

BIOGRAPHICAL SKETCH

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NAME: Jennifer S. Singh

eRA COMMONS USER NAME (credential, e.g., agency login):

POSITION TITLE: Assistant Professor of Sociology

EDUCATION/TRAINING *(Begin with baccalaureate or other initial professional education, such as nursing, include postdoctoral training and residency training if applicable. Add/delete rows as necessary.)*

INSTITUTION AND LOCATION	DEGREE <i>(if applicable)</i>	Completion Date MM/YYYY	FIELD OF STUDY
California Polytechnic State University (Cal Poly), San Luis Obispo, CA	B.S.	06/1993	Biological Science
University of Washington, Seattle, WA	M.P.H.	06/2003	Public Health Genetics
Association of Schools of Public Health Research Fellow, Center for Disease Control & Prevention, Atlanta, GA		07/2004	Public Health Practice
University of California, San Francisco (UCSF), CA	Ph.D.	08/2010	Sociology

A. Personal Statement

I am particularly well positioned to carry out this project due to my training and work experience in the life sciences, public health, and social sciences, which is reflected in my research and teaching. I received my undergraduate training in biological sciences at Cal Poly and worked in the biotech industry for eight years, where I became an expert in the science and practice of recombinant DNA technologies. I also supervised and trained many research assistants as a senior research associate and led projects designed to identify secreted human proteins for therapeutic use. My training in public health consists of a Masters of Public Health at the University of Washington and a Research Internship and Fellowship at the Centers for Disease Control and Prevention (CDC). As a public health professional, I developed knowledge, aptitude, and skills in epidemiology, public health services, and the development and evaluation of public health programs and interventions. I received a PhD in Sociology at the University of California, San Francisco, where I gained expertise in quantitative and advanced qualitative research methodologies, such as conducting interviews, participant observation, and the development and administration of surveys. During this time, I worked as a graduate research assistant at the Center for Integration of Research on Genetics and Ethics at Stanford University, where I began my research on the social, ethical, and legal implications of conducting genetics research on autism. It was during this time that I began investigating the inequities in research funding toward family and adult services. My current research at Georgia Tech is situated at the intersections of medicine, health, and society with a particular focus on the social and structural inequalities to autism diagnosis and services. A subset of this research focuses on the ranges of work parents must negotiate when navigating the processes of obtaining an autism diagnosis, educational services, and a sense of personhood for their child. This work has been published in a leading journals and book listed below. I also have over ten years of experience and engagement with the autism community and have been a member of the Atlanta Autism Consortium (AAC), the International Society for Autism Research (INSAR), and the INSAR Cultural Diversity Group since in 2011. My position at Georgia Tech, previous affiliations with the CDC, and intimate relations established with key stakeholders involved with ASD research, service, and community make me well suited for the research proposed.

1. Singh, Jennifer S. *Multiple Autisms: Spectrums of Advocacy and Genomic Science*. Minneapolis and London: University of Minnesota Press, 2016.
2. Singh, Jennifer S. "Parenting Work and Autism Trajectories of Care," *Sociology of Health and Illness* 38(7) (September 2016): 1106-1120.
3. Singh, Jennifer S. "Narratives of Participation in Autism Genetics Research." In *Science, Technology and Human Values* 40 (March 2015): 167-175.
4. Singh, Jennifer, Illes, Judy, Lazzeroni, Laura, and Hallmayer Joachim. "Trends in US Autism Research Funding." *Journal of Autism and Developmental Disorder* 39(5) (May 2009): 788-795.

