1
Introduction and Overview

Recent epidemiological studies have documented a worldwide increase in the number of individuals identified with autism over the past decade (Tidmarsh & Volkmar, 2003). Whereas early research suggested classic autism to be relatively rare (4 to 6 per 10,000 or about 1 per 2,000; Lotter, 1967), more recent findings suggest that when viewed as a spectrum of disorders and including children at the milder end of the spectrum (i.e., Asperger's Disorder and Pervasive Developmental Disorder—Not Otherwise Specified), autism is much more prevalent than previously thought (60 per 10,000 or approximately 1 per 160; Chakrabarti & Fombonne, 2001; Fombonne, 1999; 2003a; 2003b). Although improved diagnostic practices and expanded classification systems account for a portion of this increase, some researchers now believe that yet to be identified environmental factors may have emerged in recent decades that place infants and children at increased risk for developing autism (Ozonoff & Rogers, 2003). Regardless of the cause (or more likely the causes) of this increased rate of autism spectrum disorders (autism or ASD), it is clear that today's school professionals are more likely to identify and be asked to serve students with autism than in years past.

For instance, the results of a recent electronic survey of school psychologists found 95 percent of the respondents reported an increase in the number of students being referred for assessment of autism (Kohrt, 2004). On average the respondents reported seeing 8 students with autism per year. Not surprisingly, the increased incidence of autism has resulted in an increased number of children with this disability being served in special education programs. Specifically, between 1994 and 2003 the number of students with autism, served under the *Individuals with Disabilities Education Act* (IDEA), increased more than 600 percent (from 22,664 in 1994 to 141,022 in 2003; US Department of Education, 2005). Given this new reality, it is essential that school professionals better understand autism and become better prepared to identify and serve these students. Facilitating attainment of such knowledge and readiness is the primary goal of this book.

Why School Professionals Should Read This Book

In addition to the increased frequency of these disorders, there are several other reasons why school professionals should increase their knowledge of autism. In this section, we review some of the issues that have generated an imperative for school psychologists and other educators to become better prepared to address autism.

Early identification and intervention are important determinants of the course of autism. An important reason for devoting increased attention to autism is the fact that early identification is not only feasible but is also an important determinant of its course (Baird, Cass, & Slonims, 2003; Goin & Myers, 2004). Research suggests that 75 to 88 percent of children with Autistic Disorder show signs of this condition in the first two years of life, with 31 to 55 percent displaying symptoms in their first year (Young & Brewer, 2002). These data combined with additional research suggesting relatively substantial cortical plasticity during early development and findings that intensive early intervention results in improved outcomes for children with autism (Ozonoff & Rogers, 2003; Rogers, 1998; Rogers, 2001) have led to a consensus that such early intensive intervention is essential (Mastergeorge, Rogers, Corbett, & Solomon, 2003). Thus, it is critical for school professionals, in particular those working in infant and preschool settings, to ensure that children with autism are identified as soon as possible.

Not all children with autism will be identified before children enter school. Although it should be expected that most of the more severe cases of autism will be identified before children reach school age, it must be acknowledged that many will "slip through the cracks" and go undiagnosed until after they enter kindergarten. Howlin and Asgharian (1999) reported data from a survey conducted in the United Kingdom that reveals the average age of diagnosis (at the time of their survey) for children with Autistic Disorder was about 5.5 years. In particular, it is not unusual for students with milder forms of autism (i.e., Asperger's Disorder) to go undiagnosed until after school entry. Among this group the average age of diagnosis was reported to be 11 years. Autism was rarely diagnosed under the age of 5 years (Howlin & Asgharian, 1999). Consistent with these data is the fact that the number of children with autism served under *IDEA* reaches its peak among children ages 6 to 11 years (US Department of Education, 2003). Thus, it is critical for all school professionals (not just those working in infant and preschool settings) to understand autism and be vigilant for early indicators of these disorders.

