SOCIOLOGY OF ILLNESS: THE NORMAL AND PATHOLOGICAL THROUGH THE LENS OF GENETICS

Instructor: Santiago J. Molina, santiagojmolina@berkeley.edu

Seminar: Mondays, 12:10-2:00pm in 106 Wheeler Hall

Office Hours: Mondays 4:00pm-6:00pm (https://www.wejoinin.com/santiagojmolina)

I. SUMMARY AND GOALS

Since the mid-Twentieth century, scientists' understanding of the molecular basis of human biology has grown exponentially. Correspondingly, this knowledge has trickled out into the public sphere. Today, the relevance of this knowledge to modern societies is reflected in record sales of personal genetic tests, holiday package discounts for DNA ancestry services, the normalization of pre-natal genetic screening and the emergence of a flourishing industry for preserving human tissue samples and genetic data for commercial, clinical and criminological uses. Additionally, the advent of new tools in genetic engineering, has put more pressure on societies to engage in public discussions about how to ensure that scientific research is conducted ethically, that the safety risks of new technology are mitigated and that the products of this research reach the communities that most stand to benefit.

However, many of the issues that "arise" from these technologies are not entirely new. Instead, Western societies have been obsessed with the idea that a person's characteristics are passed down to their children and that wealth, status, and group membership is tied to your bloodline. Additionally, since the industrial revolution, both states and individual actors have produced a swath of eugenic policies aimed at "improving" the nation or "alleviating" poverty. On a more personal level, who we are and what we are has always had at least something to do with our bodies, whether its our height, skin color, ability, health, sex or gender. This course surveys a variety of topics in the sociology of illness and social studies of science and threads them together with a common goal: to unpack the entanglements of society with the science of human genetics and biomedicine. Through the readings, students will engage with themes that are central to sociological thought: identity, knowledge, power, categorization, race, politics, etc. albeit in the context of science and illness. By the end of the course students will be able to sharply interrogate how social and political conditions shape the production of claims about the genetic basis of illness and difference.

II. ASSIGNMENTS AND GRADING

a) Participation. You are expected to come to class having done the readings and prepared to actively discuss, compare and critique the readings with your peers. Both active *listening* and *contributing* are required for participation.	**20%**
b) 8 response memos. (300-500 words) Here you should aim to: summarize the argument in one of the readings; reflect on the readings in relation to your own experience, ask clarifying questions and connect the readings (from any week) to each other. Along with the Reading Guide, these are meant to help you keep on track with the readings and to prepare you for doing a literature review for your midterm. There are twelve weeks in the semester, so you are able to skip up to two weeks. Response memos must be submitted to bCourses by Sunday 10:30pm.	**20%**
c) Presentations. Every week two students must additionally prepare a short 10-minute summary of the readings along with five discussion questions for the seminar. Basically to get the ball rolling. These discussion questions should be sent to me via email the Sunday before you present. You will be able to sign up for the week you would like to present during the first two meetings of the seminar. You can see the current presentation schedule here: https://tinyurl.com/PresentationSheet	**10%**
d) Midterm paper. (4-5 pages double spaced) Halfway through the course, students will identify a particular phenotype they think is interesting. It could anything from a disease (like hemophilia or diabetes), a behavior (aggressiveness for example), or an attribute (like height or skin color). The midterm consists of the introduction and literature review for a research paper about this phenotype. Students will have to justify their choice of phenotype and connect it to at least three of the readings. (Due November 1st)	**20%**
e) Final paper. (15 pages double-spaced) Students must research the social, political, and/or economic dimensions of their phenotype. The direction you take this in is fairly open; as you will see throughout the course there are multiple ways of unpacking and interrogating claims about the genetic basis of illness and difference. Consider the following questions: What are the technologies surrounding it? Who are the relevant stakeholders? How is knowledge about that phenotype produced? How does the phenotype shape a persons' sense of self? Students are encouraged to look at the history of their phenotype to better situate it in relation to the conditions that made knowledge about it possible. (Due December 10th)	**30%**

III. COURSE MECHANICS

Ground Rules for the Seminar.