B. Positions and Honors

Positions and Employment

1993 – 1995	Biochemical Technician, Cell Culture Operations, Genentech Inc., South San Francisco, CA
1995 – 2001	Senior Research Associate, Department of Molecular Biology, Genentech, Inc. South San Francisco, CA
2002	Association of Schools of Public Health Research Fellow, Center for Disease Control and Prevention, Office of Laboratory Genomics, Atlanta, GA
2003 – 2004	Association of Schools of Public Health Research Intern, Center for Disease Control and Prevention, Office of Public Health Genomics, Atlanta, GA
2004 – 2008	Graduate Research Assistant, Center for Integration of Research on Genetics and Ethics, Stanford Center for Biomedical Ethics, Palo Alto, CA
2010 – 2011	Instructor, Dept. of Sociology & Criminal Justice, Kennesaw State University, Kennesaw, GA
2011 – 2017	Assistant Professor, School of History and Sociology, Georgia Institute of Technology, Atlanta, GA
2017 – pres.	Associate Professor, School of History and Sociology, Georgia Institute of Technology, Atlanta, GA

Other Experience and Professional Memberships

2004 -	American Sociological Association, Member Sections: Medical Sociology, Disability and Society, Sociology of Mental Health, Collective Behavior and Social Movements, and Sociological Practice and Public Sociology.
2006 -	Society for Social Studies of Science, Member
2008 -	International Society for Autism Research, Member; Committee: Cultural Diversity
2011 -	Atlanta Autism Consortium, Member
2015 -	Autism Advisor Council, Georgia Plan for Autism

Honors

2012 & 2013	Thank a Teacher Award, CETL, Georgia Institute of Technology
2011	Nominated by the UCSF Graduate Division for the 2011 Council of Graduate Schools/University Microfilms International Distinguished Dissertation Award in Humanities/Fine Arts
2010	Anselm Strauss Special Award for Distinguished Qualitative Dissertation, Department of Social and Behavioral Sciences, UCSF
2009 – 2010	Andrews Scholarship, School of Nursing, UCSF
2009	Diana Forsythe Memorial Dissertation Award for Social Studies of Science Technology & Health, Department of Anthropology, History and Social Medicine, UCSF
2009	Anselm Strauss Dissertation Research Award, Department of Social and Behavioral Sciences, UCSF
2008	International Meeting for Autism Research Travel Award
2004 – 2009	National Institute of General Medical Sciences Fellowship, UCSF
2003 – 2004	Association of Schools of Public Health Research Fellowship
2002	Association of Schools of Public Health Research Internship

C. Contribution to Science

1. My initial research on autism charted historical research milestones in autism research, trends in autism research funding, and how autism research is portrayed in the media. At the time, there was limited social science research on autism and we saw a need for historical accounting of research trends in autism science, the representation of autism research in the media, or the distribution of funds in various areas of autism research within the U.S. A major contribution from this research was a timeline I developed that mapped out the early accounts of autism in the 1940's, the emergence of various U.S. parent advocacy groups, the development of national research centers, the expansion of the diagnosis in the Diagnostic and Statistical Manual of Mental Health, and key policy initiatives that changed the course of autism research and treatment. Second, I identified a paradox between the kinds of autism research being conducted by scientists and the kinds of autism research being reported in the international news. At the time of our analysis, there was an extreme preoccupation with the cause of autism due to the measles, mumps, and rubella vaccine, which predominated the media coverage, despite an overwhelming focus of scientific research on brain and behavioral mechanisms. This early research also quantified the number and type of autism research grants funded by the National Institutes of Health and two U.S. parent advocacy groups (1997 – 2006). This was the first study to ever quantify how autism research funds were being distributed in the U.S. and offered a first analysis of the unequal allocation of funds to people with autism and their families. I served as the lead graduate research assistant in these studies, conducted all the research, and wrote the initial manuscript drafts.

- a. Singh, Jennifer, Hallmayer, Joachim, and Illes, Judy. "Interacting and Paradoxical Forces in Neuroscience and Society." *Nature Review Neurosciences* 8 (February 2007): 153-159.
- b. Singh, Jennifer, Illes, Judy, Lazzaroni, Laura, and Hallmayer Joachim. "Trends in US Autism Research Funding." *Journal of Autism and Developmental Disorder* 39(5) (May 2009): 788-795.

