

Cross-Cultural Autism Studies, Neurodiversity, and Conceptualizations of Autism

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Published online: 1 May 2015
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This special issue of *Culture, Medicine, and Psychiatry* presents six papers along the theme of “Conceptualizing Autism around the Globe.” This collective has several important precursors, including a special issue in *Ethos* (Solomon and Bagatell 2010) and another in *BioSocieties* (Eyal et al. 2014), as well as Davidson and Orsini’s (2013) *Worlds of Autism*. Indeed, a self-conscious anthropology of autism is emerging.

In a book review, a year ago (Cascio 2014), I identify the following characteristics of this emergent field: “(1) A holistic view that considers the place of autism in the larger sociocultural context. (2) Attention to the local and historical particularity of the concept of autism. (3) Attention to the lived experience of people with autism and those close to them” (Cascio 2014:307). Previous reviews have identified similar characteristics and themes in the social study of autism. Solomon’s (2010) review of autism and the anthropology of the senses identifies three major contributions of anthropology to the study of autism:

- (1) Anthropology conceptualizes intersubjectivity and empathy in a practice-based way, not assuming that the anthropologist preternaturally can think like the people he or she is trying to study, but rather stressing careful attention and observation;
- (2) Anthropology takes a hermeneutic, interpretive stance focused on lived experience; and
- (3) Anthropology’s meaning-centered ethnographic methodology attends to everyday practices.

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Silverman's (2008) review of such social science "fieldwork on another planet" identifies four major areas of study that such scholarship has addressed: (1) autistic cultures; (2) theorizing treatment; (3) autism and subjectivity; and (4) social movements. In their edited volume, Davidson and Orsini describe the central features of their "critical autism studies" as a careful attention to power relations, advancement of enabling (not deficit-focused) narratives of autism, and commitment to inclusive and non-reductive frameworks (Davidson and Orsini 2013:12). These reviews and overviews highlight the important themes and topics in the anthropology of autism, consistently stressing the importance of the anthropological attention to subjectivity, intersubjectivity, and lived experience.

The papers in this collection contribute to the anthropology of autism through several of these themes and topics. They consider the larger sociocultural context, attend to local and historical particularity, ethnographically explore autistic cultures, theorize treatment, and analyzes social movement. This special issue differs from previous special collections through its explicit attention to autism across several geographic contexts. The bulk of English-language social science literature on autism has focused on major Anglophone countries: the United States, Canada, United Kingdom, and Australia. Some scholars have offered comparisons between these countries, particularly with respect to policy (Baker 2007; Baker and Steuernagel 2009; Baker and Stokes 2007). However, a broader cross-cultural literature is growing. Anthropologists and other scholars have investigated autism with particular attention to local particularity in Brazil (Block and Cavalcante 2012), Cuba (Sotgiu et al. 2011), France (Chamak 2008; Chamak et al. 2010; Chamak and Bonniau 2013; Orchard 2013), India (Daley 2002, 2004; Daley and Sigman 2002; Mehrotra and Vaidya 2008; Sarrett 2015a), Israel (Bilu and Goodman 1997; Vogel and Reiter 2003, 2004), Italy (Cola and Crocetti 2011; Sotgiu et al. 2011), Morocco (Haldane and Crawford 2010; Hart 2014), Singapore (Poon 2011), South Africa (Grinker et al. 2012), and South Korea (Grinker and Cho 2013; Grinker et al. 2012; Kang-Yi, Grinker, and Mandell 2013). One goal of this special issue is to stimulate conversation about autism between researchers working in different countries, thereby internationalizing the conversation about autism.

The articles in this special issue describe experiences in Brazil (Rios and Costa Andrade 2015), India (Sarrett 2015b; Brezis et al. 2015), Italy (Cascio 2015), and the United States (Fein 2015; Solomon 2015). They address how autism is conceptualized at several different levels. Rios and Costa Andrade describe the conceptualization of autism-as-a-disability versus autism-as-mental-suffering at the level of national policy in Brazil. Cascio looks at conceptualizations of autism within several autism intervention programs discussed by Italian professionals, particularly the concept of rigidity as a characteristic of both people with autism and professionals who work with them. Sarrett and Brezis and colleagues look at conceptualizations of autism within the home. Sarrett compares homes in the United States and homes in India, loosely classifying them as therapeutic and custodial, respectively. Brezis and colleagues, also working in India, analyze parent narratives to understand their conceptualizations of their children with autism and their relationships with them before and after a parent training program. Finally, Fein and Solomon look at conceptualizations of autism within specific therapeutic or