Most children with autism are identified by school resources. In a study by Yeargin-Allsopp and colleagues (2003) of the 1996 prevalence of autism in Atlanta, it was found that only 3 percent of children with autism were identified solely by non-school resources. All other children were identified by a combination of school and non-school resources (57 percent), or by school resources alone (40 percent). Thus, it might be argued that school professionals are expected to be involved in the identification process.

Full inclusion of children with autism in general education classrooms. Finally, it is important to acknowledge that current research and practice are moving toward the integration of special and general education (Koegel & Koegel, 1995). Students with disabilities are increasingly placed in full-inclusion settings. In addition, the results of recent studies suggesting that there are fewer children with autism who are also diagnosed mentally retarded further increases the likelihood that these students will be mainstreamed (Chakrabarti & Fombonne, 2001). Consequently, today's school professionals are more likely to encounter children with autism during their careers. It is essential that both special and general educators alike have up-to-date information regarding autism.

The Autism Spectrum Disorders

As currently conceptualized, the term "autism" includes several different (yet overlapping) disorders. This section reviews the evolution and current conceptualizations of the autism spectrum disorders.

Evolution of the term "autism." According to Rau (2003), the term "autism" appears to have first been used by Swiss psychiatrist Eugen Bleuler in 1911. Derived from the Greek *autos* (self) and *ismos* (condition), Bleuler used the term to describe the concept of "turning inward on one's self" and applied it to adults with schizophrenia. In 1943, Leo Kanner first used the term "infantile autism" to describe a group of children who were socially isolated, behaviorally inflexible, and who had impaired communication. Initially viewed as a consequence of poor parenting, it was not until the 1960s, and recognition of the fact that many of these children had epilepsy, that the disorder began to be viewed as having a neurological basis (Bryson, Rogers, & Fombonne, 2003).

In 1980, infantile autism was first included in the third edition of the *Diagnostic and Statistical Manual* (DSM), within the category of Pervasive Developmental Disorders [American Psychiatric Association (APA), 1980]. Also occurring at about this time was a growing awareness that Kanner's autism (also referred to a *classic autism*) is the most extreme form of a spectrum of autistic disorders (Bryson et al., 2004).

Autistic Disorder is the contemporary classification used since the revision of *DSM*'s third edition (APA, 1987). Currently, in the fourth edition of *DSM* (2000), Autistic Disorder is placed within the subclass of "Disorders Usually First Diagnosed in Infancy, Childhood, or Adolescence" known as "Pervasive Developmental Disorders." In addition to Autistic Disorder, the other specific Pervasive Developmental Disorders (PDD) include Asperger's Disorder, Pervasive Developmental Disorder, Not Otherwise Specified (PDD-NOS), Rett's Disorder, and Childhood Disintegrative Disorder. Figure 1.1 illustrates the relationships among these PDDs.

For the purposes of this book, the terms "autism" and "autism spectrum disorder" (ASD) are used to refer to a group of five specific diagnoses found within the

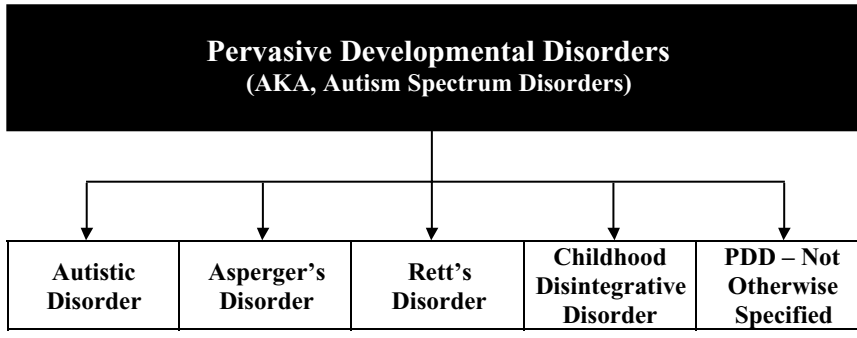

FIGURE 1.1. According to the *DSM IV-TR* (APA, 2000), Pervasive Developmental Disorders (or PDD) include five different diagnostic categories.

