

Multicultural Issues in Autism

Tina Taylor Dyches,^{1,4} Lynn K. Wilder,¹ Richard R. Sudweeks,¹
Festus E. Obiakor,² and Bob Algozzine³

The professional literature provides ample evidence that individuals with autism exhibit a myriad of unusual social, communication, and behavioral patterns of interactions that present challenges to their families and service providers. However, there is a dearth of quality works on multicultural issues regarding autistic spectrum disorders. In this article, we explore issues surrounding autism and multiculturalism, with the intent not to provide answers but to raise questions for further examination. We focus our discussions on two primary issues: autism within cultural groups and multicultural family adaptation based on the framework of pluralistic societies in which some cultural groups are a minority within the dominant culture. We found differences in prevalence rates across races for autism and little information regarding how multicultural families adapt to raising a child with autism. Further, students with multicultural backgrounds and autism are challenged on at least four dimensions: communication, social skills, behavioral repertoires, and culture. Future research in these areas is clearly warranted.

KEY WORDS: Autism; cross-cultural studies; etiology; incidence; genetics.

The identification and treatment of individuals with autism have international roots. Swiss psychiatrist Eugen Bleuler used the term “autism” in the early 1900s to describe individuals who exhibit fundamental disturbances of contact with the social world. Two Austrian-born professionals in child psychiatry and pediatrics, Leo Kanner and Hans Asperger, respectively, suggested a new diagnostic category based on Bleuler’s conceptualization of autism, distinct from mental retardation and other psychiatric disorders. Today, Kanner’s autism is seen as a specific disorder separate from the broader range of autistic spectrum disorders including Asperger’s Disorder, Rett Syndrome, Childhood Disintegrative Disorder, and Pervasive Developmental Disorder–Not Otherwise Specified. Although the lists of the symptoms defining autism have changed

frequently during the last 80 years (National Research Council, 2001, p. 12), yet a few core characteristics of autism have passed the test of time: deficits in social interactions and communication skills and restricted or unusual behavioral repertoires.

Autism is considered to be a severe disability because of the intense lifelong effects it has on the individual and his or her family. Present from birth or very early in development (National Research Council, 2001), autism coexists with mental retardation in approximately 75% of those with the disorder (American Psychiatric Association, 1994), and 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 for families beyond those only characteristic of autism. Parents raising a child with autism have reported extreme difficulties in dealing with challenging behaviors, teaching their child to communicate, teaching basic life skills, guarding their child from danger, and preparing their child for adult life (Randall & Parker, 1999).

These difficulties may be greater among children with autism than among those with other developmental

¹ Brigham Young University, Provo, Utah.

² University of Wisconsin-Milwaukee, Milwaukee, Wisconsin.

³ University of North Carolina at Charlotte, Charlotte, North Carolina.

⁴ Correspondence should be addressed to Tina Taylor Dyches, 340-F McKay Bldg., Brigham Young University, Provo, UT; e-mail: tina_dyches@byu.edu

disabilities (Randall & Parker, 1999), warranting study in isolation from other disabilities. Researchers have “not paid sufficient attention to interactions between child factors—such as degree of cognitive and language impairment, severity of autistic involvement, and specific diagnosis on the spectrum of autism—and family characteristics that may influence both the ease with which parents can teach their child and the stress level in the household” (National Research Council, 2001, p. 39). Numerous research reports have been published regarding how families adapt to having a child with a disability (Bennett, DeLuca, & Allen, 1996; National Research Council, 2001; Olsen *et al.*, 1999; Seligman, 1999); however, little research exists regarding family adaptation to autism specifically, and most research regarding autism emanates from Western cultural perspectives (see National Research Council, 2001).

Educating children from diverse family backgrounds and communities is becoming increasingly common in America’s schools (Obiakor, 1994, 1999, 2001). Though sometimes downplayed, multiculturalism has always been a part of American society (Gonzalez, Brusca-Vega, & Yawkey, 1997; O’Shea, O’Shea, Algozzine, & Hammitte, 2001). Diverse home values, family traditions, and social-cultural experiences are important considerations for teachers and other professionals working to improve the lives of children with disabilities (Gonzalez, Brusca-Vega, & Yawkey, 1997; Utley & Obiakor, 2001; Ysseldyke, Algozzine, & Thurlow, 2000). The purpose of this article is to explore issues surrounding autism and multiculturalism. Because little empirical evidence has been published regarding these concerns, our primary intent is not to provide answers but to raise questions for further examination. Our discussion focuses on issues regarding autism within cultural groups and adaptation within families with multicultural backgrounds in the framework of a pluralistic society in which some cultural groups are a minority within the dominant (Western or Anglo) culture.

AUTISM WITHIN MULTICULTURAL GROUPS

For almost a century, autism has puzzled both parents and professionals, with no topic in the field of autism left unchallenged. The professional literature is replete with controversy, and even hostility, in the exploration of ways to define, assess, and diagnose the disorder; document its prevalence; delimit its effects on families; identify goals and characteristics of effective interventions; establish public policies; and prepare

personnel to meet the needs of individuals with autism (see National Research Council, 2001). Although concepts that were previously considered controversial may be generally accepted today, some ideas are accepted without empirical support from the literature. One example is the ubiquitous nature of autism.

Etiological Theories and Race in Autism

A general perception today is that autism occurs equitably across demographic groups. The largest professional organization in the field asserts: “Autism . . . knows no racial, ethnic, or social boundaries. Family income, lifestyle, and educational levels do not affect the chance of autism’s occurrence” (Autism Society of America, 2000, p. 3). This claim appears to be an attempt to discount Kanner’s original hypotheses regarding the association between parental characteristics and children with autism. After describing the children who had autistic disturbances of affective contact, Kanner made observations regarding their parents: “There is one other very interesting common denominator in the backgrounds of these children. *They all come of highly intelligent families*” (1943, p. 248). Reporting a “great deal of obsessiveness in the family background,” (p. 250), Kanner described many of the parents as being professionals with high levels of education, “strongly preoccupied with scientific, literary, or artistic work,” with “limited genuine interest in people” (p. 250). He added, “in the whole group, there are very few really warm-hearted fathers and mothers The question arises whether or to what extent this fact has contributed to the condition of the children” (p. 250). Kanner suggested biological rather than psychogenic causation when he posited that autistic characteristics are “inborn” and that such children have an “innate” inability to form affective contact with others.

