Autism in the Black Community

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April 18, 2024





Acknowledgment

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At the time of this publication, Miriam E. Delphin-Rittmon, Ph.D., served as Assistant Secretary for Mental Health and Substance Use in the U.S. Department of Health and Human Services and the Administrator of the Substance Abuse and Mental Health Services Administration.

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Presented 2024



The purpose of the MHTTC Network is technology transfer - disseminating and implementing evidence-based practices for mental disorders into the field.

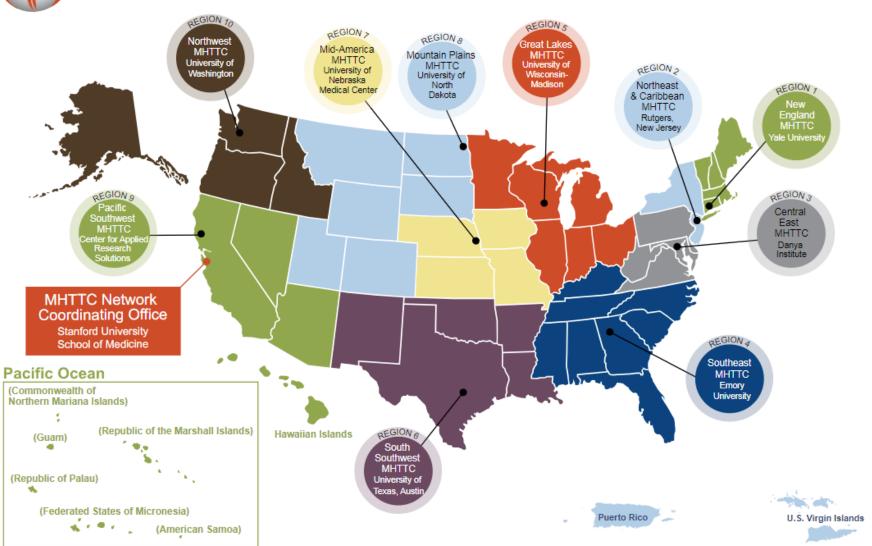
Funded by the Substance Abuse and Mental Health Services Administration (SAMHSA), the MHTTC Network includes 10 Regional Centers and a Network Coordinating Office.

Our collaborative network supports resource development and dissemination, training and technical assistance, and workforce development for the mental health field. We work with systems, organizations, and treatment practitioners involved in the delivery of mental health services to strengthen their capacity to deliver effective evidence-based practices to individuals. Our services cover the full continuum spanning mental illness prevention, treatment, and recovery support.

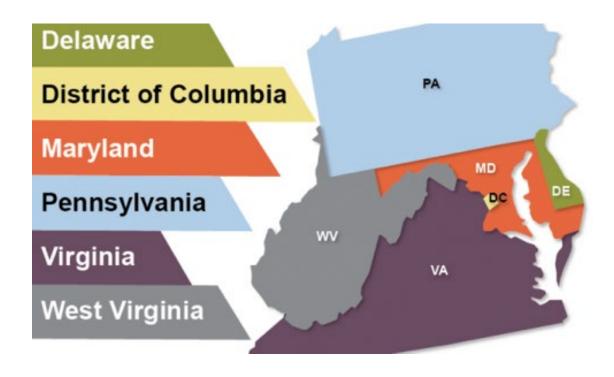


Mental Health Technology Transfer Center Network Funded by Substance Abuse and Mental Health Services Administration

MHTTC Network



Central East Region 3



The MHTTC Network uses affirming, respectful and recovery-oriented language in all activities. That language is:

STRENGTHS-BASED AND HOPEFUL

INCLUSIVE AND
ACCEPTING OF
DIVERSE CULTURES,
GENDERS,
PERSPECTIVES,
AND EXPERIENCES

HEALING-CENTERED AND TRAUMA-RESPONSIVE

Inviting to individuals PARTICIPATING IN THEIR OWN JOURNEYS

PERSON-FIRST AND FREE OF LABELS

NON-JUDGMENTAL AND AVOIDING ASSUMPTIONS

RESPECTFUL, CLEAR AND UNDERSTANDABLE

CONSISTENT WITH OUR ACTIONS, POLICIES, AND PRODUCTS

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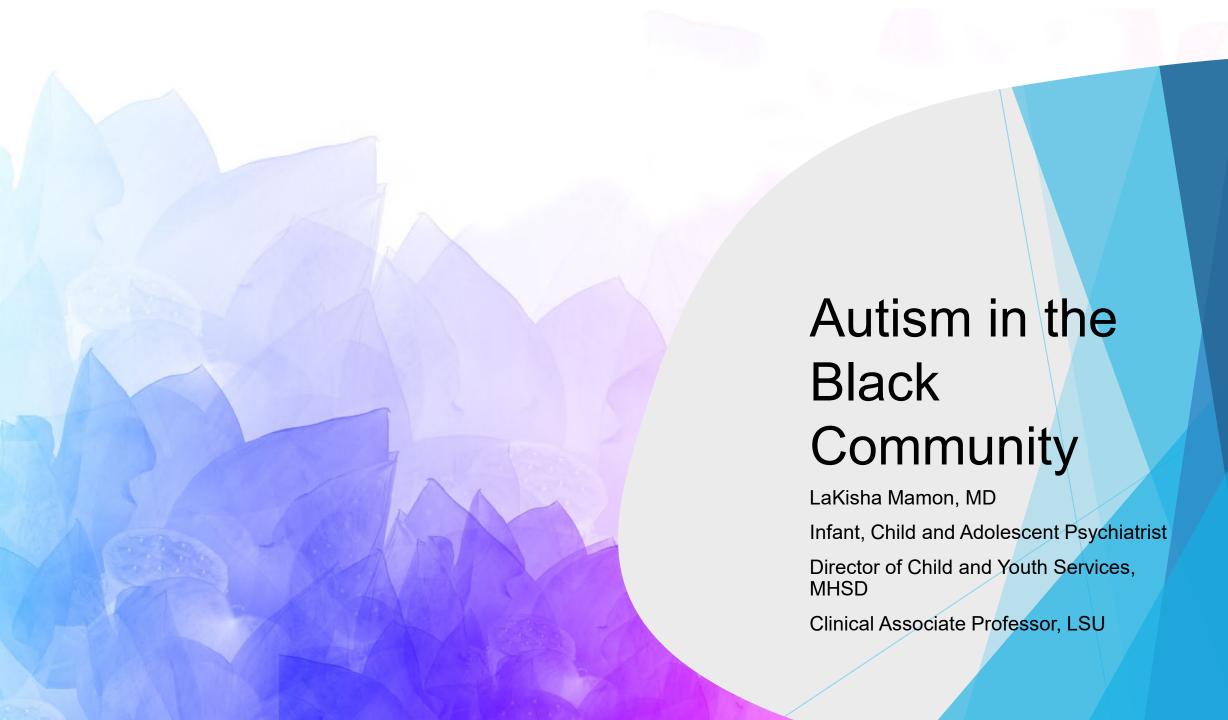
Moderator: Annelle Primm, MD, MPH Black Psychiatrists of America, Council of Elders

April 18, 2024



Today's Webinar

- April is Autism Awareness Month, a good time to discuss Autism, and the need to maximize the quality of life of children and adults with this condition; which affects all demographics, including Black communities.
- We thank the SAMHSA CE-MHTTC for its partnership on the BPA Health Equity Webinar series.
- Content has both Central East region and national relevance.
- Our featured speaker is LaKisha Mamon, MD





Review Statistics and Prevalence

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Review Cultural Awareness and Recognition of Autism in Black Communities 3

Review Disparities and Barriers to Access, Diagnosis and Treatment 4

Review Solutions to Barriers

Goals and Objectives



autism

noun [ä·ti·zəm]

Autism, or autism spectrum disorder (ASD), refers to a broad range of conditions characterized by challenges with social communication skills and repetitive or restricted behaviors or thinking

"If you've met one person with autism, you've met one person with autism."





Autism Spectrum Disorder (ASD)

- "ASD is a neurological and developmental disorder that affects how people interact with others, communicate, learn, and behave."- National Institute of Mental Health
- Difficulty with communication
- Difficulty with social interactions
- Restricted interests and repetitive behaviors
- Typically appears by age 2

The diagnosis of autism knows no racial, ethnic or cultural boundaries.

