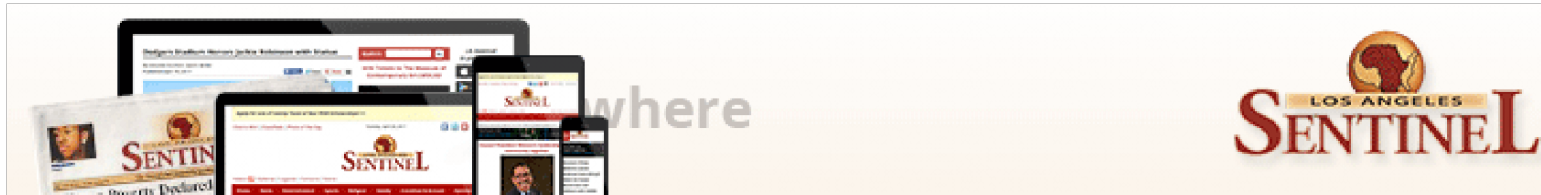




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Overcoming Barriers To Autism Diagnosis In The African American Community

By Daniel H. Geschwind, M.D., Ph.D.

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Research suggests that African American children are diagnosed with Autism Spectrum Disorder (ASD) at a later age compared to children of European ancestry. The question is, "Why?"

What is ASD?

Autism Spectrum Disorder is a neurodevelopmental disorder characterized by social communication difficulties and restrictive/repetitive behavior. Common symptoms of autism may include:

Difficulty reading other's emotions or understanding social situations

Highly focused on certain objects

Difficulty changing routines

Limited eye contact

Sensitivity to certain sounds

Trouble speaking

In short, no two individuals with ASD are the same, which is why we now call autism a spectrum.

Because autism is a spectrum, the process of recognizing symptoms and getting an ASD diagnosis can be challenging. The fact that autism looks different in each person may help explain why many African American children are diagnosed with autism later than European ancestry children. This delay in diagnosis prevents African American children with ASD from receiving prompt treatment, which may negatively affect their response to treatment when they finally receive services.

Why the delay in ASD diagnosis?

There are many possible explanations for why African American children are diagnosed later. On the one hand, clinicians may not always be available or equipped to work with African American families. On the other hand, African American families may not always be prepared to receive an autism diagnosis.

There may be blind spots in clinical care that contribute to the delay in ASD diagnosis for African American families. First, there may be a very long wait time to see an autism specialist in many areas that service African American children. Second, cultural bias may

cause a delay in diagnosis if clinicians are not sensitive to the ways in which autism may appear differently in African American children. Third, misdiagnosis may also play a role in the delay. According to a 2009 research report, many autistic African American children have been diagnosed with Attention Deficit/Hyperactivity Disorder (ADHD) or behavioral disorders, rather than ASD. Since previous guidelines did not allow clinicians to diagnose both ASD and ADHD at the same time, they may have given a child a diagnosis of ADHD instead of ASD, especially in children whose autism symptoms were less severe.

There may be unique experiences and points of view among African American families that contribute to the delay in ASD diagnosis as well. First, financial and social barriers may pose a challenge to obtaining an early diagnosis. Some African American families may be lower income, leaving them with limited resources (e.g., money, time, transportation) to access quality healthcare. Second, some family members may be hesitant to seek an ASD evaluation or diagnosis due to concern about their child being labeled with a mental disorder. Third, if and when families are able to visit an autism specialist, they may lack trust or confidence in medical professionals due to historical mistreatment of the African American community.

All of these circumstances combined may make the diagnostic process more difficult for African American families affected by autism.

What can you do as a parent or loved one of a child with ASD?

If any of these experiences and challenges sound familiar to you, please know there are several options available. To overcome barriers to ASD diagnosis, you must be proactive. Take steps to educate yourself about ASD and if you recognize the signs and symptoms listed here, make a point to reach out to your child's doctor or school for a referral to an autism specialist. There are several local non-profit organizations across the Los Angeles metro area that can be helpful resources in your child's ASD journey: Autism Speaks, The Help Group, Special Needs Network (SNN), Healthy African American Families (HAAF) and the University of California, Los Angeles Center for Autism Research and Treatment (UCLA CART) are a few to consider. Local Regional Centers will be helpful as well, and specialize in providing ASD diagnosis and services.

In addition, the Autism Genetics and Human Diversity study at UCLA is currently investigating genetic risk for autism in the African American community in order to increase racial diversity in autism research. By participating in this study, African American families who suspect their child has autism can receive a free assessment by trained autism specialists to determine if a diagnosis of Autism Spectrum Disorder (ASD) is appropriate. The study can also help families whose child has already been diagnosed with ASD by providing basic recommendations

based on the autism specialist assessment. In addition, all participating families will gain access to educational resources and future research opportunities through the UCLA Center for Autism Research and Treatment (CART).

For more information about the Autism Genetics and Human Diversity study, please contact Erin Graham, Ph.D., at 310-794-4090 or egraham@mednet.ucla.edu.

Thank you to Dr. Erin Graham, Edna Hubbard, and Nina Sheridan for their work in drafting this informational document. DHG

Daniel H. Geschwind, M.D., Ph.D. is the Director of the Center for Autism Research and Treatment, the Gordon and Virginia MacDonald Distinguished Professor in Neurology, Psychiatry and Human Genetics, and the Senior Associate Dean and Associate Vice Chancellor for Precision Health at the University of California, Los Angeles.



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