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BioPrivilege

Lisa C. Ikemoto*

I. INTRODUCTION

In *Privilege Revealed: How Invisible Preference Undermines America*,¹ Stephanie Wildman and her co-conspirators, Margalynne Armstrong, Adrienne Davis, and Trina Grillo, exposed privilege as the unseen partner of domination and subordination. They demonstrated how implicit social norms and law intertwine to form systems of privilege. These systems operate as enforcers of the slightly more visible—in an iceberg kind of way—mechanisms of subordination, such as racism and patriarchy. *Privilege Revealed* emphasized the visible role of law but argued that silent normative preferences pervade our ways of knowing and living. The analysis invites all to participate in the project of making visible the substance and pervasiveness of privilege.²

This Essay expands the privilege inquiry into the fields of biomedicine. BioPrivilege, as I define it, uses the characteristics of the dominant or privileged group to set the normative standards in health, define disease, and identify who does and does not comprise a risk group. I start with the normative body, used to train physicians, design research protocols, and define basic categories of health and disease. Until recently, that normative body was the white male. All others were defined by their deviance from this norm. This Essay

* Professor of Law, University of California, Davis School of Law. Special thanks to Irina Zamyatin, King Hall Class of 2013, who provided excellent research assistance. I also want to express my deep appreciation to Danielle Hart and Stephanie Wildman, for their spirit of collaboration in the pursuit of justice.

1. STEPHANIE M. WILDMAN, with Trina Grillo, Margalynne Armstrong & Adrienne Davis, *PRIVILEGE REVEALED: HOW INVISIBLE PREFERENCE UNDERMINES AMERICA* (1996).

2. *Id.* at 180 (“We cannot do this work alone; yet we must individually take responsibility for large parts of our own learning. We need to work both on ourselves and with each other . . . It is up to those of us with privilege to take our first steps toward dismantling this world of invisible preference and examining the privilege revealed.”).

uses this example and others to start a catalog of the forms and functions of BioPrivilege. The handful of examples I use show that, like privilege, BioPrivilege sometimes hides in plain sight. At other times, BioPrivilege is invisible until one remembers that BioPrivilege requires finding others deviant or problematic. BioPrivilege is the invisible enforcer of those categories.

I have, in previous work, critiqued the privilege accorded to scientific knowledge.³ I challenged as often misplaced the presumption that scientific knowledge is more salient and more reliable than, for example, experiential knowledge. Here, I use the deference given to science as a starting point. The status accorded science magnifies BioPrivilege. I focus, however, on the content of biomedical knowledge. In other words, I explore, in a biomedical scientific context, Wildman & Co.'s premise that privilege pervades our ways of knowing.

Part II of this Essay provides a more detailed definition of BioPrivilege and examines the role of the status accorded science in magnifying BioPrivilege. Part III parses some of the ways in which BioPrivilege functions. More specifically, this analysis focuses on how biomedical knowledge is formed around and enforces subordination. Part IV looks to projects that have achieved some success in revealing and challenging BioPrivilege. Those initiatives suggest both next steps and potential pitfalls in working toward BioEquality. Part V concludes with a summary of the issues we face in the future.

II. BIOPRIVILEGE BASICS

BioPrivilege is simply a subset of privilege. The discussion that follows describes the parameters of that subset. Two points undergird the concept of BioPrivilege. First, biomedical knowledge includes normative content. Second, biomedicine draws much of its power from the status of science, and as a result, science has norm-making power.

3. Lisa C. Ikemoto, *The Code of Perfect Pregnancy: At the Intersection of the Ideology of Motherhood, the Practice of Defaulting to Science, and the Interventionist Mindset of Law*, 53 OHIO ST. L.J. 1205, 1286–90 (1992).

A. *BioPrivilege Defined*

Privilege uses the characteristics of the privileged group as the affirming societal norm.⁴ That is, the characteristics of those on the dominant side of power⁵ define “normal,” “meritorious,” “reasonable,” and other standards used to justify particular conferrals of benefit and advantage. Thus camouflaged, the systemic nature of those conferrals remains invisible until deliberately exposed. Peggy McIntosh’s list of quotidian examples in *White Privilege: Unpacking the Invisible Backpack*⁶ illustrates that point. The very ordinariness of the examples gives them punch.

Consider Professor McIntosh’s Example 24.⁷ “I can be sure that if I need legal or medical help, my race will not work against me.”⁸ Professor McIntosh may have been acknowledging the ways in which race mediates access to health care. In general, whites are more likely to have health insurance and therefore, access to health care.⁹ She may have been highlighting the ways in which a patient’s race affects the decisions the provider makes in treating patients. For example, studies show that providers are more likely to treat disease aggressively in white males and least likely to treat disease aggressively in Black women.¹⁰ In many ways, race allocates access to and quality of care unequally.¹¹ Broadly speaking, Example 24 implicates structural racism that constrains access for some but not others as well as cultural racism that intervenes in the provider-patient relationship. In effect, these systems confer advantage and

4. WILDMAN, *supra* note 1, at 13.

5. *Id.* at 29.

6. Peggy McIntosh, *White Privilege: Unpacking the Invisible Knapsack*, PEACE & FREEDOM MAG., July–Aug. 1989, at 10–12.

7. *Id.* at 11.

8. *Id.*

9. KAISER COMM’N ON MEDICAID & THE UNINSURED, THE UNINSURED: A PRIMER 6 (2012), available at <http://www.kff.org/uninsured/upload/7451-08.pdf>.

