

## **“Backdoor to Eugenics”? The Risks of Prenatal Diagnosis for Poor, Black Women**

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*This article is situated at the intersection of three of the conference’s stated subject areas: Race and Healthcare, Reproductive Rights, and Race and the Family. My recent research has focused on the manner in which pregnant women who learn of fetal genetic abnormalities prenatally receive counseling as they decide whether to terminate or bring their fetuses to term. The decision whether to terminate on genetic grounds is particularly vexing because it often turns on speculative medical information, and it can result in elevated rates of grief, depression, and post-traumatic stress. Though the prenatal genetic counseling offered to expectant women learning of a fetal abnormality exists ostensibly to provide them with objective information rather than to encourage or discourage pregnancy terminations, the reality is that such counseling is often coercive in the direction of aborting genetic anomalous fetuses. Because genetic counseling tends to consider family factors such as wealth and perceived preparedness to raise a child with a persistent medical condition or disability—and because the vast majority of genetic counselors are highly educated white women—the pro-termination norms of prenatal genetic counseling disproportionately impact nonwhite, non-affluent pregnancies. This observation is consistent with prior state and private practices aimed at controlling black reproduction. Because the detection of prenatal genetic abnormalities will soon rise sharply due to advances in technology and increased access to prenatal genetic analysis under the Patent Protection and Affordable Care Act, far more poor, black pregnant women will receive genetic counseling that will make them more likely to abort their fetuses in future years. This article describes the scale and scope of this potentially far-reaching problem and offers suggestions for how to eliminate racial and class bias in prenatal genetic counseling.*

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## INTRODUCTION

The social, psychological, and cultural implications of pregnancy terminations due to a fetal abnormality is an understudied area within legal scholarship. Though Congress and eleven states have passed legislation aimed at providing women learning of a fetal genetic abnormality prenatally with adequate information to assist them in deciding whether to terminate, there has been little written in law reviews about the need for such legislation and its effectiveness in better informing choice. In a companion article to this one,<sup>1</sup> I attempt to do just that, with an emphasis on describing methods of improving both existing legislation and the ground-level delivery of information and support services to women learning of a fetal abnormality. The proposals set forth in the companion article are aimed primarily at alleviating the significant psychological impacts on couples who terminate for a fetal abnormality, which include elevated rates of grief, depression, and post-traumatic stress.

But whereas the companion article addresses the shortcomings of prenatal genetic counseling in general terms, this Article sets forth concerns relating specifically to the delivery of genetic counseling to poor, black women. As genetic analysis becomes a normalized component of prenatal care, far more women will face the choice of whether to abort their genetically anomalous fetuses, resulting in an increase in the need for prenatal genetic counseling for which the field is woefully unprepared. Due to the expansion of Medicaid in many states and other components of the Affordable Care Act granting free or low-cost access to prenatal genetic analysis, a large portion of this new cohort of women requiring counseling will come from marginalized populations. Given the historical relationship between genetic counseling and eugenics movements—as well as the hostility toward black reproduction that characterized reproductive medicine for much of the twentieth century—there is reason to question the quality and nature of the counseling these women will receive.

This Article sounds the alarm on how, if left unchecked, widespread prenatal genetic analysis during the pregnancies of poor, black women, combined with inadequate and coercive genetic counseling, can serve as a means of achieving what Troy Duster has called “eugenics by the back door.”<sup>2</sup> It does so in three parts. Part I describes the relationship between prenatal genetic analysis and eugenics movements of the early twentieth century aimed at culling disfavored populations. This Part also describes how perceptions about black inferiority helped to shape genetics as an academic field and provides examples of how black reproductive and sexual freedoms have been degraded and abused over the past 100 years. Part II explains the shortcomings of contemporary genetic counseling, highlighting the manner in which it is failing to abide by its nondirective aspirations and, at times, encouraging the termination of genetically anomalous fetuses. Because the genetic counseling process factors in

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1. Bret D. Asbury, *Fostering Informed Choice: Alleviating the Trauma of Genetic Abortions*, 25 CORNELL J.L. & PUB. POL'Y (forthcoming 2016).

2. TROY DUSTER, BACKDOOR TO EUGENICS 114-131 (2d ed. 2003) (describing some of the implications of efforts to control human heredity through elimination of the “defective fetus” in a chapter titled “Eugenics by the Back Door”).

socioeconomic and demographic characteristics in assessing the fitness and ability of potential parents, poor, black women are particularly at risk for coercive counseling toward termination. Part III describes how to stave off the possibility that increases in the availability of prenatal genetic analysis could result in the virtual elimination of births of genetically anomalous children to poor, black mothers.

## I. THE EUGENIC MARGINALIZATION OF BLACK REPRODUCTION

The origins of genetic counseling can be traced back to the rise of eugenics in the late 1800s.<sup>3</sup> Though eugenics originally encompassed almost any form of genetic medicine,<sup>4</sup> in contemporary debates, it most often refers to prenatal practices that promote or coerce the termination of certain undesirable pregnancies.<sup>5</sup> As will be shown below, there is a tension between prenatal genetic counseling’s nondirective aspirations and its frequently directive practices, situating the field in a challenging space between informing choice and coercing the abortion of genetically anomalous fetuses—particularly those of disfavored classes of women. But before discussing this tension, it is useful to offer some background. This Part provides an overview of genetic counseling’s close ties with eugenics at the time of its origin, the manner in which theories of black inferiority drove its growth as it began to take its modern form after World War II, and the persistent, eugenic efforts to curtail black reproduction over the past 100 years.

### A. Eugenic Roots

The late 1800s in America was a period wrought with “perceived social ills,” an era in which empirical science had begun to emerge as the predominant method of explaining phenomena as diverse as disease outbreaks, class conflict, social stratification, and racial strife.<sup>6</sup> In 1865, Sir Francis Galton, building on the work of his first cousin Charles Darwin,<sup>7</sup> published a two-part article in *Macmillan’s Magazine* in which he set forth the simple, provocative thesis that would define his career: “Talent is transmitted by inheritance in a very remarkable degree.”<sup>8</sup> Though the article drew a great deal of criticism that he had overstated the case for heredity,<sup>9</sup> Galton was not deterred, and he continued

3. See Daniel J. Kevles, *Out of Eugenics: The Historical Politics of the Human Genome*, in THE CODE OF CODES: SCIENTIFIC AND SOCIAL ISSUES IN THE HUMAN GENOME PROJECT 3, 4 (Daniel J. Kevles & Leroy Hood eds., 1992).

4. See RUTH SCHWARTZ COWAN, HEREDITY AND HOPE: THE CASE FOR GENETIC SCREENING 39 (2008) (describing the “mixed bag” of different views of eugenicists).

5. See DIANE B. PAUL, CONTROLLING HUMAN HEREDITY: 1865 TO THE PRESENT 133 (1995) (“When eugenics reincarnates this time . . . it will not come through the front door, as with Hitler’s *Lebensborn* project. Instead, it will come by the back door of screens, treatments, and therapies.”) (internal quotations omitted).

