

Autism Spectrum Disorder in the Black Community

William Lawson, MD, PhD

June 17, 2021



Central East (HHS Region 3)

MHTTC

Mental Health Technology Transfer Center Network

Funded by Substance Abuse and Mental Health Services Administration

MHTTC Network

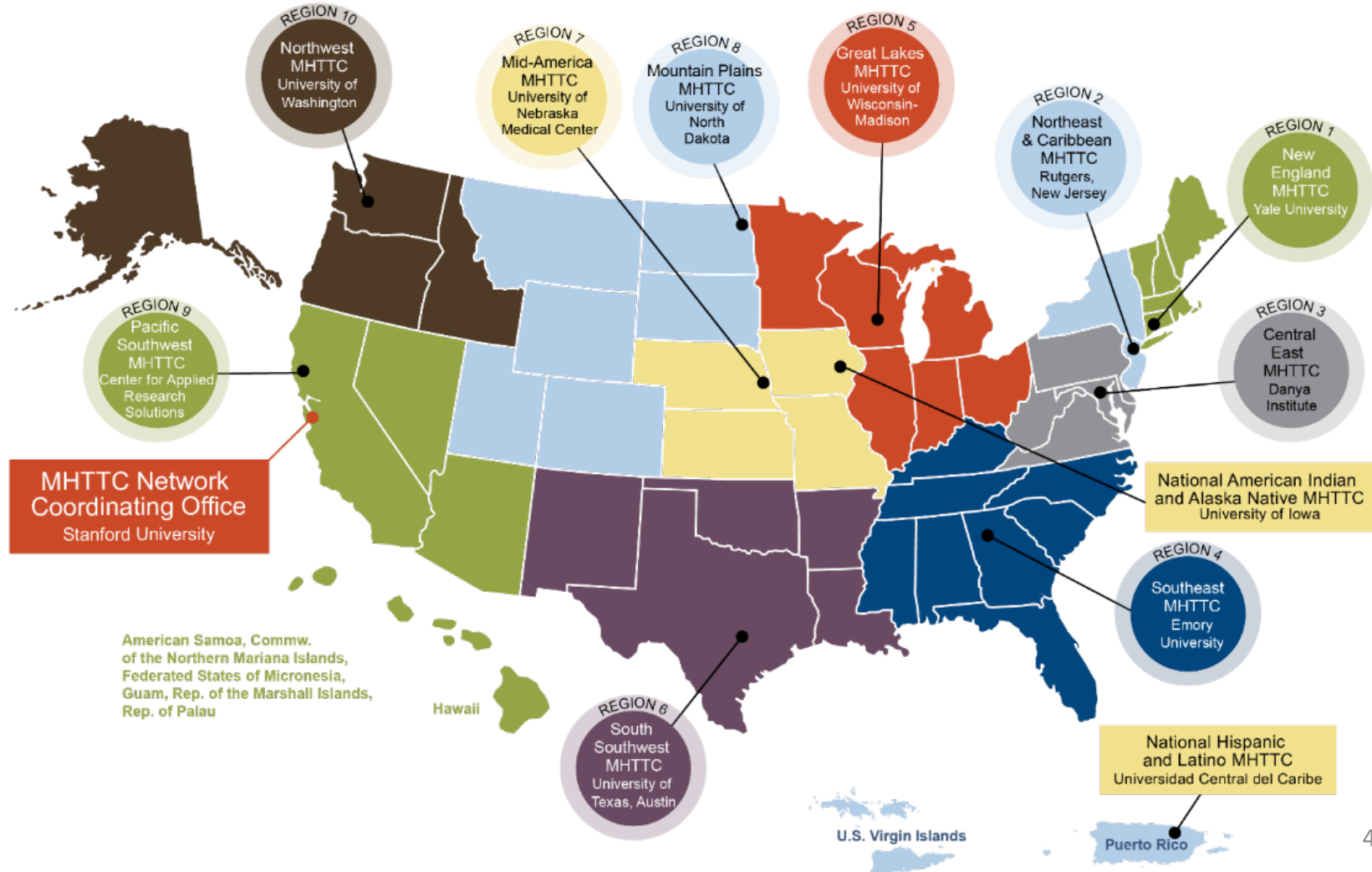


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MHTTC Purpose

The MHTTC Network vision is to unify science, education and service to transform lives through evidence-based and promising treatment and recovery practices in a recovery-oriented system of care.