10. See Kevin A. Schulman et al., *The Effect of Race and Sex on Physicians’ Recommendations for Cardiac Catheterization*, 340 NEW ENG. J. MED. 618, 624 (1999). Tables 4 and 5 and the accompanying text indicate that physicians refer women, particularly Black women, for cardiac catheterization far less frequently than men.

11. See generally UNEQUAL TREATMENT: CONFRONTING RACIAL AND ETHNIC DISPARITIES IN HEALTH CARE (Brian D. Smedley et al. eds., 2003).

disadvantage among patients by race.¹² What Professor McIntosh's example shows is how the advantage rests on and is exploitative of systemic disadvantage.

I want to use the point about medical help in Example 24 to illustrate what I mean by BioPrivilege. BioPrivilege operates on the microlevel of biomedical science. BioPrivilege is formed by the incorporation of privilege into biomedical knowledge itself. As noted in Part I, until fairly recently, the normative body in medicine and biomedical research was white and male. A study of anatomy textbooks found that in the non-reproductive illustrations, the male body was represented at a substantially higher rate than the female body.¹³ More specifically, the study showed that "women constituted an average of 11.1% of nonreproductive anatomy illustrations and an average of 8.8% of nonreproductive physical diagnosis illustrations, while men were drawn in 43.1% and 23.7% of the respective illustrations."¹⁴ The finding suggests gender bias and indicates that medical students acquire "an incomplete knowledge of normal female anatomy."¹⁵ Incomplete knowledge may undercut quality of care. Privilege, as Wildman & Co. show, runs along many axes.

BioPrivilege uses the characteristics of the privileged group to define the medical norm, the standard of health, even the symptoms of disease, in a way that confers benefit or advantage on members of the privileged group. Use of the male body as the typical human reinforces male privilege.¹⁶ In Donna Haraway's words, "bodies,

12. See Kristine Martin-McDonald & Alexandra McCarthy, 'Marking' the White Terrain in *Indigenous Health Research: Literature Review*, 61 J. ADV. NURS. 126, 129 (2007) ("The socio-cultural 'terrain' of whiteness is constituted by three linked dimensions: a location of structural advantage; a white standpoint or worldview of self, society and other and a set of cultural practices that are usually 'unmarked' and unnamed.") (citing RUTH FRANKENBERG, *WHITE WOMEN, RACE MATTERS: THE SOCIAL CONSTRUCTION OF WHITENESS* (1993) and B. Siegal, *The Compliance and Adherence Process in the Transplant Patient: Professional Responsibility*, 24 DIALYSIS & TRANSPLANTATION 189 (1995)).

13. Kathleen D. Mendelsohn, Linda Z. Neiman, Krista Isaacs, Sophia Lee & Sandra P. Levison, *Sex and Gender Bias in Anatomy and Physical Diagnosis Text Illustrations*, 272 JAMA 1267 (1994); see also Sandra P. Levison et al., Letter to the Editor, *In Reply*, 273 JAMA 1257 (1995).

14. Mendelsohn et al., *supra* note 13, at 1269.

15. *Id.*

16. *Id.* ("Readers may assume that what is depicted in the text is normal and what is absent is abnormal or irrelevant.").

then, are not born; they are made.”¹⁷ As a result, males who need medical help are less likely than females to find that their sex works against them.

BioPrivilege operates under cover of dominant group characteristics. This cover enables BioPrivilege to hide in plain sight. The pervasiveness of the normative male body made the predominance of male body representations in textbooks seem appropriate and neutral. The same logic may have undergirded the use of males and only males in clinical trials.¹⁸ Until the 1990s, clinical trials to study the mechanisms of disease, as well as the efficacy and safety of therapies, were run using only male bodies. Biomedical knowledge acquired by clinical trial produced knowledge based on male bodies. As a result, there is more data and understanding of men’s health, of diseases and other conditions that affect men (and often women, as well), and more accurate knowledge about treating men than women.¹⁹

Efforts to change these practices highlighted the causal link between the normative white male body and lower quality health care for women and persons of color.²⁰ They also revealed the effects of BioPrivilege. Health care disparities, resulting in part from use of a singular normative body, persist. But efforts to address the gender and race gaps in biomedical knowledge have started to improve the

17. DONNA J. HARAWAY, *SIMIAN, CYBORGS, AND WOMEN: THE REINVENTION OF NATURE* 208 (1991).

18. For another plausible explanation, see Nancy Krieger & Elizabeth Fee, *Man-Made Medicine and Women’s Health: The Biopolitics of Sex/Gender and Race/Ethnicity*, in *MAN-MADE MEDICINE: WOMEN’S HEALTH, PUBLIC POLICY, AND REFORM* 15, 21 (Kary L. Moss ed., 1996) (“In fact, by the time that researchers began to standardize methods for clinical and epidemiological research, notions of difference were so firmly embedded that whites and nonwhites, women and men, were rarely studied together. Moreover, most researchers and physicians were interested only in the health status of whites, and, in the case of women, only in their reproductive health.”).

19. See generally *MAN-MADE MEDICINE*, *supra* note 18; R. Alta Charo, *Protecting Us to Death: Women, Pregnancy, and Clinical Research Trials*, 38 *ST. LOUIS U. L.J.* 135 (1993–94); Karen H. Rothenberg, *Gender Matters: Implications for Clinical Research and Women’s Health Care*, 32 *HOUS. L. REV.* 1201 (1995–96).