1. Be respectful of others.
2. Do not interrupt another student while they are speaking. (Persistent interrupting can lead to percent loss in your participation grade)
3. We may be discussing controversial social issues in this class. In debate, listen to the other person's argument, and respond to their points. Try to understand where the other person is coming from, even if you fundamentally disagree with their position.
4. Do not make personal attacks or make fun of anyone's argument.
5. Do not dominate discussion; let others speak.
6. Our goal is to include everyone in discussion. So, if you reference an outside author, please take time to explain to the other students what the author's argument is, and how it's relevant to the current readings and discussion. If you do bring outside material you should know it well enough to explain it to us. This way, we can *teach* each other, rather than exclude each other. To make discussions as participatory as possible (and welcoming to students coming from multiple disciplines), I discourage "namedropping" and "-ism-dropping."
7. These same rules apply to me and I intend to work by them. If I do interrupt someone or break these rules, call me out on it. Please. I hope to learn from our conversations just as much as you do.
8. Any other suggestions and feedback about how the seminar is run, in-seminar activities, preferences and questions are welcomed.

Academic Integrity. Much of your learning in this class will come from the contributions and ideas of your classmates through discussion; in this respect, collaboration is encouraged. However, remember to give credit where credit is due, and know that in your papers and tests it is *your own* ideas we need to hear about. Note that plagiarism is not limited to stealing an entire paper. Using quotes without properly citing them or using ideas without acknowledging their source also constitute plagiarism. Any form of cheating and plagiarism will lead to zero on the assignment and to disciplinary action. For specific guidelines on citation and Berkeley policies on plagiarism, please refer to http://www.lib.berkeley.edu/TeachingLib/Guides/Citations.html

Late Assignments Policy. No late assignments will be accepted. If you know *ahead of time* that there is going to be a problem with the assignment dates, you should let me know ahead of time, but *no* retroactive excuses will be accepted. I will arrange to accept late assignments in cases of medical emergency with proper documentation. If you have a separate scheduling conflict with assignments from another class, important events, etc. you should request an extension as soon as possible [at least 7 days prior to assignment due date].

Cell Phone Policy. Cell phones should be turned off or in airplane mode. No checking messages or receiving calls during section, except in cases of extreme personal urgency.

Please let me know at the beginning of section if you think this situation might apply to you.

Email Policy. If you email me during the week I will do my best to get back to you within 24 hours, except on weekends or administrative holidays.

Disabled Students Program and Special Accommodations. If you have a documented need for special accommodations in class or on assignments, I will be happy to work out these arrangements with you. If this applies to you, please bring me a letter from your DSP specialist as soon as possible. The Disabled Student's office is located in 260 Cesar Chavez Center 642-0518, http://dsp.berkeley.edu. Student athletes, parents, and others whose commitments might affect their ability to attend class or complete assignments on time should also speak to me about possible conflicts ahead of time.

Throughout the semester you might find some of these offices quite helpful with a variety of academic and non-academic issues:

Student Learning Center (SLC) located in the Cesar Chavez Student Center offers academic support by assisting students through tutoring, study groups, workshops and courses. You might want to check this out for free spell check, copy-editing and writing tips.

Multicultural Education Program has a number of activities, offers academic consultation and diversity workshops. Similarly, the **Berkeley International Office**, located on 2299 Piedmont Ave in iHouse, provides expert advising, immigration services, advocacy and programming. They have student advisors on a daily basis.

Counseling and Psychological Services/ University Health Services, Tang Center at 2222 Bancroft Way, (510) 642-9494 (After Hours, call 643-7197) for all things mind and body.

Gender Equity Resource Center (GenEq) is a UC Berkeley community center where students, faculty, staff and alumni connect for resources, services, education and leadership programs related to gender and sexuality.