6. ALEXANDRA MINNA STERN, EUGENIC NATION: FAULTS AND FRONTIERS OF BETTER BREEDING IN MODERN AMERICA 13 (2005).

7. Kevles, *supra* note 3, at 4–5.

8. Francis Galton, *Hereditary Talent and Character*, 12 MACMILLAN’S MAG., 1865, 157, 157, <http://galton.org/essays/1860-1869/galton-1865-hereditary-talent.pdf>.

9. PAUL, *supra* note 5, at 30–31.

publishing research on the topic over the next two decades.<sup>10</sup> Eventually, buttressed by Darwin's theories of evolution and natural selection,<sup>11</sup> Galton's ideas began to take popular hold in a number of countries, most notably the United States, Britain, and Germany.<sup>12</sup>

Galton proposed that humans should take charge of their own evolution, and, in 1883, coined the term eugenics, from the Greek *eu* (beautiful) and *genes* (birth or inheritance).<sup>13</sup> At that time, Galton defined eugenics as "the science of improving stock . . . which . . . takes cognisance of all influences that tend . . . to give to the more suitable races or strains of blood a better chance of prevailing speedily over the less suitable than they otherwise would have had."<sup>14</sup> Galton believed humanity could be perfected through the gradual extinction of inferior "races,"<sup>15</sup> and by his later years—the early twentieth century—had refined his definition of eugenics as simply "the science which deals with all influences that improve the inborn qualities of a race; also with those that develop them to the utmost advantage."<sup>16</sup> Galton's eugenic aspirations begat two core prescriptions:

10. For Galton's response to the criticism of his two-part *Macmillan's Magazine* article, see FRANCIS GALTON, ENGLISH MEN OF SCIENCE: THEIR NATURE AND NURTURE (1874), <http://galton.org/books/men-science/pdf/galton-men-science-1up.pdf>. This work, based on data gathered from questionnaires sent to distinguished members of the Royal Society, found a higher "incidence of eminence" among relatives of these scientists than among others with similar educational backgrounds. PAUL, *supra* note 5, at 31. Earlier, in 1869, Galton had declared that the improvement of the natural gifts of future generations of the human race is largely, though indirectly, under our control . . . . The processes of evolution are in constant and spontaneous activity, some pushing towards the bad, some towards the good. Our part is to watch for opportunities to intervene by checking the former and giving free play to the latter.

FRANCIS GALTON, HEREDITARY GENIUS: AN INQUIRY INTO ITS LAWS AND CONSEQUENCES xxvi-xxvii, (Horizon Press 3d ed. 1952) (1869), <http://galton.org/books/hereditary-genius/text/pdf/genius.pdf>. And in 1883, Galton published *Inquiries into Human Faculty*, the culmination of twenty years of research consistently finding that "the influence of heredity was always more important than the influence of environment." COWAN, *supra* note 4, at 13; see also FRANCIS GALTON, INQUIRIES INTO HUMAN FACULTY AND ITS DEVELOPMENT (Gavin Tredoux, ed., 1st electronic ed. 2001) (1883), <http://galton.org/books/human-faculty/text/galton-1883-human-faculty-v4.pdf>.

11. PAUL, *supra* note 5, at 36 ("Darwin at most flirted with eugenics. But his work provided the context that made Galton's views on heredity compelling . . . . Eugenics was transformed from abstract idea to social movement when it became attached to widespread assumptions about evolutionary progress and decline.").

12. Kevles, *supra* note 3, at 5.

13. COWAN, *supra* note 4, at 13-14.

14. FRANCIS GALTON, INQUIRIES INTO HUMAN FACULTY AND ITS DEVELOPMENT 17 n.1 (J.M. Dent and Sons, 2d ed., 1907) (1883), <http://galton.org/books/human-faculty/text/galton-1883-human-faculty-v4.pdf>.

15. *Id.* at 200 ("There exists a sentiment, for the most part quite unreasonable, against the gradual extinction of an inferior race."). In fairness, when Galton used the term "race," it was meant to be synonymous with "nations"—Galton believed that "the human species was composed of several subspecies," and he used the two terms interchangeably. COWAN, *supra* note 4, at 15; see also PAUL, *supra* note 5, at 106 (defining race as "any population with common attributes . . . also linked by descent . . . [P]eoples with a common language, religion, and history.").

16. Francis Galton, *Eugenics: Its Definition, Scope, and Aims*, 10 AM. J. SOC. 1, 1 (1904). With respect to inborn qualities, Galton believed only in "hard heredity" focused on intelligence and rejected the then-prominent view of Darwin and others that character was inherited. PAUL, *supra* note 5, at 41.

(1) "society ought to foster the breeding of those who possessed favorable traits" (positive eugenics); and (2) "discourage or prevent the breeding of those who did not" (negative eugenics).<sup>17</sup>

Galton's broad definition of eugenics seemed innocuous at the time it was proposed, considered simply "applied human genetics."<sup>18</sup> Soon, however, eugenics evolved "from abstract idea to social movement when it became attached to widespread assumptions about evolutionary progress and decline."<sup>19</sup> This movement drew strength in its early years because commentators engaging with Galton's work tended to be university-educated, influential professionals—doctors, ministers, lawyers, teachers, and scientists—who shared a worldview in which the "fecundity of the 'lower orders' was a source of great anxiety."<sup>20</sup>

Negative eugenics began to gain momentum against the backdrop of the economic and social change of the Progressive Era,<sup>21</sup> during which it became an appealing solution to a variety of perceived social problems surfacing at the time, which included the "economic burden of pauperism," an increasing burden of immigration that was "sending degenerates to the United States," and the "social burden of crime."<sup>22</sup> The combination of these social concerns and influential support resulted in the creation of the Eugenics Record Office and American Eugenics Society—the latter consisting of approximately 1,200 prestigious individuals.<sup>23</sup> Wealthy industrialists such as John D. Rockefeller, Jr., Andrew Carnegie, and cereal king John Kellogg helped fund the movement; members of the clergy supported it; and American high schools, colleges, and universities began offering courses in eugenics as part of the curriculum.<sup>24</sup> The eugenics movement of the early twentieth century had two goals: (1) to keep degenerate immigrants out of the country and (2) to sterilize as many degenerates as possible.<sup>25</sup>

In many ways, and for a time, the eugenics movement succeeded in accomplishing these objectives. For example, Harry Laughlin (second in command at the Eugenics Record Office) appeared before Congress at the request of Albert Johnson, House majority chairman on Immigration and Naturalization and a member of the American Eugenics Society.<sup>26</sup> Laughlin's persuasive eugenic arguments were instrumental in the passage of the Immigration Restriction Act of 1924, which "virtually closed the door to

17. PAUL, *supra* note 5, at 1.

18. *Id.* at 3, 4; *see also* COWAN, *supra* note 4, at 15 (noting a three-decade delay between when Galton coined the term "eugenics" and when the term "gene" was first coined).