Kanner’s observations of the characteristics of family members closely related to children with autism have been the impetus for much research regarding etiology, with varied results. Scientific study in the 1950s and 1960s focused on possible psychopathological roots of autism, largely disregarding the possibility of genetic or biological causes. Bettelheim (1967), a strong advocate of the psychogenic theory of autism, blamed cold, “refrigerator” mothers for causing their children’s autism and suggested treatment that removed these children from their mothers. However, Kanner (1971) disputed the proponents of psychogenesis in autism when he noted that: “some people seem to have completely overlooked this statement [regarding inborn autistic disturbances], however, as well as the passages

leading up to it and have referred to the author erroneously as an advocate of postnatal ‘psychogenicity’” (p. 141). Although Kanner did not deny the “repeatedly confirmed phenomenon” of the obsessiveness and social skills deficits in the family background, he was cautious not to postulate a “direct cause-and-effect connection” (Kanner, 1971, p. 141) between this phenomenon and the children’s autism, noting that “genetic investigations are barely beginning to be conducted” (p. 145).

In the 1960s, strong evidence against the psychogenic theory of autism was presented that changed the focus of etiological study. In his book *Infantile Autism* (1964), Rimland’s denouncement of psychogenesis and support for biological etiology led to the position adopted by the Autism Society of America that specific family characteristics do not contribute to the occurrence of autism. Though such a claim discounted psychogenic etiologies, it still neglected the genetic liability that is currently gaining widespread empirical support in the etiology of some children with autism: “Autism today is thought to be one of the most heritable of all psychiatric conditions” (Szatmari & Jones, 1998, p. 109).

The genetic role in autism has been evident for decades, with well-documented overrepresentation in males and evidence since the 1950s of higher concordance rates in monozygotic than dizygotic twins (Rimland, 1964). Further, studies of the family indicate higher rates of autism among siblings than expected and higher rates of the broader autistic phenotype (e.g., social difficulties and depression) among first-degree relatives of individuals with autism (see Rodier, 2000). Finally, although recent studies have suggested linkage to chromosomes 2, 7, 15, and 16, it is clear that genes “play an influential, but not absolute, role in the development of autism” (Gleberzon & Rosenberg-Gleberzon, 2001, p. 47). Other factors such as environmental influences (e.g., exposure to ethanol and valproic acid; in utero exposure to rubella and thalidomide; Rodier, 2000), neurochemical and neurostructural damage, and immune deficits also contribute to the expression of autism (Gleberzon & Rosenberg-Gleberzon, 2001). The possible association between autism, which is “under a high degree of genetic control” (Tanguay, 2000, p. 1086), and another heritable trait, race, has not been fully investigated.

The vast majority of research in the field of autism has largely ignored or minimized race (Connors & Donnellan, 1998), despite accepted claims regarding the universal nature of autism. The trend of studying primarily Anglo-Saxon children began with Kanner’s

original group of 11 children, two of whom were of Jewish descent and nine of whom were of Anglo descent. Although one child was born in England, this family later immigrated to the United States (Kanner, 1943). During his practice in the United States, Kanner observed more children from Anglo families than from other races. Likewise, Asperger studied primarily Anglo children in Vienna, Austria. The race of these samples should not be surprising, given the proportion of Anglo children in these countries at this period of time. However, because the earliest identification of autism occurred with mainly children of Anglo descent, the generalizability of research findings for almost 60 years may be called into question relative to racial and cultural issues. One such query is the prevalence of autism among racial groups.

Prevalence of Autism within Multicultural Groups

Although most researchers ignore race, some have challenged the claim of universality of autism among races, reporting a low incidence of autism in many Latin American countries (e.g., Peru, Argentina, Brazil, and Venezuela) and in several developing countries such as Kenya, India, and Hungary (Sanua, 1981a, 1981b, 1984). Sanua hypothesized that autism is more prevalent in Western, highly technological countries, where the nuclear rather than the extended family is predominant. His conclusions and hypotheses, although based primarily on anecdotal evidence, purport psychopathological rather than biological etiologies of autism. Sanua’s work is notable and unique, however, because he focused his investigations on groups other than the highly studied Anglo.

Hypotheses such as this suggested by Sanua have diminished in the literature over the last 20 years, in large part because of the advances in the fields of neurology and genetics. Sanua’s assumptions, in light of genetic predisposition rather than psychogenicity, may eventually be empirically confirmed (i.e., lower prevalence among certain racial groups) or contradicted (i.e., higher prevalence among certain racial groups) if it is found that the genetics of autism are related to familial racial origin. If no relationships are found, then other factors must be investigated to explain some of the differences found between races and occurrence of autism as reported in the literature.

The literature that reports occurrence of autism among racial groups must be critically analyzed. Some studies are criticized for having small sample sizes, limiting the generalizability of the results. One way to reduce this threat to validity is to conduct a

comprehensive epidemiological study. Although not as precise as biological studies (e.g., studying differences in neurostructure, neurochemistry, physiognomy), epidemiological surveys provide a big picture of the reported incidence or prevalence of autism in a given community. A meta-analysis of 19 epidemiological surveys conducted in 10 countries over 30 years (from the first such study in 1966 until 1997) indicated prevalence rates of autism ranging from 0.7 to 15 per 10,000, with a median rate at 4.8 (Fombonne, 1998). Conspicuously absent in most of these surveys are analyses of data regarding the exact proportion of children with autism from immigrant families. Fombonne (1998) reports that among these surveys, only three provide sufficient data regarding the proportion of "immigrants."

The present status of the research regarding the association between race and autism is unconfirmed and conflicting. Of the research that accounts for cultural differences, most report "immigrant" status, with the intent to study first-degree families who have recently moved from one country to another, rather than to study families from minority races regardless of recent family origination. Most of these epidemiological surveys indicate a higher proportion of children with autism from immigrant families compared with the nonimmigrant population (Gillberg, Steffenburg, Börjesson, & Andersson, 1987; Gillberg, Steffenburg, & Schaumann, 1991; Goodman & Richards, 1995; Wing 1980). One study found significantly greater numbers of migrants than natives with autism (these individuals were not immigrants from other countries, but within-country migrants of whom all were from the same race except for one; Tanoue, Oda, Asano, & Kawashima, 1988), and another found no significant differences between immigrant and nonimmigrant status (Powell *et al.*, 2000). Because many epidemiological studies do not report or analyze data regarding racial or immigrant status of the population studied, conclusions are difficult to make in respect to over- or underrepresentation of autism across races. However, the majority of the current literature reports a higher prevalence of autism among immigrants.

