

Interrogating Equity: A Disability Justice Approach to Genetic Engineering

My approach to human genetic engineering draws on 10 years of research on the social impact and meaning of emerging biotechnologies, in particular regenerative medicine and genomics, in which I have examined the relationship between innovation and equity as it connects to socioeconomic class, gender, race and ethnicity, citizenship, and disability. In what follows, I will focus primarily on disability with the understanding that these forms of social stratification, and their intersection with science and technology, are inextricably connected. With that, my intervention is twofold.

First, I would like to highlight that the distinction commonly made between genetic therapy and enhancement is not at all straightforward or stable. The bright line we may wish to draw between laudable and questionable uses of gene editing techniques is more porous than we realize. Many practices that were optional yesterday are medicalized today. Likewise, traits and behaviors that we may regard as “enhancement” today may very well find a therapeutic justification tomorrow. As the disability studies scholar Tom Shakespeare commented, “To fix a genetic variation that causes a rare disease may seem an obvious act of beneficence. But such intervention assumes that there is robust consensus about the boundaries between normal variation and disability.” Indeed, there is not, even though that distinction has become ubiquitous in reporting on gene editing.

The second point is this: Questions of equity and justice as they relate to human gene editing and related fields should not be mistaken as a kind of “special interest” or simply another angle from which to approach these topics or even solely a “problem” to be overcome. But rather, the work of interrogating equity serves as a vital framework for democratizing science more broadly because of the way it causes us to wrestle with some of the foundational assumptions of biotechnology, to the extent that we take up the challenge. I will briefly elaborate on these two points below, but first some background on the empirical basis of my comments.

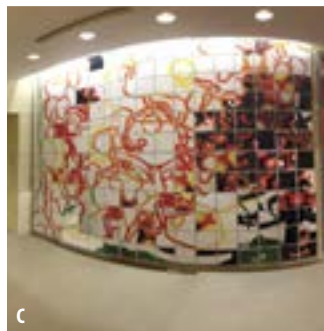
In 2005, I began researching the passage and implementation of California’s Stem Cell Research and Cures Initiative. Proposition 71, as it was commonly known, successfully passed in November 2004, becoming the largest single source of stem cell funding in the world, authorizing the sale of state bonds in the amount of \$3 billion to be managed by a new stem cell agency and governed by the Independent Citizens’ Oversight Committee. This unprecedented state investment is protected by a new constitutional “right to research” amendment that requires a 70% legislative super majority to modify, and it is in this context of a political right to scientific inquiry that I used as a window to analyze the relationship between innovation and equity more broadly. I conducted a two-year, mixed-method study of the initiative, and through a formal affiliation with the state agency as part of its first cohort of training fellows, I conducted interviews with key proponents and opponents of the initiative, as well as people affected by conditions that could potentially be treated by stem cell therapies. I also produced a

mixed archive of documents and media that allowed me to analyze the contours of social inclusion and exclusion.

One of my observations throughout this process was that to the extent that nonscientists were involved, a particular subset of patient advocates were positioned as the “default public” to whom the new state apparatus was most accountable. And although patient advocates hold a wide variety of perspectives on these issues, those that were most vocal in the California context framed their demands in terms of medical consumer rights, or what scholars have dubbed an “upwardly tilted public agenda” that appeals to middle-class supporters. Such advocacy is unlikely to represent the vast majority of disabled people for whom dismantling policies and prejudices that cast them as second class is often more vital than access to “miracle cures.” The fact is that innovation and inequity too often go hand-in-hand. Social science research piled high shows that as we develop the capacity to control disease and death, the benefits go disproportionately to those who already monopolize resources. So we either decide to prioritize issues of equity and justice early and often, or we ensure a world in which the health and longevity of some are predicated on the disposability of others.

To fully “interrogate equity,” we must foster deliberation that moves beyond questions of access to treatment, however important, and think very seriously about the design of research—who does it and with what guiding questions and assumptions—because how research is framed is never neutral, universal, or inevitable. Gene editing techniques are seeded with values and interests—economic as well as social—and without careful examination, they will easily reproduce existing hierarchies, including assumptions about which lives are worth living and which are worth “editing” out of existence.

