



SESSION IV

Autism & Race: Engaging Racially & Ethnically Diverse Communities in Autism Research

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July 15, 2021 // 10:00 am EDT

Course Materials

The purpose of these materials is to help provide an introduction to the INSAR Institute session on understanding autism research and the experiences of racially and ethnically diverse autistic people. The materials were designed to prepare students and trainees who are unfamiliar with this research with the general background to receive the most educational benefit from the session. Toward this objective, we have prepared the following: (1) learning objectives for this session, (2) key terms and concepts, (3) a selection of recommended resources. These materials are considered supplemental to the presentation.

In collaboration with Dr. Sarah Dababnah, Yetta Myrick, and Dr. Charina Reyes, these materials were developed by **Dr. Alana McVey** (Postdoctoral Research Fellow at The University of British Columbia, Canada; amcvey@psych.ubc.ca), **Fathima Kodakkadan** (Doctoral Student at Anglia Ruskin University, Cambridge, UK; muhsinak19@gmail.com), **Dr. Nick Fears** (Postdoctoral Research Fellow in the School of Kinesiology at the University of Michigan, USA; nfears@umich.edu), and **Desi Jones** (4th year doctoral student at the University of Texas at Dallas, USA; desi.jones@utdallas.edu). Feel free to contact us with questions/comments. Register for this webinar and other sessions in this series at: <https://www.autism-insar.org/page/Institute2021>.

Learning Objectives

The INSAR Institute for Autism Research was established in direct response to requests from students and trainees for multidisciplinary training opportunities. The INSAR Institute team is also working to engage stakeholders. The INSAR Institute priorities are to provide a (1) freely available, (2) multidisciplinary training platform for young scientists and others from various backgrounds that (3) allows for international participation. The overarching goal of the INSAR Institute is to expose junior scientists to topics they are not currently engaged in, with the hope that basic scientists and clinical scientists may learn from each other to ultimately advance the understanding of autism.

The current session, “Autism & Race: Engaging Racially & Ethnically Diverse Communities in Autism Research,” is led by Dr. Sarah Dababnah, Yetta Myrick, and Dr. Charina Reyes. At the conclusion of this session, participants will:

1. **Understand** the disparities racial and ethnic minorities face in receiving autism diagnostic and treatment services
2. **Discuss** the racist and classist history that contributes to barriers for Black and African American families in engaging in autism research and how to facilitate engagement
3. **Learn** about the barriers Asian American families experience in engaging in autism research and how to overcome them

Key Terms

African Americans/Black Americans: The US Black population has a variety of cultural and ethnic identities and experiences. This includes those who identify their race as Black, with or without other racial backgrounds, as well as Asian and/or Hispanic/Latinx people who identify their race as Black.

(<https://www.pewresearch.org/social-trends/fact-sheet/facts-about-the-us-black-population/>)

Asian Americans: This group is comprised of people who originate from more than 20 countries in East and Southeast Asia and the Indian subcontinent, although 6 origins represent 85% of Asian Americans

(<https://www.pewresearch.org/fact-tank/2021/04/29/key-facts-about-asian-americans/>)

Black: “of or relating to any of various population groups of especially African ancestry often considered as having dark pigmentation of the skin but in fact having a wide range of skin colors.” “NOTE: Capitalization of Black in this use is now widely established.”

(<https://www.merriam-webster.com/dictionary/black>)

Community-Based Participatory Research (CBPR): CBPR is an approach in which researchers undertake research in partnership with those affected by the issue being studied, for the purpose of taking action or effecting social change; it can also incorporate those who will use the results to change practice and inform policy.

(<https://www.oxfordbibliographies.com/>)

Research-Community Partnerships: Refer to formal collaborative relationships between researchers and community stakeholders regardless of the purpose of the collaborative activities and theoretical model used to define the partnership.

(<https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4500757/>)

Clinical-Community Partnerships: Relationships to connect health care providers, community organizations, and public health agencies so they can improve patients' access to preventive and chronic care services by coordinating services at one location, coordinating services between different locations, and developing ways to refer patients to resources.

(<https://www.ahrq.gov/ncepcr/tools/community/index.html>)

Culture: A pattern of learned and shared behavior and beliefs of a particular social, ethnic, or age group.

(<https://courses.lumenlearning.com/culturalanthropology/chapter/what-is-culture/>)

Disparities: Generally, a disparity is a large difference between two things. Health disparities are defined as preventable differences in the burden of disease, injury, violence, or opportunities to achieve optimal health that are experienced by socially disadvantaged populations.

(<https://www.cdc.gov/healthyyouth/disparities/index.htm#1>)

Ethnicity: Groups that share a common identity-based ancestry, language, or culture. It is often based on religion, beliefs, and customs as well as memories of migration and colonization. Ethnicity is distinct from race. For instance, a person may identify their race as Black while also identifying as Latina in terms of ethnicity.

(<https://genderedinnovations.stanford.edu/terms/race.html>)

Intellectual Disability: A neurodevelopmental disorder defined by limitations in cognitive abilities that affect both intellectual and adaptive functioning. Ability to learn, problem solve, and reason are all involved in intellectual functioning, which is generally quantified using an intelligence quotient (IQ) test. Intellectual disability is defined as an IQ ≤ 70 and reduced adaptive functioning. Adaptive functioning is typically measured using standardized questionnaires or interviews completed by caregivers and/or teachers. Skills that are necessary

for day-to-day functioning, such as communication and practical skills, make up the adaptive functioning domain. At least one-third of autistic people have co-occurring intellectual disability.