Possible explanations for more reports of the increased prevalence of autism in children born to "exotic" immigrant parents have been noted: genetic disorders specific to the parents' homeland, higher rates of brain damage in developing countries, and increased intrauterine viral infections such as rubella among immigrant mothers who do not have viral antibodies to combat such infections (Gillberg *et al.*, 1987; Gillberg, Steffenburg, & Schaumann, 1991; Goodman & Richards, 1995).

Genetic disorders common to specific regions of the world have not been investigated in the etiology of autism. However, evidence is emerging that links genetic predisposition with environmental assaults such as infections as possible causative factors in autism. Recent evidence points to *HOXA1* as one of the many genes involved in the causation of autism. This gene is active in the brain stem when the first neurons are developing—approximately 20–24 days after conception—before many women know they are pregnant (Rodier, 2000). Intrauterine rubella has been a known causative factor in autism following an epidemic that swept the United States in 1964, with the prevalence rate in children so affected being 741 per 10,000 (Chess, 1971), astronomically higher than the typical rate worldwide, which ranges from 0.7 to 15 per 10,000 (Fombonne, 1998). Several questions should be investigated regarding how such infections, which are not eradicated even in Western countries, in isolation or combined with other causative factors magnify the occurrence of autism.

Is it possible that female immigrants with genetic liability for autism such as a variant allele of *HOXA1*, or those who have no maternal immunity and receive rubella vaccinations without the knowledge of their pregnancy, are at risk for having a child with autism? Or, conversely, might such vaccines during, or even up to, 3 months before pregnancy cause deviations associated with autism? No evidence has been found to directly relate maternal vaccinations around the time of conception to birth defects (Centers for Disease Control and Prevention, 1989); however, because many symptoms of autism are not recognizable until 18 months of age, such cases may be missed in the accounting of vaccine-related injury. The Centers for Disease Control and Prevention still contraindicate rubella vaccinations for immunodeficient or pregnant women to reduce the risk of damage to the fetus. Another question that may be asked is whether it is possible that because vaccinations are not required of visitors to any country (including the United States), viruses such as rubella are carried from countries where they are widespread (very few countries require rubella immunizations). The possible role of rubella in the causation of autism among immigrants warrants further investigation.

Although there are conflicting reports regarding the prevalence rates of autism among immigrants over the last 30 years, a more recent epidemiological study reported racial, rather than immigrant status, finding no significant differences for ethnicity (Fombonne, Simmons, Ford, Meltzer, & Goodman, 2001). This epidemiological survey differs from all others by

surveying a whole nation (United Kingdom), rather than a region, and by using a randomized, stratified sample of children, allowing greater generalizability of the results. Surveying more than 12,000 children, no differences were found for ethnicity regarding occurrence of pervasive developmental disorders, including autism. These results need to be considered in light of the nonparticipation of one-fifth of the sample. Higher rates of psychopathology are likely among nonrespondents (Fombonne, 1998; Fombonne *et al.*, 2001), and it is possible that nonnative English speakers or recent immigrants unknowledgeable about such surveys may also be a high proportion the group of nonrespondents.

The methodological differences found in surveys reporting racial differences or similarity in occurrence of autism warrant caution in their interpretation. Many of the methodological differences are found in the selection of the population or sample: racial groups, geographical location, diagnostic criteria, and recruiting methods.

First, the differences between immigration status and racial status should be noted when analyzing these data, for they may represent two separate groups. Also, the accuracy of racial identification is called into question. Parental place of birth is often used; however, this is an "imperfect and ambiguous marker for race, culture and ethnicity" (Goodman & Richards, 1995, p. 367). Future investigations should ascertain whether true differences exist in prevalence of autism between immigrants and racial status, and point to explanations for such differences, if they exist.

Second, prevalence data should be analyzed while considering rural and urban areas, as some evidence indicates differences in prevalence rates between minorities in such areas (Gillberg *et al.*, 1991). Variable migration patterns should also be considered while conducting such studies, as a large influx of immigrants in an area may artificially alter prevalence rates. Further, most epidemiological studies have been conducted in Western countries and cannot be generalized to other countries, particularly developing nations.

Third, racial prevalence rates should be interpreted with consideration of the diagnostic criteria used. Prevalence data should not be compared between studies using various editions of the *Diagnostic and Statistical Manual of Psychiatric Disorders* (DSM) and the *International Classification of Diseases*, as each edition describes a slightly different population. For example, the criteria of the DSM III-R tended to result in a high rate of false positives, particularly among those with severe mental retardation (Volkmar & Lloyd,

1998). When following the DSM III guidelines, the symptoms of children diagnosed with autism more closely resemble Kanner's original descriptions of the disorder, and stronger genetic correlations may be found using the DSM III than using DSM IV guidelines. Further, some studies report prevalence rates on autism only, while others include a wider range of autistic spectrum disorders. Unfortunately, many studies report no reliability data to substantiate the diagnoses of the children included in the sample or population (see Fombonne, 1998), and psychometric instruments used to determine the range of autistic spectrum disorders do not typically test for specific racial groups (Obiakor & Wilder, in press). Future studies should clearly report diagnostic procedures, including the types of pervasive developmental disorders studied, specific tools or guidelines used for diagnosis, and reliability measures.

Finally, methods by which agencies recruit families for study should be reported in detail, as some families from minority cultures may not readily participate because of language barriers, mistrust, fear, or misunderstanding. Resulting sample sizes should be large enough to statistically analyze the data and make valid conclusions. In light of the current discrepancies regarding race/immigrant status and occurrence of autism, and the methodological problems found in the literature, it is safe to concur with Fombonne (1998), who, following his meta-analysis of 19 epidemiological studies, concluded, "the association of immigrant status with autism remains therefore uncertain" (p. 59).

One example of the discrepancies in the occurrence of autism among races is found when analyzing data from the annual reporting of all children who are served under the Individuals with Disabilities Education Act of 1997 (IDEA '97) (United States Department of Education, 2002, 2001). These reports indicate the number and percentage of students served in various disability categories, and just recently these data have been presented according to racial categories. Both the 22nd and 23rd Annual Report to Congress on the Implementation of IDEA '97 indicated that an average of .08% of children aged 6–21 years in the United States and outlying areas (e.g., American Samoa, Guam, U.S. Virgin Islands) were served under the label of autism in 1998–1999, and .10% in 1999–2000. These averages are approximately twice the median rate of the previously mentioned epidemiological meta-analysis (.048%), falling midpoint of that reported range (Fombonne, 1998).