19. PAUL, *supra* note 5, at 36.

20. *Id.* at 39.

21. *See id.* at 77–84 (attributing the rising appeal of eugenics to conditions in the United States between the Reconstruction and World War I).

22. COWAN, *supra* note 4, at 18.

23. PAUL, *supra* note 5, at 8.

24. *Id.* at 8–11.

25. COWAN, *supra* note 4, at 18. Eugenics in America during this time also had a very racial undertone, as many well-reputed individuals (including prominent physicians) worried that "dark-skinned persons were destroying the purity of the white race." *Id.* at 153–54. For a more complete overview of the racial impact, *see id.* at 151–80; PAUL, *supra* note 5, at 97–115.

26. COWAN, *supra* note 4, at 21.

immigrants who were not Protestants from Northern Europe.”<sup>27</sup> In addition, states passed laws prohibiting mixed-race marriages, as well as marriages of the “feebleminded,” habitual drunkards, criminals, and those with venereal diseases.<sup>28</sup> Perhaps the culmination of this movement was the infamous 1927 Supreme Court opinion in *Buck v. Bell*, which upheld the constitutionality of a law allowing for the involuntary sterilization of a “feebleminded” woman named Carrie Buck.<sup>29</sup> In an opinion that has never been expressly overruled, Justice Oliver Wendell Holmes declared:

We have seen more than once that the public welfare may call upon the best citizens for their lives. It would be strange if it could not call upon those who already sap the strength of the State for these lesser sacrifices, often not felt to be such by those concerned, in order to prevent our being swamped with incompetence. 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. The principle that sustains compulsory vaccination is broad enough to cover cutting the Fallopian tubes. Three generations of imbeciles are enough.<sup>30</sup>

By 1940, twenty-one states had involuntary sterilization laws, and by 1960, as states began repealing or ceasing to administer of these laws, it is estimated that nearly 60,000 Americans were surgically sterilized without consent.<sup>31</sup>

Building upon eugenics’s origins in Britain and its wide appeal in the United States, Nazi Germany is most notorious for changing the course of medical genetics.<sup>32</sup> Though familiar, it is worthwhile to offer a brief summary of German eugenics. Under Hitler, ideologies of anti-Semitism and Nordic supremacy flourished.<sup>33</sup> The devastations of Germany’s defeat in World War I caused a decade of “internal disarray and external humiliation,” which allowed the German eugenics movement to evolve from moderate to increasingly polarized and radicalized.<sup>34</sup> Eugenics was the backbone of Hitler’s National Socialist Party, a characteristic distinguishing it from Marxist socialism.<sup>35</sup> When

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27. DUSTER, *supra* note 2, at 14; COWAN, *supra* note 4, at 21.

28. COWAN, *supra* note 4, at 22 (discussing Connecticut and Indiana laws).

29. *Buck v. Bell*, 274 U.S. 200, 208 (1927). To date, it remains unclear whether Carrie Buck was in fact mentally deficient. See Robert Mullan Cook-Deegan, *Mapping the Human Genome*, 65 S. CAL. L. REV. 579, 593 (1991) (“Subsequent research suggests that Carrie Buck was not feebleminded but rather a young woman made into a social outcast by pregnancy resulting from rape.”); DUSTER, *supra* note 2, at 32.

30. *Buck*, 274 U.S. at 207 (internal citations omitted).

31. DUSTER, *supra* note 2, at 32.

32. See Kevles, *supra* note 3, at 10–11 (describing Nazi Germany’s powerful union of eugenic research and public policy); DUSTER, *supra* note 2, at 141 (noting that the Germans cited California’s development in sterilization laws as justification for its extreme application of eugenics).

33. See COWAN, *supra* note 4, at 28 (noting that “Hitler was both a eugenicist and a virulent racist” and that in the period between 1933 and 1945 he “put these prejudicial ideas into dictatorial practice with devastating consequences”).

34. *Id.* at 31.

35. *Id.*; see also *id.* at 27–28 (noting that Marxist socialism and Stalin’s Soviet Russia rejected eugenics as bad biology and bad politics, because it contradicted their fundamental premise of

the Nazis assumed power in 1933, they quickly set to work implementing their eugenic goals. They first passed the Law for the Prevention of Genetically Diseased Progeny (1933), which forcibly sterilized those suffering from "feeble-mindedness, schizophrenia, manic-depression, severe physical deformity, hereditary epilepsy, Huntington's chorea, hereditary blindness and deafness, and severe alcoholism."<sup>36</sup> Two years later, Hitler began regulating citizenship and marriages with the passage of the Nuremberg Laws which stripped Jews of German citizenship and prohibited marriages or sexual relations between Aryans and non-Aryans.<sup>37</sup> Finally, in 1939, acknowledging the mounting costs of administering sterilization programs in the face of the impending costs of war, the Nazis "stopped sterilizing disabled people and began murdering them."<sup>38</sup> This transition resulted in both euthanasia programs targeted at children and designed to "rid the nation of its mental patients" and the mass exterminations and suffering of the Holocaust.<sup>39</sup>

By the end of World War II,

six million people were categorized as members of degenerate races and were slaughtered; four hundred thousand "pure-blooded" Germans were categorized as genetically defective and were sterilized; and seventy-five thousand disabled "Aryans" whose care was deemed "too expensive" were murdered in hospitals, sanatoria, and nursing homes.<sup>40</sup>

This deplorable outcome, intertwined as it was with emerging studies and advances in human genetics as a medical practice,<sup>41</sup> informed the development of genetic counseling. The horrors of the Holocaust abruptly halted the momentum of the eugenics movements of the early twentieth century,<sup>42</sup> both directly (as will be shown below) and indirectly (societies and organizations were relabeled, replacing "eugenics" with "human genetics").<sup>43</sup> And whether by coincidence or otherwise, it was with the decline of eugenics at the close of World War II that medical genetics—and with it the modern practice of genetic counseling—began to rise.<sup>44</sup>

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biological equality).

36. PAUL, *supra* note 5, at 86.

37. COWAN, *supra* note 4, at 34–35; PAUL, *supra* note 5, at 90–91.

38. COWAN, *supra* note 4, at 33.

39. PAUL, *supra* note 5, at 90–91.

40. COWAN, *supra* note 4, at 36.

41. Evelyn Fox Kelly, *Nature, Nurture, and the Human Genome Project*, in *THE CODE OF CODES: SCIENTIFIC AND SOCIAL ISSUES IN THE HUMAN GENOME PROJECT* 281, 284–85 (Daniel J. Kevles & Leroy Hood eds., 1992) (noting the aftermath of Nazi Germany as having shaped much of genetic medicine's landscape).

