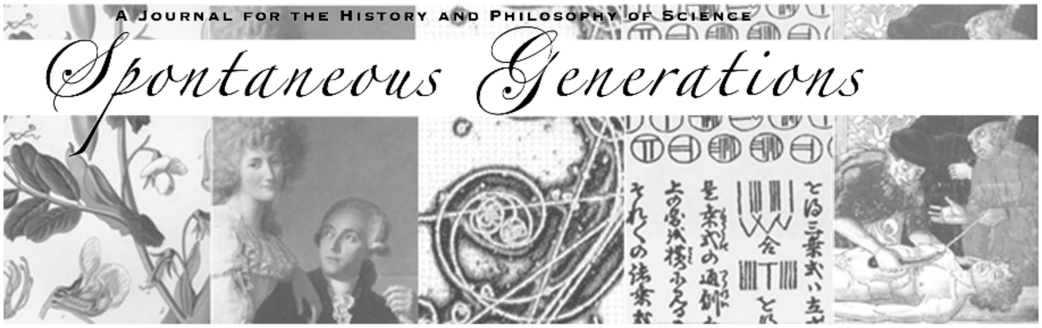

Studying Science and Social Inequalities: Resurgences and Divergences

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Studying Science and Social Inequalities:
Resurgences and Divergences[*]

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Spontaneous Generations deserves credit for calling attention to the histories and futures of scholarship that critically investigates the science/technology/inequality nexus. My own suggestion in this regard is modest: Rather than assuming that there is any single or obvious way in which scientific knowledge and technologies, on the one hand, and social inequalities, on the other, might be related (causally or otherwise), we ought to embrace complexity by considering some of the different sorts of things that the phrase "science and social inequality" might connote. However, I should signal from the outset that I won't be taking for granted that the "reproduction" of inequality—that is, how "science and technology reflect and create social inequalities," to quote from the opening sentence of the call for papers for this special issue—is the only relevant mode of activity that we ought to examine. Instead I will assume it to be helpful to consider how scientific knowledge and technological systems might be related to *reproducing, reinforcing, challenging, transforming, or eliminating* inequalities.

As an (admittedly inadequate) gesture at the kind of complexity I hope to signal, I will take up just three of many possible points of linkage between technoscience and the reproduction of, reinforcement of, challenge to, transformation of, or elimination of inequalities. These are: the causes and consequences of unequal access to participation in knowledge-making; scientific practices of difference-making and their consequences for social categories, identities, and hierarchies; and the scientization of everyday concepts and its implications for inequalities.

The first case, that of unequal access to participation in knowledge-making, relates to a growth area in STS, where scholars

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for quite some time have moved beyond asking questions about the public's *understanding* of scientific knowledge or the public's involvement in *regulating* scientific activity to look in addition at the diversification of epistemic contributions to the production of certified knowledge (Wynne 1992). I examined such issues in my research on the AIDS epidemic and the unanticipated contributions of AIDS activists in the late 1980s and early 1990s (Epstein 1995; 1996; 1997a; 1997b). As activists taught themselves relevant aspects of virology, immunology, and biostatistics, they cultivated and wielded a hybrid form of expertise that combined the local or situated knowledge of the patient with the specialized knowledge of the self-educated "lay expert." On the basis of that hybrid expertise, they were, among other things, able to speed the development and licensing of antiviral drugs.

More generally, many different scholars have identified how health advocates concerned with an extremely wide range of health conditions have changed not only government policies, attitudes of health professionals, and cultural norms, but also processes of biomedical knowledge production (Epstein 2008; 2011). Patient groups have raised funds for research and have doled them out to support the lines of research they deem most important; have gained a seat at the table to make decisions about research directions; have promoted ethical treatment of participants in clinical trials; have attempted to police perceived ethical abuses such as conflicts of interest in research; have challenged the techniques for conducting and interpreting clinical trials; and have helped create disease and treatment registries. Patients have organized conferences, coauthored publications, and pioneered new models of participatory research that joins the efforts of lay citizens with those of experts (Rabeharisoa and Callon 2002; Murphy 2006; Klawiter 2008; Bell 2009; Eyal et al. 2010; Hoffman et al. 2011; Benjamin 2013; Nelson 2013). Of course, biomedicine is only one of many scientific domains in which lay outsiders may pose such challenges. But the immediacy of embodied concerns in that arena gives challengers both a particular stake and an easily recognizable moral claim, and it creates new possibilities for the extension of citizenship as a domain of embodied political claims-making.