quasi-therapeutic programs. Fein presents a rich ethnographic account of a roleplaying camp for youth with autism, arguing that the camp services as a “folk healing system” which rejects and blurs the line between the “sick patient” and “well healer.” Solomon presents detailed transcripts of therapeutic encounters with and without the presence of therapy dogs, arguing that “being with” these animals creates a different intersubjective environment and therefore different opportunities for sociality than human-only contexts. Both of these articles challenge stereotypical conceptualizations of people with autism as people unable to engage in certain social activities: Fein challenges the idea that autism “preclude[s] sociocultural participation” and Solomon that people with autism are “impaired in intersubjective understanding of others.” Fein shows how participants in a roleplaying camp instead create their own cultural space, and Solomon shows how children with autism engage in intersubjective understanding with therapy dogs and exercise different ways of “being social.”

Fein’s article in particular addresses a further facet of what might be considered “cross-cultural” in the study of autism—the idea that people with autism have a distinct culture, different from that of neurotypical (i.e., non-autistic) people. Silverman (2008:327) explains, “By emphasizing both the validity and distinctiveness of autistic experience, self-advocates have encouraged both anthropologists and journalists to explore the idea of autism as a culture, a project that has its precedents in classic studies of Deaf culture.” Research investigating autistic cultures tends to use a non-deficit view of autism, and, like Fein and Solomon, challenge the stereotype that people with autism are isolated and alone.

Although I use the term “culture” in this introduction, not all of the authors in this collection employ the culture concept. I want to acknowledge that this concept has been and should be problematized due to its potential for fetishization, exoticization, and Othering. This risk is a remaining challenge and sometimes our language fails us. It is difficult to insist on a cross-cultural and autism-friendly scholarly attention to the topic without reifying culture and, particularly in the broader world of autism research, implying that culture is something Others (Brazilians, Indians, Italians, ‘Aspies’) “have” and a “default” white Anglo-Saxon neurotypical person does not. Indeed, another important facet shared by the works in this special issue is their focus on non-deficit and neurodiversity perspectives. Rios and Costa Andrade discuss the neurodiversity movement as one of many social movements with a stake in the definition of autism in Brazil. Cascio suggests that the shared metaphor of rigidity may help bridge a gap between autistic and neurotypical minds following a perspective of neurological diversity. Sarrett compares therapeutic and custodial homes with levels of parental acceptance of autism, and suggests exposure to neurodiversity perspectives as a way to foster parent acceptance. Brezis and colleagues report on this very narrative of parental acceptance and the lack of a reliance on a notion of “normal” after a parent training program. Fein focuses neurodiversity in practice, exploring the potential of neurocognitive variation as a source of commonality, community, and doing “the work of culture.” Solomon challenges the deficit perspective by broadening the concept of intersubjectivity, which people with autism are often said to lack, and suggesting that the context may greatly impact how much a child with autism “is”

intersubjective and social. Following the neurodiversity perspective, some authors (e.g., Sarrett) have chosen to use identity-first language (e.g., “autistic people”) instead of person-first language (e.g., “people with autism”), respecting the preference of many people who identify as autistic.¹

Through both the geographical broad scope and the non-deficit lens of these works, the articles in this special issue strive to increase local and historical particularity and decenter white Anglo-Saxon neurotypical norms.

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¹ Despite the influence of neurodiversity on my thinking and writing, I have chosen to use person-first language (“people with autism”) in my writing at this time. I make this decision in an attempt to avoid the negative connotations often attached to adjectival language when it is used (as it often has been) by researchers who do not follow a neurodiversity perspective. Although many self-advocates embrace identity-first language, much use of this language outside advocacy contexts still connotes dehumanization, rather than identity. As a relative outsider (particularly one working in a non-English-language context), I have chosen to use person-first language in order to distance myself from the harm of other outsiders in the field who have used adjectival language in negative ways. Like Sarrett, I want to acknowledge the reasoning behind this choice. I support either language choice (and a number of others) as long as these choices are made intentionally and with care.

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