

# Racial Disparities in the Age of Diagnosis of Autism Spectrum Disorder: Examining Factors That May Contribute to Delayed Diagnosis in African-American Children

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## Abstract

*Autism is a neurobiological disorder that affects approximately 1 child in 150 and occurs equally across demographic groups. While there is a similar rate of occurrence among African-American children and Caucasian children, there is a disparity in the age of diagnosis between the two groups. African-American children are likely to be diagnosed 1.5 years later than Caucasian children. Because it is critical to the long-term outcomes of children with autism to be diagnosed as early as possible and to participate in interventions, it is imperative that the reasons for this later diagnosis of African-American children be understood and action be taken to eliminate this disparity. This paper will identify possible factors that may contribute to the disparity in age of diagnosis between African-American and Caucasian children, make recommendations for intervention and policy, and discuss implications for social workers.*

## Introduction

A recent study released by the Centers for Disease Control and Prevention calls Autism Spectrum Disorder (ASD) a continuing public health concern (Centers for Disease Control and Prevention, 2007a). Autism, a neurobiological disorder of development, has been described as a “national crisis” and is the fastest growing disability in the United States, with approximately one child diagnosed with autism every twenty minutes (Autism Speaks, 2007). Rates of autism have increased from 1 child in every 166 to 1 child in every 150 as reported in January 2004 (Centers for Disease Control and Prevention, 2007b).

Although autism has a similar prevalence rate for African-American and Caucasian children, a disparity in the age of diagnosis has been identified for these two populations (Mandell, Listerud, Levy, & Pinto-Martin, 2002). It is important that the reasons for this disparity are identified so children can begin necessary interventions as soon as possible. This paper will examine factors that may contribute to late diagnosis in African-American children, make recommendations for intervention and policy, and discuss implications for social workers.

## Prevalence and Diagnosis of Autism

Autism falls under the umbrella of Pervasive

Developmental Disorders (PDD) which includes conditions such as Rett’s Disorder, Childhood Disintegrative Disorder, and Asperger’s Disorder. Pervasive Developmental Disorders share the characteristics of a delay in the development of social skills, language and communication, and behavioral repertoire. According to the American Psychiatric Association (2000), autism is the most well known of the PDD’s and is characterized by sustained impairment in comprehending and responding to social cues, aberrant language development and usage, and restricted, stereotypical behavioral patterns. The American Academy of Pediatrics (2001) writes:

Children with autism demonstrate behaviors and skills that span a broad continuum extending from very mild peculiarities to severe developmental challenges. It is now known to be a very heterogeneous disorder, with milder forms being more common than the classic form. Although clinical patterns vary depending on severity, all children with autism demonstrate some degree of qualitative impairment in reciprocal social interaction, qualitative impairment of communication, and restricted, repetitive, and stereotypic patterns of behaviors, interests, and activities. Because of qualitative and quantitative variations in symptoms, autism is often referred to as autistic spectrum disorder (ASD) (p. 1221).

Autism knows no racial, ethnic, or social boundaries. “Family income, lifestyle, and educational levels do not affect the chance of autism’s occurrence” (Dyches, Wilder, Sudweeks, Obiakor, & Algozzine, 2004, p. 212); however, a difference in the occurrence of autism between genders has been found, with autism affecting one girl for every four boys. A study on the prevalence of autism found that prevalence rates were remarkably similar when examined by race, but a predominance of males was found in each racial category (Yeargin-Allsop et al., 2003). Because of the racial homogeneity of the children included in published studies, little has been done to specifically examine the prevalence of autism by race. In one study of 987 Caucasian and African-American children, it was found that the prevalence of autism did not vary by race, even within race and sex subgroups (Yeargin-Allsopp, Rice, Karapurkar, Doernberg, Boyle &

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Murphy, 2003).