20. See generally U.S. DEP’T OF HEALTH & HUMAN SERVS., *REPORT OF THE SECRETARY’S TASK FORCE ON BLACK AND MINORITY HEALTH* 12 (1985) (“Many professionals and lay persons, both minority and nonminority, do not know that heart disease may be as common in Black men as in nonminority men or that Black women die from coronary disease at a higher rate than nonminority women.”).

quality of care for women and some racial and ethnic populations. Adrienne Davis's insight that inequality does not run on the single engine of subordination but on a hydra-headed machine of subordination, domination, and privilege²¹ helps explain the persistence of norms and practices that give rise to health care inequalities. Improvements in quality of care provide evidence that revealing BioPrivilege and acting to change the structures and norms that support it can reduce inequalities in health care that give rise to health care disparities.²²

B. Science as Privileged Knowledge

BioPrivilege draws much of its power from the status that science holds. Science as knowledge carries great weight in many contexts and is privileged over other forms of knowledge and other types of enterprise.²³ Science, then, magnifies the influence of norms and standards used in medicine, health, and biomedical research.

1. Privileged Knowledge

Science as a form of knowledge receives deferential treatment.²⁴ Other forms of knowledge are respected in discrete contexts. Often, however, we regard other forms of knowledge either as more trivial or less reliable than science. Compare the way we value scientific knowledge production with the way we value cultural knowledge production. The National Institutes of Health (NIH) receives substantially greater funding than the National Endowment for the Arts (NEA).²⁵ Both produce knowledge for the greater social good.²⁶

21. WILDMAN, *supra* note 1, at 19–20; *see also generally, e.g.*, Martin-McDonald & McCarthy, *supra* note 12.

22. WILDMAN, *supra* note 1, at 24.

23. STANLEY ARONOWITZ, SCIENCE AS POWER: DISCOURSE AND IDEOLOGY IN MODERN SOCIETY 8 (1988) (“In the knowledge hierarchies of postfeudal societies, modern scientific rationality is the privileged discourse, and all others are relegated to the margins.”).

24. Science's status as privileged knowledge has been under attack for the past forty years. *Id.* at 11.

25. For fiscal year 2012, Congress appropriated \$32 billion for the NIH. NAT'L INSTS. OF HEALTH, OVERVIEW BY INSTITUTE (2011), *available at* http://www.nih.gov/about/director/budgetrequest/NIH_BIB_020911.pdf. For the same fiscal year, the NEA received \$146 million—\$8.7 million less than the Endowment's total budget for 2011. *National Endowment*

Both receive only a portion of the total funding provided to biomedical science and art in the United States. But both are emblematic of our disparate national commitments to science and art. The funding gap between the NIH and the NEA provides a rough measure of the relative weight society places on the two endeavors.

Consider, also, our responses to contests between scientific and experiential knowledge. Science does not always prevail. But consider the distinctions deployed in contest. Fact versus belief. Data versus anecdote. Rational versus emotional. Testable versus unreliable.²⁷ In science, law, and public policy discourse, “data,” “rational,” and “testable” are positive terms. They endorse. Not coincidentally, they describe what we mean by “science.” “Anecdotal” and “emotional” are not necessarily negative terms, but science, law, and public policy discourse use those terms as synonyms for “weak.” In nearly every context, “unreliable” carries negative meaning.

We defer to science for several reasons, all of which reflect some version of Western secular rationalism.²⁸ First, we value scientific knowledge on the premise that it is testable and ideologically neutral. We also highly value the training and supposedly resulting expertise of those who work in science. On those grounds, we presume that science is more reliable and credible than other forms of knowledge. Third, we presume scientific enterprise will produce benefits that will accrue to many, if not all. We regard those benefits—products and knowledge—as social goods. We regard the enterprise as socially

for the Arts Appropriations History, NAT'L ENDOWMENT FOR THE ARTS, <http://www.arts.gov/about/Budget/AppropriationsHistory.html> (last visited Feb. 7, 2013); see also Jacqueline Trescott, *In 2012 Federal Budget, NEA is Cut and Smithsonian Gets a Raise*, WASH. POST (Dec. 20, 2011, 12:14 PM), http://www.washingtonpost.com/blogs/arts-post/post/in-2012-federal-budget-nea-is-cut-and-smithsonian-gets-a-raise/2011/12/20/gIQAXy8D7O_blog.html.

26. “NIH’s mission is to seek fundamental knowledge about the nature and behavior of living systems and the application of that knowledge to enhance health, lengthen life, and reduce the burdens of illness and disability.” *Mission*, NAT'L INSTS. OF HEALTH, <http://www.nih.gov/about/mission.htm> (last visited Feb. 7, 2013). The mission of the NEA is “to advance artistic excellence, creativity, and innovation for the benefit of individuals and communities.” NAT'L ENDOWMENT FOR THE ARTS, STRATEGIC PLAN (2010), available at <http://www.nea.gov/about/Budget/NEAStrategicPlan2012-2016.pdf>.

27. See generally DONNA J. HARAWAY, *MODEST_WITNESS@SECOND_MILLENIUM.FEMALEMAN@_MEETS_ONCOMOUSE™* 277 (1997).

28. See generally ARONOWITZ, *supra* note 23, at 9.

valuable.²⁹ In addition, we tend to equate scientific innovation with progress.³⁰ This last equation serves two functions: it justifies the privilege accorded science and buffers science from serious challenge as a valuable enterprise.