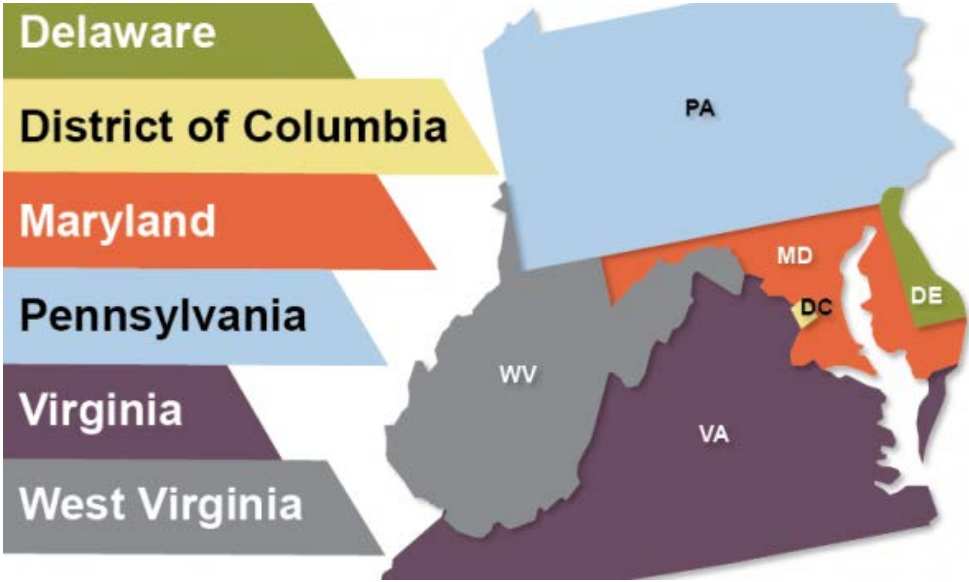


Central East MHTTC Goals

Funded by SAMHSA to:

- **Accelerate** the adoption and implementation of mental health related evidence-based practices
- **Heighten** the awareness, knowledge, and skills of the behavioral health workforce
- **Foster** alliances among culturally diverse practitioners, researchers, policy makers, family members, and consumers
- **Ensure** the availability and delivery of publicly available, free of charge, training and technical assistance

Central East Region 3



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Autism Spectrum Disorder in the Black Community

William Lawson, MD, PhD
Treasurer, Black Psychiatrists of America

Health Equity Webinar Series
A collaboration of the CE-MHTTC and the Black Psychiatrists of America
June 17, 2021

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

COVID-19: Unprecedented Disaster

- Catastrophic impact on Black and other marginalized communities with disparate levels of illness, death, and economic fallout superimposed on layers of pre-existing inequities
- Symptoms of anxiety and depression
- Potential exacerbation of underlying mental disorders such as Autism Spectrum Disorder