Diagnostic and Statistical Manual of Mental Disorders (*DSM IV-TR*; APA, 2000). The reason for this choice of terminology is that autism has been suggested to be much more readily recognized and understood by parents and professionals than PDD (Baird et al., 2003). Each of these five PDDs (or autism spectrum disorders) is briefly described below.

Autistic Disorder. This is the form of autism most like Kanner's infantile autism and is sometimes referred to as classic autism. The primary symptoms of Autistic Disorder are "markedly abnormal or impaired development in social interaction and communication and a markedly restricted repertoire of activity and interests" (APA, 2000, p. 70). Diagnosis requires the presence of 6 or more of 12 symptoms, with at least two being symptoms of impaired social interactions, at least one being a symptom of impaired communication, and at least one being a symptom of restricted repertoire of activities and interests. Tidmarsh and Volkmar (2003) offer the following description of what they consider a "typical example" of a child with Autistic Disorder:

> . . . a 3-year-old child who does not speak and does not respond when parents call his or her name. Such children seem to be in their own world when left alone; in day care, they tend to isolate themselves from the group. They do not play with toys but, instead, perhaps repetitively stack blocks or push a toy car back and forth while lying on the floor. They are sensitive to loud noises and cover their ears when trucks pass by. They flap their hands and turn their bodies in circles. (p. 518)

Although they do have much in common, the manifestations of Autistic Disorder vary greatly across individuals, and many individuals diagnosed with autism do not display all of the characteristics (Travis & Sigman, 2000). As illustrated in Figure 1.2, Autistic Disorder symptom severity falls along a continuum. Among many children with autism, there is an associated diagnosis of mental retardation (Fombonne, 1999; Ghaziuddin, 2000; National Institute of Mental Health, 1997).

The long-term prognosis for individuals with autism also varies greatly, depending on the timing and effectiveness of interventions utilized and the degree of

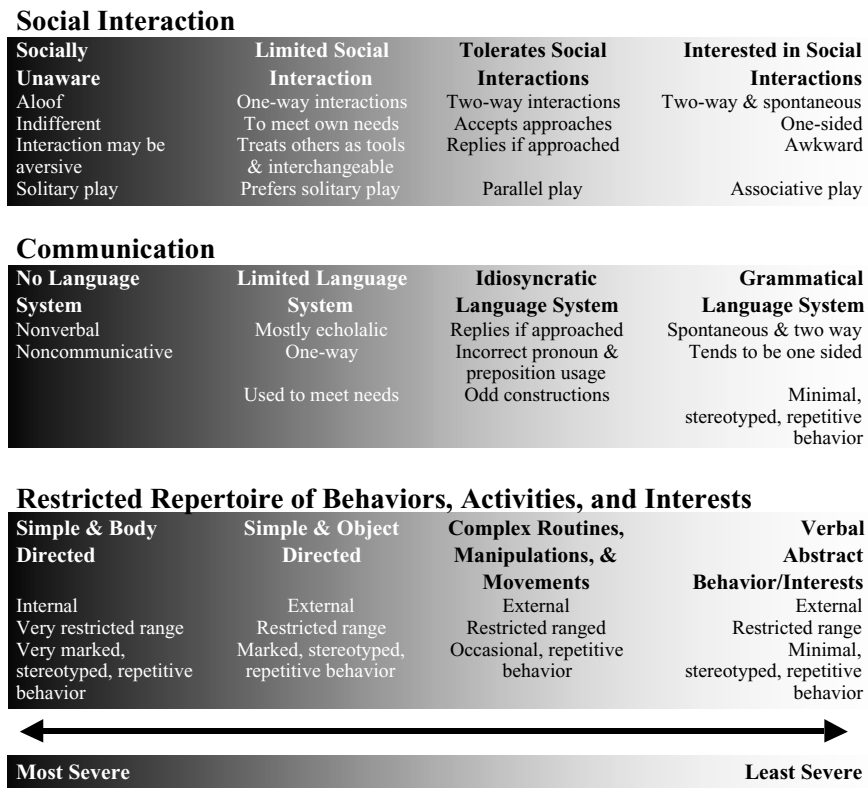

FIGURE 1.2. Autistic Disorder symptoms present along a continuum of severity. As one moves along this continuum (from left to right), symptoms have a reduced impact on adaptive functioning and the potential for independent functioning increases. These symptoms change over time, with IQ and language being the best predictors of movement from most to least severe. Adapted from Wing (1991).