2. Norm-Making Power

Because of the deference given to science, scientific knowledge has norm-making power. Social norms incorporate science in at least four ways. Scientific knowledge is sometimes translated directly into legal rules. Changes in social norms follow. For example, social practices used as health and safety precautions often arise in response to public health education efforts that in turn were based on public health science. Science demonstrated serious health risks of social activities such as drinking and smoking. Both legal rules and social norms for acceptable alcohol and tobacco use have changed substantially, in part, because so many deferred to the data showing significant risk.

Science does not always direct the norm. Sometimes, a norm or even a normative change draws on science to explain the norm. In his historiography of gender, Thomas Lacquer examines the switch from a one sex model to an opposite sex model for understanding the human body.³¹ He theorizes that the switch was not driven by new biological knowledge. Rather, broad changes in epistemology and politics initiated adoption of the opposite sex model, which then drew on biology to explain the opposite sex model as preferable.³²

Science is also used to reinvigorate norms premised on outmoded explanations. For example, the concept of biological race was used to

29. See generally *Moore v. Regents of the Univ. of Cal.*, 793 P.2d 479, 487, 495 (1990) (discussing “medical research of importance to all of society” as “implicat[ing] policy concerns” and implying a need to avoid compromising the exchange of scientific materials for experimental purposes with lawsuits); *Wash. Univ. v. Catalona*, 490 F.3d 667, 674 (8th Cir. 2007) (observing, as an integral part of the holding that biological samples belonged to the University and not to a particular researcher, that donors of the samples intended their donations as “a free and generous gift of [biological materials] to research that may benefit society”).

30. Ikemoto, *supra* note 3, at 1286.

31. THOMAS LAQUEUR, *MAKING SEX: BODY AND GENDER FROM THE GREEKS TO FREUD* (1990).

32. *Id.* at 10–12.

justify racial subordination and claims of white supremacy as well as practices—including slavery, eugenics, and segregation—premised on those systems.³³ Biological race fell into disrepute as respected scientists challenged the “science” in eugenic science and the world acknowledged the role that biological race played in Nazi ideology.³⁴ Since the 1940s, science has declared biological race dead or near dead more than once. Notably, at a White House press conference convened to announce the success of the Human Genome Project, President Bill Clinton stated, “I believe one of the great truths to emerge from this triumphant expedition inside the human genome is that in genetic terms all human beings, regardless of race, are more than 99.9 percent the same.”³⁵ And yet, genetics has become the most significant new vehicle for explaining racial difference.³⁶

Sometimes, science-like cover is given to norms, often controversial norms, as apparent justification. The claim of genetic race or the new biological race is methodologically unsound.³⁷ For the moment, however, genetic science is a dominant explanatory paradigm. It holds such sway that claims made as genetic science seem logical and entitled to deference. Consider a more contested example. In the past few years, abortion opponents have framed their arguments in medicalized terms.³⁸ Some claim that women who

33. See generally Stephen Jay Gould, *American Polygeny and Craniometry Before Darwin: Blacks and Indians as Separate, Inferior Species*, in *THE “RACIAL” ECONOMY OF SCIENCE: TOWARD A DEMOCRATIC FUTURE* 84, 111–14 (Sandra Harding ed., 1993); DOROTHY ROBERTS, *FATAL INVENTION: HOW SCIENCE, POLITICS, AND BIG BUSINESS RE-CREATE RACE IN THE TWENTY-FIRST CENTURY* 35–43 (2011).

34. ROBERTS, *supra* note 33, at 43.

35. *Remarks Made by the President, Prime Minister Tony Blair of England (via satellite), Dr. Francis Collins, Director of the National Human Genome Research Institute, and Dr. Craig Venter, President and Chief Scientific Officer, Celera Genomics Corporation, on the Completion of the First Survey of the Entire Human Genome Project*, THE WHITE HOUSE—OFFICE OF THE PRESS SECRETARY (June 26, 2000), available at <http://www.genome.gov/10001356>.

36. See generally ROBERTS, *supra* note 33; MICHAEL J. MONTOYA, *MAKING THE MEXICAN DIABETIC: RACE, SCIENCE, AND THE GENETICS OF INEQUALITY* (2011).

37. See Deborah A. Bolnick, *Individual Ancestry Inference and the Reification of Race as a Biological Phenomenon*, in *REVISITING RACE IN A GENOMIC AGE* 70 (Barbara A. Koenig et al. eds., 2008).

38. See Reva B. Siegel, *The Right’s Reasons: Constitutional Conflict and the Spread of Woman-Protective Antiabortion Argument*, 57 *DUKE L.J.* 1641 (2008).

obtain abortions have an increased risk of breast cancer,³⁹ that women who obtain abortions risk their mental health.⁴⁰ Actual scientific evidence weighs against both claims.⁴¹ Both claims have been contested in public discourse in ways that genetic race has not. And yet, in his opinion for the Court, Justice Kennedy used the risk of “regret” as part of the justification for upholding the law at issue in *Gonzales v. Carhart*, even as he acknowledged that “no reliable data”⁴² backed the claim. Characterizing a claim in medical terms indicates the influence that science has in public discourse and in the law.

The irony is that science is valued in large part because we regard it as apolitical. At the same time, the distinctions drawn to privilege science are contested and those contestations are political in nature. The power to draw those distinctions, to define what counts as science and not science, is what is at stake.⁴³

C. *Privilege and Biomedicine*

BioPrivilege draws some or much of its power from the status of science in general. Yet, the field of biomedical science seems to be particularly influential. Broader political and economic forces probably explain the particular influence of biomedical science at this time.⁴⁴ It is also likely that biomedicine’s direct applicability, or at least its potential for applicability to the individual human makes biomedical science seem more relevant and more interesting. We

39. *Id.* at 1653.