Today's Program

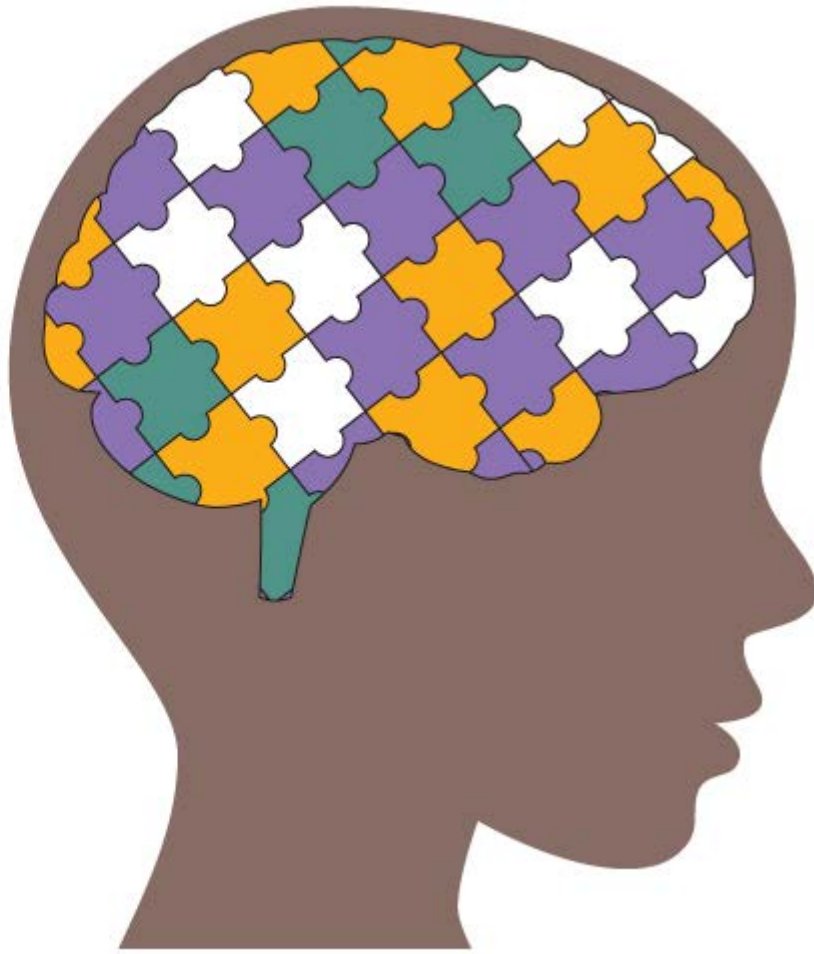
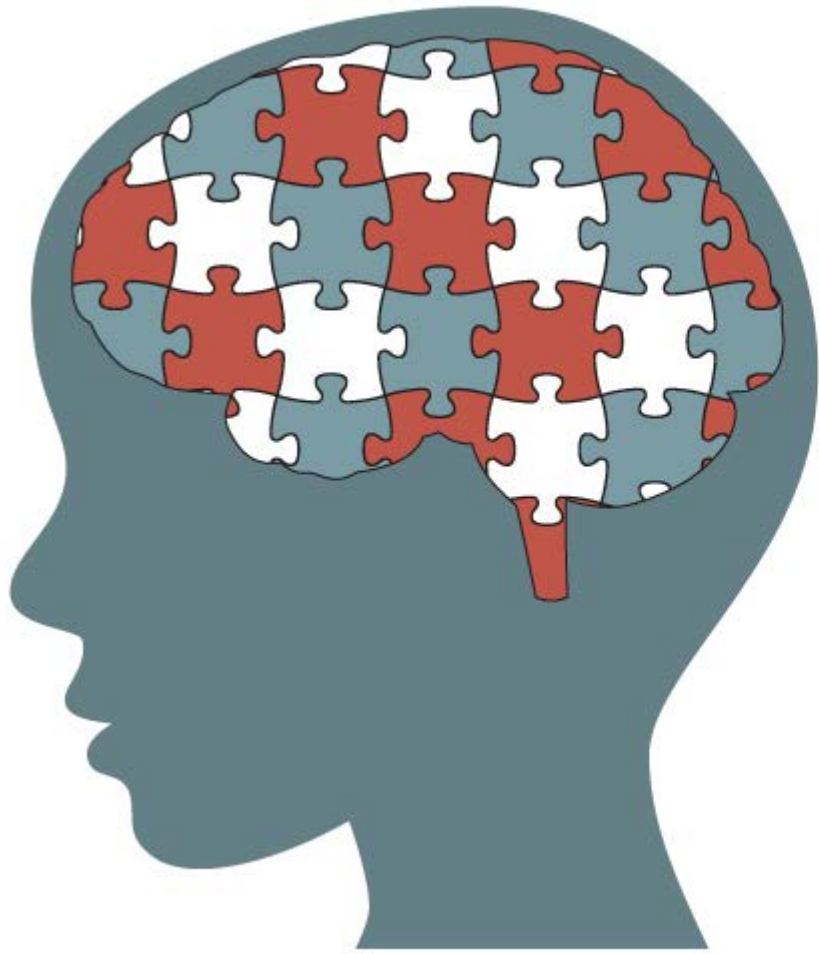
- Special thanks to the CE-MHTTC for its support of this twelfth session of the Black Psychiatrists of America Health Equity Webinar Series
- Today's program features William Lawson, MD, PhD, Treasurer of the Black Psychiatrists of America

Autism Spectrum Disorder in the Black Community

William B. Lawson, MD, PhD, DLFAPA

- *Adjunct Professor*
Department of Psychiatry
University of Maryland School of
Medicine
- *Professor Emeritus*
Dell Medical School
University of Texas, Austin
- *Professor Emeritus*
Department of Psychiatry and
Behavioral Sciences
Howard University College of
Medicine

[Email Dr. Lawson](#)



AUTISM Spectrum Disorder

- ▶ Autism spectrum disorder (ASD) and autism are both general terms for a group of complex disorders of brain development. These disorders are characterized, in varying degrees, by difficulties in social interaction, verbal and nonverbal communication and repetitive behaviors.
- ▶ ASD can be associated with intellectual disability, difficulties in motor coordination and attention and physical health issues such as sleep and gastrointestinal disturbances. Some persons with ASD excel in visual skills, music, math and art.