impairment. As discussed earlier, children who receive intensive early intervention tend to have better outcomes than those who do not receive such intervention. In addition, children who have more severely delayed cognitive functioning and language tend to have a poorer outcome than do their peers without such delays (Mastergeorge, Rogers, Corbett, Solomon, 2003; Wing, 1995).

Asperger's Disorder. First described by Hans Asperger in 1944, the primary symptoms of Asperger's Disorder are "severe and sustained impairment in social interaction . . . and the development of restricted, repetitive patterns of behaviors, interests, and activities" (APA, 2000, p. 80). With the exception of not requiring symptoms of delayed communication [Asperger's Disorder criteria require "no clinically significant general delay in language" (p. 84)], the diagnostic criteria for Asperger's and Autistic Disorders are essentially the same. However, diagnosis

requires that Autistic Disorder be ruled out before Asperger's Disorder is considered. Thus, it is not surprising that the rate of Asperger's is lower than that of Autistic Disorder.

Although early language skills are preserved, their circumscribed interests, about which they may speak incessantly, adversely affect the conversational reciprocity of children with Asperger's Disorder. In addition, they tend to make socially inappropriate statements and often sound like little professors, using unusual and sophisticated words. The rhythm, stress, and intonation (prosody) of their language are affected, and these children often speak in a monotone (Tidmarsh & Volkmar, 2003).

The cognitive functioning of individuals with Asperger's Disorder is much more homogeneous than that found among individuals with Autistic Disorder. Although individuals with Autistic Disorder are often cognitively impaired, the intellectual functioning of individuals with Asperger's Disorder is typically within normal limits. These individuals can complete high levels of education; however, their adult functioning is often adversely affected by their impaired social skills (APA, 2000; Tidmarsh & Volkmar, 2003).

It is important to note that the functional difference between Asperger's Disorder and *High Functioning* Autistic Disorder (i.e., those who meet the criteria for Autistic Disorder and who have IQs above 70) is not clear. There are no indications of the need for different treatment approaches for these two groups and the two are more alike than they are different (Ozonoff, Dawson, &, McPartland, 2000; Ozonoff & Rogers, 2003).

PDD-NOS. This classification is reserved for individuals who experience difficulty in at least two of the three Autistic Disorder symptom clusters but who do not meet the complete diagnostic criteria for any other PDD (APA, 2000). According to Filipek and colleagues (1999), PDD-NOS is not a distinct clinical entity. However, individuals with this diagnosis typically have milder symptoms.

It is important to acknowledge that the PDD-NOS diagnostic classification is sometimes employed when a diagnostician is simply reluctant to use the Autistic Disorder label. In fact, in one study 176 children with Autistic Disorder were judged to not be significantly different from 18 children with PDD-NOS on any neuropsychological or behavioral measure (when nonverbal IQ was controlled; Rapin et al., 1996; cited in Filipek et al., 1999).

Childhood Disintegrative Disorder. Also known as Heller's syndrome, Childhood Disintegrative Disorder is a very rare condition with a prevalence rate of 1.7 per 100,000. It is more likely to affect males. Like Autistic Disorder, it involves impaired development of social interaction and communication; and restricted, repetitive, and stereotyped patterns of behaviors, interests, and mannerisms. However, a distinct pattern of regression (occurring before 10 years of age) following at least two years of normal development distinguishes it from Autistic Disorder. This pattern includes the ubiquitous loss of speech and frequent deterioration

of bladder/bowel and motor skills (Bray, Kehle, & Theodore, 2002; Malhotra & Gupta, 2002). Severe cognitive deficits are typically associated with Childhood Disintegrative Disorder (APA, 2000; Tidmarsh & Volkmar, 2003).

