Introduction

Autism: Rethinking the Possibilities

Olga Solomon
Nancy Bagatell

Abstract This special issue of Ethos brings together the work of scholars from multiple disciplines including anthropology, occupational science, and education. The authors share two main goals. First, this interdisciplinary collection of articles highlights the importance of rethinking research on autism. Each article encourages movement away from dominant biomedical discourses that focus largely on symptoms to a more phenomenological and ethnographic stance that addresses experiences of living with autism. The second goal is to rethink possibilities for social interaction and participation for people with autism. In this introduction, we briefly review current biomedical accounts of autism as a disorder that affects social cognition and explore the importance of rethinking these assumptions. We suggest that this discussion is particularly well suited for psychological anthropology’s concerns with the psychological and the social in an individual’s experience and place in society. [autism, ethnographic research, intersubjectivity, neurodiversity, sociality]

This special issue of Ethos, “Rethinking Autism, Rethinking Anthropology,” has two goals. First, the articles and commentaries encourage scholars to rethink the possibilities for research on autism from an interdisciplinary, social science perspective. The second goal is to rethink the possibilities of social engagement for those affected by autism, their family members, therapists, and others. Such a perspective is steadfastly ethnographic, and it resonates with psychological anthropology’s concerns with interconnections between the psychological and the social in an individual’s experience and position in society.

Beginning with its anthropological origins in Malinowski’s (1961) Argonauts in the Western Pacific, ethnography has been used to document and understand the Other. “Like translation,” Vincent Crapanzano (1986:51) writes, “ethnography is a . . . somewhat provisional way of coming to terms with the foreignness of . . . cultures and societies.” Many preceding ethnographic enterprises, Mary Louise Pratt (1986) reminds us, defined themselves against adjacent and antecedent discourses to “usurp their authority and correct their abuses” (Pratt 1986:27), especially when these abuses involved describing “the native as a distorted, childish caricature of a human being” (Malinowski 1961:11).

The ethnographic enterprise of describing and understanding autism faces a similar challenge; grappling with the dominant biomedical discourse that casts symptoms of autism and their consequences for individuals and their families in a categorically deficit-based framework. Keeping in line with the experience-near (Geertz 1973) orientation to the study
of social behavior across cultures, the ethnographic studies presented in this issue seek to rethink and reimagine autism from a phenomenological, rather than a biomedical, point of view.

Interdisciplinary ethnographic studies on autism are especially timely now that neuroscience has transitioned from the “Decade of the Brain” (e.g., Andreasen 2001) into the new millennium that began with the completed sequencing of human genome and the beginning of functional genomics (e.g., Collins and McKusick 2001). Basic research on autism has been influenced by this scientific direction as evidenced in biomedical attempts to capture the heterogeneity in sociocommunicative and cognitive manifestations of autism in purely genetic terms. Consequently, there is less and less attention in autism research to phenomena that cannot be studied at the neurobiological or molecular level, such as human experience, social interaction, and cross-cultural variation. This situation is made even more complex by the expanding boundaries of the autism spectrum and its increasing prevalence. With medical anthropologist Byron Good (1997), we believe that, “the behavioral sciences in general, and cross-cultural and ethnographic studies in particular, have become more rather than less important” (Good 1997:230) at the present time. It is this perspective that makes the special issue particularly relevant to the contemporary state of autism research.

Moreover, although biomedicine claims “culture-free” objectivity, it is subject to culturally and institutionally organized practices of imagination and interpretation (DelVecchio Good 2007). Yet the images and interpretations of autism produced by these practices are cast as objective truths and permeate spheres of social life where cultural notions of autism are reproduced and recirculated. Dawn Eddings Prince, an anthropologist diagnosed with Asperger’s disorder as an adult, succinctly describes the impact that these images have on the popular understanding of autism:

> When most people think of autism they think of violent, unreachable people in worlds completely of their own making, worlds without keys, feeling no empathy, lacking imagination, and unavailable to the deepest of human needs for contact and love. Having autism is the worst fate parents can imagine befalling their children and they dread its impact on their families. [Prince this issue]

