

norms exhibit a strong correlation over the course of an entire decade net of structural factors, suggesting strong independent cultural continuity in features of a neighborhood's local culture.

Based on 18 months of ethnographic fieldwork with young men involved in street violence, Joseph C. Krupnick and Christopher Winship examine the social norms of street encounters that help these young men to avoid violent confrontations. They ask why there is not more violence in inner-city neighborhoods. Their micro-sociological analysis proposes that the answer is that well-established norms for casual street encounters provide a structure to such interactions that allows individuals to substitute verbal play for physical altercations. In so doing, Krupnick and Winship illustrate the power of a detailed study of micro-level social norms for explaining individual behavior and patterns of violence in poor neighborhoods.

Drawing on a novel analysis of inner-city students bussed to suburban schools and a comparison group of those who were not, Simone Ispa-Landa shows how schools can act as agents of socialization and cultural transmission for poor students. She finds that the bussed students developed middle-class understandings of authority structures and strategies for navigating these authority structures, providing them with the cultural tools to more successfully interact with authority figures. Specific school personnel were instrumental in such socialization efforts. Ispa-Landa's findings suggest that, under the right circumstances and with deliberate effort, schools can be institutions

of opportunity and cultural cultivation, preparing disadvantaged students to successfully navigate and leverage resources from middle-class institutions.

### A New Agenda?

Like any innovative piece of scholarship, *The Cultural Matrix* raises as many questions as it answers. What does it mean to say that culture has an independent effect on black youth in a world in which culture and structure are so closely intertwined, and how would we isolate an independent effect if it exists? What new data need to be collected, and new measurement strategies developed, in order to fully leverage cultural concepts (whether they be values, norms, scripts, frames, narratives, repertoires, or symbolic boundaries) in the study of poverty, inequality, and race? What are the processes of cultural diffusion and cultural isolation that either constrain or enable opportunities for black youth? The theoretical and methodological challenges of an intellectual agenda that can make progress on these questions are deep, but *The Cultural Matrix* provides an exciting point of departure.

### References

- Patterson, Orlando. 2014. "Making Sense of Culture." *Annual Review of Sociology* 40:1-30.
- Small, Mario Luis, David J. Harding, and Michèle Lamont. 2010. "Reconsidering Culture and Poverty." *Annals of the American Academy of Political and Social Science* 629:6-27.
- Wilson, William Julius. 1987. *The Truly Disadvantaged: The Inner City, the Underclass, and Public Policy*. Chicago: University of Chicago Press.

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## Stem Cell Initiatives as a New Window into Health Disparities

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At a time of profound social inequalities in the United States, high-tech medicine is nonetheless touted for its potential to save all lives through miracle cures. The fact that these types of advances would likely be available only to people who are already privileged by the best health care is rarely

*People's Science: Bodies and Rights on the Stem Cell Frontier*, by **Ruha Benjamin**. Stanford, CA: Stanford University Press, 2013. 272 pp. \$24.95 paper. ISBN: 9780804782975.

woven into the narrative about medical progress. In her book *People's Science: Bodies and Rights on the Stem Cell Frontier*, Ruha Benjamin critically examines California's 2004 stem cell initiative as a so-called populist project. By using a lens of health disparities to understand the role of stem cell science, Benjamin deftly analyzes what such funding priorities mean for those who are systematically disadvantaged in society. For those of us working in the sociology of science, knowledge, and technology—or science and technology studies (STS) more generally—this approach to the topic is an innovative and refreshing empirical and conceptual choice. Whereas many STS scholars might select a laboratory for their ethnographic work, Benjamin brackets the science of stem cell research to instead trace how a publicly supported ballot measure engaged, eschewed, and intersected with multiple stakeholder groups within and beyond California. As a result, the book contributes not only to STS but also more broadly to the field of sociology for those with interests in medicine; race, class, and gender; disability studies; political economy; and poverty and inequality.

The context for Benjamin's study is the politically contentious domain of funding for U.S. stem cell research. Given that some of this research utilizes human embryos, stem cell science is entrenched in moral debates about what constitutes human life and is, thus, deeply influenced by abortion politics. Trying to navigate these fraught waters, the government had enacted restrictions on embryonic stem cell research through regulations associated with the receipt of federal funding. Specifically, in 2001 President George W. Bush made it illegal to use federal funds to produce new embryonic stem cell lines and allowed funding from the National Institutes of Health (NIH) to be granted only for research using existing cell lines. In this restrictive environment, California proposed to create its own source of funding for stem cell research through a bond measure allocating nearly \$300 million per year to such science. Through Proposition 71, California citizens voted to approve this massive and unprecedented initiative. To help illustrate the magnitude of California's commitment to stem

cell science, Benjamin points out that the NIH had awarded less than \$25 million in funding to stem cell researchers in 2003. This positioned California as a "colleague and competitor" to national governments around the world (p. 13).