Rett's Disorder. With a prevalence rate of 1 per 20,000, Rett's Disorder is a progressive developmental disorder that occurs primarily among females. Examination of diagnostic criteria reveals that Rett's Disorder is relatively distinct. A pattern of head growth deceleration (between the ages of 5 and 48 months), a loss of purposeful hand skills, and the presence of awkward gait and trunk movement distinguish Rett's from the other PDDs. Because affected girls gradually lose gross motor function, motor delays and not language delays are often the initial referring concern. Although social difficulties characteristic of Autistic and Asperger's Disorders may be observed, they are not as pervasive and tend to be transient. In the later stages of the disorder (between 2 and 10 years) social skills improve. Severe to profound cognitive deficits are typically associated with Rett's Disorder. By adolescence, girls with this disorder have muscle wasting, scoliosis, spasticity, and decreased mobility (APA, 2000; Tidmarsh & Volkmar, 2003).

Regarding these latter two classifications (Childhood Disintegrative and Rett's Disorders), it is important to acknowledge that as researchers have come to understand more about them and their respective etiologies (particularly of Rett's Disorder), their relationship with other autism spectrum disorders has been called into question (Szatmari, 2004). In fact, Ozonoff and Rogers (2003) have speculated: "It is likely that these conditions will not be so closely associated with autism in the future and will be considered distinct neurodegenerative disorders (p. 11). Because of this unclear relationship between Rett's Disorder, CDD, and autism spectrum disorders, this book will emphasize research dealing with Autistic and Asperger's Disorders.

Autism and Special Education Eligibility

One of the more important intervention options to be considered by school professionals serving students with autism is special education services, and as was mentioned earlier in this chapter, the past decade has seen a dramatic increase in the number of students with autism receiving special education assistance. Thus, this book begins with an exploration of how school professionals can better identify and serve students with autism and a brief review of the topic of special education eligibility.

First, and foremost, it is critical to recognize that *DSM IV-TR* diagnoses are not synonymous with special education eligibility (Fogt et al., 2003; US Department of Education, 2000). According to proposed *Individuals with Disabilities Education Improvement Act* (IDEIA) 2004 regulations [US Department of Education, 2005 (c)(1)(i)], eligibility for special education services as a student with autism is defined as follows:

1. Autism means a developmental disability significantly affecting verbal and nonverbal communication and social interaction, generally evident before age three that adversely affects a child's educational performance. Other characteristics often associated with autism are engagement in repetitive activities and stereotypical movements, resistance to environmental change or change in daily routines, and unusual responses to sensory experiences.
   i. Autism does not apply if a child's educational performance is adversely affected primarily because the child has an emotional disturbance, as defined in paragraph (c)(4) of this section.
   ii. A child who manifests the characteristics of autism after age three could be identified as having autism if the criteria in paragraph (c)(1)(i) of this section are satisfied.

It has been argued that, given this eligibility classification statement, distinctions among the various *DSM IV-TR* PDDs may not be important. Specifically, Shriver, Allen, and Mathews (1999) suggest that for special education eligibility purposes, "the federal definition of 'autism' was written sufficiently broad to encompass children who exhibit a range of characteristics of autism such as PDD-NOS and Asperger's Disorder" (p. 539). However, Fogt and colleagues (2003) suggest that it is less clear if students with milder forms of autism would be eligible. In their review of published case law addressing the eligibility of students with autism for special education, Fogt and her colleagues observed that "adjudicative decision makers almost never use the *DSM IV-TR* criteria exclusively or primarily for determining whether the child is eligible as autistic" (p. 211). Although *DSM IV-TR* criteria were considered in just over half of the cases reviewed, all but one case acknowledged *IDEA* as the "controlling authority" (p. 211). Thus, when it comes to special education, it is state and federal education codes and regulations (not *DSM IV-TR*) that drive eligibility decisions. School professionals involved in making eligibility decisions for students with autism are advised by Fogt and her colleagues "to become thoroughly familiar with the diagnostic criteria for autism specified in the *IDEA* and to bear clearly in mind that the DSM definition is not legally controlling" (p. 211).

