Chapter 9
Improving Accuracy of Assessment, Diagnosis, and Treatment Outcomes for Black Children With Autism Spectrum Disorder

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ABSTRACT

While the prevalence of ASD is equivalent across racial demographics, there persists a significant difference in identifying developmental concerns and accurately diagnosing children from Black backgrounds as compared to their white peers. Research has identified a number of barriers to accurate diagnosis including inadequate screening, slow response to parent concerns, lack of awareness of symptoms, and misdiagnosis. This chapter will explore systematic factors such as socioeconomic inequities leading to lack of access to adequate clinical services, historical medical mistrust, racial bias within healthcare leading to improper diagnosis, and barriers to appropriate services and interventions for Black children with ASD. Additionally, a closer examination of the diagnostic criteria for ASD will be discussed alongside cultural factors that should be considered when interpreting the behavioral and developmental profile of the Black child.

INTRODUCTION

Autism spectrum disorder (ASD) is currently understood as a neurodevelopmental disorder character-ized by deficits in social communication and interactions, in addition to the presence of restrictive and repetitive behaviors and interests (Issarras et al., 2019). The diagnosis of ASD has increased by 175% since epidemiological surveillance of the disorder began in 1998 (Tincani et al., 2019; Maener et al., 2020). Recent research has reported that the prevalence of ASD amongst children aged eight years of age and four years of age is 1.7% and 1.85% respectively (Bougeard et al., 2021). When analyzing data with respect to individual racial and ethnic backgrounds, research has determined the prevalence of ASD to be equivalent across racial and ethnic groups, with the exception of Hispanic/Latinx children who consistently report decreased prevalence as compared to white, Black, and Asian/Pacific Islander children (Shaw et al., 2020).

There persists a wide disparity in the time to [accurate] diagnosis for Black autistic children, as com-pared to their white peers, despite research supporting that the prevalence of ASD amongst children of diverse backgrounds has consistently been determined to be equivalent (Durkin et al., 2017). In clinical practice, ASD can be diagnosed as early as two years of age, however Black children receive their ASD diagnosis significantly later than their peers. Research has shown that the age at which minority, more specifically Black children, receive their diagnosis is on average one and a half to two years later as compared to white children (Burkett et al., 2017). There are many reasons to explain and future outcome implications to consider when attempting to understand the barriers that Black autistic children face in receiving an accurate diagnosis.

Barriers to Accurate Diagnosis

While the prevalence of ASD is essentially equivalent across racial and ethnic demographics, there persists a difference in identifying and providing a proper diagnosis to children [suspected of autism] from Black and Hispanic backgrounds as compared to white children (Durkin et al., 2017; Shaw et al., 2020). To understand both the cause and effect of this disparity in the under- and misdiagnosis of Black children, we must first understand the complex intersectionality between time of diagnosis, so-cioeconomic status, and race/ethnicity affecting diagnosis of ASD amongst Black children (Durkin et al., 2017). Aforementioned, clinicians can diagnose ASD in children by two years of age, however there is a significant time delay for Black children to receive a proper diagnosis of ASD (Constantino et al., 2020). Recent research has reported that Black children receive their ASD diagnosis on average one and a half to two and a half years later as compared to their white peers (Burkett et al., 2017). In addition, the diagnostic period, the period from when developmental concerns are initially apprised to when the child receives a proper diagnosis, that Black children suspected of ASD undergo requires three times as many medical visits over a period that is three times as long, before they receive an ASD diagnosis (Gourdine & Algood, 2014; Tincani et al., 2009). However, there are barriers that exist prior to even receiving an evaluation, and throughout the evaluation process, that lead to inadequate and inefficient diagnostic and treatment outcomes. These barriers are intersectional and are influenced by socioeconomic and cultural factors including inadequate screening, clinician bias leading to delayed responses to parent concerns, variances in symptoms apprised and lack of symptom awareness by parents and guardians, and overall under- and misdiagnosis of symptoms and behaviors.

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