Interestingly, the rate of identification differs across racial categories. Students with autism who were

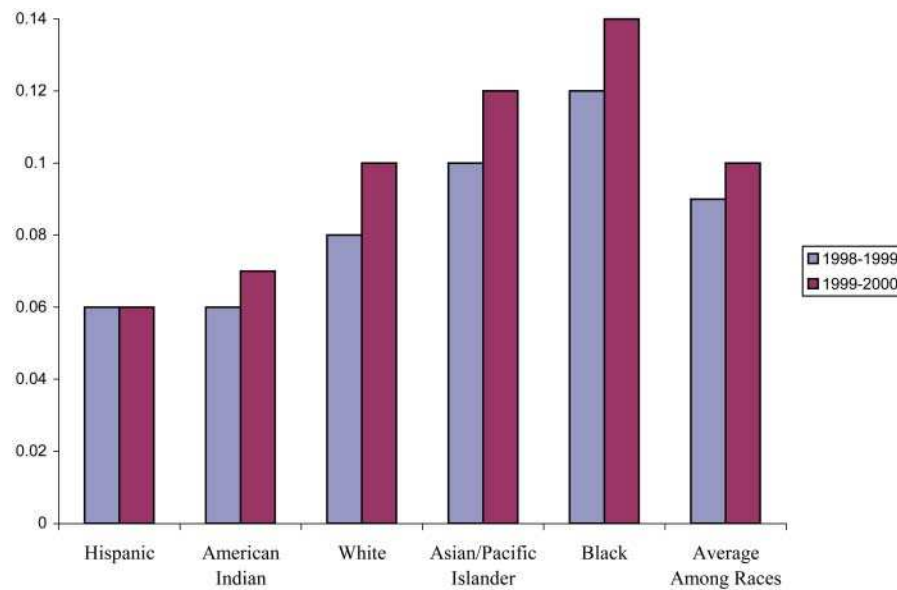


Fig. 1. Percentage (based on estimated resident population) of students with autism aged 6–21 years served under IDEA, Part B, during the 1998–1999 and 1999–2000 school years.

Black or Asian/Pacific Islander were being served under the label of autism at approximately twice the rate of students with autism who were American Indian/Alaskan or Hispanic (see Fig. 1; United States Department of Education, 2002, 2001).

Comparisons between racial groups of students with autism and students served under all 13 diagnostic IDEA '97 categories, including autism, also indicate racial disparities. For example, students who are Asian/Pacific Islanders are being served under the label of autism almost three times as often (4.63%, 4.77%) as those Asian/Pacific Islanders averaged across all disabilities (1.72%, 1.81%). However, the percentage of children with autism corresponds roughly with 1999 United States Census population estimates, with 4.0% of the population claiming Asian/Pacific Island descent (United States Census Bureau, 2001). Conversely, American Indian and Hispanic students with autism are served under the label of autism less frequently than students within their racial groups having any kind of disability, yet these proportions to the racial group as a whole are similar to, if slightly lower than, those reported in the census data. The racial groups with the largest numbers of students with disabilities, White and Black, have very little variation in the rates served over both reporting years. The IDEA '97 data from 1998–1999 and 1999–2000 are presented in a logarithmic chart to display differences within each reported race rather than between races (see Fig. 2).

As reported earlier, approximately one-tenth of 1% of the population of children in the United States have been identified with autism. The information in Table I was compiled to determine to what extent this percentage varies across racial groups. The total number of children aged 5–19 years for each racial group is based on the U.S. Census report for the year 2000. The percentage of children classified with autism is based on data reported in IDEA. Because the IDEA data reported the number of children with autism ages 6–21 years (a 16-year age span) and the U.S. Census data reported the number of children in racial categories for ages 5–19 years (a 15-year age span), to make the data comparable, it was necessary to multiply the IDEA autism data by 15/16ths (.9375) in each racial category. The percentages reported in Table I reflect this transformation. The χ^2 exceeded the critical value at the .0001 level, clearly indicating a dependent relationship between race and students identified with autism under IDEA. The cell entries in Table I show that the percentage of Black (0.13%) and Asian/Pacific (0.13%) children identified with autism is disproportionately high and that the percentage of Native American (0.05%) and Hispanic (0.06%) children identified with autism is disproportionately low.

In addition to variability between racial groups, regional variability was also found. It is well known that individual states exert autonomy in classifying and serving students with disabilities, which could explain

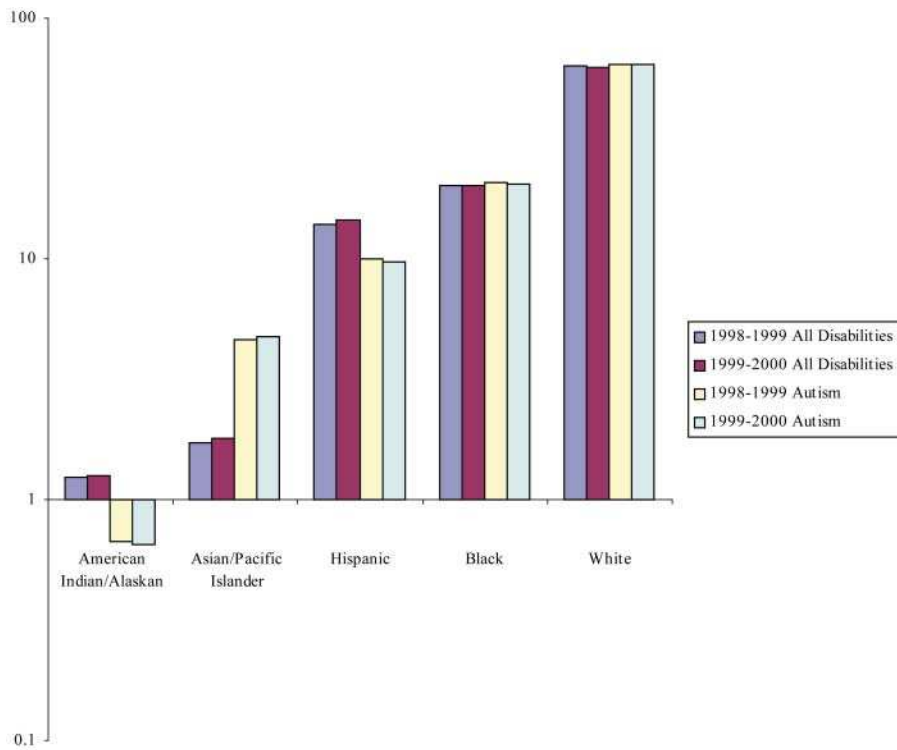


Fig. 2. Percentage of students with autism aged 6–21 served under IDEA, Part B, during the 1998–1999 and 1999–2000 school years, by racial category.