- ▶ Autism spectrum disorder (ASD) is a developmental disorder that affects communication and behavior. Although autism can be diagnosed at any age, it is said to be a “developmental disorder” because symptoms generally appear in the first two years of life.
- ▶ According to the Diagnostic and Statistical Manual of Mental Disorders (DSM-5), a guide created by the American Psychiatric Association used to diagnose mental disorders, people with ASD have:
 - ▶ Difficulty with communication and interaction with other people
 - ▶ Restricted interests and repetitive behaviors
 - ▶ Symptoms that hurt the person’s ability to function properly in school, work, and other areas of life

Using the previous version of the DSM, people could be diagnosed with one of several separate conditions:

Autistic disorder

Asperger's' syndrome

Pervasive developmental disorder not otherwise specified (PDD-NOS)

In the current revised version of the DSM (the DSM-5), these separate conditions have been combined into one diagnosis called **“autism spectrum disorder.”**

Restricted and repetitive behaviors

Repetitive body movements (e.g. rocking, flapping, spinning, running back and forth)

Repetitive motions with objects (e.g. spinning wheels, shaking sticks, flipping levers)

Staring at lights or spinning objects

Ritualistic behaviors (e.g. lining up objects, repeatedly touching objects in a set order)

Narrow or extreme interests in specific topics

Need for unvarying routine/resistance to change (e.g. same daily schedule, meal menu, clothes, route to school)

Restrictive / repetitive behaviors may also include:

Repeating certain behaviors or having unusual behaviors. For example, repeating words or phrases, a behavior called echolalia

Having a lasting intense interest in certain topics, such as numbers, details, or facts

Having overly focused interests, such as with moving objects or parts of objects

Getting upset by slight changes in a routine

Being more or less sensitive than other people to sensory input, such as light, noise, clothing, or temperature

Social communication challenges

Difficulty with verbal and non-verbal communication. For example, they may not understand or appropriately use:

Spoken language (around a third of people with autism are nonverbal)

Gestures

Eye contact

Facial expressions

Tone of voice

Expressions not meant to be taken literally

Also difficulty with

Recognizing emotions and intentions in others

Recognizing one's own emotions

Expressing emotions

Seeking emotional comfort from others

Feeling overwhelmed in social situations

Taking turns in conversation

Gauging personal space (appropriate distance between people)

Demographics

- ▶ The number of U.S. children with autism has surged to one in 68, the Centers for Disease Control and Prevention reported, a 30 percent increase since the agency estimated just five years ago that one child in 88 suffered from the disorder.
- ▶ ASD affects over 2 million individuals in the U.S. and tens of millions worldwide. Prevalence rates have increased 10 to 17 percent annually in recent years.
- ▶ It is found in all ethnic groups, among all socioeconomic groups but very high rates have been found in some locations and in the US Whites are diagnosed more often than Blacks or Hispanics

Autism Spectrum Disorder

- ASD is four times more common in males than females
- ASD affects 1 in 68 children
- Autism is found throughout the world amongst all racial, ethnic, and socioeconomic backgrounds
- The cause of Autism is unknown
- Individuals with ASD have a normal life span
- ASD runs in families

Comorbidities

- ▶ Intellectual disability
- ▶ Tourette syndrome
- ▶ Seizure disorders
- ▶ Anxiety
- ▶ Attention-deficit hyperactivity disorder



Dysfunction

- ▶ About 40 percent have average to above average intellectual abilities. Indeed, many persons on the spectrum take deserved pride in their distinctive abilities and “atypical” ways of viewing the world. Others with autism have significant disability and are unable to live independently. About 25 percent of individuals with ASD are nonverbal but can learn to communicate using other means.

However-

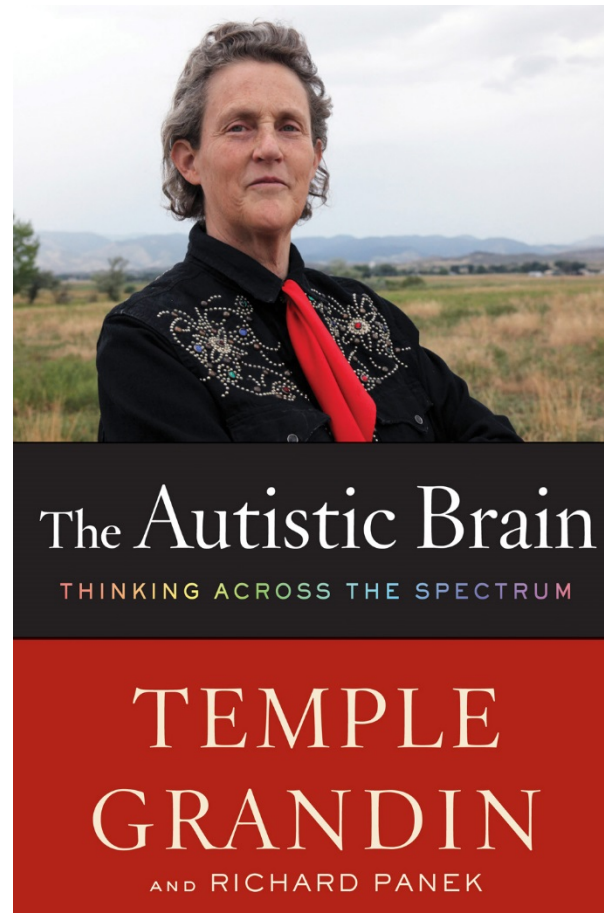
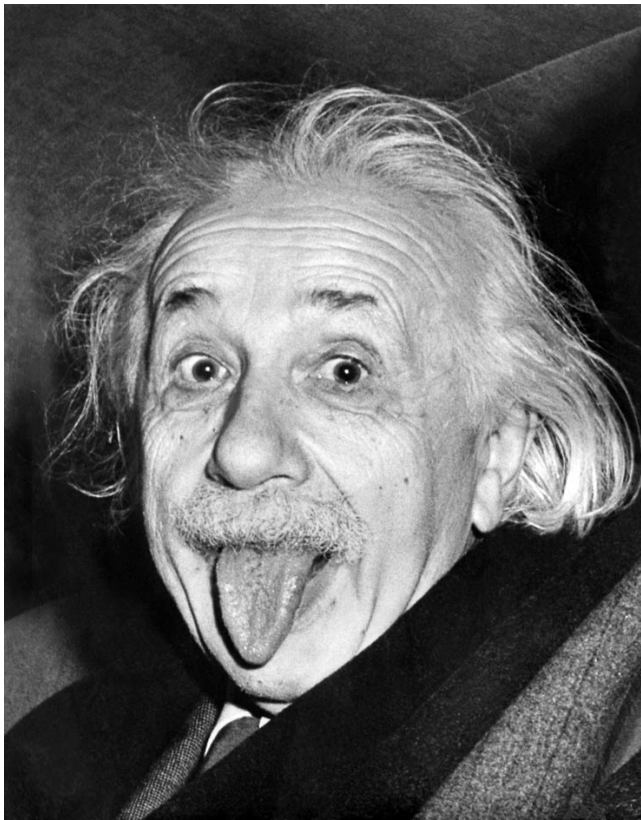
People with ASD may also experience sleep problems and irritability. Although people with ASD experience many challenges, they may also have many strengths, including:

Being able to learn things in detail and remember information for long periods of time

Being strong visual and auditory learners

Excelling in math, science, music, or art

Celebrities



Famous Folks

Dan Aykroyd - Comedic Actor

Hans Christian Andersen - Children's Author

Benjamin Banneker - African American almanac author, surveyor, naturalist, and farmer

Susan Boyle - Singer

Tim Burton - Movie Director

Lewis Carroll - Author of "Alice in Wonderland"

Henry Cavendish - Scientist

Benjamin Banneker

1731-1806



Benjamin Banneker was an African-American author, surveyor, naturalist, astronomer, inventor, and farmer who lived as a free man in 18th century America. Plenty of contemporary documents refer to Banneker's "unparalleled brilliance" and "odd methods of behavior," lending credence to the common idea that Banneker had a high-functioning form of autism. He was known to fixate on certain objects, such as a friend's watch, until that fixation ultimately led to an experiment or invention of his own.

Autism Spectrum

Doctors diagnose ASD by looking at a person's behavior and development. ASD can usually be reliably diagnosed by the age of two. It is important for those with concerns to seek out assessment as soon as possible so that a diagnosis can be made, and treatment can begin.

Diagnosing ASD in adults is often more difficult than diagnosing ASD in children. In adults, some ASD symptoms can overlap with symptoms of other mental-health disorders, such as anxiety or attention-deficit/hyperactivity disorder (ADHD).

Adults who notice the signs and symptoms of ASD should talk with a doctor and ask for a referral for an ASD evaluation. While testing for ASD in adults is still being refined, adults can be referred to a neuropsychologist, psychologist, or psychiatrist who has experience with ASD. The expert will ask about concerns, such as:

- Social interaction and communication challenges
- Sensory issues
- Repetitive behaviors
- Restricted interests
- Information about the adult's developmental history will help in making an accurate diagnosis, so an ASD evaluation may include talking with parents or other family members



Genetics

- ▶ In identical twins who share the exact same genetic code, if one has ASD, the other twin also has ASD in nearly 9 out of 10 cases. If one sibling has ASD, the other siblings have 35 times the normal risk of also developing the disorder. Having a child increases the risk of subsequent children.
- ▶ Most people who develop ASD have no reported family history of autism, suggesting that rare variants of common genes and probably many gene mutations are likely to affect a person's risk.
- ▶ At least 100 risk genes have been identified.
- ▶ Recently we found shared genes for schizophrenia, bipolar disorder, depression, and attentional deficit disorder.