In the words of geneticist James Watson, “From this perspective seeing the bright side of being handicapped is like praising the virtues of extreme poverty. To be sure there are many individuals who rise out of its inherently degrading states. But we perhaps most realistically should see it as the major origin of asocial behavior.” This statement reflects the default setting of much biotechnology—a benevolent medical missionary ethos that says essentially: “We know what you need better than you do.” For this reason, it is crucial that we take the disability justice refrain “Nothing About Us, Without Us” seriously, noting that there is substantial stratification among disabled people. And in the same



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Views of the Broad Institute, including *Instance of a DataSet*, 2013 (C, D), and *Sets and States*, 2010 (A, B, E).



way we do not expect scientists from a single field to address all the technical complexity associated with gene editing, surely we need to be equally attentive to social complexity, so that white middle-class patient advocates do not continue to serve as the default public to whom science and technology is accountable.

These were among the issues discussed at the National Convening on Disability Rights and Genetic Technologies, where participants noted that, of course, “Some people with disabilities eagerly await gene therapies. But many people are concerned that the increasing use of genetic technologies in this context reflects and reinforces societal assumptions that disability is always harmful and should be prevented.” The concern here is that people with disabilities would be less valued at a societal level as genetic technologies become more common, especially in the absence of public education and media campaigns on disability and genetics. In a similar vein, commenting on the 2015 International Summit on Human Gene Editing, biochemist and disability scholar Gregor Wolbring explained: “The disability-rights community has a history of disagreement with scientific and clinical experts over their perception of people with disabilities. This is summarized as ableism, a view that disability is an abnormality instead of a feature of human diversity. It can lead to flawed ‘solutions’ and disempower those affected.”

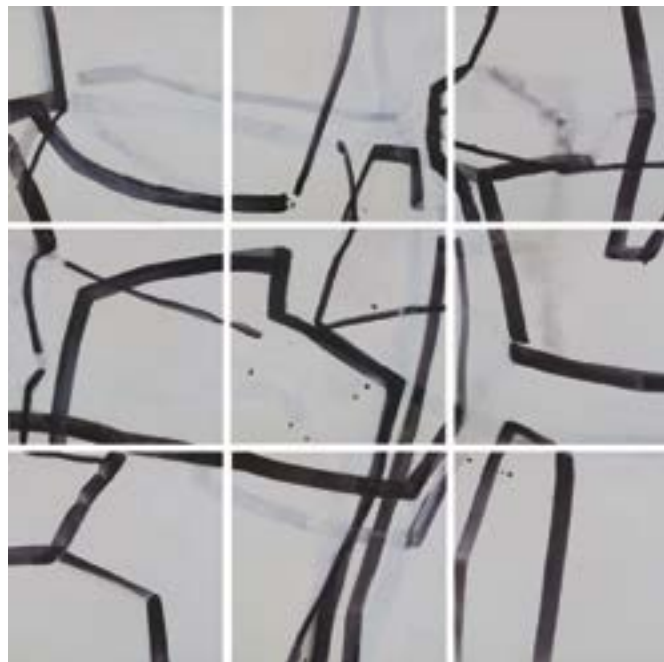
So then, how do we reflect carefully on ableist norms that are often embedded in genetic technologies? I will briefly flag five ways we routinely constrict what counts as relevant and meaningful to scientific innovation.

The first is an ahistorical fallacy, which is the tendency to project forward in time without the temporal corollary—a careful reflection on historical precedents and processes. Too often the contours of our thinking mirror the hyperbolic rhetoric of science—“breakthrough,” “cutting edge,” “breathtaking,” and “miraculous”—leading us to overlook continuities as we train our attention on all that appears novel. My observations at a number of meetings such as this Summit is that those seeking to dismiss the need to interrogate equity do so by assuming a hard break between past harms and future possibilities.

The second is a legalistic fallacy when we assume that reforming policies and laws is sufficient to shaping the context of science for the greater good. The passage of the Genetic Non-Discrimination Act, for example, was necessary but not sufficient



DANIEL KOHN, *BlackMol 1–9*, from *Sets and States*, Oil on canvas, 2010.



to ensure that genetic predisposition to illness will not result in employer or insurance bias. That is, legal change must go hand-in-hand with public engagement and deliberation well beyond the staging of a single summit.

