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CARLOS T. CARTER

Autism

What can we do to increase early identification and referrals for autism spectrum disorder (ASD) in the Black community?

As a society, we need to recognize that Autism Spectrum Disorder (ASD) affects every race and ethnic group regardless of socio-economic status. However, we do know there are clear racial disparities when it comes to healthcare, and it is disheartening to learn that our Black children are being diagnosed much later than their White counterparts.

Parents play a crucial role in early detection, so it's important they understand ASD signs, some of which can manifest when a child is as young as six months. That's why helping to educate parents about ASD and equipping them with the right set of tools is key—both before, during, and after pregnancy. The earlier ASD is diagnosed, the better chance parents have of reducing the effects of autism.

The Urban League of Greater Pittsburgh has been a partner of the Pledge to Protect campaign for the last three years. One of the most important messages we try to convey to parents is that it's critical to stay on top of well-child visits. At these visits, parents can voice their concerns and tell their pediatrician the signs they are seeing.

Parents and caregivers need to be vocal advocates for their children's health starting at birth. As a community, we can help by having information available where parents live—at schools, libraries, barber shops, hair salons, and community centers. We can all do our part.

What are ways that we can reduce the stigma and isolation experienced by autistic individuals and their families?

One way to reduce stigma is to get people talking about ASD and recognizing that many young people with autism can thrive. It's important to let people know ASD is nothing to be ashamed of and that parents/caregivers of children with ASD are not alone.

Let's launch social media campaigns directed to the Black Community where people with autism can tell their success stories. Let's help families understand and take advantage of resources and support that's available to everyone as early as possible.

The more we humanize and tell the stories of Black people living and thriving with autism, the less stigma there will be. It also goes back to educating parents and caregivers about the disorder. The more people are educated about ASD, the better prepared they will be to help their children.

(Carlos T. Carter is President & CEO, Urban League of Greater Pittsburgh)

Black autistic lives matter

In the United States, people of all races and ethnicities are diagnosed with autism spectrum disorder (ASD) each day.

According to the Autistic Self Advocacy Network, every autistic person experiences autism differently, but there are some things that many of them have in common. That includes thinking, processing senses, moving, communicating, and socializing differently. Some autistic people may also need help with daily living.

Statistics on how many children in the U.S. are diagnosed with ASD varies. According to the CDC, it is 1 in 44 children. Boys are diagnosed more often than girls. However, researchers believe that girls are not being diagnosed as much as they should be.

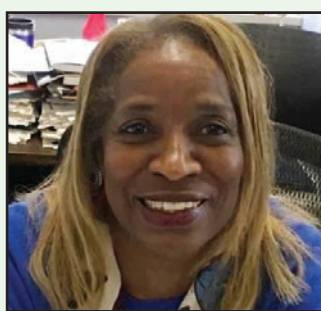
Black children are often diagnosed later than White children. While the rate of diagnosis for autism is the same for all racial groups, Black children are diagnosed later (in some studies, up to 3 years) than their white counterparts.

This is important. When this happens, children and families aren't receiving services to better help their child.

Early intervention programs are free and help children make gains in communication and social interactions early. The longer it takes to correctly diagnose autism, the longer families go without help.

There are many reasons why Black children are not being diagnosed as early. "Often, as parents, we don't know what we're looking for," says University of Pittsburgh's Dr. Valire Copeland, professor in the School of Social Work and in the Department of Behavioral and Community Health Services.

"This is especially true for first-time parents. If you do



DR. VALIRE COPELAND

notice your child has speech delays or motor delays, or engages in repetitive movements or behaviors, you might just think 'he'll catch up or grow out of it.'"

This is the same for teachers and other professionals who misinterpret signs.

"For example, a Sunday School or daycare teacher may not be familiar with autism," Dr. Copeland explains. "Instead, she may suggest your child has behavioral issues."

There is also the problem of autism stigma, which is common among all people. "Sadly, no matter what color our skin, we all have bias about mental illness and disability," Dr. Copeland states.

What does autism look like in a child?

While Dr. Copeland notes that autism is unique to everyone, there are some early signs.

It is important to note that any one sign by itself is typically not cause for concern. If you have noticed multiple signs, it may be worth discussing them with your child's pediatrician.

For example:

- Limited eye contact (e.g., looking more at toys than people)
- Difficulty in gaining child's attention, including not responding to their name
- Not being interested in other children
- Not sharing enjoyment

(smiling/laughing) with others

- Difficulty with change in routine
- Presence of sensory sensitivities (loud noises, selective food intake, staring closely at objects)
- Having interests that are intense or repetitive
- Developmental delays, such as few to no single words by 18 months
- Any loss of speech, babbling, or social skills at any age.

Not every child with autism will have all these signs. In addition, many children with these signs will not end up with an autism diagnosis.

Some children show signs of autism before one year of age, but for some, autism is not easily noticeable before 2 or 3 years.

Autism, like many conditions that involve healthcare and Black Americans, includes racial inequities, such as a lack of easy and affordable access to doctors who treat the disorder.

"Ideally, you want your child diagnosed and treated by a pediatric autism specialist," Dr. Copeland adds.

"Unfortunately, there aren't a lot of them in the system and most of them are not Black, so they don't understand the African American community. Therefore, first see your regular pediatrician."

"The entire process can be overwhelming," says Dr. Copeland. "How do you find a doctor? How do you take time off from work to see the doctor? How do you pay for the doctor visits, required testing, treatment, and support services if your insurance doesn't cover all the costs, you don't have insurance, or your copay is high? We must acknowledge that this is a stressful situation for families to deal with, and it goes on for a lifetime."

