
WILL THE PAST BE PROLOGUE? RACE, EQUALITY, AND HUMAN GENETICS[†]

ALLISON M. WHELAN* & MICHELE GOODWIN**

Historically, presumptions about human genetics fueled racial stereotypes and weaponized law and medicine to inflict harm on vulnerable populations. Nowhere is that clearer in law than Supreme Court jurisprudence. Rulings in *Dred Scott v. Sanford*,¹ *Ozawa v. United States*,² *United States v. Thind*,³ and *Buck v. Bell*⁴ reflect implicit and explicit racial assumptions tied to biological and genetic presumptions and stereotypes. Even as these cases may appear distinct, harmful and injurious racial presumptions thread through each, baking and entrenching racial hierarchy based on biology and genetics into law. Indeed, there have been more Supreme Court cases instantiating notions of biological difference and hierarchy than cases assertively dismantling them.

To what extent does contemporary discourse on genetics reify the old or chart new and different pathways forward? We consider this question in our review of Dr. Paul Enríquez's book, *Rewriting Nature*.⁵ In this book, Enríquez provides readers with a scientifically rigorous yet accessible overview of the possibilities and limitations of genome editing for agricultural and human purposes. The book engages readers, taking them on a journey from the origins of genome editing to the present. Throughout, Enríquez weaves in important

[†] © Allison M. Whelan and Michele Goodwin.

This Essay was submitted as part of the *Boston University Law Review Online*'s November 2022 symposium on *Rewriting Nature* by Dr. Paul Enríquez. Online Editors Erin Beaton and Kaitlin Ostling organized the symposium, and Professors Christopher Robertson and Kevin Outterson moderated.

* Sharswood Fellow, University of Pennsylvania Carey Law School; Associate Fellow, Leonard Davis Institute of Health Economics, University of Pennsylvania. The author extends her sincere thanks to the editors of the *Boston University Law Review Online*.

** Chancellor's Professor of Law & Founding Director, Center for Biotechnology & Global Health Policy, University of California, Irvine School of Law. The author is grateful to the editors at the *Boston University Law Review Online*.

¹ 60 U.S. (19 How.) 393 (1857) (enslaved party) (denying citizenship to formerly enslaved person), *superseded by constitutional amendment*, U.S. CONST. amend. XIV.

² 260 U.S. 178 (1922) (denying citizenship to person of Japanese race born in Japan).

³ 261 U.S. 204 (1923) (denying citizenship to person of Indian race born in India).

⁴ 274 U.S. 200 (1927) (upholding statute permitting forcible sterilization of persons deemed "unfit" to procreate).

⁵ PAUL ENRÍQUEZ, *REWRITING NATURE: THE FUTURE OF GENOME EDITING AND HOW TO BRIDGE THE GAP BETWEEN LAW AND SCIENCE* (2021).

considerations, such as who should regulate genome editing, how government should regulate it, and whether individuals have a constitutional right to genome editing for therapeutic and nontherapeutic purposes. Enríquez accomplishes this without reductive, unhelpful, and slippery slope narratives of Frankenstein monsters and an explosion of “designer babies.”⁶ In short, *Rewriting Nature* raises important and timely issues that require greater understanding and further discussion by scientists, lawyers, politicians, jurists, and the public. In this piece, we discuss a few critical points that must be examined further: accessibility, affordability, and whether a greater understanding of the human genome can promote equality.

An overarching goal of *Rewriting Nature* is to “guide[] readers through complex legal, scientific, ethical, political, economic, and social issues concerning” genome editing.⁷ Enríquez briefly touches on economic considerations in his discussion of agriculture, such as how opposition to genetically modified organisms (“GMOs”) sometimes stemmed from “trade protectionism” and other economic interests.⁸ But economics and potential financial costs are largely absent from the book’s discussion of human genome editing, as is a nuanced treatment of questions and concerns about race and genetics. This may be a deliberate choice—indeed, it is impossible to cover every issue associated with genome editing in one book—but any conversation about whether and how we will use human genome editing must consider two important matters. First, whether the technology will be affordable and accessible. And second, the future potential for reifying harmful racial tropes.

Simply put, our growing understanding of the human genome and related technologies can be used for good or for ill. On the one hand, there are many potential dangers of genome editing, such as its manipulation to modify and thereby entrench certain “socially desirable” traits such as intelligence, beauty, or athleticism.⁹ On the other hand, after the human genome’s mapping in 2003, a common hypothesis was that understanding the human genome could promote equality and reduce differences in health care outcomes.¹⁰

Almost twenty years later, those ambitions remain out of reach. Turning that hypothesis into a reality requires, among other things, that genome editing be affordable and accessible throughout the world. If the technology remains accessible only to wealthier and generally privileged populations, genome

⁶ See *id.* at 266-67.