Given the *IDEA* requirement that autism must "adversely affect a child's education performance" before a given student can be found eligible, some generalizations about the likelihood that a specific autism spectrum disorder will result in special education eligibility can be made. First, given that a majority of students with Autistic Disorder are also mentally retarded (Fombonne, 1999), it should be expected that a majority of students with this diagnosis would also be eligible for special education under *IDEA* (Fogt, Miller, & Zirkel, 2003). However, the intellectual functioning of individuals with Asperger's Disorder is typically within the average range. Hence, it is suggested that students with Asperger's Disorder will require more careful examination by an Individual Educational Planning (IEP) team to determine if their learning needs necessitate special education assistance. Similarly, individuals with PDD-NOS and high functioning autism are typically viewed as having milder symptoms. Given this fact, these students may also require

more careful examination by an IEP team to determine if their learning needs necessitate special education assistance. Finally, given the severe to profound cognitive deficits typically associated with Childhood Disintegrative and Rett's Disorders, it is expected that IEP teams will typically certify these students as eligible for special education assistance.

Purpose and Plan of This Book

In the pages that follow, school professionals are provided with the information they need to be better prepared to identify and address the needs of students with autism. Chapter 2 offers an exploration of the complex etiology of autism. In Chapter 3, epidemiological issues are reviewed. Included here will be a discussion of the changing rates of autism both in special education and in the general population. Chapters 4, 5, and 6 review information essential to identification and assessment, and, finally, Chapter 7 presents a summary of research examining the effectiveness of interventions for children with autism.

2
Causes

Researchers have been attempting to find the causes of autism since it was first identified by Kanner in 1943. Although Kanner initially suggested autism to have a biological basis; most early efforts to identify the causes of autism focused on inadequate nurturance by emotionally cold and indifferent parents (Ozonoff & Rogers, 2003). However, in the words of Ozonoff and Rogers (2003): "It is now abundantly clear that autism is a biological disorder and is not caused by parenting deficiencies or other social factors" (p. 18). Today, it is accepted that the behavioral manifestations of autism are a consequence of abnormal brain development, structure, and function. The brain structures implicated in autism are illustrated in Figure 2.1 (Strock, 2004).

Although it is clear that autism has an organic etiology, the underlying causes of these neurological differences, and exactly how they manifest themselves, is much more controversial. Literature reviews conducted by Muhle, Trentacoste, and Rapin (2004), Rapin and Katzman (1998), and Newschaffer, Fallin, and Lee (2002) suggest the etiology of autism to be complex and multifaceted, resulting from the interaction of genetic, neurological, and environmental factors. Specifically, it has been suggested that some combination of genetic predisposition(s) and gene by environmental interaction(s) result in the brain abnormalities, which in turn are the causes of the range of behaviors we currently refer to as autism spectrum behaviors. These hypothetical relationships are summarized in Figure 2.2.

Genetics

There is strong evidence that autism is heritable (Muhle et al., 2004). Ozonoff and Rogers (2003) suggest that there are four primary lines of research pointing to the role of genetic factors in autism. First, they refer to research that has documented a 3 to 6 percent increased risk for autism among the siblings of children with an autism spectrum disorder, a rate that far exceeds that found in the general population. Second, they site research that has found that if one identical twin has Autistic Disorder, 60 percent of the time the other twin will also have this condition. This percentage jumps to 90 percent when both twins are viewed from