In these contexts, "inequality" means a number of different and important things. First and most immediately, these struggles concern what, loosely borrowing the Marxian terminology, we might term ownership of the *forces* of knowledge production and locations within the *relations* of knowledge production. These struggles are aimed at shifting the balance of power between the knowers and the known-about, or better put, to blur the boundaries between such categories. In this sense, the term *inequality* references a particular set of problems that confront formally democratic societies that are heavily dependent on expertise (Jasanoff 1990; Irwin 1995). The issue of how to promote more egalitarian access to knowledge production in such settings is by no means a simple one, and challenging groups, even the most successful ones, have been beset by difficulties that include disputes over internal representation (Who speaks for the community of patients or other lay actors?), risks of cooptation, and the emergence of new divisions or hierarchies of expert labor within advocacy communities themselves. Recent scholarship on public engagement with science and technology has also raised fascinating questions about the dynamics of these struggles. For example, scholars such as Javier Lezaun and Linda Soneryd (2007) have looked at how formal, state-directed efforts (especially in European countries) to mobilize and measure public views on scientific questions (say, by means of focus groups or other "technologies of elicitation," to borrow their term) can have the effect of packaging public participation in science in ways that redirect or even subvert the goal of democratization.

But in addition to this particular sense of inequality between the knowledge-makers and the knowledge-disenfranchised, such struggles also intertwine in complicated ways with the more conventional categories of inequality with which sociologists are broadly familiar. Knowledge hierarchies are rarely "accidental" in their origins: they tend both to build upon, and reinforce, social cleavages based on other markers of inequality—class, formal education, race, gender, sexuality, or nation. In the case of AIDS activism, for example, the epistemic contributions of activists of color often escaped notice, while the ability of the movement to win a seat at the biomedical table had at least something to do with the presence within its ranks of many relatively privileged, if in some important ways disenfranchised, well-educated, middle-class white gay men. Therefore an important area for research is investigating the specific ways in which knowledge hierarchies and other social hierarchies interweave or collide in all the diverse domains where individuals or groups either do or do not seek out a role for themselves in the production or evaluation of scientific knowledge claims (Epstein 2010).

My second "take" on the broader theme of science, technology, and inequality is what I will call scientific practices of difference-making and their consequences for social categories, identities, and hierarchies. My research interest here has been in the workings of a double-sided relationship: on the one hand, the influence of the politics that surrounds categories like race, class, gender, and sexuality on the organization and content of scientific work and technological products, and, on the other hand, the role of technoscientific practices in transforming the accepted meanings and ontological statuses of those very same categories and identities. So, for example, in my book *Inclusion* (Epstein 2007), I asked questions like: have women been underrepresented as research subjects in clinical trials? And: how did activists change biomedical research policies and practices to test for ethnic differences in the effects of medications? But I also took up questions like: how are abstract dimensions of social hierarchy like race and sex "operationalized" in biomedicine and transformed into categorical variables? How might current biomedical research practices and new inclusionary policies have the effect of changing what we imagine race and sex actually to be, as biological and cultural entities that may be linked in various ways to health and disease? And: does the technoscientific rendering of human differences as a matter of our biology unintentionally hinder our capacity to address embodied social inequalities, such as health disparities, that at root reflect our social arrangements and inequalities of power and of life chances, rather than group differences at the level of biology?

I think that the exploration of this dialectical relationship between embodied identity categories and technoscientific processes and objects is a distinctive and important contribution of a substantial amount of recent STS scholarship. It has long history (Duster 1990; Fausto-Sterling 1992; 2000), but I can hint at the vitality of this body of work by gesturing at substantial publications in just the past few years, such as Michael Montoya's (2011) book on *Making the Mexican Diabetic*; Rebecca Jordan-Young's (2010) book *Brain Storm: The Flaws in the Science of Sex Differences*; Sarah Richardson's (2013) critique, in her book *Sex Itself*, of the intrusion of invidious gender distinctions into the history of research human genetics research; Ann Morning's (2011) analysis, in her book *The Nature of Race*, on how expert conceptions of race are transmitted to popular audiences in codified forms such as high-school textbooks; Anne Pollock's (2012) book on the intersecting trajectories of race, pharmaceuticals, and cardiovascular disease; Janet Shim's (2014) book, *Heart-Sick*, that shows how the familiar categories of race, gender, and class are inserted into epidemiological knowledge-making in ways that strip them of social significance; Lundy Braun's (2014) book on the racialized history of the spirometer; Rene Almeling's (2011), critique of the differential valuation of human eggs and sperm in her book *Sex Cells*; Dorothy Roberts's (2011) critique of the embedding of race in a variety of technologies and social practices in her book *Fatal Invention*; Jonathan Kahn's (2012) pointed investigation into the history of a "race-specific" medicine in his book *Race in a Bottle*; Sara Shostak's (2013) analysis of the linkage of racial meanings to research into "gene-environment interactions"; Catherine Bliss's (2012) exploration of geneticists' attitudes toward race in her book *Race Decoded*; as well as studies by Joan Fujimura and Ramya Rajagopalan (2011) on the making of "race" in the laboratory, and Tom Waidzunas's (2013) work on how gay as well as "ex-gay" activists have pressured mental health experts to redefine notions of sexuality and sexual identity.