some of the regional variability found in the following data: In 1998–1999, Oregon reported .26% of the estimated resident population as having autism, whereas American Samoa reported only .01%. Similar extremes are found in the 1999–2000 data. Without additional information regarding how these data were obtained and what they actually represent, no firm conclusions can be made. However, some critical questions surface regarding the discrepancies in numbers of minority students who are being served under the IDEA '97 label

of autism. Are there actual differences in the prevalence of autism across races? How are individuals with autism being categorized ethnically (e.g., Asians and Pacific Islanders are considered as one group under IDEA '97)? Are families from some minority cultures reluctant to have their children identified as having autism or identified as having a disability at all? Do families of some cultural or socioeconomic groups advocate for a diagnosis of autism rather than mental retardation to avoid a stigma? Are diagnosticians more

Table I. Incidence of Autism among U.S. Children (ages 5–19 years) by Racial Group

Racial group	Percentage classified with autism (IDEA data)	Percentage not classified with autism (U.S. Census data)	Total
Caucasian	0.09%	99.91%	42,434,668
Black	0.13%	99.87%	9,256,595
Hispanic	0.06%	99.94%	9,958,738
Asian/Pacific	0.13%	99.95%	2,221,175
Native American	0.05%	99.95%	717,035
Total	0.09%	99.91%	64,588,211

Note: $\chi^2 = 3,207.74$. Degrees of freedom = 4. $p < .0001$

likely to give the label of autism to children from some minority cultures than others? Are behaviors of some children with autism not considered to be problematic by people of some cultures (e.g., avoiding eye contact or displaying hyperactivity or aggressive behaviors), resulting in the child not being referred? Are children with autism from different racial origins being served under different classifications (e.g., mental retardation, developmental delay, multiple disabilities, emotional disorder) rather than under the classification of autism?

Clearly, attention to racial classification of individuals with autism, whether they live in Western countries or not, has been largely ignored, and current research has not fully investigated the relationships, if any, between genetic or biological etiologies of autism and race. One possible explanation for the discrepancies found in the existing literature is the cultural context in which screening, diagnosis, and treatment take place. Because the most basic unit of cultural identity is the family, the existing data must be interpreted while understanding families' perceptions of disability and access to governmental or medical services.

MULTICULTURAL FAMILY ADAPTATION TO AUTISM

The literature is replete with reports regarding how families adapt to raising a child with developmental disabilities (Bennett, DeLuca, & Allen, 1996; National Research Council, 2001; Olsen *et al.*, 1999; Seligman, 1999), yet few distinguish autism from other developmental disabilities. It is crucial for autism to be isolated as its own group within the family adaptation research, as it is known to be a more debilitating disorder than many of the others (Randall & Parker, 1999), with the possibility of having more profound effects on family members' adaptation.

Family adaptation researchers are just beginning to recognize race as a separate variable for exploration. The Resiliency Model of Family Stress, Adjustment, and Adaptation was developed to address issues of ethnicity and culture in the adaptation of multicultural families with low socioeconomic status. The Resiliency Model is an extension of earlier models that were based primarily on the study of Caucasian, middle-class families. It "emphasizes the family's appraisal processes involving ethnicity and culture that facilitate the family's ability to institute new patterns of functioning and achieve harmony while promoting the well-being and development of its members" (McCubbin, McCubbin, Thompson, & Thompson, 1998, p. 5). For a full

discussion of the Resiliency Model, readers are referred to the 1998 book, *Resiliency in Native American and Immigrant Families* by McCubbin, Thompson, Thompson, and Fromer.

The Resiliency Model comprises two phases: adjustment and adaptation. Each phase contains many interacting components that shape the processes and outcomes for families. In short, family adjustment is determined by the interaction between the stressor and the family's vulnerability, patterns of functioning, resources, appraisal of the stressor, and problem-solving and coping strategies. Family adaptation to a stressor is determined by the interaction between the pileup of demands created by the situation, the family's resources, appraisal of the situation, paradigms, sense of coherence, schema, and problem-solving and coping repertoire. Two interacting components are particularly pertinent to the current discussion because of possible cultural differences in how families appraise disability and how they access social support. The paucity of research linking race, family adaptation, and autism necessitates the discussion of developmental disabilities in general and, when possible, autism in particular.

Family Appraisal of the Stressor

A "stressor" is a component of the adjustment phase of the Resiliency Model, and it has been identified as a "demand placed on the family that produces, or has the potential of producing, changes in the family system" (McCubbin *et al.*, 1998, p. 6). Stressors are not necessarily negative life events, but within the Western context of disability, they are often regarded as such (Connors & Donnellan, 1998). Families raising children with autism may be affected differently by the stressor of receiving the child's diagnosis than families raising children with other developmental disabilities. Because many children with autism are born without any indication of behavioral, physical, or intellectual abnormalities, their parents have "normal" expectations for them. Unlike parents who are informed of their child's disability near the time of the child's birth (e.g., Down syndrome and cerebral palsy), parents of children with autism deal with the stressor of losing their previously "normal" child.

The severity of the stressor is determined by the degree to which it "threatens the stability of the family unit, disrupts the functioning of the family unit, or places significant demands on and depletion of the family's resources and capabilities" (McCubbin *et al.*, 1998, p. 6). It is possible that "there are few developmental disorders of childhood that create such complex

stressors for families as autism" (Randall & Parker, 1999, p. 1). These stressors are complex not only because the disability hidden behind a normal or even "beautiful" appearance but because behavioral manifestations may be physically and emotionally taxing on the family, diagnosis may be difficult to obtain, and coordination of services is often fragmented (see Randall & Parker, 1999).

Obviously, when the child's symptoms of autism are extreme, a high level of stress is felt by the family (Bristol, 1984) and the parents are likely to appraise their situation earlier than if the child's symptoms are mild. Appraisal is defined as "the family's definition of the seriousness of a stressor and its related hardships" (McCubbin *et al.*, 1998, p. 6). Members of various cultures may appraise the stressor of autism differently, and these appraisals may be considered to be negative or positive.

A negative appraisal after learning that a child is not developing normally follows the medical model of diagnosing and treating the malady. The child is seen as "imperfect" or "defective," and needing to be "fixed." Other negative appraisals consider the child to be a burden or a threat to the family (Rogers-Dulan & Blacher, 1995).