40. *Id.*

41. *Id.* at n.44.

42. *Gonzales v. Carhart*, 550 U.S. 124, 159 (2007).

43. See generally HARAWAY, *supra* note 27, at 89 (“My goal is to help put the boundary between the technical and the political back into permanent question as part of the obligation of building situated knowledges inside the materialized narrative fields of technoscience.”).

44. See MELINDA COOPER, *LIFE AS SURPLUS: BIOTECHNOLOGY & CAPITALISM IN THE NEOLIBERAL ERA* 3 (2008) (“... the biotech era poses challenging questions about the interrelationship between economic and biological growth, resurrecting in often unexpected ways the questions that accompanied the birth of the modern political economy . . .”).

each have a stake in biomedicine's potential and its power.⁴⁵ BioPrivilege, then, is worth examining as a particular political force.

III. BIOPRIVILEGE AS THE INVISIBLE ENFORCER

A. *BioPrivilege as Club Doorman*

BioPrivilege is the invisible enforcer of norms and practices⁴⁶ used to perpetuate exclusion or subordination in the name of medicine and science. Consider the effect of the normative male body on non-normative bodies. Bodies that do not fit the standard might be understood as nonstandard in a positive way. We laud atypical height and strength. In some communities, persons with conditions we consider to be “disabilities” are not regarded as problematic, and may even be seen as blessings.⁴⁷ But BioPrivilege functions more like a club doorman, the guy who controls access to nightclubs. For those the doorman admits, both the admission and the barring of the objectionable affirm the club's merit and the patron's sense of belonging. Privilege, then, requires situating the nonstandard as objectionable. Thus, while “it was assumed that males, particularly Caucasian males, provided the ‘norm’ or ‘standard,’ . . . there was a tendency to view females as being ‘deviant or problematic, even in studying diseases that affect both sexes.’”⁴⁸

45. See generally Adele E. Clarke, Laura Mamo, Jennifer Ruth Fosket, Jennifer R. Fishman & Janet Shim, *Biomedicalization*, in *BIOMEDICALIZATION: TECHNOSCIENCE, HEALTH & ILLNESS IN THE U.S.* 4–6 (Adele E. Clarke et al. eds., 2010).

46. WILDMAN, *supra* note 1, at 7–24, 27

47. See, e.g., KAJA FINKLER, *EXPERIENCING THE NEW GENETICS: FAMILY AND KINSHIP ON THE MEDICAL FRONTIER* 177–78 (2000); ANNE FADIMAN, *THE SPIRIT CATCHES YOU AND YOU FALL DOWN: A HMONG CHILD, HER AMERICAN DOCTORS, AND THE COLLISION OF TWO CULTURES* (1997).

48. 1 INST. OF MED., *WOMEN AND HEALTH RESEARCH: ETHICAL AND LEGAL ISSUES OF INCLUDING WOMEN IN CLINICAL STUDIES* 8 (A.C. Mastroianni et al. eds., 1994) (“Two forms of unconscious gender bias have particular relevance for the design and conduct of clinical studies: male bias (observer error caused by adopting a male perspective and habit of thought) and the male norm (the tendency to use males as the standard and to see females as deviant or problematic, even in studying diseases that affect both sexes). Both have been thought to contribute to a predominant focus on men's health problems and on men as research participants.”).

As noted above, until the 1990s researchers relied on this view to exclude white women⁴⁹ and women and men of color from clinical trials. According to “rational” design principles, homogeneity of the study population strengthened study design and prevented variables, such as hormonal cycles, from becoming confounding factors.⁵⁰ White males, as the normative humans, were the study population for decades. During that period, drugs, devices, procedures, and biomedical knowledge were produced in a way that made the products and knowledge less likely to help and more likely to harm members of the excluded populations than those of the normative population.⁵¹ The invisibility of the normative white male body removed it as an explanation for this phenomenon. While the normative body remained unseen, the ascribed deviance of the non-normative patients explained the lower rates of efficacy and the higher rates of harm.

Characterizing female bodies and, in fact, all bodies not white and male as deviant and problematic expressed social bias in medical terms. That bias became the justification for exclusion and the explanation for exclusion’s effect. The invisibility of privilege made the circularity of that logic difficult to see.

49. INST. OF MED., EXPLORING THE BIOLOGICAL CONTRIBUTIONS TO HUMAN HEALTH: DOES SEX MATTER 24 (Thereza M. Wizemann & Mary-Lou Pardue eds., 2001) (“Although none of these provisions excluded specific subpopulations from clinical research, the policies stated that subjects who were vulnerable because of physical, mental, or social circumstances must not be exploited. Hence, few women were included, as pregnant women and their fetuses were grouped into the category of “vulnerable populations.”).

50. *Id.* at 25 (“Scientifically, women were excluded as clinical research participants because (1) there was a general belief among clinical researchers that men and women will not differ significantly in response to treatment in most situations, and (2) the inclusion of women introduces additional variables (in the form of hormonal cycles) and decreases the homogeneity of the study population. Ironically, even as it was acknowledged that the female hormonal cycle is a significant confounding variable and test substances might respond unpredictably to hormonal fluctuations, it was nonetheless widely believed that men and women were similar enough that it was acceptable to then treat women with therapies developed solely on the basis of the results of studies performed with men as research subjects.” (internal citations omitted)).

51. *See generally id.*; 1 U.S. PUB. HEALTH SERV., REPORT OF THE PUB. HEALTH SERV. TASK FORCE ON WOMEN’S HEALTH ISSUES 73–104 (1985), available at <http://www.ncbi.nlm.nih.gov/pmc/articles/PMC1424718/pdf/pubhealthrep00101-0075.pdf>.