A key point here is that studies of such matters as how a lab sample becomes "raced," or how a chromosome becomes "sexed," or how a technology becomes "gendered" have enormous relevance for understanding not only the making and remaking of inequalities but also the practical reification or transformation of the very categories by which inequalities make themselves known to scholars or to the public at large. For example, in my own work, I described the unintended consequences of the turn to the biological as a means for grounding political claims in arenas like health. In light of the long history within medicine of conceptualizing difference as pathology, it may be highly problematic for groups that in the past have borne the brunt of such pathologizing—women, racial and ethnic minorities, sexual minorities, and the disabled, among others—to invoke biomedical notions of difference to legitimate their claims vis-à-vis biomedical institutions. That history does not preclude the possibility that those actors might change the cultural meanings of biological differences and wrest them out from under the shadow of pathology. But it does suggest that "positive" assertions of biological difference may readily backfire or lend tools to those who seek to reinforce old hierarchies. They also may provide a beachhead to those whose interest is to convert social identities into "market niches" for profit-making purposes (Epstein 2007).

An additional concern in relation to the downstream effects of scientific practices of difference-making is the way that they flatten out the political analysis suggested by the term "inequalities" precisely by rendering inequality as mere *difference*. The reformers I studied who promoted inclusion of underrepresented groups as biomedical research subjects pointed to health disparities—especially disparities by race—as part of the justification for changing biomedical research practices, but they did so typically without extended analysis of the complex array of conditions that might generate those disparities. Instead, they often fell back on a vaguer and less charged conception of group "difference," one that was explicitly or implicitly biological, and that often had to do with things like ethnic or sex differences in the metabolizing of pharmaceutical drugs. To invoke "disparities" is to invoke a criterion of social justice; to refer to "differences" is to advance a somewhat more neutral understanding, one that lends itself to a wide array of uses. Differences do call out to be recognized, and to be responded to in a non-homogenizing way. But disparities, by contrast, call out for their own elimination.

In 2002, Secretary of Health and Human Services Tommy Thompson declared: "Our goal is to eliminate disparities in health among all population groups by 2010." Yet in late 2003, when his agency released a 196-page National Healthcare Disparities Report that it had been required by law to prepare, critics discovered that the final version deleted most of the original draft's uses of the very word "disparity." The original draft presented the data on what it called "a broad array of differences related to access, use, and patient experience of care by racial, ethnic, socioeconomic, and geographic groups" and suggested it was reasonable to treat many of these as evidence of health inequalities. But the revised version instead stated: "Where we find variation among populations, this variation will simply be described as a 'difference.' By allowing the data to speak for themselves, there is no implication that these differences resulted in adverse health outcomes or imply prejudice in any way" (Epstein 2007, 298-99). The risk here is that while the language of difference may provide an important opening for making claims about the need for group-tailored remedies, it fails to demand adequate attention to a crucial set of issues—specifically, the ways in which inequalities and power differentials in the broader society affects people's exposure to health risks, their capacity to access quality medical care, and the likelihood that they will be subject to conscious or unconscious discriminatory treatment by health care professionals. To the extent that difference also is construed largely in biological terms, it becomes even less likely that these other issues will receive their due.

Let me say a brief word about a third theme, what I will the scientization of everyday concepts and its implications for inequalities. My concern in this case is with the downstream consequences of the scientization or biomedicalization of complex social issues—and the example I'll take up is human sexuality. In a recent unpublished paper coauthored with Laura Mamo, and in my ongoing research that I hope will culminate in a book, I address the case of sexual health, a term that emerged in its modern guise in the late 1960s and which, I argue, has been a ubiquitous and important buzzword since the early 1990s. The term references a wide range of practical concerns and initiatives, from preventing sexually transmissible infections, to enabling or regulating reproductive capacity, to curing sexual dysfunction, to promoting sexual rights, to securing freedom from sexual violence, to overcoming sexual compulsivity, to enhancing cardiovascular health through sexual activity, and so on. In part because of its fuzziness and ambiguity, and in part because the positive valences of "health" appear to cancel out the potentially negative valences of "sexual," sexual health has become the convenient catchphrase for manifold projects which, once billed under that label, seem more difficult to oppose. Much as it seems to be not just morally unconscionable but almost logically impossible to stand "against health" (Metzl and Kirkland 2010), so sexual health has come to seem an undeniable good—whatever the term is taken to connote. Moreover, once the term began to spread, it was available to be taken up for diverse instrumental, opportunistic, and euphemistic uses. The more it has become institutionalized, the more it creates pressure for others to adopt it as a term du jour that will be immediately recognizable to reviewers of grant proposals, editors of journals, and funders of clinics, training programs, and advocacy campaigns.

