Reframing the Science and Anthropology of Autism

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The papers in this collection represent an important step forward in the ethnographic study of autism. Their focus on sociality and social context is especially important today as so much of the attention paid to autism in the scholarly literature and in the media concerns advances in neuroscience, cellular and molecular biology, and does not examine the non-medical aspects of autism. The field of genetics, to cite just one example, offers an enormous range of possibilities for using genetic variations to identify the alleles and mutations that influence neurological development. But as the papers in this collection suggest, we can take the medicalized, genetic approach to autism too far, to a point at which a disease construct is so profoundly fetishized that we fail to question the validity of the construct, and to see its cultural constitution. Medicalized approaches to autism, at least as autism is now conceptualized as an expansive spectrum, also risk making a disease out of traits that are likely distributed in varying degrees among the general population, obscuring the positive characteristics of autism that contribute to human diversity and creativity, neglecting the possibility for new forms of sociality to emerge, and diminishing the role that autism can play in forming new social identities.

The value of an *anthropologically* informed approach to autism, in my view, has less to do with relativism—in which we recognize autism as just another form of being, and then appreciate that form for its differences from an assumed norm—than with its ability to unmask the cultural foundations of scientific representations, and to comprehend both the social life of autism, as a construct, and autistic sociality. The experiences of an autistic person—whether his strengths and abilities

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are supported or neglected, whether he is idealized or demeaned and bullied, whether he is integrated into community life or excluded—are not written in his cells. As Olga Solomon suggests in her arguably post-humanist study in this volume, animal companionship shows that sociality is less an individual trait and more “a capacity realized through certain kinds of social interactions.” Yet much scientific research often depersonalizes—or perhaps de-socializes—forms of human difference by explaining them in terms of biological mechanisms.

When Francis Collins was Director of the National Human Genome Research Institute, he articulated his vision for the future:

The time is right for a focused effort to understand, and potentially to reclassify, all human illnesses on the basis of detailed molecular characterization. Systematic analyses of somatic mutations, epigenetic modifications, gene expression, protein expression, and protein modification should allow the definition of a new molecular taxonomy of illness, which would replace our present, largely empirical, classification schemes, and advance both disease prevention and treatment (Collins et al. 2003: 841).

This view expresses a problematic expectation that a genetic foundation would establish disorders as “real” and thus lead to a more valid genetic nosology in all areas of medicine, including psychiatry. It is problematic because while the relationship between a biomarker and a constellation of behaviors might be empirically verifiable, those behaviors only become a “disorder” when society constructs them as such, and a “disability” only when the social environment cannot accommodate them.

Biological descriptions of human differences certainly cannot help us understand the role *social context* plays in the identification and treatment of autism. Indeed, all of the articles in this collection stress the need to study what people experience, and how they understand their experience. As Sarrett shows in this volume, the explanatory models people develop for autism are engines for social action. They affect how people think *and* behave in every domain of life—from religion, kinship and marriage, to medical care, social participation, labor, education, esthetics, and play. Explanatory models can be deeply rooted in society, as when autism is conceived in terms of longstanding religious beliefs about supernatural causation. Even moribund models, like the psychoanalytic belief that autism is caused by cold, unloving mothers, can have a long legacy. One wonders how the kind of parent–child training in India described by Brezis et al. in this volume might be received in the United States where, due to the refrigerator mother hypothesis, any sort of intervention aimed at parents suggests that the providers blame the parent for the child’s autism.

Now imagine if there had been a biomarker in the early twentieth century for the group of symptoms we today call autism. In the United States at least, the condition might have been called autism. But it is likely that, apart from possessing the knowledge of, say, a DNA sequence implicated in autism, little would have been different. Parents might still have been blamed for their children’s problems. People with autism would still have been institutionalized. They would have had few educational or job opportunities, and they and their families would still have been

stigmatized, because the core features of autism would still have existed in the historical context of early twentieth century psychiatry.

It is important to remember that the diagnosis of diseases made on the basis of an identified bacterium, virus, or cancer, are also grounded in society and history. Yet, biomedical approaches to diseases (and disabilities) often assume that disease constructs are stable, uniform, or grounded in nature rather than culturally and historically contingent (Wilce 2009; Hahn and Kleinman 1983). The rich metaphors societies employ to give meaning to AIDS (plague, punishment, military invasion), cancer (evil, insatiable invader, death sentence), or leprosy (corruption, decay), for example, show that even conditions one might think are based on empirically verifiable phenomena are always constituted by normative values. By reducing disease, and even identity, to biological materials and mechanisms, genetics poses a challenge to the view represented in this volume—that societies construct their own worlds—a view we should not forget is fundamental to anti-racist and other anti-discriminatory ideologies. Difference constructed on the molecular level is still difference, with all the same (and perhaps even more powerful) possibilities a purely social classification presents for shaping and entrenching inequality.