The third way we routinely constrict our ethical imagination is an informed fallacy when we presume that standard approaches to informed consent are sufficient in arenas that are characterized by so much scientific and medical uncertainty. The best that researchers can really promise is a partially informed consent—so that we urgently need to re-think and re-invest in technologies of trust and reciprocity that address the many uncertainties involved.

The fourth is a fixed fallacy, which is the tendency to assume that the way in which scientific harms get enacted in the present will look the same way they did in the past, rather than mutating with the times. This fallacy has us look for examples of state-sponsored eugenics, for instance, overlooking the way that market logic puts the responsibility of “racial fitness” in the hands of the consumer. In this way, the fixed fallacy serves as a counterweight to the ahistorical fallacy, by alerting us to the mercurial and often “liberal” context in which individual choices reinforce oppressive hierarchies.

The fifth and final way we may inadvertently constrict our ethical imagination with respect to genetic engineering is the euphemistic fallacy, which is the tendency to adopt language that is already seeded with a particular ethical perspective on the techniques in question. The word “editing” itself sounds benign and even beneficial. Whereas for those struggling against the many forms of stigma and marginalization that grow out of ableist norms, editing may be more akin to being pushed through a shredding machine.

In moving forward, then, there are many ways to expand our scientific and ethical imagination. First, we need to remain watchful of how safeguarding “medical consumer freedom” displaces many other concerns. It is not coincidental that this notion of medical choice goes hand-in-hand with competitive chants of winning a global scientific race. As renowned legal scholar Patricia Williams noted with respect to CRISPR: “What’s going on now is also a rat race to beat out others in the charge to the patent office. Hence, much of this has an urgency to its framing that exploits our anxiety about mortality itself. Hurry up, or you’ll die of an ugly disease! And do it so that ‘we’ win the race—for everything’s a race. A race against time. A race to file patents. A

race to market. A race to better babies, better boobs. There is never enough glory or gain, there is always the moving goal post.” The rhetoric of urgency, in other words, is not neutral or inherently good.

An expansive approach to genetic technologies, one that avoids the many fallacious constrictions I outlined earlier in this article, is one that includes disabled people “at the table and not just on the table of the life sciences.” The insights and expertise of those who have been harmed and exploited in the name of progress offer us a more rigorous foundation by which to democratize science than the current model in which citizens are imagined to be “We, the patients” waiting for the fruits of science to ripen. To begin this shift, we must become just as inventive about addressing social complexity as we are about biological complexity. If our bodies can regenerate, let us not imagine our body politic as so utterly fixed.

Recommended Reading

Ruha Benjamin, *People’s Science: Bodies and Rights on the Stem Cell Frontier* (Palo Alto, CA: Stanford University Press, 2013).

Generations Ahead, *A Disability Rights Analysis of Genetic Technologies: A Report on a National Convening of Disability Rights Leaders* (2009), available at: http://www.generations-ahead.org/files-for-download/articles/GenerationsAhead_DisabilityRightsConveningReport.pdf.

Jo C. Phelan and Bruce G. Link, “Controlling Disease and Creating Disparities: A Fundamental Cause Perspective,” *Journal of Gerontology* 2 (2005): 27-33.

Tom Shakespeare, “Gene Editing: Heed Disability Views.” *Nature* 527 (2015).

Theda Skocpol, “Voice and Inequality: The Transformation of American Civic Democracy.” *Perspectives on Politics* 2, no. 1 (2004): 3-20.

Patricia Williams, “Precision Medicine: Who’s Getting Rich Off Your Genes?” (2015), available at: <https://madlawprofessor.wordpress.com/2015/04/08/precision-medicine/>.

Gregor Wolbring, “Confined to Your Legs,” from *Living with the Genie: Essays on Technology and the Quest for Human Mastery*, edited by Alan Lightman, Daniel Sarewitz, and Christina Desser (Washington, DC: Island Press, 2003).

Gregor Wolbring, “Gene Editing: Govern Ability Expectations.” *Nature* 527 (2015).

Ruha Benjamin is an assistant professor of African American Studies and a faculty associate in the Program on History of Science at Princeton University.