I believe that the recent refraction of a vast array of sexual issues through the prism of health has opened broad avenues for scientific and practical action and created a wealth of possibilities for the development of new initiatives, expertise, and organizational infrastructure. But I also want to call attention to the consequences of requiring that matters of sexuality receive the imprimatur of health and, more often than not, take on the mantle of science in order to be deemed worthy. The broad transformation of sexuality into sexual health has precluded alternative visions of how sexuality might legitimately be understood—especially in relation to forms of pleasure—and it has privileged some meanings of sexual health over others—and thus some varieties of sexual expression over others.

Even as sexual health is increasingly made into a concern for everyone, it comes to hold different implications according to location in social hierarchies. To give just one obvious example, it is unlikely that the stakes of sexual health are ever identical for women and men—but there is no doubt much more to be said, certainly in relation to race, ethnicity, social class, gender expression, sexual identity, religion, and geographic location. My suggestion, therefore (although here I cannot flesh this out in a more satisfactory way) is that as sexuality increasingly came to pass through the prism of health—as it became reconstituted as a more-or-less scientific object in this particular, modern way—the old links between sexuality and social inequalities necessarily became reconfigured, perhaps in some ways for the better, though perhaps in other ways for the worse. In the future I would like to treat this reconfiguration of inequalities as an instance of a broader phenomenon, looking at how the uptake of realms of social experience as matters of scientific investigation may build on, resurrect, undermine, or reshape social relations of inequality.

In this short and incomplete review, I hope I have suggested that while I certainly do think that scientific knowledge production is intimately tied to issue of social inequalities, we should pluralize and complicate the discussion as much as possible. We should be attentive to the quite varied ways in which knowledges, technologies, powers, and inequalities of all different sorts come together in specific social domains and historical instances. We should also pay close attention to the multiple valences of knowledge and its complex effects—that is, we should recognize that scientific activity is neither inherently inequality-engendering nor inherently inequality-resisting—and as analysts we should therefore begin by putting away our broad brushes.

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References

Almeling, Rene. 2011. *Sex Cells: The Medical Market for Eggs and Sperm.* Berkeley: University of California Press.

Bell, Susan E. 2009. *DES Daughters: Embodied Knowledge and the Transformation of Women's Health Politics*. Philadelphia: Temple University Press.

Benjamin, Ruha. 2013. *People's Science: Bodies and Rights on the Stem Cell Frontier*. Stanford, CA: Stanford University Press.

Bliss, Catherine. 2012. *Race Decoded: The Genomic Fight for Social Justice.* Stanford, CA: Stanford University Press.

Braun, Lundy. 2014. *Breathing Race into the Machine: The Surprising Career of the Spirometer from Plantation to Genetics*. Minneapolis: University of Minnesota Press.

Duster, Troy. 1990. *Backdoor to Eugenics*. New York: Routledge.

Epstein, Steven. 1995. The Construction of Lay Expertise: AIDS Activism and the Forging of Credibility in the Reform of Clinical Trials. *Science, Technology, & Human Values* 20 (4): 408-437.

Epstein, Steven. 1996. *Impure Science: AIDS, Activism, and the Politics of Knowledge*. Berkeley: University of California Press.

Epstein, Steven. 1997a. Activism, Drug Regulation, and the Politics of Therapeutic Evaluation in the AIDS Era: A Case Study of ddC and the 'Surrogate Markers' Debate. *Social Studies of Science* 27 (5): 691-726.

Epstein, Steven. 1997b. AIDS Activism and the Retreat from the Genocide Frame. *Social Identities* 3 (3): 415-438.

Epstein, Steven. 2007. *Inclusion: The Politics of Difference in Medical Research.* Chicago: University of Chicago Press.

Epstein, Steven. 2008. Patient Groups and Health Movements. Pp. 499-539 in *The Handbook of Science and Technology Studies*, eds. E. J. Hackett, O. Amsterdamska, M. Lynch and J. Wajcman. Cambridge, MA: MIT Press.