Autism is believed to have a genetic component as the underlying cause of the disorder with possible environmental triggers, but its exact etiology is not known. Collins, Ma, Whitehead, Martin, Wright, Abramson, et al. (2006) found that the malfunctioning of two receptor genes, GABRB1 and GABRA4, contribute to autism susceptibility among African-Americans and Caucasians. Although the susceptibility is the same, evidence suggests that some autistic characteristics, such as “indicators of language development, may be more severe in African-Americans, compared to non-Hispanic Caucasians” (Collins et al., 2006, p. 168). Researchers have also looked at possible neurological, environmental, and immunization links, but nothing conclusive has been found to cause autism (American Academy of Pediatrics, 2001).

Although much is still unknown about the cause(s) of autism, a body of knowledge has been accumulating on the diagnosis and treatment of autism. Autism can be diagnosed as early as 18 months of age. A child may exhibit autistic behaviors in infancy or develop normally for a year or more and then begin to exhibit autistic behaviors. Autism typically comes to the attention of a pediatrician from parents sharing their concerns and/or observing delays in the child meeting developmental milestones. A screening tool may be used and further testing can be done if autism is suspected. The process of diagnosing ASD entails a comprehensive evaluation by a medical team, including a psychologist, neurologist, psychiatrist, and speech, developmental, and occupational therapists. The process of identifying and diagnosing children early is critical as “early diagnosis resulting in early, appropriate, and consistent intervention has . . . been shown to be associated with improved long-term outcomes” (American Academy of Pediatrics, 2001, p. 1223).

Once children have been appropriately diagnosed with ASD, they and their families can have access to and receive appropriate services and interventions to improve outcomes for children and to help families cope with the disabling effects of autism, which can be a constant source of stress on a family system (Mandell et al., 2002; Higgins, Bailey, & Pearce, 2005). Beginning at the age of three, children diagnosed with ASD are covered under the Individuals with Disabilities Education Act (IDEA) and are eligible to receive services through the public education system for special education and related services (Mandell et al., 2002). Children under the age of three are eligible for the Early Intervention Program, which identifies children with developmental delays and works with them to improve their skills in the areas where they are deficient. Other interventions may be in the areas

of speech, communication, or sensory processing. Services received in Early Intervention can be continued in the public school system.

Despite the increasing ability to identify the early signs of ASD, knowledge of the benefits of identifying and treating children with ASD early, and the general growing awareness of this set of disorders, children with ASD often do not receive a diagnosis until they enter elementary school (Mandell, Novak, & Zubritsky, 2005). Although no significant difference in prevalence of autism among African-Americans and Caucasian children has been found, a study of 406 Medicaid-eligible children found that African-American children with ASD received a diagnosis an average of 1.5 years later than Caucasian children did (Mandell et al., 2002). In this study, Caucasian children received a diagnosis at an average of 6.3 years of age and African-American children at an average of 7.9 years of age (Mandell et al., 2002). Although there may be several reasons for the delay in diagnosis of ASD in children in the general population, the disparity in the age of diagnosis between African-American and Caucasian children is disturbing and necessitates further examination.

### **Factors Contributing to the Disparity in Age of Diagnosis**

There are a number of factors that may contribute to African-American children being diagnosed with ASD 1.5 years later than Caucasian children. Misdiagnosis, pediatrician-parent relationships, access to health care, and biases of healthcare providers have been studied and discussed in the literature as factors contributing to the delay in diagnosis of African-American children.

The misdiagnosis of autism seems to be a factor contributing to a delay in the diagnosis of ASD in general, but particularly to the later diagnosis of ASD in African-American children. Symptoms common to autism, such as delayed speech, poor response to others, and behavioral difficulties, can lead to a misdiagnosis of language impairment or Attention Deficit/Hyperactivity Disorder (ADHD). In older children, repetitive behavior may steer clinicians toward a diagnosis of Obsessive-Compulsive Disorder and non-compliance related to resistance to change may lead clinicians to diagnose Oppositional Defiant Disorder (Mandell, Ittenbach, Levy, & Pinto-Martin, 2006). Mandell et al. (2006) examined the disparities in the diagnosis of children with autism using insurance claims of 406 Medicaid-eligible children, including 242 African-American, 118 Caucasian, 33 Latino, and 13 children falling into other categories. They found that African-American children were three times more likely than Caucasian children to receive another

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diagnosis first and were 2.6 times less likely than Caucasian children to receive an autism diagnosis on their first specialty care visit (Mandell et al., 2006). Once African-American children entered treatment, they required three times the number of visits over a period three times as long as Caucasian children before receiving an autistic disorder diagnosis (Mandell et al., 2006).