42. See RAYNA RAPP, *TESTING WOMEN, TESTING THE FETUS: THE SOCIAL IMPACT OF AMNIOCENTESIS IN AMERICA* 37 (1999).

43. COWAN, *supra* note 4, at 40.

44. "Medical genetics" developed separately from eugenics (or at least its extreme forms). Before the field was named in the 1930s, British physician Archibald Garrod and biologist William Bateson are credited with its founding, and neither "had any particular enthusiasm for eugenics as it was being practiced" at the time. COWAN, *supra* note 4, at 41, 48. Many physicians before World War II regarded human genetics as just a guise for eugenics, and eugenicists "made no secret of their disdain" for physicians, believing that "[m]odern medicine . . . sustains the unfit." *Id.* at 63–64. After

## B. The Role of Notions of Black Inferiority in Shaping Genetics

Though scientists worldwide discarded racial categories and hierarchies after World War II,<sup>45</sup> the emergence of human genetics in the middle of the twentieth century was inextricably tied to eugenic conceptions of race. As one author explains, “[h]uman genetics has never been able to escape theories of race, even when seeking to transcend rigid categories of race and identity.”<sup>46</sup> Consistent with this observation, while the eugenic atrocities of World War II rendered the promotion of stark racial hierarchies no longer politically or socially practicable, what emerged in its place was not an egalitarianism valuing all lives equally, but rather a shift toward the targeted regulation of reproduction (rather than wholesale extermination) and reinforcement of racial segregation.

In certain settings, the concept of “race” evolved into the concept of “population,” and a number of early geneticists lectured frequently on the need to control population explosions in the “third world,” with an eye toward educating the masses to have fewer children.<sup>47</sup> Other early geneticists received seed funding for population-control projects from Wickliffe Draper, a millionaire, Hitler admirer, and firm believer in the “Back to Africa” movement of forced relocation of American blacks.<sup>48</sup> But perhaps the most crucial role geneticists played in the years immediately after World War II was that of genetic counselor in the context of evaluating a newborn for an adoptive placement.<sup>49</sup> These counselors helped uphold the racial ordering of society by ensuring that children with any “appreciable ‘Negroid ancestry’” not be placed with white families.<sup>50</sup> Genetic counselors focused on the children’s ability to appear convincingly white, relying upon examination of the “sacral spot at the base of the spine,” nose width, lip thickness, hair texture and shape, and even

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World War II, however, when eugenic ideologies were in disrepute, physicians and geneticists partnered up to make significant advancements in medical genetics. *Id.* at 66. Some have argued that it is a “genealogical fallacy” to link modern medical genetics—“the effort to develop, administer, and evaluate genetic tests with the intention of curing or preventing diseases and other disabling conditions”—with its historical origins in eugenics. *Id.* at 67. But even if it can be argued that “[p]renatal diagnosis has almost nothing in common with eugenics, neither historically nor technologically . . . [because] none of the basic parts of prenatal diagnosis was developed by eugenicists,” the scientific and technological advancements of early medical genetics undoubtedly facilitated genetic pregnancy terminations—the source of contemporary eugenic fears. *Id.* at 114. Indeed, by way of example, Jérôme Lejeune, who discovered the extra chromosome linked to Down syndrome in hopes that it would lead to a cure, came to abhor that it led to the “widespread use of amniocentesis to prevent the birth of babies with that disabling condition.” *Id.* at 87.

45. ALEXANDRA MINNA STERN, TELLING GENES: THE STORY OF GENETIC COUNSELING IN AMERICA 55 (2012).

46. *Id.*; see also PAUL, *supra* note 5, at 121 (“From the start, human genetics was intertwined with—and sometimes indistinguishable from—eugenics.”).

47. STERN, *supra* note 45, at 56–58.

48. *Id.* at 58 (“Draper devoted his enormous resources to such causes [as the Back to Africa movement] and associated himself with scientists who appeared to be sympathetic to theories that blacks were biologically inferior.”).

49. See *id.* at 63 (noting that this was the most common role for genetic counseling in the 1940s and 1950s).

50. *Id.* at 63. “The most common reason for an adoption consult was not to determine the existence of a genetic disorder but to detect any possible trace of ‘Negroid’ ancestry.” *Id.* at 64.

scrotum coloration.<sup>51</sup> Babies passing all of these tests could be placed with the white families interested in adopting them; others could not.

In this regard, the role of the genetic counselor as racial gatekeeper should be read as building upon the eugenic roots of genetics. To be sure, efforts aimed at the extermination of black Americans or their forced relocation to Africa would have been more transparent, but the eugenic racial anxiety evidenced by searching infants from head to scrotum to toe for signs of "Negroid" characteristics before allowing them to be placed in a loving white home is profound. The racism animating this use of genetic counseling stems from one of the simplest and most candid justifications for segregation: "the negro race as a whole is possessed of undesirable transmissible qualities both physical and mental, which seem to justify not only a line but a wide gulf to be fixed permanently between it and the white race."<sup>52</sup>

Early geneticists were unabashedly active eugenicists, believing that "human genetics should serve to improve the race."<sup>53</sup> Indeed, of the first six presidents of the American Society of Human Genetics, five served simultaneously as members of the board of directors of the American Eugenics Society (AES).<sup>54</sup> Members of the AES were interested in genetics because they sought to "change the distribution of births in the population" and believed that the "heredity of the population should be a matter of public concern."<sup>55</sup> Accordingly, as genetic counseling evolved from examining infants for signs of blackness to providing advice to expectant parents, it was explicitly directive, taking aim at the elimination of undesirable genetic traits.<sup>56</sup> The population control and family planning programs that these early practitioners of genetic counseling supported were inevitably "racialized endeavors"<sup>57</sup> that, in combination with genetic counseling's initial efforts aimed at investigating the possible blackness of infants and early association with the racism of the Back to Africa movement, helped to establish skepticism toward genetic counseling within the black community.<sup>58</sup> This skepticism does not exist in isolation—it is but part of a larger tapestry of black skepticism toward the medical profession, particularly as it relates to procreative and reproductive rights. And as will be shown in the following Section, there is good reason for such skepticism.

### C. The Degradation of Black Reproductive Rights

Though control of black reproduction can be traced back to slavery—during which black women were customarily forced, often through rape or other coercive means, to reproduce as many revenue-producing children as possible—

51. *Id.* at 64. Adoptive parents feared that future offspring "could revert to 'Negroid,' sometimes referred to as an atavistic 'throwback.'" *Id.*

52. PAUL, *supra* note 5, at 111 (quoting EDWARD M. EAST, *MANKIND AT THE CROSSROADS* 133 (Scribner's, 1928)).

53. PAUL, *supra* note 5, at 124.

54. *See id.* at 121.

55. *Id.* at 125.

56. *Id.* at 126.