B. BioImmunity

In biomedical terms, the immune system functions by differentiating between self and other and then protecting self against the other. Biomedicine often performs a similar function.⁵² The science of disease etiology incorporates social concepts of self and other that, in effect, maintain those boundaries. BioPrivilege performs important work in holding the boundaries, often with negative health consequences for those outside the resulting bio-normative line.

1. Building BioPrivilege into Disease Models

In some cases, etiological science imbues disease with the social identity of those deemed objectionable. Disease etiology may locate causation or origin within a population itself. Etiological hypotheses and explanations that incorporate characteristics of outsider identities maintain boundaries between the diseased other and the normative self. Disease models that focus on the other help maintain the invisibility of BioPrivilege. They simultaneously and quietly position the privileged group as normally healthy and disease-resistant.

Not surprisingly, the history of scientific racism provides some interesting examples. Many are familiar with the early nineteenth-century development of comparative anatomy to justify racial hierarchy. This work signaled a shift in scientific focus from external features to the body's internal features and functions.⁵³ Theories about the origins and causes of disease in different populations soon followed. During the nineteenth century, before the advent of germ theory, several explanations for tuberculosis emerged. Some proponents of scientific racism insisted that tuberculosis in whites was not the same disease as tuberculosis in Blacks. "Negro

52. See HARAWAY, *supra* note 17, at 204–05 (“... the immune system is a map drawn to guide recognition and misrecognition of self and other in the dialectics of Western biopolitics.”).

53. See generally STEPHEN JAY GOULD, *THE MISMEASURE OF MAN* (1981); see also WILLIAM A. TUCKER, *THE SCIENCE AND POLITICS OF RACIAL RESEARCH* 12–13 (1994).

consumption,” then, was particular to Blacks.⁵⁴ Those who embraced this theory believed that Blacks were predisposed to illness and that whites were not.⁵⁵ “White consumption” afflicted only whites. In this view, white consumption did not evidence weakness and may have even suggested physiological superiority.

Some diseases are specifically associated with the privileged group. For example, heart disease, including myocardial infarction, had higher incidence rates among men. As a result, the disease enjoyed the privilege of its at-risk population: higher risk rates among men produced close attention to and substantial funding for the study and prevention of heart disease. Even now, when we know that rates of heart disease as a cause of death differ little by sex,⁵⁶ “research funding for coronary heart disease in men is far greater than for women.”⁵⁷ Thanks to that research and to public health education, many know that common symptoms of myocardial infarction include tight, often intermittent, chest pain, shortness of breath, and pain in other upper body parts, including the right arm. Yet, less than ten years ago, researchers acknowledged that “[l]ittle is known about early warning or prodromal [coronary heart disease] symptoms in women.”⁵⁸ Very recently, research has shown that women may experience or report different symptoms, and women are less likely to experience the chest pain that has been considered emblematic of heart attack onset.⁵⁹ “Instead, they may experience shortness of breath, pressure or pain in the lower chest or upper abdomen,

54. SAMUEL KELTON ROBERTS, JR., *INFECTIOUS FEAR: POLITICS, DISEASE, AND THE HEALTH EFFECTS OF SEGREGATION* 44 (2009).

55. *See generally id.*

56. *See* Melonie Heron, U.S. Ctrs. for Disease Control & Prevention, *Deaths: Leading Causes for 2009*, 61 NAT'L VITAL STAT. REP. 7, 5–9 (2012), available at http://www.cdc.gov/nchs/data/nvsr/nvsr61/nvsr61_07.pdf.

57. Anita Holcroft, *Gender Bias in Research: How Does It Affect Evidence Based Medicine?*, 100 J. ROYAL SOC'Y MED. 2 (2007).

58. Jean C. McSweeney et al., *Women's Early Warning Symptoms of Acute Myocardial Infarction*, 108 CIRCULATION 2619 (2003).

59. *Id.* at 2622; *see also* John G. Canto et al., *Association of Age and Sex with Myocardial Infarction Symptom Presentation and In-Hospital Mortality*, 307 JAMA 813, 816 (2012). Some findings about gender differences in reported chest pain have been inconsistent, but most research indicates that women experience symptoms not previously recognized as myocardial infarction symptoms. *See* Johanna Berg et al., *Symptoms of a First Acute Myocardial Infarction in Women and Men*, 6 GENDER MED. 454, 455 (2009).

dizziness, lightheadedness or fainting, upper back pressure or extreme fatigue.”⁶⁰ Since patients who do not report chest pain are less likely to be correctly diagnosed and receive aggressive treatment for myocardial infarction, heart disease’s normative model disproportionately harms female heart attack victims.⁶¹

Heart disease has been the leading cause of death for both men and women.⁶² But the disease model was built on the experience of males. Privilege played at least two roles. Privilege helped prioritize heart disease on the biomedical research and public health agendas. In addition, building a disease model for the default normative body enabled the model to be universalized without question. The normative disease model, like the body, set diagnosis and treatment standards for all.

