

Navigating Cultural Bias with a Child on the Autism Spectrum

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Plan

- ◆ ASD Diagnostic Criteria & Characteristics
- ◆ Prevalence statistics & Comorbidities
- ◆ Cultural bias/systemic racism in ASD
 - Definitions
 - Impacts
 - Strategies

DSM-5-TR Definition:

Autism Spectrum Disorder (ASD)- 299.00

A. Persistent deficits in **social communication and social interaction** across multiple contexts, as manifested by **all of the the following**, currently or by history (examples are illustrative, not exhaustive; see text):

1. Deficits in social-emotional reciprocity, ranging, for example, from abnormal social approach and failure of normal back-and-forth conversation; to reduced sharing of interests, emotions, or affect; to failure to initiate or respond to social interactions.
2. Deficits in nonverbal communicative behaviors used for social interaction, ranging, for example, from poorly integrated verbal and nonverbal communication; to abnormalities in eye contact and body language or deficits in understanding and use of gestures; to a total lack of facial expressions and nonverbal communication.
3. Deficits in developing, maintaining, and understand relationships, ranging, for example, from difficulties adjusting behavior to suit various social contexts; to difficulties in sharing imaginative play or in making friends; to absence of interest in peers.

DSM-5-TR Definition: Autism Spectrum Disorder 299.00

B. Restricted, repetitive patterns of behavior, interests, or activities, as manifested by at **least two of the following**, currently or by history (examples are illustrative, not exhaustive; see text):

1. Stereotyped or repetitive motor movements, use of objects, or speech (e.g., simple motor stereotypes, lining up toys or flipping objects, echolalia, idiosyncratic phrases).
2. Insistence on sameness, inflexible adherence to routines, or ritualized patterns of verbal or nonverbal behavior (e.g., extreme distress at small changes, difficulties with transitions, rigid thinking patterns, greeting rituals, need to take same route or eat same food every day).
3. Highly restricted, fixated interests that are abnormal in intensity or focus (e.g., strong attachment to or preoccupation with unusual objects, excessively circumscribed or perseverative interests).
4. Hyper- or hyporeactivity to sensory input or unusual interest in sensory aspects of the environment (e.g., apparent indifference to pain/temperature, adverse response to specific sounds or textures, excessive smelling or touching of objects, visual fascination with lights or movement).

DSM-5-TR Definition:

Autism Spectrum Disorder 299.00

C. Symptoms must be present in the early developmental period (but may not become fully manifest until social demands exceed limited capacities or may be masked by learned strategies in later life).

D. Symptoms cause clinically significant impairment in social, occupational, or other important areas of current functioning.

E. These disturbances are not better explained by intellectual disability (intellectual developmental disorder) or global developmental delay. Intellectual disability and autism spectrum disorder frequently co-occur; to make comorbid diagnoses of autism spectrum disorder and intellectual disability, social communication should be below that expected for general developmental level.

ASD- Quick Facts

- ◆ 1 in 44 children identified with ASD in US during 2018 (Center for Disease Control ADDM Network; 2018 report)
- ◆ White > Black > Hispanic
- ◆ 33% also diagnosed with ID
- ◆ 43% identified with ASD when evaluated for developmental concerns by age 3
- ◆ Black & Hispanic kids less likely to be identified for developmental concerns by age 3
- ◆ Most not diagnosed by community provider until >4 years
- ◆ Boys 4.5X more likely to be dx than girls

ASD Quick Facts

- ◆ Fragile X Syndrome, Tuberous Sclerosis associated with ↑ ASD risk
- ◆ Other genetic mutations account up to 20% of all cases
- ◆ Increased risk of seizure disorder- 20-30% develop epilepsy by adulthood
- ◆ Complicated disorder- genetics + environment
- ◆ In families with one child with ASD, risk of 2nd child with dx increases
- ◆ Increased risk of ASD with older parents
- ◆ Emotional disorders occur more frequently in ASD families

Diagnosing ASD

- ◆ Neurodevelopmental Disorder
- ◆ Wide variety of presentations
- ◆ Symptoms change in nature and severity over time
- ◆ Consider comorbidities
- ◆ Particularly challenging to diagnosis in adulthood

Diagnosing ASD

- ◆ Individuals with expertise in ASD
 - Psychologist
 - Pediatrician
 - Neurologist
 - Psychiatrist
 - Speech/Language Pathologist
 - Occupational Therapist

Diagnosing ASD

- ◆ Components of comprehensive evaluation:
 - Developmental history with focus on social functioning (collateral sources)
 - IQ
 - Neuropsychological evaluation (include assessment of emotional functioning)
 - Adaptive functioning assessment
 - Speech/language evaluation

Diagnosing ASD

- ◆ Common measures:
 - Autism Diagnostic Interview-Revised (ADI-R)
 - Autism Diagnostic Observation Schedule-Second Edition (ADOS-2)
 - Social Responsiveness Scale- Second Edition (SRS-2)
 - Social Communication Questionnaire (SCQ)

ASD & Co-morbidities

- ◆ Intellectual Disability
- ◆ Learning Disabilities
- ◆ Mood Disorders
- ◆ Anxiety Disorders
- ◆ Attention-Deficit/Hyperactivity Disorder

Defining Important Terms

(APA Guidelines on Race & Ethnicity in Psychology, 2019)

Race:

the social construction and categorization of people based on perceived shared physical traits that result in the maintenance of a social hierarchy

Although definitions of race

historically included a biological/genetic basis, current scholarship is that race is a social and political construction with no basis in a coherent biological reality

Defining Important Terms: Racism Subtypes

(Derman-Sparks & Brunson Philips, 1997)

Institutional Racism:

Institutional racism occurs within and between institutions. Institutional racism is discriminatory treatment, unfair policies and inequitable opportunities and impacts, based on race, produced and perpetuated by institutions (e.g., schools, mass media, etc.,). Individuals within institutions take on the power of the institution when they act in ways that advantage and disadvantage people, based on race.

Defining Important Terms: Racism Subtypes

(Derman-Sparks & Brunson Philips, 1997)

Systemic/Structural Racism:

The normalization and legitimization of an array of dynamics- historical, cultural, institutional and interpersonal- that routinely advantage whites while producing cumulative and chronic adverse outcomes for people of color. It is a system of hierarchy and inequity, primarily characterized by white supremacy- the preferential treatment, privilege and power for white people at the expense of Black, Latino, Asian, Pacific Islander, Native American, Arab and other racially oppressed people.

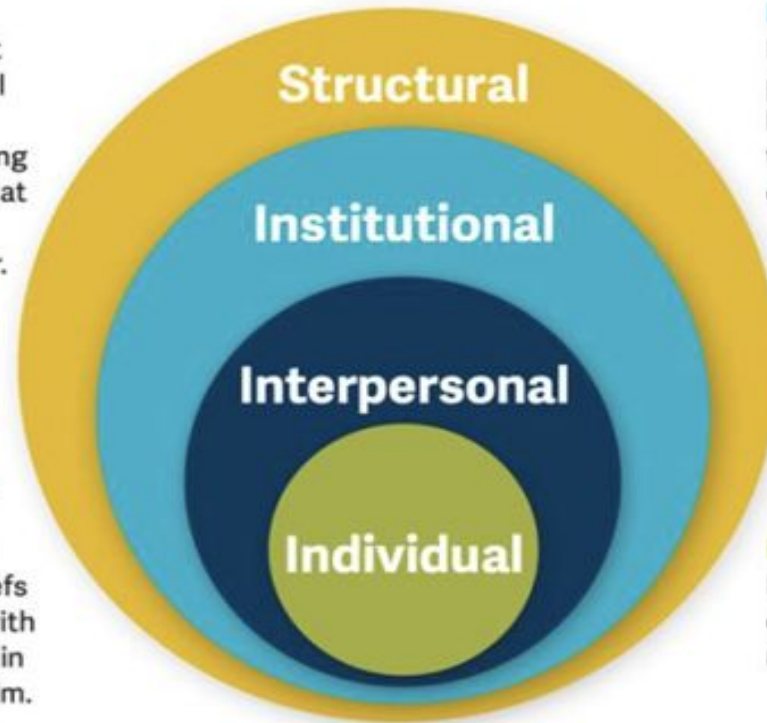
Four levels of change to address four forms of racism