What does NOT cause autism

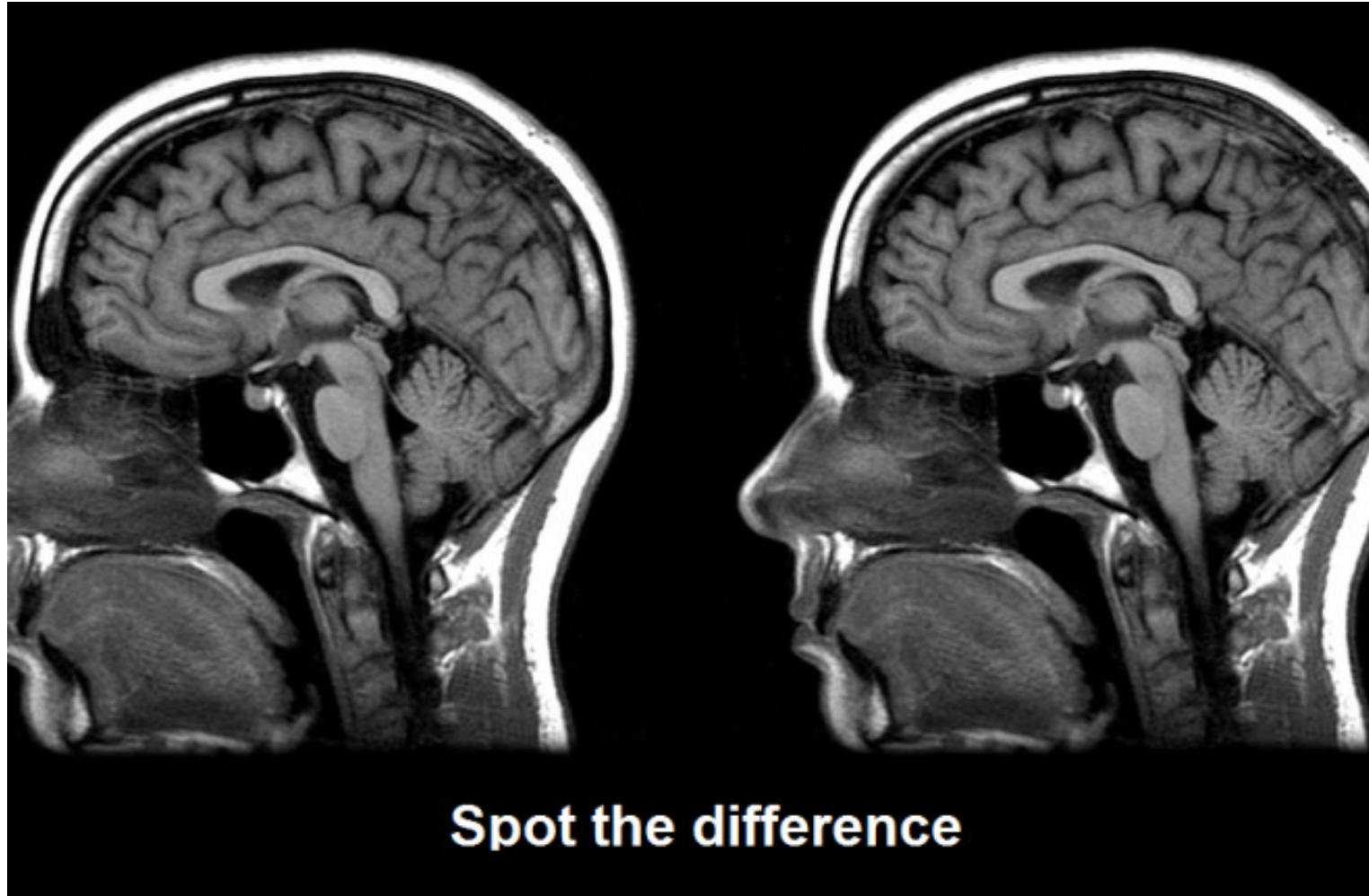
- ▶ It is NOT caused by poor parenting or cold, indifferent mothers
- ▶ There is no need to turn to the supernatural for an explanation
- ▶ No relationship has been found to a specific environmental toxin or viral or other biologic (e.g., no relationship has been found to any vaccine)
- ▶ Genetics is only a partial explanation

Dr. Harry Hercules Wright
January 4, 1948 ~ April 21, 2017 (age 69)



But does it travel in families?

- ▶ Having one child increases the risk but not as much as a single gene disease would
- ▶ It can and does skip generations or occur where there is no family history
- ▶ Many genes involved in brain development are probably involved and these genes do occur in individuals who will never develop autism

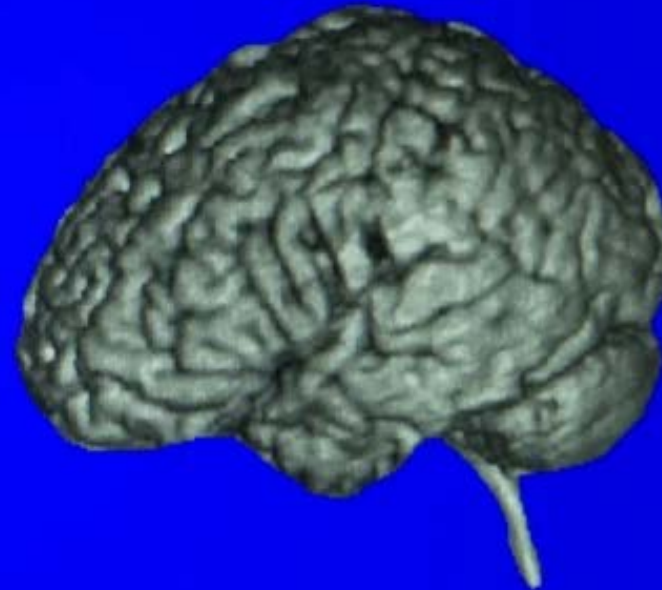


Spot the difference

Autistic Child



Average Normal Child



50mm

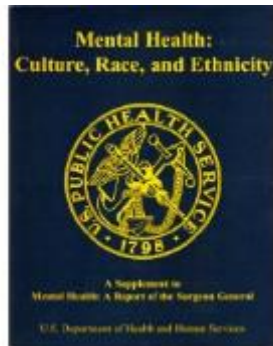
CONSPIRACY BELIEFS WITCHCRAFT



Landmark Reports



Mental Health: A Report of the Surgeon General (1999)
First Surgeon General's Report on Mental Health



Mental Health: Culture, Race, and Ethnicity
A supplement released in 2001

REPORTS

- ▶ SUPPLEMENTAL SURGEON GENERAL'S REPORT ON MENTAL HEALTH OF MINORITIES 2001
- ▶ NO SUBSTANTIAL DIFFERENCE IN PREVALENCE
- ▶ SIGNIFICANT ILLNESS BURDEN
- ▶ LACK OF ACCESS

Autism Spectrum

- ▶ Although it's now possible to diagnose autism in children before age 2, most kids are 4 or older when they receive a diagnosis. In this study involving 584 African American children at four autism centers across the United States, the average African American child already was almost 5½ years old at the time of diagnosis, despite the fact parents first had expressed concerns about their kids' development more than three years earlier. Nationally, White children are diagnosed an average of six months earlier than African American children.

- ▶ The AAP recommends developmental screenings at 9, 18 and 30 months and screening for autism at ages 18 and 24 months. Researchers analyzed data on 584 Black children with autism enrolled in an autism research network at one of four sites and found that on average, children were diagnosed at 65 months, according to [“Timing of the Diagnosis of Autism in African American Children,”](#) (Constantino JN, et al. Pediatrics. Aug. 24, 2020)
- ▶ After parents expressed concerns about their child’s language, development or behavior, it typically took more than three years before being diagnosed with autism, despite almost all of the families having some form of insurance.
- ▶ About 36% reported a significant wait time to see a professional, 42% saw multiple professionals and 14% saw at least six professionals before being diagnosed, according to the study.

Disparities

- ▶ Lack of available professionals to make the diagnosis
- ▶ No medical test to diagnose autism spectrum disorder
- ▶ Access to intervention services

Disparities (cont.d)

- ▶ Hispanic children are 65 percent less likely and black children 19 percent less likely than white children to be diagnosed with autism
- ▶ African-American children on the autism spectrum are 5.1 times more likely to be misdiagnosed with behavior disorders before they are correctly diagnosed with autism

Disparities (cont.d)

- ▶ Poverty levels often are higher in Black communities than in white, non-Hispanic communities. And children of lower socioeconomic status are less likely to be evaluated and diagnosed with ASD than children of higher socioeconomic status.
- ▶ Individuals with ASD and their caregivers face higher costs for things like medical and health care services, therapies and supports, respite care and education than people not affected by ASD. They also face greater loss of productivity at work.
- ▶ There's a lack of quality resources, such as medical providers, schools and inclusive community activities. There's also a lack of support from our faith-based organizations.
- ▶ Janet Williams Outreach director for Autism Speaks

Disparities (cont.d)

- ▶ One of the most common and ominous markers of the effects of these racial disparities in the lives of children with autism involves the rate at which they are additionally affected by intellectual disability. Recently published data collected by Constantino, Rob Fitzgerald, PhD, assistant professor of child psychiatry, and colleagues at other academic institutions, as well as the U.S. Centers for Disease Control and Prevention, show that 22% of White children with autism also have intellectual disability. But among African American children, the rate of intellectual disability in those with autism tops 44%.

Treatment

Medication

A doctor may use medication to treat some symptoms that are common with ASD. With medication, a person with ASD may have fewer problems with:

- Irritability
- Aggression
- Repetitive behavior
- Hyperactivity
- Attention problems
- Anxiety and depression

Treatment

Behavioral, psychological, and educational therapy

People with ASD may be referred to doctors who specialize in providing behavioral, psychological, educational, or skill-building interventions. These programs are typically highly structured and intensive and may involve parents, siblings, and other family members. Programs may help people with ASD:

Learn life-skills necessary to live independently

Reduce challenging behaviors

Increase or build upon strengths

Learn social, communication, and language skills

Nongenetic causes include:

- ▶ Advanced parental age at time of conception (both mom and dad), maternal illness during pregnancy and certain difficulties during birth, particularly those involving periods of oxygen deprivation to the baby's brain. It is important to keep in mind that these factors, by themselves, do not cause autism. Rather, in combination with genetic risk factors, they appear to modestly increase risk.
- ▶ Having a sibling with ASD
- ▶ Having older parents
- ▶ Having certain genetic conditions—people with conditions such as Down syndrome, fragile X syndrome, and Rett syndrome are more likely than others to have ASD
- ▶ Very low birth weight

Applied behavior analysis (ABA)

- ▶ The goals of ABA are to shape and reinforce new behaviors, such as learning to speak and play, and reduce undesirable ones. ABA, which can involve intensive, one-on-one child-teacher interaction for up to 40 hours a week, has inspired the development of other, similar interventions that aim to help those with ASD reach their full potential. ABA-based interventions include:
- ▶ **Verbal Behavior**—focuses on teaching language using a sequenced curriculum that guides children from simple verbal behaviors (echoing) to more functional communication skills through techniques such as errorless teaching and prompting
- ▶ **Pivotal Response Training**—aims at identifying pivotal skills, such as initiation and self-management, that affect a broad range of behavioral responses. This intervention incorporates parent and family education aimed at providing skills that enable the child to function in inclusive settings.

Other interventions

- ▶ Developmental, Individual Difference, Relationship-based(DIR)/Floortime Model
- ▶ TEACCH (Treatment and Education of Autistic and related Communication handicapped Children)
- ▶ Interpersonal Synchrony
- ▶ For children younger than age 3, these interventions usually take place at home or in a child care center. Because parents are a child's earliest teachers, more programs are beginning to train parents to continue the therapy at home.
- ▶ Students with ASD may benefit from some type of social skills training program.

OUTCOMES

Can be positive

Treatment can work



When Medication is Necessary

- ▶ Unfortunately current medications do NOT treat the core disorder
- ▶ Comorbidities may interfere with behavioral and cognitive treatment
- ▶ Treatment behaviorally may cost up to \$60,000 (US) per year
- ▶ Active research in Alzheimer's and schizophrenia to find treatments of these disorders that may overlap autism

Other Medications

- ▶ **Antidepressant medications** are usually prescribed to treat depression and anxiety but are sometimes prescribed to reduce repetitive behaviors. Some antidepressants may also help control aggression and anxiety in children with ASD.
- ▶ **Stimulant medications** Methylphenidate has been shown to effectively treat hyperactivity in children with ASD.

Antipsychotic Medications

- ▶ Long used to treat autistic features these medicines may help reduce aggression and other serious behavioral problems in children, including children with ASD. They may also help reduce repetitive behaviors, hyperactivity, and attention problems.
- ▶ Agents include pimozide (used exclusively for autism in US and haloperidol
- ▶ Only approved medications currently are: risperidone (Risperdal) and aripipazole (Abilify).

Other Areas of Investigation

- ▶ Oxytocin:
 - ▶ Neuromodulator produced by the hypothalamus and released from the pituitary associated with maternal bonding and lactation. It may promote trust and empathy. Unfortunately, there have not been consistent positive results.
 - ▶ Cognitive enhancers of various types including nicotine agonists

Conclusion

- ▶ 1. Early diagnosis is important
- ▶ 2. Every individual is different and needs different treatment options
- ▶ 2. Behavioral treatment options are very effective
- ▶ 3. Medication can help but it is not curative or directly address the core symptoms but hope may be on the horizon
- ▶ 4. Many disciplines are necessary to work together with the family for a good outcome

MUCH NEEDS TO BE DONE



▶ BUT THE PROMISED LAND IS IN SIGHT!

Questions



Appreciation



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