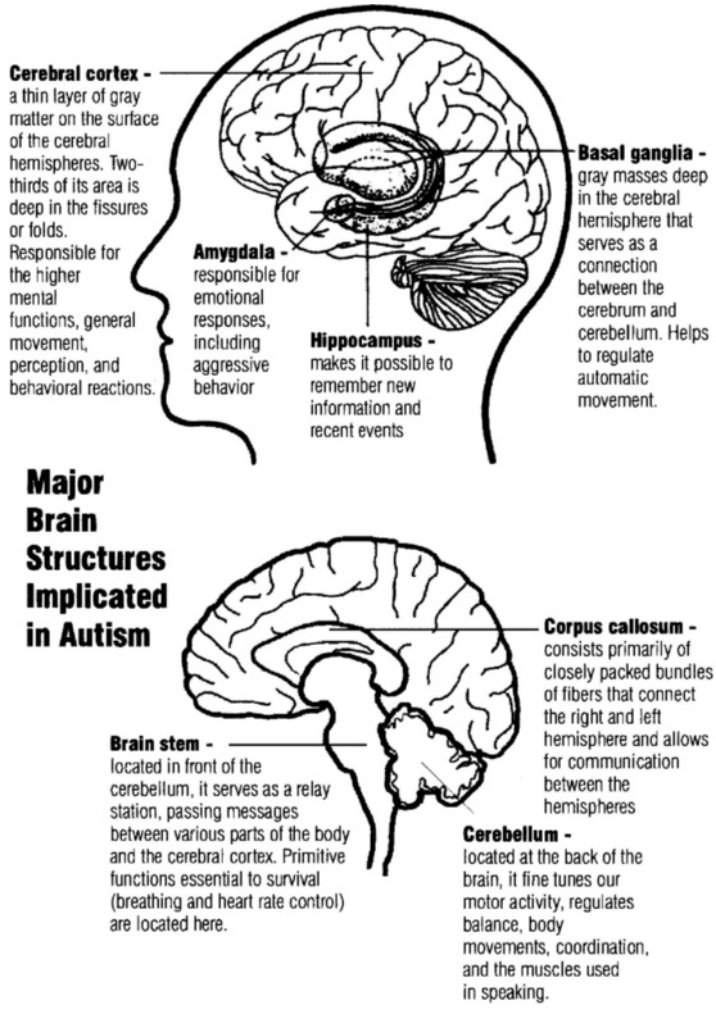

FIGURE 2.1. The brain structures implicated in autism. [Reprinted from Margaret Strock (2004), *Autism Spectrum Disorders.* Bethesda, MD: NIMH (p. 29). This work is in the public domain.]

the perspective of the broader autism spectrum. Conversely, among fraternal twins (who have developed from two separate ova), the risk of both twins having autism is no greater than that found among non-twin siblings.

Third, Ozonoff and Rogers (2003) acknowledge research that has documented autism to be associated with a variety of genetic and chromosomal abnormalities. However, it is important to note that current estimates suggest that less than 10 percent of all autism cases are caused by a diagnosable medical condition, chromosomal abnormality, or genetic defect (e.g., tuberous sclerosis, fragile X;

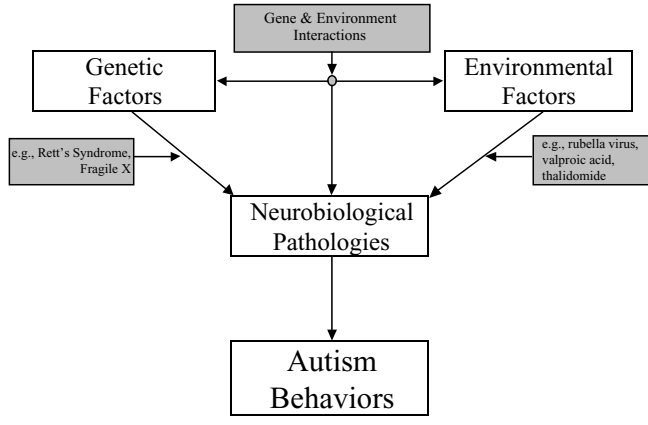

FIGURE 2.2. The hypothetical relationships between genetics, the environment, and the brain abnormalities that are the likely causes of autism.