Social Services is located in Room 2280 in the Tang Center and provides confidential services and counseling to help students with managing problems that can emerge from illness or life things. Such as financial, academic, legal, and family concerns. They specialize in helping students with pregnancy resources and referrals; alcohol/drug problems related to one's own or a family member's use; sexual assault/rape; relationship or other violence; and support for health concerns-new diagnoses or ongoing conditions.

IV. SCHEDULE OF READINGS AND ASSIGNMENTS

Week 1. 8/27 Introduction to Course: Unpacking science and society. (11 pages)

keywords: heritability, medicalization, biomedicalization, genetic determinism

Duster, T. (1996). The prism of heritability and the sociology of knowledge. in *Naked Science: Anthropological Inquiry Into Boundaries, Power, and Knowledge*. Routledge. pp. 119--130

CNN (2009) Blame genetics for bad driving, study finds: http://www.cnn.com/2009/TECH/science/10/29/bad.driver.gene/index.html?_s=PM:TECH

Week 2. 9/3 (No class, academic holiday) Biomedicalization (26 pages)

Clarke, A. E., & Shim, J. (2011). "Medicalization and biomedicalization revisited: technoscience and transformations of health, illness and American medicine." In *Handbook of the sociology of health, illness, and healing* (pp. 173-199). Springer New York.

Week 3. 9/10 Stigmatization and genetic determinism (68 pages)

keywords: biomedicalization, geneticization theory, attribution theory, inherent, interaction

Goffman, E. (2009). "Ch.1 Stigma and Social Identity" (pp. 1-40) and "Ch.4 The Self and Its Other" (pp.126-139) in *Stigma: Notes on the management of spoiled identity*. Simon and Schuster.

Phelan, J. C. (2005). Geneticization of Deviant Behavior and Consequences for Stigma: The Case of Mental Illness∗. *Journal of Health and Social Behavior*, *46*(4), 307-322.

Film Suggestion: *Gattaca (1997)*

Week 4. 9/17 Disability and the Normal Body (35 pages)

Wilson J. (2002) Ch.5 "(Re)Writing the Genetic Body-Text Disability, Textuality, and the Human Genome Project" (pp. 87-78) in Davis, L. ed. *The Disability Studies Reader,* Routledge: NY

Benjamin, R. (2016). Interrogating equity: a disability justice approach to genetic engineering. *Issues in Science and Technology*, *32*(3), 51.

Frederick, A. (2017). Risky Mothers and the Normalcy Project: Women with Disabilities Negotiate Scientific Motherhood. *Gender & Society*, *31*(1), 74-95.

Film Suggestion: *Fixed – The Science/Fiction of Human Enhancement (2013)*

Week 5. 9/24 Theories of biological discourse. (53 pages)

keywords: discourse, technologies of reproduction, technology of self

Canguilhem, G. (1991). "Introduction to the Problem," (pp.321-325) "Normality and Normativity" (pp.351-357, 369-378) in *The Normal and the Pathological*. NY: Zone Books.

Foucault, M. (1988). Technologies of the self. In *Technologies of the self: A seminar with Michel Foucault* (pp. 16-49).

Week 6. 10/1 Making people: how categories work. (67 pages)

MIDTERM PAPER DUE

keywords: looping effects, classification struggles, self-knowledge

Hacking, I. (1986). "Making up people" in *Historical Ontology* (pp. 222-236).

Navon, D., & Eyal, G. (2016). "Looping genomes: Diagnostic change and the genetic makeup of the autism population." *American Journal of Sociology*, *121*(5), 1416-1471.

Park, A. (2017) "How Much of Autism is Genetic?" *TIME.* [Available online at http://time.com/4956316/how-much-of-autism-is-genetic/]

Week 7. 10/8 Biopolitics (42 pages)

Keywords: biopolitics, biopower, scientia sexualis

Foucault, Michel (1984) *The History of Sexuality: Vol. 1 An Introduction,* Random House: NY. (pp. 57-73, 115-127 **only**)

Rose, N. (2001). "The politics of life itself." *Theory, culture & society*, *18*(6), 1-30.