Intersectionality: “The term intersectionality, coined by Dr. Kimberlé Crenshaw in 1989, refers to the way in which categories such as sex, gender, disability, and ethnicity do not stand alone but rather interact (and intersect) in complex ways that affect individual experience, notably to increase marginalization and discrimination” (see the reference to Cascio et al., 2021 below). In this event, we focus on the intersectionality between autism and poverty, and how they interact and influence individual experience.

Hispanic vs. Latino, Latina, Latinx/Latine, Latin America: The terms Latino (masculine) and Latina (feminine) are ethnicities that have historically been used to refer to anyone born in or with ancestors from Latin America. Recently, the terms Latinx and Latine have emerged as more inclusive, gender-neutral alternatives to these terms. Hispanic is a narrower term that includes only people from Spanish-speaking Latin America, and Spain itself. Both are considered ethnicities and include members from a variety of different races. Latin America refers to countries in the Americas in which Spanish, Portuguese, or French have historically been spoken, including Mexico, Haiti, the Dominican Republic, and all of South America. (<https://www.britannica.com/story/whats-the-difference-between-hispanic-and-latino>; <https://www.pewresearch.org/hispanic/2020/08/11/about-one-in-four-u-s-hispanics-have-heard-of-latinx-but-just-3-use-it/>; <https://www.vox.com/the-highlight/2019/10/15/20914347/latin-latina-latino-latinx-means>; <https://www.britannica.com/place/Latin-America>)

Poverty: Not having enough money to meet basic needs including food, clothing, healthcare, and shelter.

(https://www2.gnb.ca/content/gnb/en/departments/esic/overview/content/what_is_poverty.html; <https://www.habitat.org/stories/what-is-poverty>)

Race: While race has historically been defined in numerous ways from social, biological, anthropological, and genetic perspectives across time and countries. Modern research suggests that racial identities are abstract, and not strongly associated with genetic or biological diversity. Instead, race is considered a social construct, based on shared physical and cultural characteristics. Currently, the United States government uses a social definition of race based on place of origin. For example, Black or African American is defined as “a person having origins in any of the Black racial groups of Africa” and Asian is defined “as a person having origins in any of the original peoples of the Far East, Southeast Asia, or the Indian subcontinent including, for example, Cambodia, China, India, Japan, Korea, Malaysia, Pakistan, the Philippine Islands, Thailand, and Vietnam”. Many people are biracial or multiracial, with roughly 7 percent of Americans identifying as two or more races.

(<https://www.livescience.com/difference-between-race-ethnicity.html>; <https://www.census.gov/topics/population/race/about.html>; <https://www.theatlantic.com/national/archive/2013/05/what-we-mean-when-we-say-race-is-a-social-construct/275872/>;

<https://www.scientificamerican.com/article/race-is-a-social-construct-scientists-argue/>;
<https://www.pewresearch.org/social-trends/2015/06/11/chapter-2-counting-multiracial-americans/>
)

Stigma: This involves negative attitudes or discrimination against someone based on a distinguishing characteristic such as a mental illness, health condition, or disability.
(<https://www.verywellmind.com/mental-illness-and-stigma-2337677>)

Recommended Readings & Resources

Cascio, M. A., Weiss, J. A., & Racine, E. (2021). Making Autism Research Inclusive by Attending to Intersectionality: A Review of the Research Ethics Literature. *Review Journal of Autism and Developmental Disorders*, 8(1), 22–36. <https://doi.org/10.1007/s40489-020-00204-z>

Čolić, M., Araiba, S., Lovelace, T. S., & Dababnah, S. (2021, January 28). Black Caregivers' Perspectives on Racism in ASD Services: Towards Culturally Responsive ABA Practice. *Behavior Analysis in Practice*, 1-10. <https://doi.org/10.31234/osf.io/rp9am>

Dababnah, S., Shaia, W. E., Campion, K., & Nichols, H. M. (2018). "We Had to Keep Pushing": Caregivers' Perspectives on Autism Screening and Referral Practices of Black Children in Primary Care. *Intellectual and Developmental Disabilities*, 56(5), 321-336.
<https://doi.org/10.1352/1934-9556-56.5.321>

Dababnah, S., Kim, I., & Shaia, W. E. (2021). I am so fearful for him: a mixed-methods exploration of stress among caregivers of Black children with autism. *International Journal of Developmental Disabilities*, 1-13. <https://doi.org/10.1080/20473869.2020.1870418>

Habayeb, S., Dababnah, S., John, A., & Rich, B. (2020). Cultural experiences of Arab American caregivers raising children with autism spectrum disorder. *Journal of autism and developmental disorders*, 50(1), 51-62. <https://doi.org/10.1007/s10803-019-04218-3>

Katigbak, C., Foley, M., Robert, L., & Hutchinson, M. K. (2016). Experiences and lessons learned in using community-based participatory research to recruit Asian American immigrant research participants. *Journal of Nursing Scholarship*, 48(2), 210-218.
<https://doi.org/10.1111/jnu.12194>

Kim, I., Dababnah, S., & Lee, J. (2020). The influence of race and ethnicity on the relationship between family resilience and parenting stress in caregivers of children with autism. *Journal of autism and developmental disorders*, 50(2), 650-658.
<https://doi.org/10.1007/s10803-019-04269-6>

Magaña, S., Lopez, K., Aguinaga, A., & Morton, H. (2013). Access to diagnosis and treatment services among Latino children with autism spectrum disorders. *Intellectual and developmental disabilities*, 51(3), 141-153. <https://doi.org/10.1352/1934-9556-51.3.141>

Shaia, W. E., Nichols, H. M., Dababnah, S., Campion, K., & Garbarino, N. (2020). Brief report: participation of black and African-American families in autism research. *Journal of autism and developmental disorders*, 50(5), 1841-1846. <https://doi.org/10.1007/s10803-019-03926-0>