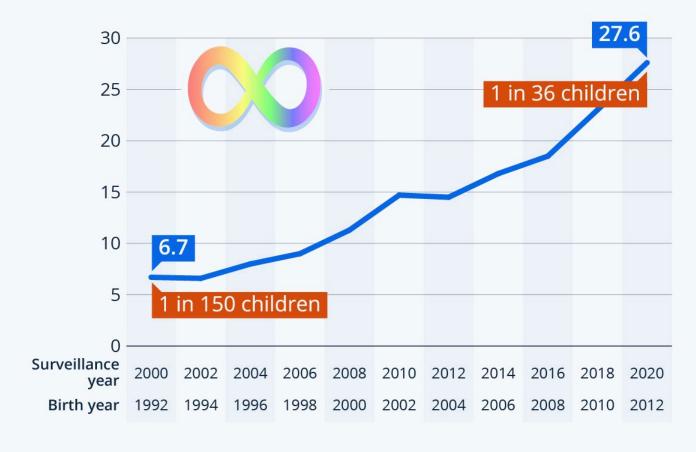
Yet, the events of recent weeks underscore the fact that racial disparities and barriers persist everywhere including the autism community.

Image from Autism NJ

STATISTICS AND PREVALENCE

The Rising Prevalence of Autism

Identified prevalence of Autism Spectrum Disorder (ASD) per 1,000 children in the U.S.



Source: Autism and Developmental Disabilities Monitoring Network via CDC





Black, Hispanic, and Asian or Pacific Islander children were more likely

to be identified with ASD than White children for the first time in ADDM.

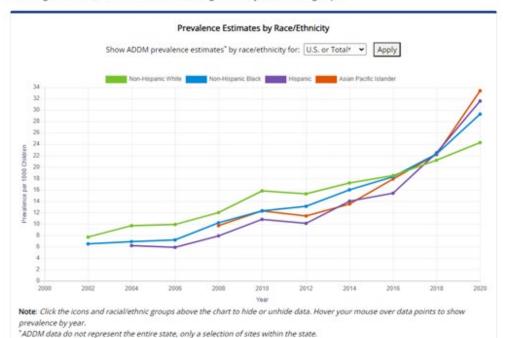
Black	29.3
Hispanic	31.6
A/PI	33.4
White	24.3
Values indicate prevalence per 1,000 chi	

2023 Newest Data!- CDC Autism and Developmental Disabilities Monitoring (ADDM) Network

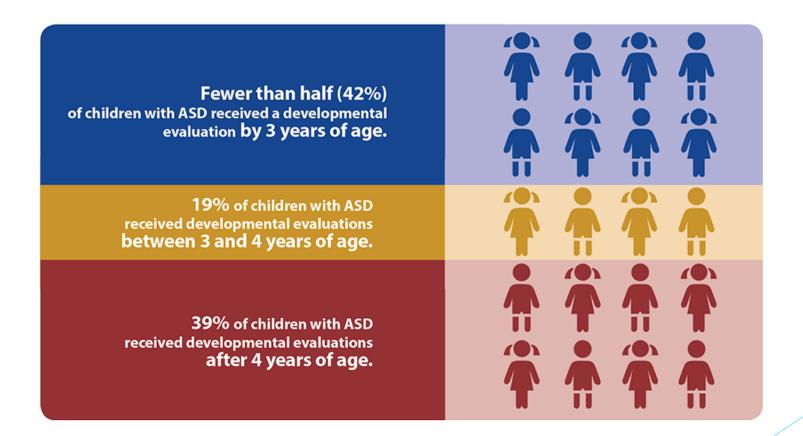
4. REPORTED PREVALENCE VARIES BY RACE AND ETHNICITY

*ADDM estimate = the total for all sites combined.

There have been racial and ethnic differences observed over the years in ADDM data. Prior to 2014, the percentage of 8-year-old White children with ASD was higher than other groups. In 2014, the percentage of Black children with ASD began to be similar to White children. Asian or Pacific Islander children began to have a similar percentage of children with ASD 2016, as did Hispanic children in 2018. For the first time in 2020, the percentage of 8-year-old Asian or Pacific Islander, Hispanic, and Black children identified with ASD was higher than among 8-year-old White children. These shifts may reflect improved screening, awareness, and access to services among historically underserved groups.