Structural racism

A history and current reality of institutional racism across all institutions, combining to create a system that negatively impacts communities of color.

Interpersonal racism

Occurs between individuals. Once we bring our private beliefs into our interaction with others, racism is now in the interpersonal realm.



Institutional racism

Policies, practices, and procedures that work better for white people than for people of color, often unintentionally.

Individual racism

Pre-judgment, bias, or discrimination based on race by an individual.

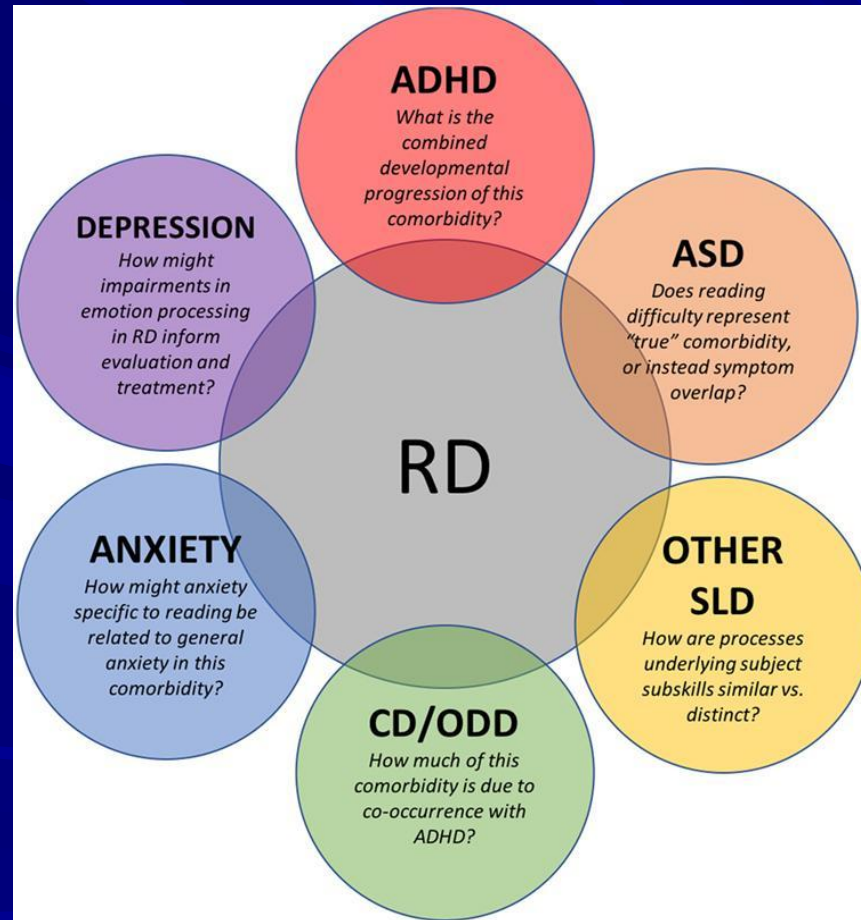
Implicit Bias

“Implicit bias refers to the attitudes or stereotypes that affect our understanding, actions, and decisions in an unconscious manner. These biases, which encompass both favorable and unfavorable assessments, are activated involuntarily and without an individual’s awareness or intentional control. Residing deep in the subconscious, these biases are different from known biases that individuals may choose to conceal for the purposes of social and/or political correctness.”