Negative appraisal may be the result of the family's interpretation of the etiology of the child's disabilities. Some Mojaves believe that mental retardation and other birth defects are caused by misdeeds of parents (Green, Sack, & Pabrum, 1981), whereas some Navajos are reported to believe that the child's autism may be the fault of the parents or a result of witchcraft. Beliefs that the mother may have seen a dead animal while pregnant or that the child was conceived by a man other than the mother's husband have also been reported (Connors & Donnellan, 1998). Young Latino mothers who have immigrated to the United States from Puerto Rico and Mexico report that older generations, "ignorant people," and people from other places still believe mental retardation or developmental disability is a punishment for the sins of the parents (Skinner, Bailey, Correa, & Rodriguez, 1999).

Positive appraisals also are the result of how families interpret etiology of disability. Some young Latino mothers accept the child as a blessing or gift from God, feeling that they have been found worthy of such a child or that they have been given this challenge to become a better person (Skinner *et al.*, 1999). The spiritual and religious paradigm of these mothers, heavily influenced by Catholicism, may have strongly affected their appraisal of their children with disabilities. Much like Mary, Saint and Sufferer, these Latino mothers see

themselves as dedicated, sacrificing, and suffering, but good mothers of their children.

African American families whose religions strongly influence their family paradigms may appraise disability positively. "The optimism and belief that all children are important typifies African American culture and is reflected in family functions and reinforced in church and religious beliefs" (Rogers-Dulan & Blacher, 1995, p. 234).

The family paradigm within the Native Hawaiian culture regarding the spiritual orientation toward life may facilitate individual families' appraisal that having a child with autism is "normal" and that this child is a valued member of the community, regardless of his or her abilities. Similarly, the paradigm of some Native American cultures emphasize the functional abilities, albeit minute, of the children, rather than on their disabilities (McCubbin *et al.*, 1998). Natives of India may be more tolerant of differences in their children. They may not be overly concerned about language deficits, believing that Indian boys speak later than other children (Daley & Sigman, 2002). The Native American/Native Hawaiian assimilation of individuals with disabilities into mainstream culture is reflected in the absence of native language "labels" or "classifications" for disabilities such as autism. Rather, descriptive statements are commonly used such as those by some Navajos including, "she runs away," or "he gets excited," or "he's in his own world" (Connors & Donnellan, 1998, p. 171).

As it appears, the literature provides some answers regarding appraisal of developmental disabilities within some cultures; however, similar reports are not readily available regarding familial appraisal of autism within a cultural context. Because appraisal of a stressor is related to social support and resulting adaptation (McCubbin *et al.*, 1998), research in this area is warranted. Families who experience high levels of stress in raising a child with autism may seek and need more social support than those who experience lower levels of stress.

Social Support

Social support is a component of the adaptation phase of the Resiliency Model and is defined as the community supports and resources "that the family may use to cope with a stressor situation" (McCubbin *et al.*, 1998, p. 20). Social support may include people, such as family and friends; organizations, such as schools, churches, parent and sibling support groups; and medical services. Social support, which has been studied

extensively in the literature, appears to mediate the effects of the stressor on the health of the family (see McCubbin *et al.*, 1998).

Family Support

The strong familial support needed to raise a child with developmental disabilities is found in many cultures. Native Hawaiians share a common concern for the well-being of all individuals in the tribal structure, which encompasses the immediate and extended family (McCubbin *et al.*, 1998). Similarly, the foundation of the family structure in Filipino American families is built on cooperation and family support and allegiance, where individual desires are sacrificed for the benefit of the family (McCubbin *et al.*, 1998).

Many individuals within the African American culture perceive care-giving for a dependent member as a responsibility to be shared among siblings and extended family members (Pruchno, Patrick, & Burant, 1997). The paucity of adaptation research with African American families who have a member with a disability (Rogers-Dulan & Blacher, 1995) is striking; however, such research on autism is even more rare.

The concept of "familismo" in Hispanic families relates to strong family cohesion. This familial cohesion may circumvent the use of professional services if family values conflict with standards of the majority culture (Blacher, Lopez, Shapiro, & Fusco, 1997). When Latino mothers of children with severe disabilities believe in their spiritual role as "sacrificing mothers," and they receive strong support from their extended family, they may take upon themselves the responsibility of raising their child with little organizational support (Bailey, Skinner, Rodriguez, Gut, & Correa, 1999; Skinner *et al.*, 1999).

Organizational Support

Reliance on organizational support varies according to many factors, including the amount of familial support received and familiarity with the majority culture. Latinos have been reported to have a lower probability of receiving services than African American families who have children with disabilities, and the predicting factor is not socioeconomic status, but familiarity with the majority culture (Bailey *et al.*, 1999). According to the 22nd and 23rd Annual Report to Congress cited earlier (United States Department of Education, 2002, 2001), Hispanic students with autism are served under this label approximately half as often as students with autism who are Black or Asian/Pacific

Islander. It appears that for cultural or other reasons, the population of Hispanic students with autism is not being served in ways that other children are being served. Given the reported rate of 40% single-parenthood in Latino families with a child with mental retardation, along with twice as much depression as other population estimates (Blacher *et al.*, 1997), it appears that the current social support system may be failing to meet some critical needs of these families.

Organizational support is unable to be of value to families that do not access the services such organizations provide. Highly discrepant rates of identification of multicultural children with autism may be related to the stigma that is attached to receiving a diagnosis. For example, some South Asian families may not refer their children for services, especially if their child is a girl, for fear that they may not be able to arrange a marriage (Raghavan, Weisner, & Patel, 1999). This appears not to be a factor in the case of autism in the United States, as Asian Americans with autism are served educationally at a rate similar to their proportion in the general population.

Fear of stigma has also been reported in African American families (Pruchno *et al.*, 1997), who tend to access services provided by professional organizations less frequently than the majority culture (see Pruchno *et al.*, 1997), and only after relying on family, friends, religion, and church support (Rogers-Dulan & Blacher, 1995). However, their caregiver burden and level of stress are less than those of Whites, and their satisfaction greater, while caring for children with developmental disabilities (see Pruchno *et al.*, 1997; Rogers-Dulan & Blacher, 1995).

A review of the literature yields little information regarding how multicultural families appraise their family situation when raising a child with autism, and how such families gain support. Some hypotheses may be made, gleaned information in these areas in relation to raising a child with another developmental disability. For example, it can be hypothesized that the appraisal of autism varies between racial groups and is likely to be more extreme than those reporting their perceptions of raising a child with milder disabilities. It may also be hypothesized that because the challenges of autism are so intense and enduring, families from various cultures may access social support more frequently than families raising children with other disabilities. However, because these hypotheses have not been examined for families raising children with autism, it is critical that ongoing research address these issues. When professionals in the field of autism ascertain how families from various cultures appraise

their children with autism and understand how they perceive their need for and access to social support, more effective treatment and education of multicultural students with autism may occur.

