive fit, which could also be called goodness of fit, by suggesting an assessment in which the teacher considers the following factors:

- The autistic child's behavior (different, delayed, and/or deviant) in the specific setting
- The autistic child's functional level and competence
- The autistic child's tolerance for the context and expectations
- The adult's level of tolerance for differences

An ECA (Ecological Consequence Assessment) (Meloni, Brasher, & Neitzel, 2002) process builds on Thurman's

An ECA (Ecological Congruence Assessment) (Wolery, Blasier, & Neizer, 2002) process builds on Martin's work. It identifies the need for teachers of inclusionary classes to increase their participation in goal setting and interventions and for specialists to acquire more information about the child's functioning in the typical setting. It addresses an important collaborative issue with some very practical and simple suggestions. Support, with suggestions from Wolery et al., (2002) who developed guidelines and forms for inclusionary child care settings, can assist preschools as well. These procedures suggest preparation of an assessment of the ecology of the classroom, its routines and activities, as an aid in setting goals and interventions, and makes available a form which captures information about the classified child's everyday behavior and ability to participate during daily routines and activities such as arrival and departure; snack and meals, free play and group time, transition, etc. A teacher generated report identifies the times of day and scheduled activities at which a child, in this case Martin, is likely to need extra help.

A plan developed by the team used Martin's interest in pictures and letters to help him understand and anticipate confusing new experiences. In order to prepare him for the daily routines at school, photos and then icons (picture symbols), paired with words (which he recognized very easily) showed him his schedule; i.e., "First, we arrive by bus, enter our class," etc. Cards and pictures clarified the sequence of events and served to remind and prepare Martin for transitions. And, most importantly, Martin was helped through the use of pictures (always with words underneath) to understand the classroom expectations. In addition, a picture exchange

system (Frost & Bondy, 1994) taught him to use symbols to make requests. For Martin, the team's reliance on photos, icons, and other pictorial representations increased his understanding of his daily school schedule, reduced his distress, and helped him anticipate and accept change. As a result, he became more receptive to other everyday learning opportunities.

One of the more significant developments in the education of autistic children has been an increased understanding of their communication difficulties (National Research Council, 2001). An IEP should always target objectives that will enhance the child's communication competence and build on the inclination typical of most autistic children; to learn through the visual modality. Recent studies suggest that autistic children will acquire language skills and increase their vocabulary more easily and quickly from a computer than they will from a teacher (Autism Research Review International, 2000). As a result, computer lessons were added to Martin's instructional program.

In summary, we can see that this team's eclectic approach, which emphasized a pictorial program and a behavioral orientation with a daily schedule of discrete trial activities and individual sessions that relied upon a procedure that set goals, gave the child instructions (e.g., "Sit in your seat," or "Look at me"), and rewarded compliance with treats (food or objects) and, ultimately, praise. Equally important in Martin's inclusionary class was an emphasis on a naturalistic approach with interventions that were embedded in the everyday environment wherever possible.

At home, Martin's parents were encouraged to work on goals that dealt with his sleep routines and mealtime behaviors. They utilized the techniques from school and took advantage of natural opportunities to reinforce his goals (e.g., Bath time: "point to eyes," "point to nose"; Pouring water down: "down," etc.). Wherever possible, interventions were embedded in his usual activities using the strategies that were identified in the parent-training sessions; but also were more finely tuned for this family and child. In this instance, the team's preparation, intervention plan, and collaboration with parents led to an increase in Martin's functional vocabulary, ability to understand and respond to adult instructions, and tolerance for activities with his peers.

Impact of Child's Disability on the Family System

While involving parents of autistic children in their education is a major priority, their ability to become engaged is likely to be affected by their emotional reaction to this unanticipated event and their limited understanding (initially) of the nature of the disability.

Planning for parenthood and anticipating the birth of a child, or adopting and adding a child, are major developmental milestones in family life (Carter & McGoldrick, 1989; Minuchin, 1974; Naseef, 2001). With parenthood comes an expectation that the child will be healthy and happy; an asset, although the specific form of this fulfillment depends on individual parental needs and fantasies. For many, this is a critical way to meet their desire for purpose and responsibility (Bloch, Weinstein & Seitz, in press-a; Satir, 1967).

The birth of any child changes the marital dyad, but the usual stresses accompanying change are exacerbated by an autistic child's disabilities, which require inordinate and specialized care. The extraordinary demands of daily life with a young autistic child can challenge and decimate the most competent parents. Basic routines are not likely to be in place. The child's eating, sleeping, toileting, dressing, and playtime activities are

problematic and require frequent attention and skilled intervention. The child's inability to occupy himself and his behavior patterns, both inside and outside the home, tend to limit and interfere with the usual course of family life.

Under these conditions, many marriages become tense and joyless. A mother who cannot successfully control her child's behavior may experience intense feelings of impotence, incompetence, distress, withdrawal and depression. Some become "consumed" by efforts to meet the needs of this child and subsequently exclude other family members. Fathers can become angry at their wives and resent their preoccupation with the child. In other families, fathers may react to their own hurt and disappointment by disengaging from parenting and focusing all of their energies on work and their obligation to meet their financial responsibilities. Sometimes the

child becomes a symbol of joint failure. Weary adults, drained by powerful emotions, may see family life disintegrate and change in ways they find difficult to tolerate (Bloch, Weinstein, Seitz, in press-b).

When parents are unable to cope, their behavior is often characterized by anxiety, uncertainty, even anger. The intensity of these reactions and feelings of failure sometimes led clinicians to question the capacity of such parents to nurture their child. Decades ago, some professionals mistakenly concluded that the child's behavior was the product of poor parenting instead of the cause of distraught reactions (Bettelheim, 1967).

Threatened with the loss of their parental dream, many parents may at first try to deny the presence of the problem or tend to minimize the magnitude of the disaster. No one in the immediate family escapes from the chronic stress and anxiety that a child with autism generates. At this stage, denial of the significance or extent of the problem may be necessary for some parents. It is important to understand that given these unusual circumstances the family system does not always function, especially during this period of first identification, in a way that seems appropriate or that meets the need of all its members. Almost always, especially in the early years, family life revolves around, and is planned around, this central concern.

At first, parents are likely to focus primarily on their preschool, autistic child, putting aside other family considerations. It is good timing to help parents consider professional input and resources which will provide the support and training they will need to acquire new skills that will reinforce the program designed for their child and help them deal with worrisome problems at home (bedtime, toilet training).

Conclusion

Children with autism struggle to master the most basic human behaviors. Their difficulties with communication, interactions with significant others, and learning patterns are likely to limit and negatively impact upon their later social and work opportunities and the lives of their families. Early childhood educators, who are familiar with the early childhood developmental sequence, characteristically tend to be kind-hearted and nurturing. They are in a unique position to identify children on the spectrum and work with their parents to access entitlements. Recognition, early classification, and education of children with autism is indeed a complex process. But, successful strategies in identification at the preschool level are feasible, and these educators can play an important role in promoting outcomes that will improve the lives of autistic children and their families.

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