This conceptual framing of autism has profoundly negative consequences for persons with autism and their families, and for the design of educational programs and therapeutic interventions. However, recent ethnographic studies (e.g., Bakan et al. 2008; Bagatell 2007; Kremer-Sadlik 2004; Ochs 2002; Ochs and Solomon 2004, 2005; Ochs et al. 2001, 2004, 2005; Sirota 2004; Solomon 2004, 2008; Sterponi 2004) have challenged this view of autism, offering accounts of how persons with autism meaningfully engage in a range of ordinary everyday activities with other people. This special issue is intended not so much as a theory-driven dialogue among two opposing views, but as a multilogue of theories and voices, of scholarly research and personal experience, that intertwine perspectives intended to advance understanding of autism.
The interdisciplinary social science perspective is especially germane to autism research in light of the history of autism as a clinical diagnosis. Since its original description (Kanner 1943), theories of autism have undergone multiple and fundamental transformations. The syndrome itself has shifted from being considered a rare psychogenic condition to being classified as a neurobiological disorder with prevalence as high as one in 110 children (Centers for Disease Control 2009). Autism is currently viewed in biomedical terms as a neurodevelopmental disorder that affects social cognition. Much attention has been given to cognitive accounts of autism as a disorder of “theory of mind,” meaning the ability to infer another person’s emotions, beliefs, thoughts, and intentions (e.g., Baron-Cohen et al. 1985). Other cognitive theories of autism that continue to receive attention include the executive function theory (e.g., Russell 1997), and weak central coherence theory (e.g., Frith 1989; Frith and Hill 2004; Happé 1994). The latter suggests that autism disrupts a natural human propensity to construct “central coherence,” that is, to seek higher-level meaning in a wide range of stimuli. Other affected areas identified in experimental cognitive psychological studies are impaired joint attention, imitation, and imaginative play (e.g., Charman and Baron-Cohen 1994).

Because biomedical accounts have primarily focused on the challenges of affected individuals evinced in laboratory tasks, there is tension between biomedical perspectives on autism and the everyday experiences of individuals with autism and their families. Specifically, this tension emerges as the experiences, discourses, and ideologies of persons with autism and their families contrast with the experiences, discourses, and ideologies of doctors, therapists, teachers, and others who provide a range of services in institutional settings. The tension commonly arises at the interface of the personal and the institutional, between theories of competence and theories of disability, and among orientations toward measurable clinical change when contrasted with notions of a “good,” meaningful life.

In the first article in the collection “Regarding the Rise in Autism: Vaccine Safety Doubt, Conditions of Inquiry, and the Shape of Freedom,” Sharon Kaufman considers the ways medical practitioners and parents co-construct, negotiate and contest precarious notions of vaccine safety and autism risk. Seeking to understand and describe the cultural work that is being done by the parents and clinicians, Kaufman examines the vagaries of the vaccine–autism connection and explores parental awareness of vaccines’ safety and anxieties about vaccines’ danger.

In the two articles that follow, by Nancy Bagatell and by Dawn Eddings Prince, the authors illuminate how individuals with autism negotiate and construct, in their everyday activities and discourses, what it means to be affected by autism in the social world and to live a meaningful life. In her article, “From Cure to Culture: Transforming Notions of Autism,” Bagatell explores the idea of autism as a way of being. From the perspective of occupational science, an interdisciplinary academic discipline that examines everyday human activity and its impact on health and well-being, Bagatell considers an autistic community, a group of autistic adults who, through their discourse, lexicon, and activities are challenging traditional, biomedical interpretations of autism. Examining historical trends, she shows how the
widening of the autism spectrum, the advent of the self-advocacy movement, and the explosion of technology, have enabled individuals to claim a voice that could potentially transform societal conceptions of autism.

In “An Exceptional Path: An Ethnographic Narrative Reflecting on Autistic Parenthood from Evolutionary, Cultural, and Spiritual Perspectives,” Prince offers an emic view of autism. She vividly describes her sense of connection to the natural world and her profound sense of disconnection from the human world. From being taught about social connectedness by gorillas at the zoo to becoming a parent and raising a child, Prince illustrates how autism can be viewed as a unique way of being in the world and not merely as a medical condition. Prince’s contribution offers a highly personal, reflexive insider or “native” point of view, a view informed by her training as an anthropologist. This stance allows for a possibility of something rarely accomplished in autism research: an interaction of various intersubjectivities foundational to the ethnographic enterprise (Jacobs-Huey 2002).

