



## **SESSION 3: Cross Cultural View of ASD - An Anthropological Perspective**

**Professor Roy Richard Grinker**

**George Washington University**

3 August 2017 // 11:00 am EST //

### **Course Materials**

The purpose of these materials is to help provide an introduction to the Summer Institute session on ethics and participation in autism research. The materials were designed to prepare trainees who are unfamiliar with anthropological approaches to autism research with the general background to get the most educational benefit from Professor Grinker's presentation. Toward this objective, we have prepared the following: (1) some key terms and concepts to become familiar with ethical issues and participatory research; (2) some recommended reading. These materials could be considered "prerequisites" in preparing for Professor Grinker's presentation.

In collaboration with Professor Grinker, these materials were developed by **Ashley Stevens, PhD** (postdoctoral fellow at the University of Utah) and Abigail Pioch (George Washington University).

Register for this course and other sessions in this series at [autism-insar.org](http://autism-insar.org).

## 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 second 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.

## Terminology

**Culture:** There is no single definition of this broad term. Generally, however, it refers to the system of meanings that people attach to the phenomena they perceive and produce. Culture pervades all aspects of life, such as religion, economics, politics, and aesthetics, and comprises the shared ideas and knowledge that underlie social action.

**Society:** Unlike culture, society frequently refers to the actual patterns of interaction among humans. Some aspects of society and culture can change independently of one another, as when a set of religious beliefs persists alongside new kinds of social relations.

**Holism:** Holism refers to an analytical perspective that sees all aspects of life in relation to each other. For example, kinship, marriage, economics, politics, religion, and aesthetics may all influence society and culture as a whole.

**Normalcy:** The “normal” as well as the “abnormal” are products of the Enlightenment (roughly 1680-1800), in which scholars sought to employ a scientific rationality to order humanity. Anthropological perspectives on health and illness are founded on a critique

of the “normal,” as scholars recognize that the concept varies greatly across time and space.

**Disability:** As with the normal and the abnormal, anthropological perspectives typically argue against the universal validity of the concept of disability. Moreover, whereas a “Western” view locates the disability in the individual, anthropologists recognize disability as dependent on specific social and economic conditions. For example, what may be a disability in one location may be an ability in another.

**Prevalence:** The distribution of a condition in a population, expressed as a proportion, over a given period of time with the sample size as the denominator.

**Incidence:** The distribution of new cases of a condition over a specified period of time.

**Heritability:** Research to date strongly suggests that autism is heritable, meaning that genetic factors play a significant role in the individual variations expressed in autism phenotypes. Heritability includes both *de novo* genetic mutations (mutations that occur for the very first time in an individual) and inherited genetic information. The distinction is especially important in communities that take an individual’s traits as evidence of the value of a family unit or lineage.

**Border children:** In South Korea, resistance to the concept of autism as categorical (one is autistic or one is not) rather than dimensional (as in the concept of a dynamic spectrum) led to the folk concept of *gyonggye-seon aideul* (border children). Parents reject the conventional definition of autism as a category, including the notion that autism simultaneously involves problems with multiple functions, and prefer a concept that suggests only a tendency towards the category.

**Mixed methods:** Mixed methods typically refers to the investigation of a scientific question using both systematic (usually quantitative) and qualitative methods. By generating some knowledge that is quantifiable (for example, survey results) with knowledge that cannot be quantified (for example, narrative descriptions of experience), mixed methods produces more substantial and holistic answers to research questions.

**Cultural consensus modeling:** Cultural consensus refers to the agreement among subjects to research questions. Consensus is not an end point in research, but rather it provides the basis to study the origins and meanings of the phenomena about which people share a common set of beliefs. Because cultural consensus modeling employs systematic and statistical estimates of shared knowledge, and generates narrative discourse, it is frequently considered a mixed method.

**Stigma:** Stigma generally refers to the exclusion of individuals from social communities or practices. It is both a highly dynamic concept (as in the case of homosexuality, which was previously highly stigmatized) and an enduring one (stigma persists for individuals with schizophrenia, leprosy, AIDS, and other conditions).

**Neurodiversity:** Neurodiversity refers to one component of autistic self-advocacy that views autism as part of the normal range of variation in human societies. Rather than view autism as a disease, advocates of neurodiversity draw on the trope of diversity in civil rights and gay rights, among other movements, to explain suffering and disability among people with autism partly as the result of society's intolerance of difference.

**Schizophrenia:** Schizophrenia literally means "split mind." Named by Eugen Bleuler in 1903, the term referred to the splitting of psychic functions. Unfortunately, the term tends to be associated with "multiple personality disorder." Research by historians with an anthropological perspective has shown that the concept derives from a pervasive view in the 18th and 19th centuries that the human mind was a fragile aggregation that could deteriorate over time into a split mind. Writers and artists portrayed the mind as potentially bifurcated into good and evil, sane and insane, as in the dualities that comprise the great works of "Frankenstein," "Dr. Jekyll and Mr. Hyde," and "The Portrait of Dorian Gray," among others.

### **Recommended reading**

Kim, Y. S., Leventhal, B. L., Koh, Y. J., Fombonne, E., Laska, E., Lim, E. C., ... & Song, D. H. (2011). Prevalence of autism spectrum disorders in a total population sample. *American Journal of Psychiatry, 168*(9), 904-912.

Grinker, R. R., Chambers, N., Njongwe, N., Lagman, A. E., Guthrie, W., Stronach, S., ... & Yucel, F. (2012). "Communities" in community engagement: Lessons learned from autism research in South Korea and South Africa. *Autism Research, 5*(3), 201-210.

Grinker, R. R., Yeargin-Allsopp, M., & Boyle, C. (2011). Culture and autism spectrum disorders: The impact on prevalence and recognition. *Autism spectrum disorders, 112-136*.