African-American children were also 5.1 times more likely than Caucasian children to receive a diagnosis of Adjustment Disorder than of ADHD, and 2.4 times more likely to receive a diagnosis of Conduct Disorder than of ADHD (Mandell et al., 2006). Diagnosing children with Adjustment Disorder may allow clinicians more time to evaluate a child, enable reimbursement for services and the opportunity to see the child again. Clinicians may diagnose Conduct Disorder when they interpret the child's behavior as disruptive or aggressive or see other characteristics associated with Conduct Disorder manifested in the child's behavior (Mandell et al., 2006). Mandell et al. (2006) state,

...the more frequent diagnosis of Conduct Disorder among African-Americans may be associated with clinicians' erroneous beliefs regarding the higher prevalence of Conduct Disorder among African-American children, while the more frequent diagnosing of Adjustment Disorder among all groups other than Caucasian children may be the result of clinicians' misinterpretations of parental concerns (p. 1483).

The quality and continuity of pediatrician-parent relationships is another factor contributing to the disparity in age of diagnosis between African-American and Caucasian children. "Early diagnosis of ASD is challenging in the context of primary care visits, because there is no . . . laboratory test to detect it" (American Academy of Pediatrics, 2001, p. 1221). If a pediatrician consistently sees the same child and has a relationship with the parents, identifying atypical behavior may be easier. Mandell et al. (2005) found that children who had four or more primary care physicians before diagnosis received a diagnosis an average of 0.5 years later than children who had one primary care physician. "Children who were referred to a specialist in response to parental concerns received a diagnosis an average of 0.3 years earlier than other children" (Mandell et al., 2005, p. 1483). Having many primary care physicians may be related to poor access to healthcare that results in discontinuity of care and misdiagnosis. As reported by Weinick and Krauss (2000),

studies have shown that Black and Hispanic children are more likely to lack a usual

source of care and less likely to have an office-based source of care than are White children . . . Black and Hispanic children are more likely than White children to be uninsured . . . Children without health insurance are more likely to lack a usual source of care, a regular clinician, and access to after-hours medical care than those with coverage (p. 1771).

Because children with autism manifest a complex array of deficits in communication and social interaction skills as well as behavior patterns, obtaining an accurate diagnosis is often the culmination of a long and protracted evaluation period, including the efforts of multiple professionals from a variety of disciplines (Seltzer, Krauss, Orsmond, & Vestal, 2000). If African-American children are more likely to not have access to healthcare, experience greater discontinuity in healthcare, and/or are more likely to see multiple primary care physicians, the opportunity for a provider to make an accurate and timely diagnosis is greatly jeopardized.

Physician bias is another possible factor contributing to the disparity of diagnosing ASD in African-American children. Since cultural factors are intertwined with thoughts and behaviors and can contribute to bias, culture may assume a major role in the way physicians see and respond to deviations in their patients' development and may influence the extent to which they subscribe to assessment, diagnosis and intervention strategies (Mandell & Novak, 2005). A family's culture and a physician's lack of knowledge about that culture could contribute to a child being misdiagnosed.

Clinicians may be influenced in their decision to screen for ASD in African-American children due to having different expectations about treatment and service needs by ethnicity and may therefore not screen for ASD as quickly as they would among Caucasian children (Mandell & Novak, 2005). "Physicians may also more quickly discount the concerns of African-American parents than they do the concerns of white parents related to their children's developmental delays, or not elicit those concerns in the first place" (Mandell & Novak, 2005, p. 112). Cooper-Patrick et al. (1999) found, in 32 primary care practices, that African-Americans rated their visits as significantly less participatory than Caucasians did. This could be due to racial and ethnic differences between physicians and their patients (Cooper-Partrick et al, 1999).