Age of Diagnosis

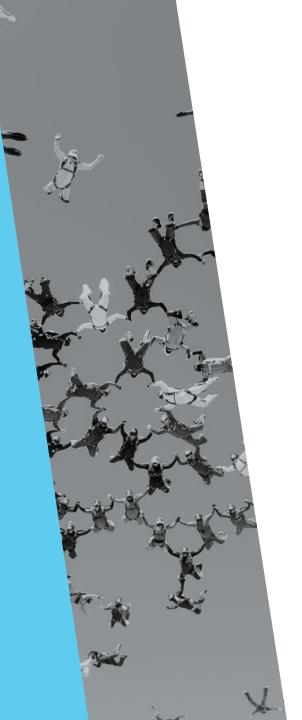




Benefits of Early Diagnosis and Treatment

- Increases developmental outcomes and improves adaptive skills
- Earlier start of interventions for the specific needs e.g., social communication, language development, and behavioral challenges
- Allows families to access appropriate support services, educational resources, community programs
- Facilitates improved coping mechanisms, reduces parental stress, and increases independence

Cultural Awareness and Recognition of Autism in Black Communities



Barriers to Early Diagnosis and Treatment in the Black Community

- ASD diagnosis process can be long, complex, emotionally challenging, and financially draining for families due to the comprehensive work-up by multiple providers in multiple systems of care.
 - Implicit Bias and Racism
 - Misdiagnosis
 - Access to Care

Implicit Bias and Racism in Healthcare and within the Community

Parents reluctant to bring up concerns to child's doctor.

Providers are dismissive of parent concerns

Blame/Shame

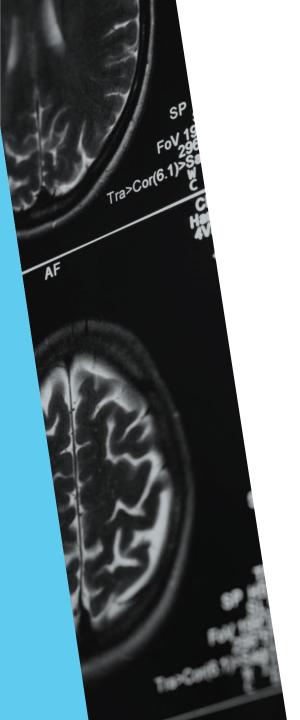
 Disruptive behaviors attributed to poor parenting or stereotypes

Labeling and stigmatization

Concerns of placement in special education

Cultural and Societal Barriers

- Black community less likely to talk about mental health struggles.
 - Parents feel isolated and afraid of judgment
 - Lack of naming/acknowledgment
- Lower awareness and recognition of Autism
- Cultural differences in communication styles and social norms can contribute to misinterpretation of autistic behaviors
 - Ex: "Boys are slower to develop than girls"



Misdiagnosis

- Complex history of misdiagnosis and mistreatment of Black community struggling with mental health issues.
 - Examples:
 - ▶ Increased diagnosis of schizophrenia instead of mood disorder
 - Increased misdiagnosis of conduct disorder ("bad") vs mood disorder or trauma ("sad")
 - ▶ More incidence of involuntary psychiatric holds
- More often diagnosed with intellectual disabilities
- Diagnosed with mood disorders instead of ASD

Access to Services:

- Socioeconomic factors can impact access to healthcare and educational services, potentially limiting opportunities for early diagnosis and intervention.
- Some communities may face barriers such as transportation, financial constraints, and limited availability of specialized services.
- Costs:
 - Predicted US costs in 2025: \$461 billion
 - Average cost per year: \$60,000
 - Costs increase with intellectual disability
 - Mothers are often the primary caregivers
 - ▶ Earn 35% less than mothers of children with other health conditions
 - Earn 56% less than mothers of children with no disabilities or disorders

SOLUTIONS



Cultural Competence

- Healthcare providers and educators need to be culturally competent to understand the unique needs and perspectives of individuals from the Black community
- Building trust and rapport with families is crucial for effective collaboration in providing support and interventions

Community Support

- Establishing community support networks and resources can be vital for families and individuals affected by Autism
- Culturally relevant support groups and advocacy organizations can help bridge gaps and provide a sense of belonging

Advocacy

Advocacy efforts within the Black community can focus on increasing awareness, reducing stigma, and improving access to resources and services

Education programs that emphasize early identification and intervention can be instrumental in addressing the challenges associated with Autism

Build trust to address the underrepresentation of Blacks in Autism research studies

Resources:



CDC's Milestone Tracker App

https://www.autisminblack.org/



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Questions



Appreciation



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Let's connect:





