



SESSION I

The Role of Culture on Autism Diagnosis and Treatment

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Course Materials

The purpose of these materials is to help provide an introduction to the INSAR Institute session on understanding autism research and autistic people's experiences across cultures. 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. Angelina Kakooza-Mwesige, these materials were developed by **Sowmyashree Kaku** (Postdoctoral Clinical Research Associate at St John's Medical College Hospital, Bangalore, India; sowmeey@gmail.com), **Fathima Muhsina Kodakkadan** (Doctoral Student at Anglia Ruskin University, UK; muhsinak19@gmail.com), **Alan Gerber** (Doctoral Student at Stony Brook University, USA; alan.gerber@stonybrook.edu) and **Hillary Schiltz, M.S.** (Doctoral Candidate at Marquette University, USA; hillary.schiltz@marquette.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, The Role of Culture on Autism Diagnosis and Treatment, is led by Dr. Angelina Kakooza-Mwesige. A team of trainees worked in tandem to prepare this handout and the web presentation. *At the conclusion of this session, participants will:*

1. **Understand** cultural perspectives, and their influence on the etiology, diagnosis, and treatment of autism
2. **Identify** cultural perspectives from both the developing and developed world
3. **Discuss** implications of these cultural perspectives for professionals for understanding family beliefs about autism, treatment, and family expectations

Key Terms

Culture: Culture is the collective term used for the ideas, customs, and social behaviour of a particular people or society. It includes collective beliefs, customs, values, and behaviors of a group as well as values, norms, folkways, and symbols of people. It can also be described as the complex whole of collective human beliefs with a structured stage of civilization that can be specific to a nation or time period.

Developing/Developed World: Countries are placed into groups to try to better understand their social and economic outcomes. The most widely accepted criterion is labeling countries as either developed or developing countries. Global South, Low and Middle Income Countries are terms for developing countries. High Income Countries, Advanced/Industrialized countries are the terms for developed countries

Etiology: Etiology is the cause or set of causes of a specific condition. It can also refer to the investigation of the cause or reason for something.

Evidence-Based Treatments: Evidence-based treatments (EBTs) are supported by current research evidence. EBTs require integration of three major components for medical decision making: 1) the external evidence, 2) individual practitioner's clinical expertise and experiences, and 3) patients' preferences, values and concerns.

References for key terms -

- <http://people.tamu.edu/~i-choudhury/culture.html>
- <https://www.a4id.org/policy/understanding-the-developeddeveloping-country-taxonomy/>
- <https://www.merriam-webster.com/dictionary/etiology>

- <https://www.apta.org/patient-care/evidence-based-practice-resources/components-of-evidence-based-practice>

Recommended Readings & Resources

Al Maskari, T. S., Melville, C. A., & Willis, D. S. (2018). Systematic review: cultural adaptation and feasibility of screening for autism in non-English speaking countries. *International journal of mental health systems*, 12(1), 1-19. <https://doi.org/10.1186/s13033-018-0200-8>

Burkett, K., Morris, E., Manning-Courtney, P., Anthony, J., & Shambley-Ebron, D. (2015). African American families on autism diagnosis and treatment: The influence of culture. *Journal of Autism and Developmental Disorders*, 45(10), 3244-3254. <https://doi.org/10.1007/s10803-015-2482-x>

Cascio, M.A. Cross-Cultural Autism Studies, Neurodiversity, and Conceptualizations of Autism. *Cult Med Psychiatry* 39, 207–212 (2015). <https://doi.org/10.1007/s11013-015-9450-y>

Davenport, M., Mazurek, M., Brown, A., & McCollom, E. (2018). A systematic review of cultural considerations and adaptation of social skills interventions for individuals with autism spectrum disorder. *Research in Autism Spectrum Disorders*, 52, 23-33. <https://doi.org/10.1016/j.rasd.2018.05.003>

de Leeuw, A., Happé, F., & Hoekstra, R. A. (2020). A conceptual framework for understanding the cultural and contextual factors on autism across the globe. *Autism Research*, 13(7), 1029-1050. <https://doi.org/10.1002/aur.2276>

Ennis-Cole, D., Durodoye, B. A., & Harris, H. L. (2013). The impact of culture on autism diagnosis and treatment: Considerations for counselors and other professionals. *The Family Journal*, 21(3), 279-287. <https://doi.org/10.1177/1066480713476834>

Freeth, M., Milne, E., Sheppard, E., & Ramachandran, R. (2014). Autism across cultures: Perspectives from non-western cultures and implications for research. *Handbook of Autism and Pervasive Developmental Disorders, Fourth Edition*. <https://doi.org/10.1002/9781118911389.hautc43>

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La Roche, M. J., Bush, H. H., & D'Angelo, E. (2018). The assessment and treatment of autism spectrum disorder: A cultural examination. *Practice Innovations*, 3(2), 107-122. <https://doi.org/10.1037/pri0000067>

Mandell, D. S., & Novak, M. (2005). The role of culture in families' treatment decisions for children with autism spectrum disorders. *Mental retardation and developmental disabilities research reviews*, 11(2), 110-115. <https://doi.org/10.1002/mrdd.20061>

Olusanya, B. O., de Vries, P. J., & African Consortium of The Global Research on Developmental Disabilities Collaborators (2018). Nurturing care for children with developmental disabilities: a moral imperative for sub-Saharan Africa. *The Lancet Child & Adolescent Health*, 2(11), 772-774. [https://doi.org/10.1016/S2352-4642\(18\)30281-5](https://doi.org/10.1016/S2352-4642(18)30281-5)

Qi, X., Zaroff, C. M., & Bernardo, A. B. (2016). Autism spectrum disorder etiology: Lay beliefs

and the role of cultural values and social axioms. *Autism*, 20(6), 673-686.
<https://doi.org/10.1177/1362361315602372>

Ravindran, N., & Myers, B. J. (2012). Cultural influences on perceptions of health, illness, and disability: A review and focus on autism. *Journal of Child and Family Studies*, 21(2), 311-319. <https://doi.org/10.1007/s10826-011-9477-9>