Muhle et al., 2004). Finally, they cite research suggesting that besides autism, the families of individuals with autism tend to demonstrate a set of cognitive and social differences that are not seen in other family groups. Although these data are very powerful, at present the identity and number of genes associated with autism is not known and is the focus of much scientific inquiry.

Identification of Autism Genes

The human genome is composed of 23 pairs of chromosomes (numbered 1 to 22, with X and Y designating the sex chromosomes). Combinations of 30,000 to 40,000 different genes form each chromosome. Composed of deoxyribonucleic acid (DNA), genes function as blueprints for growth and development. If a particular gene is changed in some way, its ability to direct normal development is affected. Similarly, if a chromosome is damaged in some way, it can affect normal development by altering the numerous genes located in that part of the chromosome (Exploring Autism, 2002; The National Autistic Society, 2004). To better understand the genetics of autism, researchers currently employ several different methods. Muhle and colleagues (2004) divide these methods into: (a) cytogenetic studies, (b) genome searches, and (c) candidate gene searches.

Cytogenetic studies. This type of research examines chromosome number and/or structure to identify abnormalities that may be associated with autism. Using various viewing techniques, researchers examine the chromosomes of individuals with autism and search for visible breakpoints, translocations, duplications, and deletions (Exploring Autism, 2002). When such abnormalities are found, the hunt for specific autism genes within that region begins. Muhle and colleagues (2004) suggest that among individuals with autism, abnormalities are "fairly frequent" on chromosome 15 (15q) (p. 472). Currently it is speculated that there are at least

TABLE 2.1. Genes suspected to be involved in autism.

Gene(s)	Chromosome(s)
5-hydroxytryptamine (serotonin) transporter (*5HTT*) gene	17
Gamma-aminobutyric acid A receptor b3 (*GABRB3*) gene	15
Reelin (*RELN*) gene	7
Homeobox (*HOX*) genes	7, 17, 2
Fragile X genes	X
C-Harvey-ras (*HRAS*) gene	11

Sources: Muhle et al. (2004) and Newschaffer et al. (2002).

22 chromosome regions containing genes associated with autism (Xu, Zwaigenbaum, Szatmari, & Scherer, 2004). It is important to note that while cytogenetic studies are helpful in identifying regions of interest in and of themselves, these techniques cannot identify the specific genes that may cause autism.

Genome searches. This type of research examines the genetic material of families that include individuals with autism. Within these families, DNA sequences (or markers) along different chromosomes are examined by researchers for slight differences (referred to as polymorphisms). Researchers then try to find differences that are consistently found among family members who have autism, but not among those without the disorder. By determining how close the polymorphism, unique to the autism family members, are to a specific gene (done via statistical methods), the polymorphism can be "linked" to that gene (Exploring Autism, 2002). When such linkages are made, the hunt for a specific autism gene within that chromosome region begins. Muhle and colleagues (2004) suggest that at least 10 different genes have been associated with autism using this technique, with the putative speech and language region (7q31–q33) "most strongly linked with autism" (p. 472). Here again it should be noted that these studies are helpful in identifying chromosomal regions of interest. However, linking a given polymorphism and a given gene does not mean that a specific gene has been found. Rather, it means that it is likely that such a gene is nearby.

Candidate gene searches. This research begins with the assumption that certain specific genes are likely to be associated with autism. These prior assumptions are based upon clinical and empirical evidence (including whole genome searches and cytogenetic analysis) that a specific gene is associated with the development of specific autism symptoms. Using this method, several research teams have found associations between autism and at least six different genes or gene groups. These genes are listed in Table 2.1. However, there has been no consistent replication of positive findings for any of these genes (Newschaffer et al., 2002).

Concluding Comments Regarding the Role of Genetics

It is not likely that autism is a purely genetic disorder (Ozonoff & Rogers, 2003). With the exception of Rett's Syndrome [which is caused in the majority of cases by