In some cases, the social identity that informs the disease model may be so visible that it precludes application to those who report the same symptoms but do not match the model’s social profile. For example, breast cancer has a higher incidence rate in white women in the United States. This had at least two effects on non-white women. Women of color reporting symptoms that aligned with the disease model were less likely to be diagnosed in a timely fashion. In the United States, many doctors relied on breast cancer incidence rates collected in Asia to diagnose Asian American women. But breast cancer rates among women in Asia have been significantly lower than among all women, including Asian women—in the United States. So an Asian American woman reporting a lump to her doctor in the United States was less likely to be tested for breast cancer on the assumption that Asian women do not get breast cancer. While breast cancer rates for Asian American women are lower than for white women in the United States, Asian American women are at significant risk for breast cancer. Similarly, federally required data collection by race and ethnicity revealed not only that women of color have significant risks of breast cancer, but also that Black

60. *Heart Attack Symptoms in Women*, AM. HEART ASS’N (Feb. 6, 2013), http://www.heart.org/HEARTORG/Conditions/HeartAttack/WarningSignsofaHeartAttack/Heart-Attack-Symptoms-in-Women_UCM_436448_Article.jsp (last visited Feb. 9, 2013); see also McSweeney et al., *supra* note 58.

61. Canto et al., *supra* note 59, at 816.

62. Heron, *supra* note 56.

women are more likely than white women to die from breast cancer. This came as a shock to the medical and research communities. In the case of breast cancer, the disease and the identity of its primary risk group so closely intertwined that the most important symptom became “white woman.” When a white woman reported a breast lump, her experience echoed that of Professor McIntosh. Her race did not work against her.⁶³ The same could not be said for women of color.

2. The Persistence of BioPrivilege

Disease models that maintain political boundaries persist, even in the face of additional knowledge that counters the model’s social content. Typically, a disease model adapts to the new knowledge. Sometimes, the model simply shifts the political boundaries to encompass the new knowledge. But sometimes, the model accommodates the new knowledge without shifting the BioPrivilege boundary. Thus, the model evolves, allowing its subordinating and privileging functions to persist.

Germ theory emerged in the late nineteenth century as an explanation for infectious disease. Soon after, in 1882, Robert Koch identified the bacteria that caused tuberculosis. Acceptance of the tubercle bacillus as the causal agent of tuberculosis proved that tuberculosis was infectious. It should also have proved that tuberculosis was race-neutral. Yet, racialized explanations for the disease and its effects persisted. For example, some continued to posit race-specific predisposition to explain higher mortality rates among African Americans.⁶⁴ Others blamed emancipation—“the wages of urban freedom” that “possibly signaled the race’s degeneration or even extinction.”⁶⁵ Thus, post-Civil War interpretations of tuberculosis contained anti-emancipation ideology.

The most well-known example of the evolution of disease models is the story of epidemiological efforts to address Acquired Immunodeficiency Syndrome, or AIDS. The CDC reported the

63. McIntosh, *supra* note 6, at 11.

64. ROBERTS, *supra* note 54, at 47.

65. *Id.* at 46. For other explanations, see *id.* at 47–63.

outbreak among young gay men with *pneumocystis carinii* pneumonia and Kaposi's sarcoma in 1981. The men were later found to have died from complications of full-blown AIDS. At that time, reports framed the disease wholly in terms of its victims' sexual orientation. During this period, the name GRID or Gay-Related Immune Disease attached. Researchers found the link between the disease phenomena and the gay community so compelling that they "at first ignored cases of AIDS that did not fit the gay plague model."⁶⁶ Women, Haitians, and intravenous drug users who did not fit the profile, who were not gay men, were either placed in a different diagnostic category, or researchers assumed that males with AIDS who denied male with male sex had lied about their sexual history.⁶⁷

At that time, the dominant paradigm for most disease research was that of a universal causal agent, such as bacteria or virus.⁶⁸ Yet, the prevailing view of GRID posited a multi-causal explanation centered on a particular sexual and social identity—gay men and their ascribed lifestyle.⁶⁹ In mid-1982, the number of patients who were not gay men and yet had AIDS-related complications increased, making virus theory difficult to ignore.⁷⁰ The prevailing response in the biomedical community was to expand the social boundaries of the disease, even as it began to accept the Human Immunodeficiency Virus (HIV) as a unicausal agent. Epidemiologists then focused on the "4-H risk groups." As a result, homosexuals, Haitians, hemophiliacs, and heroin addicts became part of the disease profile.⁷¹

Biomedicine now defines tuberculosis and HIV/AIDS as diseases that may infect anyone by transmission of bacillus and retrovirus, respectively. Treatment of HIV, negotiated in part by AIDS activists,

66. Elizabeth Fee & Nancy Krieger, *Understanding AIDS: Historical Interpretations and the Limits of Biomedical Individualism*, 83 AM. J. PUB. HEALTH 1477, 1478 (1993).

67. *Id.*

68. STEVEN EPSTEIN, *IMPURE SCIENCE: AIDS, ACTIVISM, AND THE POLITICS OF KNOWLEDGE* 57 (1996).

69. *Id.*

70. *Id.* at 56. But those with HIV were also sub-categorized by the manner in which their T cells "capitulated" to the virus in ways that perpetuated gender and lifestyle segregation. See CATHERINE WALDBY, *AIDS AND THE BODY POLITIC: BIOMEDICINE AND SEXUAL DIFFERENCE* 67 (1996).

71. Fee & Krieger, *supra* note 66, at 1478.

has transformed HIV infection from a terminal diagnosis to a chronic condition, and science has removed inscriptions of social characteristics from the diseases themselves. While this demonstrates that BioPrivilege's adaptations do not all succeed, the use of "risk groups" now offers space for those characteristics to adapt and survive. In the invisible space outside those risk groups, the risk-free groups still thrive.

