Book Review/Compte rendu

Jennifer S. Singh, *Multiple Autisms: Spectrums of Advocacy and Genomic Science*. Minneapolis: University of Minnesota Press, 2016, 284 p($27.00 paper (9780816698318)

Multiple Autisms offers a compelling examination of the biosocial world of autism genetics and genomics, introducing readers to the array of social actors, organizations, technologies and materials that are involved in the constitution of the category of autism today. In the preface, Singh describes the unique vantage point from which she does this work. A trained molecular biologist, Singh worked for eight years as a research associate with the US biotech company, Genetech. "Learning, experimenting, and manipulating human DNA fascinated me" she writes, "but also opened the door to many questions no one in my laboratory seemed to be considering, much less the biotechnology industry" (xi). Vis-à-vis the industry's avowed commitment to "save lives", Singh developed concerns about the social, political and ethical dimensions of genetic and genomics research. Seeking "new tools to intellectually engage these concerns" (xi), Singh went back to graduate school, completing doctoral studies in Sociology at UC San Francisco. Her book can therefore be situated within a broader context of medical sociology and science and technology studies. It will also be of great interest to scholars working in such interdisciplinary fields as disability studies and critical autism studies.

Multiple Autisms delivers a well-documented critique of the autism research industry's narrow focus on autism genetics/genomics, and an important analysis of the consequences of this limited scope. Singh traces the boundaries of an emergent biosocial world, highlighting novel forms of community, ways of relating and identity practices, all shaped by desires for and/or concerns with contemporary autism genetics/genomics research (13). Most crucially, she rejects any fixed narrative of autism, refreshingly demonstrating that ways of seeing, living, advocating, knowing and understanding autism are neither static nor singular; rather, they are multiple, transient and evolving.

The first of the five chapters provides an historical account of autism's emergence as a clinical category of disorder and then traces key alterations to the diagnostic category over time. Interestingly, Singh situates the rise in popularity of genetic/genomic ways of knowing autism,

against the backdrop of psychogenic approaches that blamed parents (mostly mothers) for their children's autism. The idea that autism flows from a "core" neurological or genetic deficit in the child (and not, by extension, from problematic parenting practices) continues to appeal to non-autistic parent advocates seeking "better" (i.e., more targeted) treatments of autism or even its cure. Singh shows us how parent advocates have become key partners in the production and circulation of genetic knowledge: both boosting and sculpting the contemporary landscape of autism research (41).

Chapter 2 turns its attention to two prominent parent-founded US advocacy organizations: the National Alliance for Autism Research (NAAR) and Cure Autism Now (CAN) – both now absorbed into the behemoth multinational organization, Autism Speaks. Singh documents the unprecedented ways in which these organizations shaped the pace and possibility of genetic/genomic research on autism. For example, according to Singh, when NAAR and CAN were founded in the mid-90's, there was a relative dearth of biomedical research on autism (43). During their time, these parent-led organizations funded hundreds of "field building" programs, projects and fellowships worldwide (45). They were also the first to establish and fund large-scale, private autism gene repositories and bio banks, including the NAAR-founded *Autism Tissue Project* (ATP) and CAN's *Autism Genetic Resource Exchange* (AGRE). Through her detailed social history, Singh traces how these organizations effectively worked to build whole "epistemic infrastructures" of genetic/genomic science, infrastructures that have dramatically extended the scope of autism research in the fields today (39).

After 20 years of research, and over a billion dollars spent, scientists have been unable to come up with any clear answers about the relationship between autism and genetics (180). Despite the ambiguity of the scientific results, autism genetic/genomic research continues to move forward with certainty, as if it were the only way. Chapter 3 charts the shift in research away from *autism genetics*, in which autism is thought to result from a major heritable gene, and toward *autism genomics*, which contends that there are hundreds of genes working together at the molecular level to produce myriad autism phenotypes. Singh grounds this shift – and the specific enthusiasm revolving around the identification of a pattern of genetic mutations known as de novo CNVs and related theories that suggest the existence of not one but many 'autisms' – within an historical, economic, and politically specific biosocial context. Singh contends that researchers remain committed to the genetic/genomic paradigm due, in no small part, to professional and financial rewards that accompany work on autism genetics as well as the related

set of constraints associated with pursuing alternate avenues of thought. With all the funding and prestige associated with autism genetics/genomics, writes Singh, "it makes no sense for the future of research labs and scientific careers to jump off the autism genetics research bandwagon" (105). And so, with the help of an extensive network of invested and implicated social actors, technologies and biological materials, the science of autism genetics continues to reinvent itself, mutating and replicating in new ways.

A key contribution of *Multiple Autisms* lies in its careful documentation of the overwhelming dominance of genetic/genomic autism research and its demonstration of how this research is being executed at the expense of other valuable research trajectories. According to Singh, between 2008 and 2012, "the National Institutes for Health (NIH) funded $86.6 million in sixty-five projects to investigate genetic risk factors and candidate genes for autism. In contrast, NIH funding on life-span issues accounted for just over $11 million for twelve projects" (18). With this disparity in mind, the final two chapters highlight groups that are implicated in autism genetics/genomics research but are not directly benefitting from it: autistic people and their families. Chapter 4 discusses another large-scale, private autism genomic database – the Simons Simplex Collection (SSC) – focusing on the narratives of parents who donated their blood and medical information, and that of their children, in exchange for diagnostic evaluations and treatment recommendations. Chapter 5 examines the perspectives of autistic adults, including autistic self-advocates, and centers their thoughts and concerns about genetic/genomic research. Taken together these chapters importantly ask: who benefits from a near-monolithic research focus on autism genetics? In response to this question, *Multiple Autisms* shows us that the balance of power in autism research is tilted decisively in favor of the few: toward the minority of highly privileged parent advocates in search of autism prevention techniques and cure, and whole consortiums of scientists, researchers, technicians, politicians and corporate stakeholders who are profiting, professionally and financially, from their involvement in the field of autism genetics.

This uneven balance of power obscures essential political and ethical concerns at the heart of the present-day search for autism's genetic roots. Such concerns, which are routinely raised by autistic people and their organizations (e.g., the Autistic Self Advocacy Network), include: (1) ethical questions about coercive research practices (e.g., families being offered tests and treatment recommendations – valued at upwards of $2000 – in exchange for biological matter and health information); (2) legal questions about informed consent (e.g., the privacy and confiden-

tiality of children whose parents donate their biological materials and medical information, materials and information that are then owned privately and will be used in perpetuity by corporations in the development of for-profit drugs and technologies); and (3) questions about the value of autistic life in the context of whole research industries aimed at preventing and/or eliminating autistic ways-of-being. Taking these concerns seriously means prioritizing new and multiple ways of approaching and understanding autism. Singh suggests that there should be more research focused on environmental toxins and lifespan issues. However, the book can also be read as a call for all us who find ourselves in relation to autism to first identify and then work to dismantle the powerful cultural, political and economic structures that are, invariably, privileging some autism stories over and against all others. Such a call requires us to learn from those bodies, minds and narratives that work, non-normatively, to unsettle any singular interpretation of autism and that remind us that what autism is, is always and necessarily, multiple.

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