Page, Eric (2010) "Scientists Find 'Liberal Gene,' *NBC San Diego* [Available online at https://www.nbcsandiego.com/news/weird/Scientists-May-Have-IDd-Liberal-Gene-105917218.html]

Week 8. 10/15 Human genetics, identity and ethnoracial classification I. (44 pages)

keywords: social construction, political identity, groups, naturalization, reinscription

TallBear, Kim. "Genomic articulations of indigeneity." *Social Studies of*

Science 43, no. 4 (2013): 509-533.

Duster, T. (2015). A post-genomic surprise. The molecular reinscription of race in science, law and medicine. *The British journal of sociology*, *66*(1), 1-27.

Week 9. 10/22 Human genetics, identity and ethnoracial classification II. (45 pages)

Practical exercise with Martin Eiermann, interrogate genetic ancestry test methods.

keywords: purification, hybridization, admixture

Panofsky, A., & Donovan, J. (2017). When genetics challenges a racist's identity: Genetic ancestry testing among white nationalists. *Preprint.*

Liu, Jennifer A. (2010) "Making Taiwanese (Stem Cells)" (p.239-257) in *Asian Biotech: Ethics and Communities of Fate* edited by Aihwa Ong and Nancy N. Chen. Duke University Press

Ball, et. al. (2013) *Ancestry.com Ethnicity Estimate White Paper*

Week 10. 10/29 Politics of knowledge and national ancestry (58 pages)

keywords: bionation, imagined community, mestizaje

Frickel, Scott, and Kelly Moore. 2006. "Prospects and Challenges for a New Political Sociology of Science." In *The New Political Sociology of Science: Institutions, Networks, and Power*. Madison: University of Wisconsin Press. Pp. 3-14 ***only.***

Kent, M., García-Deister, V., López-Beltrán, C., Santos, R. V., Schwartz-Marín, E., & Wade, P. (2015). Building the genomic nation: 'Homo Brasilis' and the 'Genoma Mexicano' in comparative cultural perspective. *Social studies of science*, *45*(6), 839-861.

Sung, Wen-Ching (2010) "Chinese DNA: Genomics and Bionation," (pp. 263-288) in *Asian Biotech: Ethics and Communities of Fate* edited by Aihwa Ong and Nancy N. Chen. Duke University Press

Film Suggestion: *DNA Dreams (2015)*
https://www.youtube.com/watch?v=1dVv5RMwzuo

Week 11. 11/5 Social movements and "molecular" diseases (51 pages)

Nelson, A. (2011). "Ch.4 Spin Doctors: The Politics of Sickle Cell Anemia" (pp.115-152) in *Body and soul: The Black Panther Party and the fight against medical discrimination*. U of Minnesota Press.

Benjamin, R. (2011). "Organized ambivalence: when sickle cell disease and stem cell research converge." *Ethnicity & health*, *16*(4-5), 447-463.

Week 12. 11/12 (Academic Holiday)

We will schedule extended group office hours for work-shopping paper drafts and brainstorm early literature review research.

Week. 13. 11/19 Social construction of biotechnology (~36 pages)

Colyvas, J. A. (2007). Factory, hazard, and contamination: The use of metaphor in the commercialization of recombinant DNA. *Minerva*, 143-159.

Molina, S. (n/a) "Metaphors of Nature: What is CRISRP-Cas9?" *unpublished manuscript.*

Film Suggestion: *Jurassic Park* (1993)

Week 14. 11/26 (2nd Genome Editing Summit, Hong Kong: Santiago out of town)

We will schedule group meetings to workshop final paper drafts.

Week 14. 10/3 RRR Week. Extended office hours to workshop papers.