Scientific representations tend to view neuropsychiatric conditions, in general, in terms of pathology, yet even these representations do not always derive only from scientific research and writing. Robert Barrett (1998) has clearly articulated how the conceptualization of schizophrenia as the split mind (literally, *skhizein*, “to split,” and *phrēn*, “mind”) emerged out of at least two intellectual traditions in Europe. The arts and literature that emerged out of nineteenth century Europe (*Faust*, *Dr. Jekyll and Mr. Hyde*, *Doppelgänger*, *Frankenstein*, and *The Picture of Dorian Gray*, for example) proposed the existence of a binary mind, defined in large part by the oppositions dark and light, good, and evil. Similarly, in French evolutionary thought, scientists hypothesized that physical and cultural variation in the world was the result of the degeneration of the mind, or the disintegration of the mind into its parts. Europeans were models of the perfect and coherent mind, while non-Western peoples, and people with severe mental illnesses, represented the fragmentation, disintegration, and degeneration of the mind. Remarkably, more than 140 years after Dostoevsky wrote about the “second self” in *The Raw Youth* (1875), as the sign of the disintegration of the mind, even a cursory examination of advertisements for twenty-first century anti-psychotic pharmaceuticals will yield representations of psychosis as a divided mind, representations that owe their existence largely to European Romanticism, and certainly not to any scientific discoveries.

In both psychiatry and in parents’ memoirs, autism has been conceived in cultural terms as the loss of a person or the loss of soul. Consider New York University’s Child Study Center 2007–2008 outreach campaign for mental illness awareness and treatment, called “Ransom Notes” (Kras 2010). The advertisements, posted on bus stop shelters and in other print media, were letters from kidnappers. One letter to a parent, and signed “Autism,” read, “We have your son. We will make sure he will not be able to care for himself or interact socially as long as he lives. This is only the beginning.” This view of the autistic person as lost, abducted, kidnapped, is not the result of scientific research, but of a particular objectification of the human mind, and the idea that the person with autism has been damaged. The autistic person,

from this perspective, is deficient and dysfunctional. In many memoirs of autism written by parents, diagnosis becomes both a proxy for the onset of autism and the sudden disappearance of the child. Witness the opening words to the preface of the book *Strange Son*, written by Portia Iversen, the founder of Cure Autism Now, and previous member of the National Advisory Mental Health Council at NIMH (2006: 1) “It was his mind they came for. They came to steal his mind....I knew it was in our house...They were very, very dark things. Night after night, I sat beside his crib. I knew he was slipping away from us, away from our world. And there was nothing I could do to stop it from happening... And then one day, it happened. He was gone.” The first chapter is entitled “Departure of the Mind.” In her book, *The Accidental Teacher*, Annie Lehman (2009: xvi) calls autism “a greedy disability,” because it takes so much away from so many areas of functioning. In the U.S., the idiom of injury has become commonplace among some anti-vaccine advocates, who narrate their child’s experiences in terms of wrong-doing, and prefer to see their child not as autistic but as “vaccine-damaged” or “mercury poisoned.”

Narratives about autism, perhaps like all “disorders,” are social and linguistic products. Of childhood developmental disorders in general, Danforth and Navarro note that narratives are “co-fabricated within the complex construction and contestation of cultural codes, norms, and identities” (Danforth and Navarro 2001: 167). Narratives are also co-fabricated through the interaction of distinct discourses. Sometimes these narratives are in antagonistic relation. This is the true in the case of Brazil, as described by Rios and Andrada in this volume. At other times, there is a merging of ideas, as when the participants in a conversation must to some extent adopt the linguistic and conceptual framework of their interlocutors. As Cascio’s analysis of the concept of rigidity in Italy illustrates, different discourses with very different intentions not only interact with each other, but can also begin to overlap.

