



The New York State Autism Spectrum Disorder Advisory Board

From Cultural Competence to Cultural Humility: A Parent's Perspective

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Introduction

- ❖ Defining Terms
- ❖ Three Areas Affected by Lack of Cultural Humility
 - Medical
 - Clinical
 - Educational
- ❖ Next Steps
- ❖ Questions
- ❖ References



Black Indigenous People Of Color



- ❖ *BIPOC* is a term referring to “Black and/or Indigenous People of Color.” While *POC* or “People of Color” is often used as well, *BIPOC* explicitly leads with Black and Indigenous identities, which help to counter anti-Black racism and invisibilization of Native communities.



Reference: [Creating Cultures and Practices for Racial Equity: A Toolbox for Advancing Racial Equity for Arts and Cultural Organizations](#), Nayantara Sen & Terry Keleher, Race Forward (2021).

Background Information

- ❖ According to the CDC, “A growing body of research shows that centuries of racism in this country has had a profound and negative impact on communities of color. The impact is pervasive and deeply embedded in our society—affecting where one lives, learns, works, worships and plays and creating inequities in access to a range of social and economic benefits—such as housing, education, wealth, and employment. These conditions—often referred to as social determinants of health—are key drivers of health inequities within communities of color, placing those within these populations at greater risk for poor health outcomes.”

Reference: <https://www.cdc.gov/healthequity/racism-disparities/index.html>



Social Determinants of Health



Cultural Competence

❖ Says “*I know who you are.*”



HUMILITY



laot

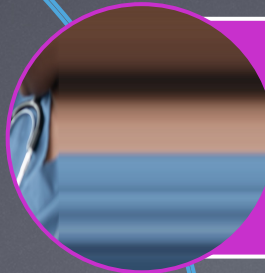
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Cultural Humility

SAYS "TELL ME WHO YOU ARE."

Important Areas Of Consideration When Thinking About Moving From Cultural Competency To Cultural Humility



Medical

❖ Doctors, Nurses, Physician Assistants and Others



Clinical

❖ Licensed Clinical Social Workers (LCSW),
Psychiatrists, Psychologists



Educational

❖ Teachers, School Psychologists, Individual Educational
Program (IEP) Teams, and Other School Personnel

this is NOT an exhaustive list

Medical

- ❖ What happens when medical professionals do not understand cultural
- ❖ humility?
 - Misdiagnosis
 - *“(Mandell et al. 2002). African American children are also 2.6 times more likely to be misdiagnosed than Caucasian children, including 5.1 times more likely to receive a “misdiagnosis of adjustment dis- order and 2.4 times more likely to receive a conduct dis- order misdiagnosis (Mandell et al. 2007).*
 - *African American children meeting ASD diagnostic criteria are less likely than Caucasian children to have a prior ASD diagnosis, but more likely to have co-occurring ASD and intellectual disability diagnoses (Baio et al. 2014; Bhasin and Schendel 2007; Mandell et al. 2009).*
 - *Lastly, African American children are more likely to be diagnosed with autism rather than Asperger subtype when compared with Caucasian children (Baio et al. 2014)”*



Clinical



❖ What happens when clinicians do not understand cultural humility?

- misdiagnosis
- missed opportunities for early intervention
- Inappropriate referrals for services
- Missed opportunities to ask questions and learn about family systems
- Implicit biases arise
- Microaggression (unintended)
- “Know it all” attitude
- Families do not return for treatment

Education

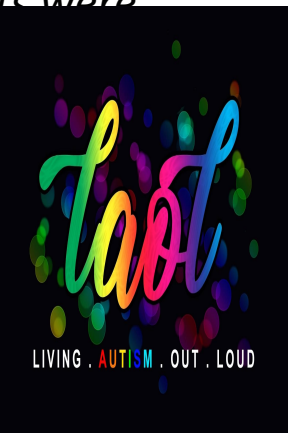


❖ What happens when educators do not understand their BIPOC students?

- higher rates of placement in special education settings for students of color (especially males)
- harsher discipline for similar behaviors (i.e., seclusion, restraints, etc.)
 - *“In schools with reported use of restraint or seclusion at least 10 times, students with disabilities were 200% more likely to be subject to restraint or seclusion relative to their peers; students attending elementary schools were more likely to receive restraint or seclusion than students attending secondary schools. Similarly, Black students were almost 200% more likely and Hispanic students were 45% more likely to experience a restraint or seclusion than their White counterparts.”*

Reference: Katsiyannis, A., Gage, N.A., Rapa, L.J. et al. Exploring the Disproportionate Use of Restraint and Seclusion Among Students with Disabilities, Boys, and Students of Color. *Adv Neurodev Disord* **4**, 271–278 (

<https://doi.org/10.1007/s41252-020-00160-z>





What happens
when
educators
don't
understand
Cultural
Humility:
Personal
Example

- ▶ My son was placed in a “specialized program” for children with Autism, however it did not take long for me to figure out that the placement was for children with mental health needs and that he was the only person with Autism in the classroom.
- ▶ Every child in the classroom was a child of color for the two years that my son remained in the program
- ▶ Teachers saw no distinction between autism and mental health
- ▶ Teachers saw no issues with three classrooms being filled with primarily black and brown children
- ▶ Teacher stated: “There is nothing you can tell me about Autism, your son is no different”

Long term affects on BIPOC families of Children with Autism/IDD



- ▶ Lack of resources to afford treatment after diagnosis (ABA therapy)
- ▶ Lack of providers who accept insurance (Medicaid)
- ▶ Lack of community resources to support families with children with disabilities which also leads to caregiver stress
- ▶ Lack of diversity in providers
- ▶ Lack of educational resources
- ▶ Lack of support for parents who have to navigate complicated systems/services
- ▶ Increased caregiver stress can lead to issues for children educational system
- ▶ Increased caregiver stress which leads to poor health care outcomes

Next Steps

- ❖ Consider changing the language from cultural competence to cultural humility.
- ❖ Build training around cultural humility.
- ❖ Consider a needs assessment specific to the areas of concern.
- ❖ Consider anti-racist training for providers.
- ❖ Work with community organizations to improve BIPOC family engagement.
- ❖ Hire diverse staff in agencies
- ❖ Open lines of communication and be open to hearing real concerns

References



- ❖ <https://www.cdc.gov/socialdeterminants/index.htm>
- ❖ <https://www.cdc.gov/healthequity/racism-disparities/index.html>
- ❖ [*Creating Cultures and Practices for Racial Equity: A Toolbox for Advancing Racial Equity for Arts and Cultural Organizations*](#), Nayantara Sen & Terry Keleher, Race Forward (2021).
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- ❖ <https://healthcity.bmc.org/policy-and-industry/cultural-humility-vs-cultural-competence-providers-need-both>



Questions/Answers

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**THANK
YOU**

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