Epstein, Steven. 2010. The Great Undiscussable: Anal Cancer, HPV, and Gay Men's Health. In *Three Shots at Prevention: The HPV Vaccine and the Politics of Medicine's Simple Solutions*, edited by K. Wailoo, J. Livingston, S. Epstein and R. Aronowitz. Baltimore: Johns Hopkins University Press. Pp. 61-90.

Epstein, Steven. 2011. Measuring Success: Scientific, Institutional, and Cultural Effects of Patient Advocacy. In *Patients as Policy Actors*, edited by B. Hoffman, N. Tomes, R. Grob and M. Schlesinger. New Brunswick, NJ: Rutgers University Press. Pp. 257-277.

Eyal, Gil, Brendan Hart, Emin Onculer, Neta Oren, and Natasha Rossi. 2010. *The Autism Matrix: The Social Origins of the Autism Epidemic.* Cambridge, England: Polity.

Fausto-Sterling, Anne. 1992. *Myths of Gender: Biological Theories About Women and Men.* 2nd ed. New York: Basic Books.

Fausto-Sterling, Anne. 2000. *Sexing the Body: Gender Politics and the Construction of Sexuality.* New York: Basic Books.

Fujimura, Joan H., and Ramya Rajagopalan. 2011. Different Differences: The Use of 'Genetic Ancestry' Versus Race in Biomedical Human Genetic Research. *Social Studies of Science* 41 (1): 5-30.

Hoffman, Beatrix, Nancy Tomes, Rachel Grob, and Mark Schlesinger. 2011. *Patients as Policy Actors.* New Brunswick, NJ: Rutgers University Press.

Irwin, Alan. 1995. *Citizen Science: A Study of People, Expertise and Sustainable Development.* London: Routledge.

Jasanoff, Sheila. 1990. *The Fifth Branch: Science Advisers as Policymakers.* Cambridge, MA: Harvard University Press.

Jordan-Young, Rebecca M. 2010. *Brain Storm: The Flaws in the Science of Sex Differences.* Cambridge, MA: Harvard University Press.

Kahn, Jonathan. 2012. *Race in a Bottle: The Story of BiDil and Racialized Medicine in a Post-Genomic Age.* New York: Columbia University Press.

Klawiter, Maren. 2008. *The Biopolitics of Breast Cancer: Changing Cultures of Disease and Activism.* Minneapolis: University of Minnesota Press.

Lezaun, Javier, and Linda Soneryd. 2007. Consulting Citizens: Technologies of Elicitation and the Mobility of Publics. *Public Understanding of Science* 16: 279-297.

Metzl, Jonathan M., and Anna Kirkland. 2010. *Against Health: How Health Became the New Morality.* New York: New York University Press.

Montoya, Michael J. 2011. *Making the Mexican Diabetic: Race, Science, and the Genetics of Inequality.* Berkley: University of California Press.

Morning, Ann. 2011. *The Nature of Race: How Scientists Think and Teach About Human Difference.* Berkeley: University of California Press.

Murphy, Michelle. 2006. *Sick Building Syndrome and the Problem of Uncertainty: Environmental Politics, Technoscience, and Women Workers.* Durham, NC: Duke University Press.

Nelson, Alondra. 2013. *Body and Soul: The Black Panther Party and the Fight against Medical Discrimination.* Minneapolis: University of Minnesota Press.

Pollock, Anne. 2012. *Medicating Race: Heart Disease and Durable Preoccupations with Difference.* Durham, NC: Duke University Press.

Rabeharisoa, Vololona, and Michel Callon. 2002. The Involvement of Patients' Associations in Research. *International Social Science Journal* 54 (171): 57-63.

Richardson, Sarah S. 2013. *Sex Itself: The Search for Male and Female in the Human Genome.* Chicago: University of Chicago Press.

Roberts, Dorothy E. 2011. *Fatal Invention: How Science, Politics, and Big Business Re-Create Race in the Twenty-First Century.* New York: New Press.

Shim, Janet K. 2014. *Heart-Sick: The Politics of Risk, Inequality, and Heart Disease*. New York: New York University Press.

Shostak, Sara. 2013. *Exposed Science: Genes, the Environment, and the Politics of Population Health*. Berkeley: University of California Press.

Waidzunas, Tom J. 2013. Intellectual Opportunity Structures and Science-Targeted Activism: Influence of the Ex-Gay Movement on the Science of Sexual Orientation. *Mobilization* 18 (1): 1-18.

Wynne, Brian. 1992. Misunderstood Misunderstandings: Social Identities and Public Uptake of Science. *Public Understanding of Science* 1: 281-304.