CONCLUSIONS AND IMPLICATIONS

Professionals who work with multicultural students with autism and their families should be concerned about the relative paucity of research specific to the challenges they face. Published research often drives what services should be available to individuals with autism. To know which interventions work most effectively for multicultural students with autism, professionals must first need to be certain they are properly classified. However, because the majority of special education research has been conducted with populations that are predominantly Anglo, and because most research has failed to identify students with autism according to culture, limited data are available to help researchers and practitioners ensure that appropriate services are provided to these students. Such limitations may reflect a lack of awareness of cultural issues (Wilder, Jackson, & Smith, 2001) and of ways that those issues affect students with autism and their families. In addition, such missing information clearly compromises the quality of the field of professionals who work with multicultural students with autism.

This article has perhaps raised more questions than it has answered, which is not unusual for the initial examination of an issue like multicultural issues in autism. It was not our intention to solve the problems surrounding this issue but, rather, to examine the current literature that affects multicultural students with autism, their families, and the professionals who work with them. Two main issues were addressed: the prevalence of autism across races, and how families of various cultures adapt to raising a child with autism. In this regard, we were surprised to see the differences in prevalence rates across races for autism, and we believe that further investigation should provide answers regarding these disparities. We were discouraged that little information regarding how multicultural families adapt to raising a child with autism was available. This issue warrants further investigation.

Evidence indicates that multicultural students have more difficulty with the academic and behavioral customs of the school culture than do students from the dominant culture. Our examination of multicultural perspectives in autism demonstrates that ethnic diversity may affect the services available for students with

autism. Students with multicultural backgrounds and autism are challenged on at least four dimensions: communication, social skills, behavioral repertoires, and culture. The professional literature continues to address the first three; it is imperative to now consider the third: multicultural issues.

REFERENCES

- American Psychiatric Association. (1994). *Diagnostic and statistical manual of mental disorders*. (4th ed.). Washington, DC: Author.
- Autism Society of America. (2000). What is autism? *Advocate: The newsletter of the Autism Society of America*, 33, 3.
- Bailey, D. B., Skinner, D., Rodriguez, P., Gut, D., & Correa, V. (1999). Awareness, use, and satisfaction with services for Latino parents of young children with disabilities. *Exceptional Children*, 65, 367–381.
- Bennett, T., DeLuca, D. A., & Allen, R. W. (1996). Families of children with disabilities: Positive adaptation across the lifecycle. *Social Work in Education*, 18, 31–44.
- Bettelheim, B. (1967). *The empty fortress: Infantile autism and the birth of the self*. New York: The Free Press.
- Blacher, J., Lopez, S., Shapiro, J., & Fusco, J. (1997). Contributions to depression in Latino mothers with and without children with retardation: Implications for caregiving. *Family Relations*, 46, 325–334.
- Bristol, M. M. (1984). Family resources and successful adaptation to autistic children. In E. Schopler & G. B. Mesibov (Eds.), *The effects of autism on the family* (pp. 289–310). New York: Plenum Press.
- Centers for Disease Control and Prevention, Advisory Committee on Immunization Practices. (1989). Current trends: Rubella vaccination during pregnancy—United States, 1971–1988. *Morbidity and Mortality Weekly Report*, 38, 289–293.
- Chess, S. (1971). Autism in children with congenital rubella. *Journal of Autism and Childhood Schizophrenia*, 1, 33–47.
- Connors, J. L., & Donnellan, A. M. (1998). Walk in beauty: Western perspectives on disability and Navajo family/cultural resilience. In H. I. McCubbin, E. A. Thompson, A. I. Thompson, & J. E. Fromer (Eds.), *Resiliency in Native American and immigrant families* (pp. 159–182). Thousand Oaks, CA: Sage.
- Daley, T. C., & Sigman, M. D. (2002). Diagnostic conceptualization of autism among Indian psychiatrists, psychologists, and pediatricians. *Journal of Autism and Developmental Disorders*, 32, 12–23.
- Fombonne, E. (1998). Epidemiological surveys of autism. In F. R. Volkmar (Ed.), *Autism and pervasive developmental disorders* (pp. 32–63). Cambridge: Cambridge University Press.
- Fombonne, E., Simmons, H., Ford, T., Meltzer, H., & Goodman, R. (2001). Prevalence of developmental disorders in the British nationwide survey of child mental health. *Journal of the American Academy of Child and Adolescent Psychiatry*, 40, 820–827.
- Gillberg, C., Steffenburg, G., Börjesson, B., Andersson, L. (1987). Infantile autism in children with immigrant parents: A population-based study from Göteborg, Sweden. *British Journal of Psychiatry*, 150, 856–858.
- Gillberg, C., Steffenburg, S., & Schaumann, H. (1991). Is autism more common now than ten years ago? *British Journal of Psychiatry*, 158, 403–409.
- Gleberzon, B. J., & Rosenberg-Gleberzon, A. L. (2001). On autism: Its prevalence, diagnosis, causes, and treatment. *Topics in Clinical Chiropractic*, 8, 42–57.
- Goodman, R., & Richards, H. (1995). Child and adolescent psychiatric presentations of second-generation Afro-Caribbeans in Britain. *British Journal of Psychiatry*, 167, 362–369.