The Impact of Systemic Racism/Cultural Bias

- ◆ Referral & Diagnosis
- ◆ Assessment
- ◆ Diagnostic classifications
- ◆ School Disciplinary Practices

The Importance (and Challenge) of an Accurate Diagnosis



Issues related to ASD Diagnosis

- ◆ Hispanic/Latinx children 1.2x less likely to be diagnosed with ASD than White children, 1.1x less likely to be diagnosed than Black children (CDC Community Report, 2021)
- ◆ Stigma, lack of access to healthcare services due to non-citizenship/low income, non-English primary language are potential barriers

Issues Related to Diagnosis- ASD

(Habayeb et al., 2021- CNMC)

Fewer Black children received 1st diagnosis of ASD (after age 6) in comparison to White children; later dx in Black children linked to lower IQ, greater # of ASD symptoms

Race-based biases: Misinterpretation of behaviors, misunderstanding cultural norms, reduced responsiveness to parental concerns regarding mild symptoms leads to misdiagnosis with other DDs

White parents more likely to seek out health professionals with ASD concerns:

- Access issues (age out of EI, decreased access to specialty care)
- Cultural- Black parents more likely to attribute subtle symptoms to temperament

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Cultural Bias in Pediatric Psychological/Neuropsychological Assessment

Research (Affeldt, 2000) indicates that discrimination through IQ testing, specifically, has been a contributor to the disproportional placement of African American children in special education (e.g., Larry P vs. Riles case in California in 1979- specifically prohibited using standardized IQ test as sole method of diagnosing MR/ID)

Observed IQ discrepancies may be accounted for by psychosocial factors such as low socioeconomic status, unsafe living conditions, absent family members, poor parental education and occupational status

Other potential sources of bias include family belief systems about illness and disability which impact child's motivation and effort, broader cultural factors (e.g., task approach, family structures), as well as experiences of racism, mistrust/distrust of institutions (disclosure of pertinent, personal information), racial trauma

African American and Hispanic/Latinx children are underrepresented in standardization samples, research on test bias lacking (i.e., psychometric properties of tests, etc.)

Cultural Bias in Pediatric Psychological/Neuropsychological Assessment

(Zuckerman et al., 2014)

Few providers provide developmental screening in Spanish

Spanish-language primary parents are less likely to be asked about their developmental concerns, even when the child is at risk for a developmental delay

Hispanic/Latinx parents frequently report that providers do not listen to their concerns or provide needed information

The Impact of Systemic Racism/Cultural Bias

- ◆ Referral & Diagnosis
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- ◆ School Disciplinary Practices

Studies have found...

- Black students are 40% more likely to be identified as having educational disabilities than their peers...and Black students are twice as likely to be identified as having emotional disturbance and intellectual disability as their peers.¹
- Among families of students with disabilities, those with lower incomes and who have children of color are less likely than their affluent and white counterparts to access their legal rights under IDEA - *GAO November 2019*¹

¹ 38th Annual Report to Congress on the Implementation of the Individuals with Disabilities Education Act, 2016



Disproportionality

Refers to a group's representation in a particular category that exceeds expectations for that group or differs substantially from the representation of others in that category.

Disproportionality/Misdiagnosis

- ◆ Hispanic/Latinx students are overrepresented in special education
- ◆ In some parts of the country- bilingual students are four times more likely to be diagnosed with a speech/language disorder than white students
- ◆ Hispanic/Latinx students more likely to be diagnosed incorrectly with a learning disability when English is not their first language

Disproportionality in Identification

“...child’s race and ethnicity are significantly related to the probability that he or she will be inappropriately identified as disabled” - National Research Council, 2002



Ages 6 to 11 Black students 1.4% identification with disability	Ages 6 to 11 White students, .9% identification with disability
USDE 2019	
Ages 6 to 21 Black Students 2.22x Intellectual Disabilities	Ages 6 to 21 Black Students 2.08x Emotional Disturbance