IV. BIOEQUALITY?

Wildman & Co. point out that "[s]ubordination will grow back from the ignored head of privilege."⁷² They identify the necessary first step in countering the hydra as seeing and revealing privilege. The next step is creating public space for a collective, multi-voiced reimagining of community and social justice.⁷³ Education offers one such space. But others have been forged, even in the sciences.

Several examples have emerged from biomedicine. More accurately, challenges to subordination and privilege in biomedicine have produced several projects that take the next step toward something like BioEquality. Each may contain limits or face challenges that constrict its potential to make biomedicine so inclusive that its benefits accrue to all and its risk of harm is spread among those who can bear it. The most obvious challenges involve existing limits on access to health care. As obvious is the fact that biomedicine is not a silo enterprise, separate and apart from other social, political, and economic enterprises. Therefore, any effort aimed at erasing BioPrivilege must be one of many. Yet, each mentioned here contains a gem.

A. *Revealing Privilege, Requiring Inclusion*

Two projects mentioned above have effected change. Feminist and civil rights challenges to the normative white male body combined with substantive requirements of inclusion simultaneously reveal privilege and curb subordination.

72. WILDMAN, *supra* note 1, at 20.

73. *Id.* at 159.

Feminist critiques of the normative male body have expanded the norm somewhat. The normative body now has more than one identity. Female bodies are often included as different but normal and thus are less likely to be described as deviant and problematic. Future providers and researchers are less likely to encounter gender bias in their curricular materials and more likely to acquire sufficient knowledge about women's bodies and health needs.

As mentioned, health disparities work became federal policy in the 1990s and overlapped with critiques of the normative body.⁷⁴ In the 1990s, federal policy began to require inclusion of women and racial and ethnic minorities in clinical trials, as well as the collection of race- and ethnic-specific data. This work has expanded the biomedical research agenda and the understanding of the nation's health care needs. If implemented vigorously, health disparities policy should help reduce significant differences in morbidity and mortality rates by sex, race, and ethnicity.

But both of these projects have internal limits. Health disparities work has been limited by its own terms. "Health disparities" work typically distances the task of understanding population differences in disease and mortality from civil rights work. "Health disparities" typically uses an acontextual, data-based approach. This framing limits space for identifying and addressing the role of subordination and privilege in contributing to or directly causing those differences. And yet, many health advocates continue to insist on addressing "health disparities" using anti-discrimination and social justice approaches.

In the meantime, the list of normative bodies has remained very short. The list still does not include persons with disabilities, persons with ambiguous genitalia, transgendered persons who have undergone sex-reassignment surgery, and others.

And the list defaults to male on a regular basis. It is most often white. And yet, advocates from many communities are working to fill the blank space that follows the very short list.

74. See *supra* Part II for a discussion of the normative body.

B. Movement Work

A second type of project uses grassroots organizing to carve out space for voices and bodies not previously included in the biomedical enterprise. The most successful efforts have directly challenged privileging norms. The Women's Health Movement, started in the 1970s, and the AIDS movement, formed in the 1980s, have both used organizing and self-education to make lay interventions and effect change in research agendas, medical care, patient support, and social norms.⁷⁵

The AIDS movement began as a broad-based, diverse movement,⁷⁶ while the Women's Health Movement grew in diversity as it evolved.⁷⁷ Both movements have used a wide range of strategies, including developing lay research experts, establishing health care clinics to provide unbiased care, drafting and promoting legislation, and mobilizing public support. Both movements have also reached out to a wide range of communities, and both have made global impacts. The AIDS movement, in particular, has impacted the way science is produced.⁷⁸ Both movements forced biomedicine to acknowledge that science does not live in a silo but in the messy world of social life and politics.

But during the past three decades, the economics of biomedicine have changed. Biomedicine is now significantly privatized. Privatization has repositioned patients as consumers. That economic shift occurred as part of a larger political embrace of neoliberalism in the United States. Within the neoliberal paradigm, patients are not only consumers, but consumers who bear responsibility for their own health status, risks, and treatment choices. Healthcare consumerism introduces new forms of BioPrivilege, particularly on the consumer side.

75. SHERYL BURT RUZEK, *THE WOMEN'S HEALTH MOVEMENT: FEMINIST ALTERNATIVES TO MEDICAL CONTROL* (1979); EPSTEIN, *supra* note 68, at 8–9.

76. EPSTEIN, *supra* note 68, at 8.

77. Jael Silliman et al., *UNDIVIDED RIGHTS: WOMEN OF COLOR ORGANIZE FOR REPRODUCTIVE JUSTICE* 34–35 (2004).

78. *Id.* at 13.

V. CONCLUSION

BioPrivilege exists because “pure science” is a fiction. Biomedical knowledge has normative content and normative force. As a result, privilege—and subordination—pervade biomedicine.

This Essay has used a handful of examples to illustrate that point. The use of a singular normative body, research design premised on that normative body, and disease models that use social identity to exclude and universalize are just a few of many forms of BioPrivilege.

The rapid expansion of biomedical enterprise in the last few decades makes revealing BioPrivilege an important duty. The power of BioPrivilege rests not only on the scope of the enterprise but also, in part, on the status of science. Science, particularly biomedicine, has contributed and continues to contribute knowledge and goods that have both clear extrinsic and immeasurable intrinsic value. But its status as a highly valuable social activity should not shield biomedicine from scrutiny or democratic participation.

This Essay taps into a vigorous discourse formed by feminist critiques of science, critical race theory, and science and technology studies. Most, but not all, of the existing work targets subordination. This Essay focuses on the first step—showing the hydra-headed nature of the beast—in the context of biomedicine.