In the next four contributions the authors offer detailed analyses of social interaction to show how children with autism participate in everyday activities and practices. Ochs and Solomon propose a notion of “autistic sociality,” an observable social phenomenon that has important implications for an anthropological understanding of human sociality. The authors outline a “domain model” of sociality that identifies particular situational conditions under which orderly social coordination increases. On the basis of this model, they proffer an “algorithm for autistic sociality” that promotes social engagement of children with autism in particular interactional contexts.

Sirota, in her article, “Narratives of Distinction,” takes readers into the everyday lives of children with autism as they interact with parents at home. Sirota provides compelling examples from video and audio data of the social competence of children with autism and suggests that through an apprenticeship of sorts, children with autism use narratives of their experience as “technologies of self” (Foucault 1988).

In the article “How to Go On: Intersubjectivity and Progressivity in the Communication of a Child with Autism,” Sterponi and Fasulo draw on conversational analysis and developmental pragmatics perspectives to examine the conversations of a five-year-old boy with autism, his parents, and a therapist. The authors consider the complex relation between intersubjectivity (as both a condition for communication and a product of communication), and progressivity (as sequentially based structural resources that afford continuity in conversation) faced by a child with autism and his interlocutors. This analysis of verbal social behavior captures complexities, contradictions, and pitfalls as human beings with and without autism pursue conversational continuity and understanding.

In the last article of the issue, “What a Dog Can Do: Children with Autism and Therapy Dogs in Social interaction,” Solomon identifies the dynamics of child–dog–other interactions that support relatively successful participation of children with autism in everyday activities. Analyzing video- and audio-recorded interactions, parental interviews, and stories
written by the children about their experiences with the dogs, Solomon describes how the inclusion of specially trained dogs mediates the social engagement and interaction of children with autism and their family members and peers.

Taken together, the collected articles encourage readers to rethink autism by embracing its complexity, from the personal experience of those diagnosed with autism and their families to issues of healthcare and educational policy. Although the contributions are situated in several branches of anthropology (cultural, existential, linguistic, medical, and psychological), in occupational science, and in education, they share a vision of autism as socially constructed across institutional, ideological, sociohistorical and social-interactional contexts. Thus, these contributions demarcate a new interdisciplinary domain of inquiry that examines autism as a contestable and contested sociocultural as well as biomedical construct. The unifying interest of the contributors to this special issue is in considering how autism figures in the lived experiences of individuals who have been diagnosed with the condition, in the life worlds of families, and in the production and contestation of knowledge within and across communities and institutions. The special issue’s interdisciplinary perspective seeks to capture both the locally situated contexts of individual and family experiences and the broader sociohistorical and institutional discourses that offer often conflicting theories of etiology, intervention, and possible futures.

We are grateful to Mary Lawlor and Richard Grinker (both this issue) for agreeing to comment on the articles included here. As they note the collection is intended to impact awareness of autism with a view toward better treatment across lifespan. Although the collection problematizes notions of sociality, intersubjectivity, and the construction of self, the articles advance (inter)disciplinary approaches that will improve the analysis of these often taken for granted constructs more generally. These insights gained from research endeavors elucidating autism promise new theoretical purchase on selves and socialities. We also hope the issue will further advance research on autism by involving multiple perspectives and theoretical orientations, and that this interdisciplinarity will more firmly bridge social science and biomedical knowledge.

OLGA SOLOMON is Research Assistant Professor, Division of Occupational Science and Occupational Therapy, University of Southern California.

NANCY BAGATELL is Assistant Professor, Department of Occupational Therapy, Quinnipiac University.

Notes

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1. In 1990, President George H. W. Bush signed a proclamation designating the last decade of the 20th century as the “Decade of the Brain.” This proclamation put forth “to enhance public awareness of the benefits to be derived
from brain research” through “appropriate programs, ceremonies, and activities” marked an acceleration of neuroscience research (Bush 1990). Although autism was not mentioned specifically in the proclamation as one of the disorders of the brain warranting further study, it was during this decade that funding for autism research began to increase.

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