....disproportionality is due to “institutional racism, stereotypes, cultural incompetence, racial bias, and inequitable discipline policies”

- Lehr and McComas’2006 article (as cited in Chakaborti-Ghosh, Mo eld, & Orellana, 2010)

The Impact of Systemic Racism/Cultural Bias

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Disproportionality in Discipline



SUSPENSIONS, RACE & DISABILITY

Likelihood of Being Suspended at Least Once

WHITE  1/20

LATINO  1/14

NATIVE AMER.  1/13

BLACK  1/6

BLACK WITH DISABILITY  1/4

Advancement Project

Black children with disabilities face an especially acute problem with being served appropriately, often being subjected to disparate discipline punishment compared to their White-non-Hispanic peers

- 2019 U.S. Commission on Civil Rights

Suspending students has dangerous recourse, including missed time from class that researchers have found can lead to more dangerous consequences, such as disenfranchisement and also including the school-to-prison pipeline

-Cavanagh et al., 2014; Rios & Galicia, 2013

The effects of irresponsible discipline, including imposing punitive measures without understanding the consequences, may affect a student's outcome in their adult life

- Gregory & Weinstein, 2008

School to Prison Pipeline

Percentage of adolescents with disabilities is 33% higher in correctional facilities than in public school special education

(Further, Quinn, Rutherford, Leone, Osher, and Poirier, 2005)

African American children make up 1/2 of all students with disabilities in correctional facilities



Sixty (60%) percent of people in local jails have some form of mental disability.

America Civil Liberties Union

ASD in the Criminal Justice System

- ◆ Research is sparse and confounded by criteria, setting, small sample sizes, questionable control samples
- ◆ Rates vary depending on setting (i.e., psychiatric hospital/prison, community), data collection point (while in custody, history of involvement but not currently incarcerated)
- ◆ Individuals with ASD likely over-represented in criminal justice system, particularly arson?
- ◆ No compelling evidence that diagnosis of ASD alone is indicative of greater likelihood of criminal involvement

Strategies: What We Can Do

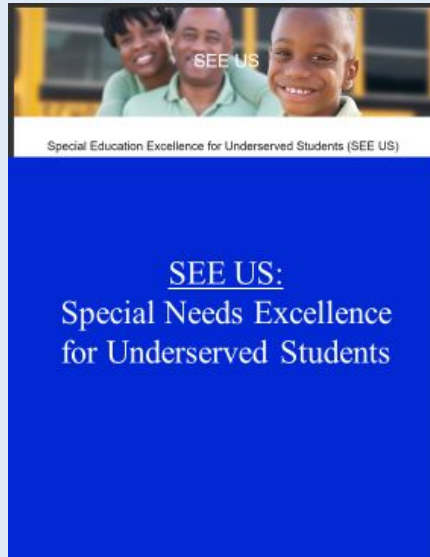
- ◆ Educate teachers/healthcare providers re: ASD, cultural bias, impact of systemic racism at all levels
- ◆ Provide parents of color more access to information on ASD
- ◆ Provide more sources of high-quality support to parents/caregivers navigating special education process and other ASD services

Anti-Racism

Individual and/or group commitment to develop the personal strength, critical-thinking ability, and activist skills to both dismantle dysfunctional and oppressive institutions and to work with others to build caring, just, diverse communities and societies for all



Free Special Education Advocacy Service, through Special Needs Excellence for Underserved Students



- Disproportionality in special education identification and services negatively impact Black students.
- WEG’s advocacy makes a difference in the identification and services for all students served. (approx. 91%)
- Black families access advocacy services less than White families.
- The WEG initiative, SEE US seeks to remove obstacles Black families may encounter in order to receive high quality advocacy services.
- WEG desires to identify and ensure appropriate services for Black students through Special Education advocacy.

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Questions?