57. STERN, *supra* note 45, at 72.

58. *See id.* at 73.

the control that is most relevant here cuts in the other direction, toward curtailing rather than encouraging black motherhood. In alignment with the eugenic attitudes described above, there arose in the early twentieth century concerns that the most genetically fit (that is, those occupying the upper strata of society) were not reproducing at a high enough rate to combat the perceived fecundity of the lower orders. This fear was encapsulated in the term “race suicide,” a favorite of Theodore Roosevelt before, during, and after his presidency. Roosevelt’s notion of race suicide contained two components. First was the concern that declining birthrates among Western nations—particularly English-speaking nations—could mean that “higher races might . . . literally die out, leaving no trace of the superior qualities which accounted for the present state of civilization and constituted the best hope for the future.”<sup>59</sup> The second concern was the “frightening prospect that lower races such as Latin Americans, blacks and East Europeans would swamp the higher orders in the ‘warfare of the cradle.’”<sup>60</sup>

Roosevelt’s fears mirror the above discussion of positive and negative eugenics.<sup>61</sup> And the response to his negative eugenic concern as it related to perceived black hyperfertility was as predictable as it was appalling. Though there are now many excellent accounts of the historical degradation of black bodily autonomy in the name of medical science,<sup>62</sup> a brief discussion of just three twentieth century movements illustrates why black skepticism toward procreative and reproductive medicine is well-founded.

Perhaps the most well-known effort aimed at curbing black reproduction was the Negro Project, which sought to educate blacks about how to control their fertility. Spearheaded by birth control pioneer Margaret Sanger, then head of the Birth Control Foundation of America (BCFA), the Negro Project launched in 1939 with pilot programs in Tennessee and South Carolina.<sup>63</sup> Though there is some ambiguity as to whether Sanger was motivated by racial animus—she notably drew the support of black leaders of the time such as W.E.B. DuBois, Adam Clayton Powell, E. Franklin Frazier, Mary McLeod Bethune and, later, Martin Luther King<sup>64</sup>—the Negro Project’s aims were unmistakably eugenic. In her 1938 proposal for the project, Sanger wrote, “[t]he mass of Negroes, particularly in the South, still breed carelessly and disastrously, with the result that the increase among Negroes, even more than among whites, is from the portion of the population least intelligent and fit, and least able to rear children properly.”<sup>65</sup>

The Negro Project took aim at this excessive “breeding” by enlisting black

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59. THOMAS G. DYER, THEODORE ROOSEVELT AND THE IDEA OF RACE 149 (1992).

60. *Id.*

61. *See supra* note 17 and accompanying text.

62. *See, e.g.,* IMAGINING, WRITING, (RE)READING THE BLACK BODY (Sandra Jackson et al. eds., 2009); DOROTHY ROBERTS, KILLING THE BLACK BODY: RACE, REPRODUCTION, AND THE MEANING OF LIBERTY (1997); HARRIET A. WASHINGTON, MEDICAL APARTHEID: THE DARK HISTORY OF MEDICAL EXPERIMENTATION ON BLACK AMERICANS FROM COLONIAL TIMES TO THE PRESENT (2006).

63. ROBERTS, *supra* note 62, at 76–78.

64. *Id.* at 77; *see also* WASHINGTON, *supra* note 62, at 197.

65. LINDA GORDON, WOMAN’S BODY, WOMAN’S RIGHT: BIRTH CONTROL IN AMERICA 328 (Penguin Books 1990) (1976) (paraphrasing W.E.B. DuBois, *Black Folks and Birth Control*, 16 BIRTH CONTROL REV. 166, 166–67 (1932)).

medical professionals, clergy, and social workers (who remained firmly under the BCFA's control<sup>66</sup>) to deliver its pro-contraception message to uneducated Southern blacks, whom eugenicists considered particularly unfit to have children.<sup>67</sup> In this way, the Negro Project relied upon birth control as "a means of controlling a population, rather than a means of increasing women's reproductive autonomy."<sup>68</sup> This approach is appalling to almost everyone today, but particularly to African Americans—the population the Negro Project sought to control. Though one can read Sanger's intentions as benign, aimed at improving the lives of poor mothers rather than eliminating their offspring,<sup>69</sup> the race-based, eugenic underpinnings of the Negro Project cannot be overlooked and invite scrutiny to this day.<sup>70</sup>

The second historical medical infringement of black reproductive autonomy relates to the disproportionate rate of sterilization of black women that occurred between the 1930s and 1980s. These sterilizations fell into two categories, lawful and coerced, with black women bearing the brunt of each. *Buck v. Bell*, the Supreme Court case discussed above,<sup>71</sup> was perhaps the most significant turning point of the mandatory sterilization movement, which began in Indiana in 1907 and peaked in 1935, when twenty-seven states mandated some form of eugenic sterilization.<sup>72</sup> Under those laws, blacks were astonishingly overrepresented among the sterilized, and by 1983, forty-three percent of women sterilized in federally funded family planning programs were black at a time when blacks made up just twelve percent of the population as a whole.<sup>73</sup>

The stereotype of the unfit, hyperfertile black mother on public assistance

66. See WASHINGTON, *supra* note 62, at 197 (noting Sanger's assurances to the BCFA board that the authority of black physicians operating Negro Project clinics would be limited). Washington further notes that "[w]hen the black Harlem clinic personnel eventually protested their lack of autonomy, the BCFA withdrew support and the clinic closed." *Id.* at 197–98.

67. ROBERTS, *supra* note 62, at 77–79. The notion that Southern blacks were "especially unfit to breed" was based on the theory of so-called "'selective migration,' which held that the more intelligent Blacks tended to migrate to the North, leaving the less intelligent ones behind." *Id.* at 79.

68. *Id.* at 80.

69. *Id.* at 81.

70. Black Republican presidential candidates Herman Cain (2012) and Ben Carson (2016) each made statements on the campaign trail linking Planned Parenthood (which arose out of an organization founded by Sanger) with efforts to control black populations such as the Negro Project. See Amita Kelly, *Fact Check: Was Planned Parenthood Started To 'Control' the Black Population?*, NPR: IT'S ALL POLITICS (Aug. 14, 2015, 12:59 PM), <http://www.npr.org/sections/itsallpolitics/2015/08/14/432080520/fact-check-was-planned-parenthood-started-to-control-the-black-population> (statements of Ben Carson); Glenn Kessler, *Herman Cain's Rewriting of Birth-control History*, WASH. POST: THE FACT CHECKER (Nov. 1, 2011), [https://www.washingtonpost.com/blogs/fact-checker/post/herman-cains-rewriting-of-birth-control-history/2011/10/31/gIQAr53uaM\\_blog.html](https://www.washingtonpost.com/blogs/fact-checker/post/herman-cains-rewriting-of-birth-control-history/2011/10/31/gIQAr53uaM_blog.html) (statements of Herman Cain); cf. WASHINGTON, *supra* note 62, at 197 (discussing a now infamous letter Sanger wrote to a colleague in which she cautioned, "We do not want word to go out that we want to exterminate the Negro population, and the minister is the man who can straighten out the idea if it ever occurs to any of their more rebellious members.").