2. My research has also contributed to the understanding of autism from the perspectives of adults on the autism spectrum. Based on interviews I conducted with 19 adults who either had a diagnosis or self-diagnosed on the autism spectrum, I demonstrated how the 1994 addition of Asperger's disorder in the DSM-IV opened a gateway for new social identities to become developed and embraced beyond diagnostic boundaries. Based on a grounded theory analysis of these interviews, I investigated how the changes to eliminate Asperger's from the DSM-5 threaten the assertions of a positive Asperger identity. This could potentially enhance stigma experienced by people with Asperger's and reduce opportunities for self-disclosure. More importantly, I show how regardless of the removal, Asperger identity must be considered within the broader context of people's everyday lives and how experiences in social interaction and communication can be strong agents of identity construction. I served as the primary investigator of this study.

- a. Singh, Jennifer S. "The Vanishing Diagnosis of Asperger's Disorder." In *Sociology of Diagnosis (Advances in Medical Sociology Volume 12)* edited by PJ McGann and David J. Hutson, 237-259. Emerald Group Publishing Limited, 2011.

3. I just completed a multi-sited ethnography that investigated the ever-expanding meaning of autism for those who study the disorder and those who live with it. Based on over 70 interviews with scientists conducting autism genetics research, parents raising a child with autism, and people living with autism, this research mapped out the social history of parental activism in autism genetics, the scientific optimism and subsequent failure of finding a gene for autism, and the various meanings attached to autism in the context of knowledge produced with emerging genomic technologies. I show how parent advocates not only pushed for more autism science but also organized and governed autism genetic research initiative. This in turn, influenced a shift in scientific practices and created new fields of exchange among scientists and families who participate in genetics research. My analysis demonstrates how despite the billion-dollar pursuit of unraveling the genetics of autism, the utility of genomic information has limited value in the immediate lives of people living every day with autism. This research demonstrates how the persistent focus on genetics and now genomic science is fragmenting, reclassifying, and reinventing the social and scientific meaning of autism rather than determining a specific etiology of a single disease. I am the primary investigator of this research project.

- a. Singh, Jennifer S. *Multiple Autisms: Spectrums of Advocacy and Genomic Science*. Minneapolis and London: University of Minnesota Press, 2016.

- b. Singh, Jennifer S. "Narratives of Participation in Autism Genetics Research." *Science, Technology and Human Values* 40 (March 2015): 167-175.

4. The amount of work and care conducted by parents who have a child with autism and the barriers they experience in getting a diagnosis and needed services for their child are social issues that I am investigating in my current research. Based on a grounded theory analysis of over 20 interviews with parents of a child with autism, this study develops the theoretical concepts of "parenting work" and "trajectories of care." The conceptualization of trajectories of care takes into account the social context and relationships in which parenting work takes place over time in both private and public spaces. This research contributes to our understanding of the expanded boundaries of work performed by parents of a child with disabilities that is embedded in a complex web of multiple clinical, educational, social and personal domains. Further, this research makes evident how and why parents embrace both the medical and social model of disability and the unique nature of work and care involved when parents are *the* main caregivers of a child with a disability, which can potentially last over a lifetime. I am the principle investigator of this research.

- a. Singh, Jennifer S. "Parenting Work and Autism Trajectories of Care," *Sociology of Health and Illness* 38(7) (September 2016): 1106-1120.

Complete List of Published Work:

<http://www.ncbi.nlm.nih.gov/sites/myncbi/1DMCnJWtN0IQ7/bibliography/49767048/public/?sort=date&direction=ascending>

D. Research Support

Ongoing Research Support

None

Completed Research Support

Center for Transforming Pediatric Delivery – Co-PI. \$50,000 (2016-2017): Assessing Quality of Care in a Community-Based Autism Clinic. Interview, participant observation, and survey-based research at Hughes Spalding Autism Clinic, an affiliate of Children’s Healthcare of Atlanta.