- Gonzalez, V., Brusca-Vega, R., & Yawkey, T. (1997). *Assessment and instruction of culturally and linguistically diverse students with or at-risk of learning problems*. Boston: Allyn and Bacon.
- Green, B. E., Sack, W. H., & Pabrum, A. (1981). A review of child psychiatric epidemiology with special reference to American Indian and Alaska Native children. *White Cloud Journal*, 2, 22–36.
- Kanner, L. (1943). Autistic disturbances of affective contact. *Nervous Child*, 2, 217–250.
- Kanner, L. (1971). Follow-up study of eleven autistic children originally reported in 1943. *Journal of Autism and Childhood Schizophrenia*, 1, 119–145.
- McCubbin, H. I., McCubbin, M. A., Thompson, A. I., & Thompson, E. A. (1998). Resiliency in ethnic families: A conceptual model for predicting family adjustment and adaptation. In H. I. McCubbin, E. A. Thompson, A. I. Thompson, & J. E. Fromer (Eds.), *Resiliency in Native American and immigrant families* (pp. 3–48). Thousand Oaks, CA: Sage.
- National Research Council. (2001). *Educating children with autism*. Committee on Educational Interventions for Children with Autism. Division of Behavioral and Social Sciences and Education. Washington, DC: National Academy Press.
- National Research Council. (2001). *Educating children with autism*. Committee on Educational Interventions for Children with Autism. Division of Behavioral and Social Sciences and Education. Washington, DC: National Academy Press.
- Obiakor, F. E. (1994). *The eight step multicultural approach: Learning and teaching with a smile*. Dubuque, IA: Kendall/Hunt.
- Obiakor, F. E. (1999). Teacher expectations of minority exceptional learners: Impact on “accuracy” of self-concepts. *Exceptional Children*, 66, 39–53.
- Obiakor, F. E. (2001). *It even happens in “good” schools: Responding to cultural diversity in today’s classrooms*. Thousand Oaks, CA: Corwin Press.
- Obiakor, F. E., & Wilder, L. K. (In press). Issues, practices, and solutions in transitioning ethnically diverse learners with emotional/behavioral disorders. In E. Cheney (Ed.), *Transition of students with emotional or behavioral disorders from school to community: Current approaches for positive outcomes (CCBD monograph)*. Arlington, VA: Council for Children with Behavioral Disorders.
- Olsen, S., Marshall, E. S., Mandleco, B., Allred, K. W., Dyches, T. T., & Sansom, N. (1999). Support, communication, and hardiness in families with children with disabilities. *Journal of Family Nursing*, 5, 275–291.
- O’Shea, D. J., O’Shea, L. J., Algozzine, R., & Hammitte, D. J. (2001). *Families and teachers of individuals with disabilities*. Boston: Allyn and Bacon.
- Powell, J., Edwards, A., Edwards, M., Pandit, B. S., Sungum-Paliwal, S. R., & Whitehouse, B. S. (2000). Changes in the incidence of childhood autism and other autistic spectrum disorders in preschool children from two areas of the West Midlands, U.K. *Developmental Medicine and Child Neurology*, 42, 624–628.
- Prizant, B. (1996). Brief Report: Communication, language, social, & emotional development. *Journal of Autism and Developmental Disorders*, 26, 173–178.
- Pruchno, R., Patrick, J. H., & Burant, C. J. (1997). African American and White mothers of adults with chronic disabilities: Caregiving burden and satisfaction. *Family Relations*, 46, 335–346.
- Raghavan, C., Weisner, T. S., & Patel, D. (1999). The adaptive project of parenting: South Asian families with children with developmental delays. *Education and Training in Mental Retardation and Developmental Disabilities*, 34, 281–292.
- Randall, P., & Parker, J. (1999). *Supporting the families of children with autism*. New York: Wiley.
- Rimland, B. P. (1964). *Infantile autism*. New York: Appleton-Century-Crofts.
- Rodier, P. (2000). The early origins of autism. *Scientific American*, 282, 56–63.
- Rogers-Dulan, J., & Blacher, J. (1995). African American families, religion, and disability: A conceptual framework. *Mental Retardation*, 33, 226–238.
- Sanua, V. D. (1981a). Autism, childhood schizophrenia and culture: A critical review of the literature. *Transcultural Psychiatric Research Review*, 18, 165–181.
- Sanua, V. D. (1981b). Cultural changes and psychopathology in children: With special reference to infantile autism. *Acta Paedopsychiat*, 47, 133–142.
- Sanua, V. D. (1984). Is infantile autism a universal phenomenon? An open question. *International Journal of Social Psychiatry*, 30, 163–177.
- Seligman, M. (1999). Childhood disability and the family. In V. L. Schwane & D. H. Saklofske (Eds.), *Handbook of psychosocial characteristics of exceptional children* (pp. 111–131). New York: Plenum.
- Skinner, D., Bailey, D. B., Correa, V., & Rodriguez, P. (1999). Narrating self and disability: Latino mothers’ construction of identities vis-a-vis their child with special needs. *Exceptional Children*, 65, 481–495.
- Szatmari, P., & Jones, M. B. (1998). Genetic epidemiology of autism and other pervasive developmental disorders. In F. R. Volkmar (Ed.), *Autism and Pervasive Developmental Disorders* (pp. 109–129). Cambridge: Cambridge University Press.
- Tanguay, P. E. (2000). Pervasive developmental disorders: A 10-year review. *Journal of the American Academy of Child and Adolescent Psychiatry*, 39, 1079–1095.
- Tanoue, Y., Oda, S., Asano, F., & Kawashima, K. (1988). Epidemiology of infantile autism in Southern Ibaraki, Japan: Differences in prevalence in birth cohorts. *Journal of Autism and Developmental Disabilities*, 18, 155–166.
- United States Census Bureau. (2001). Resident population estimates of the United States by Sex, Race, and Hispanic Origin: April 1, 1990 to July 1, 1999, with short-term prediction to November 1, 2000. Retrieved June 6, 2002, from <http://eire.census.gov/popest/archives/national/nation3/intfile3-1.txt>
- United States Department of Education (2001). *Twenty-second annual report to Congress on the implementation of the Individuals with Disabilities Education Act*. Washington, DC: Author.
- United States Department of Education (2002). *Twenty-third annual report to Congress on the implementation of the Individuals with Disabilities Education Act*. Washington, DC: Author.
- Utley, C. A., & Obiakor, F. E. (2001). *Special education, multicultural education, and school reform: Components of quality for learners with mild disabilities*. Springfield, IL: Charles C. Thomas.
- Volkmar, F. R., & Lloyd, C. (1998). Diagnosis and definition of autism and other pervasive developmental disorders. In F. R. Volkmar (Ed.), *Autism and pervasive developmental disorders* (pp. 1–31). Cambridge: Cambridge University Press.
- Wilder, L. K., Jackson, A. P., & Smith, T. B. (2001). Secondary transition of multicultural learners: Lessons from the Navajo Native American experience. *Preventing School Failure*, 45, 119–124.
- Wing, L. (1980). Childhood autism and social class: A question of selection? *British Journal of Psychiatry*, 137, 410–417.
- Wing, L., & Attwood, A. (1987). Syndromes of autism and atypical development. In D. J. Cohen & A. M. Donnellan (Eds.), *Handbook of autism and pervasive developmental disorders* (pp. 3–19). New York: Wiley.
- Ysseldyke, J. E., Algozzine, B., & Thurlow, M. L. (2000). *Critical issues in special education*. (3rd ed.). Boston: Houghton Mifflin.