71. See *supra* notes 29–30 and accompanying text.

72. WASHINGTON, *supra* note 62, at 202.

73. *Id.* at 203; see also ANGELA Y. DAVIS, *WOMEN, RACE, & CLASS* 219 (1981) (noting the same forty-three percent figure, but dating it to a 1970 study and also stating that in that same year, twenty percent of married black women had been sterilized).

fed this overrepresentation,<sup>74</sup> and a disregard for black reproductive autonomy resulted in the lion's share of black female sterilizations, which occurred outside of the law.<sup>75</sup> These sterilizations—hysterectomies—were frequently performed for training purposes, without consent or through coercive means,<sup>76</sup> and were based on the assumption that poor, black women were incapable of practicing birth control.<sup>77</sup> Medical professionals thus viewed the procedures as beneficial to both the women on whom they were performed and society as a whole, which would no longer be burdened with the offspring of unfit mothers.<sup>78</sup> Though forged consent forms and falsified medical records—describing sterilizations procedures as merely appendectomies and gall bladder removals—make precise numbers hard to come by, one study revealed that in one county in Mississippi, sixty percent of women unknowingly underwent hysterectomies after giving birth in hospitals.<sup>79</sup>

More recently, reformers have taken aim at preventing poor women from getting pregnant through use of surgical implants such as Norplant, Implanon, and Nexplanon. These implants, roughly the size of a matchstick and inserted in the upper arm, release a synthetic hormone that prevents ovulation and thickens cervical mucus to prevent sperm from reaching any eggs that are released. Approved by the FDA in 1990 and endorsed by reformers as a means of reducing welfare dependency,<sup>80</sup> Norplant was selectively marketed to poor, black women, and teenage girls.<sup>81</sup> During the 1990s, welfare reform proposals involving Norplant included conditioning cash assistance on the recipients' acceptance of the implant, incentivizing its use through cash payments on top of ordinary aid levels, and encouraging its use by welfare recipients by making it free.<sup>82</sup> The overriding premise of efforts to tie welfare benefits to the use of Norplant and other contraceptives is that doing so saves government money by reducing the number of children born into the black underclass, thereby helping to break the

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74. WASHINGTON, *supra* note 62, at 203; *see also* DAMON TWEEDY, *BLACK MAN IN A WHITE COAT: A DOCTOR'S REFLECTIONS ON RACE AND MEDICINE*, 38-39 (2015) (describing twentieth century forced sterilization programs in North Carolina and noting that the sentiment that certain young women should not "be allowed to get pregnant again" due to perceived hyperfertility and unpreparedness for motherhood persists today).

75. WASHINGTON, *supra* note 62, at 203; ROBERTS, *supra* note 62, at 90-91.

76. WASHINGTON, *supra* note 62, at 203-04.

77. ROBERTS, *supra* note 62, at 91-92.

78. *Id.* at 92.

79. WASHINGTON, *supra* note 62, at 205; *see also* ROBERTS, *supra* note 62, at 90. This abuse was so widespread in parts of the South that hysterectomies became known as "Mississippi appendectomies." ROBERTS, *supra* note 62, at 90; WASHINGTON, *supra* note 62, at 204.

80. Catherine R. Albiston & Laura Beth Nielsen, *Welfare Queens and other Fairy Tales: Welfare Reform and Unconstitutional Reproductive Controls*, 38 *HOW. L.J.* 473, 489 (1995).

81. WASHINGTON, *supra* note 62, at 207; *see also* ROBERTS, *supra* note 62, at 108-16 (describing the marketing of Norplant to the poor and the overlap between welfare policy and perceptions of black poverty). Roberts notes that some Norplant proponents "explicitly suggested distributing the contraceptive to Black women" and argues that "race lurks behind proposals to induce poor women in general to use Norplant." ROBERTS, *supra* note 62, at 110-11.

82. Albiston & Nielsen, *supra* note 80, at 490-91; *see also* Dorothy Roberts, *Unshackling Black Women's Bodies*, in *IMAGINING, WRITING, (RE)READING THE BLACK BODY*, *supra* note 62, at 73-74 (describing legislation pressuring "women on welfare to use the device either by offering them a financial bonus or by requiring implantation as a condition of receiving benefits").

cycle of intergenerational welfare dependency.<sup>83</sup> The validity and likelihood of success of these efforts is beyond the scope of this article. What is here worth noting is that the targeting of coercive contraception to poor, black women is antithetical to promoting their reproductive freedom and should be understood as a modern manifestation of historical eugenic efforts seeking to discourage reproduction by marginalized populations.

As this Part has shown, over the last century there have been a number of efforts aimed at limiting the reproductive autonomy of black women. Though we are now thankfully well past the days of the Negro Project, forced or coercive black female sterilization, and the selective targeting of long-term contraception to poor, black women, it would be shortsighted to ignore these historical efforts at curtailing black reproduction in assessing the potential costs of emerging reproductive practices. The following Part considers how prenatal genetic counseling of mothers considering bringing a genetically anomalous fetus to term might be informed by the prior marginalization of black reproduction and could, if left unchecked, reinvigorate historical eugenic practices.

## II. THE ROLE OF RACE AND CLASS IN GENETIC COUNSELING

### A. The Failure of Nondirectiveness

Pregnant women learning of a fetal abnormality customarily receive some form of genetic counseling, be it by a certified genetic counselor or other medical professional.<sup>84</sup> The core aspiration of modern genetic counseling is “nondirectiveness”: providing unbiased genetic information rather than guiding expectant mothers to proceed with or terminate their pregnancy.<sup>85</sup> But nondirectiveness is seldom achieved. In practice, “neutrality is virtually impossible” because “social values and priorities . . . are embedded in medical institutions and frameworks” and “insistence on impartiality can ultimately frustrate patients, some of whom want to receive expert advice from genetic

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83. Albiston & Nielsen, *supra* note 80, at 491.

84. Access to counselors who are members of the National Society of Genetic Counselors (NSGC) varies considerably, as they tend to be concentrated in certain large cities. See Kathryn Schleckser, Note, *Physician Participation in Direct-to-Consumer Genetic Testing: Pragmatism or Paternalism?*, 26 HARV. J.L. & TECH. 696, 725–26 (2013) (describing the high concentration of NSGC-member genetic counselors in urban areas such as New York, Philadelphia, and San Francisco and their relative dearth in and around cities such as New Orleans, Boise, and Fargo). Moreover, a recent search on the web page of the American Board of Genetic Counseling, the field’s accrediting body, found that there are just twelve certified genetic counselors in Idaho (eleven of whom are in Boise), five in Mississippi, two in Wyoming, and one in West Virginia. *Find a Counselor*, AM. BOARD OF GENETIC COUNSELING, [https://abgcmember.goamp.com/net/ABGCwcm/Find\\_Counselor/ABGCwcm/Contact\\_Management/FindCounselor.aspx?hkey=94273207-1a6e-4c6d-ac24-0c6b3793c8cd](https://abgcmember.goamp.com/net/ABGCwcm/Find_Counselor/ABGCwcm/Contact_Management/FindCounselor.aspx?hkey=94273207-1a6e-4c6d-ac24-0c6b3793c8cd) (last visited Dec. 21, 2015).