⁷ *Id.* at i.

⁸ See, e.g., *id.* at 196.

⁹ As Enríquez notes, modification of such traits is not currently possible, nor may it ever be. *Id.* at 276 (noting that using genome editing “to create tall, beautiful, highly intelligent, and athletic ‘designer babies’ [is] simply beyond what is technologically feasible at this point in time—and perhaps ever”).

¹⁰ Katrina Armstrong, *Genomics and Health Care Disparities: The Role of Statistical Discrimination*, 308 JAMA 1979, 1979 (2012) (“A common hypothesis is that advances in human genomics will reduce disparities by identifying genetic causes of disparities.”).

editing will exacerbate inequalities and racial, social, and economic tensions.¹¹ Rates of certain diseases in wealthy, largely White, populations will decrease, while those in historically marginalized or vulnerable populations will remain unchanged or even worsen.

Without a significant shift in our thinking and our approach to health care, it is difficult to be optimistic that the promises of genome editing will be widely achieved. We live in a world of “haves” and “have-nots” with respect to health care. As defined by Healthy People 2020, a health disparity is “a particular type of health difference that is closely linked with *social, economic, and/or environmental disadvantage*.”¹² Overwhelmingly, genetics is not a factor in disparate health outcomes, and thus cannot be solved through genome editing. The “have-nots” are most often “groups of people who have systematically experienced greater obstacles to health based on their racial or ethnic group; religion; socioeconomic status; gender; age; mental health; cognitive, sensory, or physical disability; sexual orientation or gender identity; geographic location; or other characteristics historically linked to discrimination or exclusion.”¹³ Problematically, these same groups typically lack sufficient political, economic, and social capital to compel significant legal and social changes in healthcare policy.

If access to genome editing follows past scientific innovations—accessible and affordable only to those with relative privilege—then health disparities and other forms of inequality will persist and likely magnify. Thus, as the scientists engaged in genome editing technologies convene with politicians and potential regulators, all parties must consider cost and accessibility. Importantly, members of historically marginalized and vulnerable populations must be part of the conversation.

Even if we assume that genome editing will be broadly affordable and accessible, mistrust in the healthcare system may diminish its potential to reduce differences in health care outcomes. This mistrust arises from a long history of discrimination in medicine.¹⁴ Nowhere is this discrimination more salient than

¹¹ See, e.g., *What Are the Ethical Concerns of Genome Editing?*, NAT'L HUM. GENOME RSCH. INST., <https://www.genome.gov/about-genomics/policy-issues/Genome-Editing/ethical-concerns> [<https://perma.cc/7J7C-W5NM>] (Aug. 3, 2017) (“[T]here is concern that genome editing will only be accessible to the wealthy and will increase existing disparities in access to health care and other interventions.”).

¹² Off. of Disease Prevention and Health Promotion, *Disparities*, HEALTHY PEOPLE (emphasis added), <https://www.healthypeople.gov/2020/about/foundation-health-measures/Disparities> [<https://perma.cc/QSC3-KQBJ>] (last visited Jan. 23, 2022).

¹³ *Id.*

¹⁴ See generally HARRIET A. WASHINGTON, *MEDICAL APARTHEID: THE DARK HISTORY OF MEDICAL EXPERIMENTATION ON BLACK AMERICANS FROM COLONIAL TIMES TO THE PRESENT* (Harlem Moon 2008) (2006) (describing how racial discrimination has shaped Black patients' attitudes toward modern medicine); Allison M. Whelan, *Unequal Representation: Women in Clinical Research*, 106 CORNELL L. REV. ONLINE 87 (2021), <https://www.cornelllawreview.org/2021/04/02/unequal-representation-women-in-clinical->

in matters of reproduction.¹⁵ This history of abuse, exploitation, and racism—which continue to this day in the healthcare system and society more generally (slavery, eugenics, Jim Crow, policy brutality, structural racism, etc.)—make it reasonable and understandable to expect hesitation¹⁶ about genome editing, grounded in fears that the technology might simply be eugenics in disguise.¹⁷ As we prepare for wider access and use of human genome editing, we must address the problematic and intertwined history of genetics, eugenics, and race-based medicine. If we fail to critically engage with this history, it will continue to repeat itself.