One key question that *People's Science* tackles is how Proposition 71 won ballot approval. Benjamin effectively describes the irony of this massive funding bill winning at the polls. The state of California was already deep in a severe budget crisis, grappling with a housing crisis marked by high rates of foreclosures and a growing gap between the state's richest and poorest residents. In the same election, another ballot measure, Proposition 72, sought to extend health care coverage to address the increasing number of residents who were un- or underinsured. Unlike the stem cell bill, however, California voters defeated Proposition 72. In other words, California voters effectively expressed their support for research purported to bring about future medical advancements while simultaneously rejecting attempts to expand access to present-day, proven therapies to patients in need. Benjamin further situates Proposition 71 within the commercial interests intrinsic to stem cell science, with the initiative explicitly promoting the commodification of research by promising investigators the ability to profit from state-funded discoveries, citing this as the only viable pathway to encourage therapeutic innovations. In spite of all this, Proposition 71 was able to succeed in large part due to its "populist packaging," setting up the semblance of a participatory movement in opposition to President Bush and establishing a "right to research" that putatively could take the politics out of science (pp. 15–16).

While Benjamin tells a fascinating—even if at times somewhat cursory—story about the political machinations undergirding California Proposition 71 and the rollout of its subsequent stem cell agency, the strongest contribution of *People's Science* is in Benjamin's detailed analysis of two of the constituent groups that are implicated in the stem cell initiative: disabled people and racial minorities. In her chapter on disability, Benjamin beautifully compares the perspectives of two advocates. The first, a father whose

adult son suffered a spinal cord injury and is wheelchair bound, supports the stem cell initiative as a patient advocate because of the promise of science to cure people who are victims of their disabilities and to return them to "normal." The other, a disability rights and racial justice activist with muscular dystrophy, criticizes Proposition 71 for its contribution to the devaluation and marginalization of people with disabilities while simultaneously noting that "there are a lot of people that make money off of disability" (p. 69). By contrasting these two perspectives through the narratives of two impassioned advocates, Benjamin illustrates the complexity of what is at stake as stem cell research is constructed as a biomedical solution to what many individuals perceived as disabled would instead consider a civil rights problem.

Benjamin's exploration of the intersection of race and the stem cell initiative weaves together an empirically grounded portrait of existing stem cell therapies for sickle cell disease and an astute analysis of the biomedical community's claim that African Americans are distrustful of research. In spite of both the populist rhetoric of Proposition 71 and the calls for attention to diversity in the rollout of the initiative, sickle cell disease was excluded from any funding in the first grant cycle and was not represented on the state's governing board, unlike 29 other disease conditions. In clinics, researchers note that there is a high rate of African American families consenting to store cord blood after the birth of an unaffected child because of its potential therapeutic use for a sibling with sickle cell disease. Yet, as Benjamin documents, only 6 percent of sickle cell patients or their caregivers agreed to a cord blood transplant when there was a good match between affected and unaffected siblings. This indicates that many African American families may not be eager to undergo experimental stem cell procedures.

While researchers seem to interpret this as a sign of African American families' distrust of research, Benjamin persuasively argues that this should instead be thought of as "ambivalence in action." Detailing stories from families with whom she met, she illustrates how caretakers perceived the research options as having uncertain benefits to sickle cell patients yet exposing their loved ones to

known risks that were higher than standard (non-research) therapies. Highlighting one caregiver in particular, Benjamin writes, "What might be regarded as her 'distrust' toward medical studies, in other words, could be understood otherwise: as her trust *in* something other than an experimental method" (p. 122, emphasis in original). Benjamin then makes a powerful case for "depathologizing" distrust in the medical realm. She argues that framing African Americans and others as "hard to reach" populations blames those groups as if they are self-selecting rather than systematically marginalized by mainstream biomedicine. It also leads to "medical racial profiling" as researchers scramble to meet federal and state guidelines mandating they enroll minority patients in their clinical trials. In this environment, distrust is perhaps warranted, Benjamin asserts, given the context of unequal free-market medicine that structures health care in the United States.

*People's Science* is a thoughtful exploration of how public support for research can contribute to longstanding social and health inequalities. By connecting the dots between state politics, clinical treatments, and the lived experiences of disadvantaged minorities in the United States, Ruha Benjamin offers her readers something truly novel here. It is also important to note that she does so through clear and accessible writing that integrates her ethnographic work with myriad secondary sources documenting California's stem cell initiative. Although it is not an in-depth ethnography, *People's Science* delivers a keen social analysis that integrates the approaches of disability studies, gender studies, and critical race theory into the study of science policy.