Early diagnosis is the key



A YOUNG GIRL WITH AUTISM holding small plastic toys to comfort herself in new situations that can be stressful. (Getty Images)

to long-term success

The earlier the diagnosis is made, the better, preferably by the age of 2-3 years old.

At this early age, interventions have a better chance for long-term positive effects on children's learning and progress (National Institute of Health). The Pennsylvania Department of Education has an early intervention program that is free to qualifying families." (Call the CONNECT Helpline at 1-800-692-7288.)

"I like to tell parents and caregivers, if you or someone you respect in the community thinks your child may have autism or mentions concerns, please see a doctor who can prove you wrong," says Dr. Copeland.

Be accepting of autism. There are many online

national resources that can help people better understand autism, including how to support autistic people in the Black community, such as Autism Urban Connections, Inc. (located in Pittsburgh), Autism in Black, Inc., and the Colors of Autism Foundation.

Dr. Copeland adds, "One of the simplest and most profound things you can do is to be accepting of people in the Black community who have autism — and their family members/caregivers. We all want to be accepted and loved, starting with where we live."

RESOURCES
<https://www.aucofpg.org/>
<https://paautism.org/>
<https://autismofpa.org/>
<https://autisticpg.org/>

Mindfulness is one way that autistic children may learn to manage emotions

Many children on the autism spectrum have trouble managing their emotions. Even though this challenge is not unique to autism—autistic children do have 4-7x higher risk for difficulty managing emotions (Conner et al., 2020). This is called "emotion dysregulation."

Emotional dysregulation may be linked to higher rates of depression, anxiety, and suicide risk in people on the autism spectrum.

There are many reasons why autistic people may have emotion dysregulation more than others. It can be worsened by difficulty noticing emotions, more social stressors, and biological processes in the brain.

It can sometimes look like going from "0 to 100 instantly", difficulty calming, and low mood. Some children may feel out of control and do things they wouldn't usually do—like yell, hit, or

injure themselves when dysregulated.

Dr. Kelly Battle Beck is an assistant professor at the University of Pittsburgh. She develops programs to help autistic youth and adults better manage their emotions. "Giving autistic people tools that help them manage their feelings can lead to better emotional wellbeing," Dr. Beck explains. "Our goal is to help autistic children learn to manage their emotions as independently as possible—hopefully improving their quality of life."

What can help?

Mindfulness is one option for therapists to teach autistic people and their family members to recognize their emotions and use strategies to calm themselves. The first step is for children to learn how strong their emotions are (1-10). It is not as important to be able to talk about their feelings during a melt-

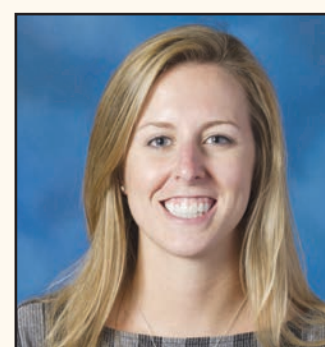
down. Noticing emotions as they get stronger is the first step.

Caregivers can start working on this with their children now. Parents or caregivers can model noticing emotions around their children—even in moments of calm. Dr. Beck explains, "The next time you're angry or frustrated about something, you may want to say to your autistic child in a simple, but clear way, 'My emotions are strong (7 out of 10). I'm going to sit here, close my eyes and breathe.' Then do those things while your child is watching."

After the child starts to learn this, caregivers can try the same thing when the child is mildly upset and work up to trying new strategies in a meltdown.

During a meltdown Dr. Beck suggests that parents/caregivers:

- Acknowledge their feel-



DR. KELLY BATTLE BECK

ings: "I see you're having strong/big feelings. All emotions are OK"

• Reduce sensory input. Turn off music, the TV, and lights.

• Create a safe space where the child can't hurt himself or someone else.

• Don't ask questions about what the child is feeling.

• Don't talk about the consequences of the meltdown

until hours later or the next day.

- Don't make eye contact.
- Use "let's" language. For example, "Let's breathe together."

Dr. Beck urges parents to trust what they know about their child, too. "You are the parent. You know what may work best for your child. For example, maybe instead of breathing as your calming strategy, your child will respond better to a warm shower."

Dr. Beck encourages parents/caregivers to keep the statements short and simple and not to give up if the method doesn't work right away. Therapists can help families with these skills too.

"The end goal is to help your child recognize their emotions and calm themselves," Dr. Beck says. "The hope is that over time, you and your child can regulate together."

Autism Urban Connections: Autism support for Pittsburgh's Black community

Black families in Pittsburgh have an autism resource many cities don't: Autism Urban Connections, Inc.

Founded in 2015, Autism Urban Connections is the first and only African American, minority, family-focused autism 501(c)(3) nonprofit in the state. The group provides education, support, advocacy, and em-

powerment to autistic individuals and their families.

This includes access to resources and services that assist autistic individuals live a meaningful and quality life.

Education & advocacy

Autism Urban Connections gives daily phone and online support to African Americans who need help with a suspected or new

autism diagnosis. The organization helps families find early screening tools for diagnosis and identify early intervention services.

Their staff provides information about healthcare, special education, housing, and justice system information and resources. The agency supports people as they learn to advocate for themselves or loved ones.

Family support

Advocating for and providing care to a loved one with autism requires patience, time, and determination! That's why Autism Urban Connections encourages family members to take care of themselves. The organization holds regular information sessions, training workshops, support groups for parents and caregivers,

and family fun community gatherings.

Self-care & empowerment

The organization helps individuals and parents develop skills to explore feelings, reconcile emotional conflicts, foster self-awareness, and advocate for themselves and their needs.

Learn more! Visit aucofpg.org.