85. See, e.g., Patricia A. Devers et al., *Noninvasive Prenatal Testing/Noninvasive Prenatal Diagnosis: The Position of the National Society of Genetic Counselors*, 22 J. GENETIC COUNSELING 291, 292 (“NSGC firmly believes that reproductive decisions should be made in the context of unbiased and comprehensive information, free from discrimination and coercion . . .”) (citing NAT’L SOC’Y OF GENETIC COUNSELING, POSITION STATEMENT: REPRODUCTIVE FREEDOM 2010, <http://nsgc.org/p/bl/et/blogid=47&blogaid=35>).

practitioners.”<sup>86</sup> As a result—and given the sheer volume of medical, scientific, and psychosocial topics that could be conveyed—genetic counseling inevitably presents selective information that tends to be directive in one direction or the other, depending on the counselor, nature of the prenatal diagnosis, and perceived parental readiness.<sup>87</sup>

A large majority of women receiving a diagnosis of a fetal genetic abnormality abort their pregnancies,<sup>88</sup> usually within a few days and at times in as little as twenty-four hours.<sup>89</sup> Directive genetic counseling that steers expectant mothers toward terminating their anomalous fetuses most often does so by providing information that focuses on the challenges of raising a child with a potential disability rather than on either the positives of bringing such a fetus to term or the potential downsides of terminating for a fetal anomaly. There are even some counselors who “display surprise or distress upon hearing that a woman wants to bring to term a fetus identified as having a disability,”<sup>90</sup> regardless of a patient’s beliefs and available resources.

Beyond being diametrically opposed to genetic counseling’s nondirective aspirations, directive counseling of this form is problematic due to the unique nature of genetic terminations and the longstanding psychological impact they can have on women who have them. As I argued in my companion article, genetic terminations are unlike ordinary abortions in that they result in the end of an initially wanted pregnancy, and unlike stillbirth or other perinatal loss insofar as the mother makes the decision to end her fetus’s life.<sup>91</sup> Women accordingly experience the death of a fetus via a genetic termination more as a trauma than a loss,<sup>92</sup> and many suffer from post-traumatic stress, complicated or

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86. STERN, *supra* note 6, at 213.

87. Counseling is often directive through subtle means, such as selective reinforcement of a patient’s apparent inclination or general attitude toward genetic abortions. See Barbara A. Bernhardt, *Empirical Evidence that Genetic Counseling is Directive: Where Do We Go from Here?*, 60 AM. J. HUM. GENETICS 17, 17, 19 (1997). Other approaches include the nondisclosure of certain relevant information or a counselor’s sharing what she considers to be the “most appropriate” course of action under the circumstances. Alan J. Belsky, *Injury As A Matter of Law: Is This the Answer to the Wrongful Life Dilemma?*, 22 U. BALT. L. REV. 185, 219–20 n.196 (1993).

88. DUSTER, *supra* note 2, at 70 (“[F]our of five women who learn of a diagnostic test that produces positive indications of a genetic abnormality that will manifest symptoms choose abortion.”).

89. See Marijke J. Korenromp et al., *Termination of Pregnancy on Genetic Grounds: Coping with Grieving*, 13 J. PSYCHOSOMATIC OBSTETRICS & GYNECOLOGY 93, 98 (1992) (finding that women who had terminated pregnancies on genetic grounds did so between one and ten days of diagnosis, with an average of 4.7 and a median of 4.4 days).

90. Erik Parens & Adrienne Asch, *The Disability Rights Critique of Prenatal Genetic Testing: Reflections and Recommendations*, in *PRENATAL TESTING AND DISABILITY RIGHTS* 3, 33 (Erik Parens & Adrienne Asch eds., 2000).

91. Asbury, *supra* note 1 (manuscript at 19–27).

92. See Marijke J. Korenromp et al., *Long-term Psychological Consequences of Pregnancy Termination for Fetal Abnormality: A Cross-sectional Study*, 25 *PRENATAL DIAGNOSIS* 253, 259 (2005) (observing that “in the long term, women apparently experience [termination of pregnancy for fetal abnormality] more as a trauma than as a loss”); Marijke J. Korenromp et al., *Psychological Consequences of Termination of Pregnancy for Fetal Anomaly: Similarities and Differences Between Partners*, 25 *PRENATAL DIAGNOSIS* 1226, 1231 (2005) (finding that both women and men experienced fetal terminations “more as a trauma than as a loss event”).

pathological grief, and depression long after termination.<sup>93</sup>

In setting forth a broad critique of directive prenatal genetic counseling, my companion article offers suggestions for how to alleviate these psychological symptoms. It first describes how to improve existing state and federal legislation in this area to make it more effective in informing choice, then advocates for the adoption of practices by medical professionals implementing such legislation that will ensure that women considering termination for a fetal abnormality have access to more balanced information prior to making their decision and adequate support whether or not they terminate.<sup>94</sup> It sets out these suggestions against the backdrop of my claim that prenatal genetic analysis—and thus the incidence of fetal abnormalities detected prenatally—will soon become normalized due to certain provisions of the Affordable Care Act that make it affordable and accessible for millions more women. Coupled with advances in Noninvasive Prenatal Diagnosis—which have the potential to eliminate any risk of harm to the fetus in diagnosing genetic disorders—expanded coverage under the Affordable Care Act has the potential to increase the number of fetuses tested annually from 100,000 to roughly 3 million.<sup>95</sup> Such an increase in testing would result in a drastic rise in the number of women in need of genetic counseling to help them understand their tests, the implications of a detected fetal abnormality, and whether to proceed with their pregnancies.

It remains to be seen how this new population of women will experience prenatal genetic counseling. What seems clear, however, is that absent drastic reforms, many women will continue to receive directive counseling, often with a bias toward aborting genetically anomalous fetuses. And those who terminate their pregnancies will continue to experience elevated levels of grief, depression, and post-traumatic stress. But the extension of genetic analysis to currently underserved patient populations—fueled by the Affordable Care Act's Medicaid expansion and reduction or elimination of copays for many maternal health expenses—invites an inquiry into how women of limited means will experience genetic counseling. Building on the historical relationship between blacks and the medical profession discussed in Part I, the following section describes why poor, black women are particularly susceptible to ineffective genetic counseling.

## B. Prenatal Counseling of Poor, Black Women

Directive genetic counseling should be of particular concern as it relates to poor, black women who learn of a fetal abnormality. Despite the prevailing mandate of nondirectiveness, the information genetic counseling presents incorporates socioeconomic, cultural, and educational factors, all of which shape both how counselors describe fetal genetic disorders to mothers and how they frame possible life outcomes.<sup>96</sup> Poor, black women undergoing prenatal genetic counseling do so at a significant disadvantage due to the extent to which their

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93. Asbury, *supra* note 1 (manuscript at 20–27).