Furthermore, although understanding the human genome shows us that genetic differences across populations are quite modest, there is a problematic history of misunderstanding, abusing, or over-relying on science and genetics to explain our differences.¹⁸ As Enríquez notes, for example, the U.S. Supreme Court’s decision in *Buck v. Bell*, which upheld a Virginia law authorizing the forcible sterilization of persons deemed “unfit” to procreate,¹⁹ “epitomizes an instance where the Supreme Court allowed a State’s erroneous scientific assertions to go unchallenged and ruled on the basis of those faulty assertions.”²⁰ Misunderstanding or abusing genetics to justify certain medical, legal, or policy

research/ [<https://perma.cc/KZ3Q-KX74>] (discussing people of color’s distrust in clinical research and the healthcare system).

¹⁵ See generally MICHELE GOODWIN, *POLICING THE WOMB: INVISIBLE WOMEN AND THE CRIMINALIZATION OF MOTHERHOOD* (2020); DOROTHY ROBERTS, *KILLING THE BLACK BODY: RACE, REPRODUCTION, AND THE MEANING OF LIBERTY* (1997); WASHINGTON, *supra* note 14, at 189-215 (describing the history of eugenic control of African American’s reproduction).

¹⁶ Cf. Whelan, *supra* note 14, at 94-103, 107-12 (describing the history and impact of unethical research on women of color); Jehonathan Ben, Donna Cormack, Ricci Harris & Yin Paradies, *Racism and Health Service Utilisation: A Systematic Review and Meta-Analysis*, 12 PLoS ONE e0189900 (2017), <https://doi.org/10.1371/journal.pone.0189900> (finding an association between racism and health service use outcomes).

¹⁷ Steven M. Weisberg, Daniel Badgio, & Anjan Chatterjee, *A CRISPR New World: Attitudes in the Public Toward Innovations in Human Genetic Modification*, 5 FRONTIERS IN PUB. HEALTH (May 22, 2017), <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5439143/pdf/fpubh-05-00117.pdf> [<https://perma.cc/7LD7-MYNR>] (finding, among other things, that African Americans, women, older people, people with less education, and those with right-leaning politics were less supportive of genetic modification than men, younger people, White and Latino Americans, people with more education, and those with left-leaning politics, possibly due to greater sensitivity to potential risks and unintended consequences of these technologies).

¹⁸ See, e.g., ROBERTS, *supra* note 15, at 59-64 (describing the eugenics movement, which was rooted in “the theory that intelligence and other personality traits are genetically determined and therefore inherited”).

¹⁹ 274 U.S. 200, 207 (1927) (“It is better for all the world, if instead of waiting to execute degenerate offspring for crime, or to let them starve for their imbecility, society can prevent those who are manifestly unfit from continuing their kind.”).

²⁰ ENRÍQUEZ, *supra* note 5, at 334.

decisions dangerously exacerbates inequality.²¹ Indeed, differences in health and health care outcomes are often *not* the result of genetics, but rather “decades of systematic inequality in American economic, housing, and health care systems.”²² When understood and used properly, advancements in science and medicine can help reduce inequality, but they are insufficient on their own and require society to reckon with a long history of racism, discrimination, and exclusion.

By seeking to help bridge the gap between the law and science of genome editing, *Rewriting Nature* provides an important part of a much broader discussion about whether and how we will use genome editing and how we can leverage our understanding of the human genome to promote equality.

²¹ See NOOR CHADHA, BERNADETTE LIM, MADELEINE KANE & BRENLY ROWLAND, TOWARD THE ABOLITION OF BIOLOGICAL RACE IN MEDICINE: TRANSFORMING CLINICAL EDUCATION, RESEARCH, AND PRACTICE (2017) (“Race is not a biological category that naturally produces these health disparities because of genetic difference. Race is a social category that has staggering biological consequences, but because of the impact of social inequality on people’s health.” (quoting Dorothy Roberts, *The Problem with Race-Based Medicine*, TED (2015), https://www.ted.com/talks/dorothy_roberts_the_problem_with_race_based_medicine/transcript?language=en [https://perma.cc/6LN5-WNEP])); *Overcoming Indoctrination: Still Struggling?*, RACE & MED., <https://www.raceandmedicine.com/overcoming-indoctrination> [https://perma.cc/3SNE-DYDD] (last visited Jan. 23, 2022) (“Chalking up lower lung capacity or higher maternal morbidity to race or individual decisions allows us to ignore policies and histories that perpetuate inequity and might better explain disparities.”); Michael Arribas-Ayllon, *After Geneticization*, 159 SOC. SCI. & MED. 132, 133 (2016) (describing one concept of “geneticization” as the “*construction* of biological phenomena through inappropriate labelling of health and disease as ‘genetic’ rather than social, structural or environmental”).

²² Sofia Carratala & Connor Maxwell, *Health Disparities by Race and Ethnicity*, AM. PROGRESS (May 7, 2020), <https://www.americanprogress.org/article/health-disparities-race-ethnicity/> [https://perma.cc/CY5H-DPNB].