The critique of biomedical representations, however, should not blind us to the problem of the culture concept. As the editor of this collection, Ariel Cascio, warns in her introduction, some culturalist formulations pose risks as well. Scholars who accept the idea that autism constitutes simply another way of being—a way of being that the medical establishment has pathologized—risk accepting at face value their interlocutors’ ideologies and categories (for example, “neurodiverse” and “neurotypical”) or, worse, fetishizing or “othering” autistic individuals. There is also a risk of both simplifying and idealizing autism. Those who embrace the view that autistic people have a distinct culture tend to represent autism through self-advocates, people who are often far more verbal, socially capable, independent, and empowered than others: autistic people who are non-verbal, self-injurious, have seizure and other comorbid disorders, and may require lifelong institutional care. It is clear that even the concept of an autism spectrum cannot easily account for the wide range of suffering that exists. Nor can suffering be accounted for in a relativist frame only as the product of a society’s norms, or intolerance of neurodiversity. Even those who challenge institutional norms and the “deficit” model of autism typically embrace the word itself and adopt their own view of what is “normal.” Scientists, it could be argued, frequently mistake social distinctions for biological ones; neurodiversity advocates, it could be argued, do the opposite.

In addition, sometimes what appears to be a product of “culture,” may be the result of something external to an individual or family’s everyday experience, and may not reflect values that are deeply rooted in their communities. So for example, while Brezis et al. note significant differences in the topics of concern voiced by poorer and wealthier families prior to the parent–child training intervention in India, those differences disappeared after the training. Similarly, disparities in diagnosis of autism among African-American children could be the result of cultural differences among African-Americans, but may just as likely be the result of forms of institutionalized racism, in which services are unequally distributed in a population. Lower rates of diagnosis of autism among Latinos in the U.S. could be the result of their attitudes toward child development and child care, but could also be due to the fact that there are fewer autism programs in regions, states, counties, or neighborhoods where these populations live. Or it could be because legislation in some locations where they live makes it more difficult for children who live there to become eligible for services.

The concept of culture in autism research is thus useful not just for characterizing a community’s system of meanings that influence how autism is identified, managed, experienced, etc., but for showing that those meanings are constructed and can therefore be changed. In an earlier volume on autism, published in *Ethos*, Nancy Bagatell (2010) describes the recent emergence of autistic communities and autistic identities as both a rejection of biomedical and deficit model, and as a new form of sociality made possible by historical conditions. In Silicon Valley, for example, autism is increasingly less stigmatized and more valued as employers begin to associate autism with the cognitive skills necessary for innovation in high technology. Bagatell (2010: 51) writes, “It is evident that as society is transformed by technology, the nature of human sociality may be scaffolded and transformed in ways that come to mirror an autistic sociality and thus reframe the disabling properties of autism itself in more positive terms.” Fein’s contribution in this volume similarly posits a reciprocal relationship between autism and culture. The teenage campers with whom she conducted fieldwork, most of them previously diagnosed with Asperger’s Disorder, engaged with their counselors in highly structured live-action roleplaying games (consisting of fairies, dragons, and other mythological characters) that were, in Fein’s words, “congruent with what participants needed from their cultural ecology in order to organize themselves and their interactions.” She reports that among the children there was a sense of belonging rather than stigma, a sense of an emerging subculture, or in the words of one teenager, “my tribe.” Cultural practices thus can shape the experience of autism, and autism can in turn shape cultural practices. Fein calls the camp a folk healing system and a “generative sociocultural space.” More than that, the camp, and all of the other ethnographic contexts described in this collection, provides opportunities for people on the autism spectrum to construct and participate in society, thus mitigating the exclusions that create stigma. All of these authors focus on what people with autism can do, rather than what they cannot do, or what might have been; and they equally focus on what societies can do to change the lives of people with autism.

Writing about a different aspect of human thought and behavior, the philosopher Paul Ricoeur (2004: 21) once warned of the tendency to think about memory as flawed, imprecise, and deficient. Memory is devalued because it is a divergence from a kind of perfection—that is, perfect knowledge of the past. For Ricoeur, memory is, paradoxically, a way of moving forward in time, and should be celebrated as a remarkable *capacity*. But this view is possible only if we shatter the historian's illusion that there is a real, objective, unfiltered, unconstructed truth to be found, and the illusion that historical memory is, like the nineteenth century concept of schizophrenia, a degeneration from a point of origin. There is a lesson for autism researchers in this critique of history. The constellation of behaviors and cognitive characteristics that we call “autism” today existed long before we made it an object of knowledge and narrative—before we interpreted it, named it, and started the ongoing process of reinterpretation and redefinition. Our capacity for culture means we have the power to change the history of autism, as we move forward and make a new past, with new narratives.

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