There may also be a bias on the part of the professional related to the notion of socioeconomic status (SES) as a relevant etiologic consideration for autism. Although it is clear that SES is not a determinant as to whether a child has autism, it may play a factor in

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whether a physician screens for ASD. Cuccaro et al. (1996) writes,

An alternative hypothesis involves the ambiguity of low SES and how clinicians factor in the contributions of disadvantage. In a low SES context, there may be a preponderance of biopsychosocial factors which could explain observed behaviors. In a high SES context, the number of possibilities is diminished as children born in “advantaged” settings are more likely to have had adequate environmental supports (p. 468).

This bias may determine how a physician reacts to parents’ concerns about their child’s development. Sociodemographic factors might also influence who gets evaluated for developmental concerns, how these concerns are documented, how soon a child is referred for specialty services, and who participates in studies (Mandell et al., 2002).

### Implications for Social Workers

Due to the rise in the number of cases of autism and the importance of early diagnosis and treatment, it is crucial that social workers become more knowledgeable about ASD and be aware of the disparity in age of diagnosis of African-American children and the factors that contribute to this disparity. Social workers are often in positions to identify and screen children for ASD, educate other professionals, advocate on behalf of children and families, and influence and develop policies to ensure appropriate and timely diagnosis and treatment of ASD and equitable care for African-American children. Because of social workers’ training and sensitivity to racial and socioeconomic factors, they are well positioned to respond to the disparity in age of diagnosis of African-American children and take steps to close the gap. Social workers are also well positioned, once children have received a diagnosis, to be culturally sensitive when intervening with children who have been diagnosed with ASD. It is also essential that social workers help families understand the life-long impact of autism and ensure that children and families are receiving culturally appropriate care, and that all available services and social supports are being used to help families cope (Newsome, 2000). “Intervention in the form of information at the family level may be an appropriate policy response, par-

ticularly among harder-to-reach subpopulations, such as those with lower incomes or lower literacy” (Porterfield & McBride, 2007, p. 328).

Social workers can also contribute to the understanding of both the disparity in the age of diagnosis of African-American children as well as the experiences of African-American families and children who have been diagnosed with ASD by conducting research targeted specifically to African-Americans and other communities of color. Despite autism being recognized as a disorder that knows no racial, ethnic, or social boundaries, the majority of research has ignored or minimized race, and autism studies that specifically target African-Americans are rare (Dyches et al., 2004; Collins et al., 2006). Few studies look at the impact autism has on African-American families and, although it is clear there is a disparity in the age of diagnosis, there is only speculation as to why. It seems researchers have attempted to generalize their findings to a population that deserves to be studied independently. Social workers can contribute to the body of knowledge on ASD by conducting research that is specific to the experiences of African-American children and families, further helping us understand the disparities in the age of diagnosis and developing specific interventions and policy recommendations from the research findings.

### Conclusion

Although we know disparities in the age of diagnosis of African-American children exist, it is unclear if the misdiagnosis of children, physician-parent relationships, access to health care, physician bias, or another factor yet to be identified is most responsible. It is likely a combination of all these that factor into African-American children being diagnosed an average of 1.5 years later than Caucasian children. Although we do have some information on the reasons for the disparity, there clearly needs to be further research to examine the various factors that contribute to the later age of diagnosis in African-American children. Because early diagnosis and treatment of ASD is so important to the long-term outcomes of children with ASD, it is crucial that we understand the factors that contribute to later diagnosis in African-American children and take steps to close the gap. Social workers are uniquely positioned to make an impact on this problem and help children and families who have been affected by ASD through clinical work with children and families, advocacy, teaching, policy development, and research.

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