



## **SESSION 6: Translation of Research and Services Across Cultures: Autism in India**

**Dr. Nidhi Singhal**

August 24, 2017 // 12:00 pm EDT

### **Course Materials**

The purpose of these materials is to help provide an introduction to the Summer Institute session on research and services for autism in India. The materials were designed to prepare trainees who are unfamiliar with research on services for individuals with autism in India with the general background to get the most educational benefit from Dr. Singhal's presentation. Toward this objective, we have prepared the following: (1) learning objectives for this session; (2) some key terms and concepts to become familiar with research and services for autism in India; (3) some broad review articles that are recommended reading. These materials could be considered "prerequisites" in preparing for Dr. Singhal's presentation.

In collaboration with Dr. Singhal, these materials were developed by the trainee group for this session:

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Feel free to contact us with questions/comments.

## **Learning Objectives**

The Summer Institute for Autism Research was established in direct response to requests from early career researchers (graduate students, postdocs, etc.), who asked INSAR for greater training opportunities in multidisciplinary topics. In designing the Summer Institute, the priorities were: (1) to provide a multidisciplinary training platform for young scientists from various backgrounds; (2) allow international participation; and (3) make it freely available. Thus, the Summer Institute covers broad topics (which are geared to researchers outside the respective topic areas), is offered over a free web platform, and allows researchers from around the world to connect with the presenter. The overarching goal of the Summer Institute is to expose junior scientists to topics they are not currently engaged in, with the hope that basic scientists and clinical scientists could learn from each other to ultimately advance the understanding of autism spectrum disorders.

The current session, Translation of Research and Services Across Cultures: Autism in India is lead by Dr. Nidhi Singhal and a team of trainees who worked in tandem to prepare these materials and the web presentation. The learning objectives for attendees of this session include:

- To obtain a broad overview of the current research and services in India for individuals with autism spectrum disorders.
- To learn about legislature for individuals with disabilities in India.
- To identify possible ethical risks involved in conducting research with individuals with ASD in low resourced countries.
- To gain knowledge of current genetic, epidemiological, and interventions currently being conducted in India with individuals with ASD

## Glossary of Terms

Below is a breakdown of some of the technical terminology used in this session.

**AFA:** Action for Autism <http://www.autism-india.org/>

**Coercive participation:** When there is implicit or overt threat of harm to potential or enrolled research participants by the research recruiters or investigators, in order to obtain consent to participate in research. This is especially common in areas with limited resources. An example might be: an investigator may tell a family that they will lose access to services if they do not participate in research.

**Ecocultural:** A term used in research when both ecological and cultural aspects are considered together. For example, when the developmental pathways considered within a cultural community. These pathways look different for each community. In autism research, daily routines are frequently an ecocultural focus, as the daily activities in which children typically engage in will differ from one culture to another.

**ELSI:** Ethical, legal and social implications

**Ethical guidelines:** Ethical guidelines are intended to minimize the possibility of exploitation and ensure that the rights and welfare of subjects are respected.

**GAPH Funding:** Autism Speaks created the Global Autism Public Health Initiative (GAPH) to collaborate with families, professionals, advocacy groups, and governments around the world. With more than 70 countries, the GAPH's initiative include innovation in service delivery, epidemiological research, and guiding policy and research priorities. GAPH funding is provided to programs who aim to work towards these initiatives, as well as developing global solutions, empowering global leaders, and creating regional networks funding.

**ICMR:** Indian Council of Medical Research <http://www.icmr.nic.in/>

**LMIC:** Low or middle income. Seventy-five of approximately 120 countries in which an ASD-specific organization has been established are low or middle income.

**NGO:** Nongovernmental organizations. NGOs typically refer to organizations that are not-for-profit, private, and self-governing.

## **Background Readings**

Vaidya, S. (2016). *Autism and the Family in Urban India - Looking Back, Looking Forward*. Springer

Daley, T.C., Singhal, N., & Krishnamurthy, V. (2012). Ethical Considerations in Conducting Research on Autism Spectrum Disorders in Low and Middle Income Countries. *Journal of Autism and Developmental Disorders*, DOI 10.1007/s10803-012-1750-2.

Daley, T. C., Singhal, N. & Barua, M. (2012, May). Autism spectrum disorders in India: A comprehensive review of the literature. Paper presented at the International Meeting for Autism Research, Toronto, Canada.

Grinker, R. R., Yeargin-Allsopp, M. & Boyle, C. (2011). Culture and Autism Spectrum Disorders: The Impact on Prevalence and Recognition. In D.G. Amaral, G. Dawson & D.H. Geschwind (Eds.), *Autism Spectrum Disorders*, pp. 112-136. New York: Oxford University Press.