94. *Id.*

95. Henry T. Greely, *Get Ready for the Flood of Fetal Gene Screening*, 469 NATURE 289, 290 (2011).

96. See Mark A. Rothstein & Sharona Hoffman, *Genetic Testing, Genetic Medicine, and Managed Care*, 34 WAKE FOREST L. REV. 849, 862 (1999) (discussing factors which make physician nondirectiveness particularly challenging).

experiences and personal characteristics diverge from those of their providers. Doctors and nurses remain far less racially and ethnically diverse than the population as a whole,<sup>97</sup> and by one estimate, licensed genetic counselors are over ninety-five percent white.<sup>98</sup> As will be discussed below, though a medical professional's race or ethnicity is unimportant to some, for many African Americans it is a crucial determinant of whether the information and advice they receive is trustworthy or, in some cases, whether it is sought in the first place. Moreover, due to wide discrepancies in educational attainment and wealth,<sup>99</sup> it can prove particularly challenging for poor, black women considering genetic terminations to form the bonds of trust with medical professionals necessary to allow them to take full advantage of their counseling services.

There are at least three possible ways that the increased availability of free or low-cost prenatal genetic analysis for poor, black women could play out. First, it could be the case that despite this increase in availability, they will refuse to undergo any form of prenatal genetic analysis. Supporting this hypothesis is the fact that black women are overall less likely than whites to participate in genetic testing and counseling,<sup>100</sup> due perhaps to "historical attempts to label certain racial groups as genetically inferior."<sup>101</sup> But the routinization of genetic analysis in the prenatal realm is likely to cut against this finding, as pregnant women offered various forms of prenatal testing or screening most often accept whatever modalities are offered, thinking that it is in the best interest of the fetus they are carrying.<sup>102</sup>

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97. Just four percent of physicians in the workforce are black (five percent are Hispanic), and nearly three out of four are white. See BUREAU OF HEALTH PROFESSIONS, HEALTH RES. AND SERVS. ADMIN., U.S. DEP'T OF HEALTH AND HUMAN SERVS., *THE PHYSICIAN WORKFORCE: PROJECTIONS AND RESEARCH INTO CURRENT ISSUES AFFECTING SUPPLY AND DEMAND*, at 93 (2008), <http://bhpr.hrsa.gov/healthworkforce/reports/physwffissues.pdf>. More than eight in ten registered nurses are white, while non-Hispanic blacks make up just 5.4 percent. See HEALTH RES. AND SERVS. ADMIN., U.S. DEP'T OF HEALTH AND HUMAN SERVS., *THE REGISTERED NURSE POPULATION: INITIAL FINDINGS FROM THE 2008 NATIONAL SAMPLE SURVEY OF REGISTERED NURSES*, at 11 (2010) [hereinafter *The Registered Nurse Population*], <http://bhpr.hrsa.gov/healthworkforce/rnsurveys/rnsurveyinitial2008.pdf>.

98. DUSTER, *supra* note 2, at 80. A more recent study of the implicit racial attitudes of genetic counselors sampled a population that was 92.5 percent white and noted that this group was "generally representative of the national population of genetic counselors." Kendra L. Schaa et al., *Genetic Counselors' Implicit Racial Attitudes and Their Relationship to Communication*, 34 HEALTH PSYCHOL 111, 115, 117 (2015).

99. Doctors are by definition highly educated, and so too are all genetic counselors certified by the American Board of Genetic Counseling, who must obtain a Master's in genetic counseling in order to sit for the certification examination. Nurses are increasingly highly educated as well, with just 13.9 percent having attained no degree beyond a high school diploma. Around that same percentage have Masters or Doctoral degrees, while seventy-two percent have earned either an Associate or Bachelor's degree. See *The Registered Nurse Population*, *supra* note 97, at 6.

100. Vanessa B. Sheppard et al., *Medical Mistrust Influences Black Women's Level of Engagement in BRCA1/2 Genetic Counseling and Testing*, 105 J. NAT'L MED. ASS'N 17, 17 (2013); Michael Hall & Olufunmilayo I. Olopade, Editorial, *Confronting Genetic Testing Disparities: Knowledge is Power*, 293 JAMA 1783, 1783-84 (2005); Katrina Armstrong et al., *Racial Differences in the Use of BRCA1/2 Testing Among Women with a Family History of Breast or Ovarian Cancer*, 293 JAMA 1729, 1731 (2005).

101. Armstrong et al., *supra* note 100, at 1730.

102. See Dorothy E. Roberts, *Race, Gender, and Genetic Technologies: A New Reproductive Dystopia?*, 34 SIGNS 783, 792 (2009) (noting that "many pregnant women now view genetic testing as a

A second, in my view more likely, possibility is that there will be no significant discrepancy in the rates at which poor, black women accept free or low-cost prenatal genetic analysis when it is offered to them as compared to other populations, but that they will be less likely to seek out and engage meaningfully with the genetic counseling services available to them. Given the historical ties between genetic counseling and eugenic notions of black inferiority,<sup>103</sup> the targeting of black reproduction during the Negro Project,<sup>104</sup> the disproportionate government-sponsored sterilization of blacks that flourished for decades,<sup>105</sup> and more recent efforts specifically targeting poor, black women for the surgical implantation of long-term, potentially hazardous birth control,<sup>106</sup> it is not difficult to understand why poor, black women might be reluctant to enter into an intense, high-stakes relationship with a (most likely) highly-educated, white medical professional counseling them about whether to bring their fetus to term. General black distrust of the medical profession has been widely noted in the literature,<sup>107</sup> and new or unfamiliar technologies and techniques are likely to be particularly impacted by the effects of this distrust.<sup>108</sup>

Understandable as it may be, poor, black women’s unwillingness to embrace genetic counseling upon the discovery of a fetal abnormality could result in significant costs. As noted above,<sup>109</sup> most women—regardless of race and socioeconomic status and notwithstanding any genetic counseling they receive—terminate their pregnancies upon the discovery of a fetal abnormality. As poor, black women gain increased access to prenatal genetic analysis—and in turn more regularly learn prenatally that their fetuses have conditions such as sickle cell anemia, Down syndrome, or spina bifida—their default option, like those of all other women, will be to terminate. While terminating on genetic grounds may be the right choice for many women, the decision to do so carries with it an elevated risk of experiencing subsequent pathological grief, depression, and post-traumatic stress.<sup>110</sup> Genetic counseling in its best form can help women consider these costs in making their decision and help them address the

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requirement of responsible mothering”).

103. See *supra* notes 45–58 and accompanying text.

104. See *supra* notes 63–70 and accompanying text.

105. See *supra* notes 72–79 and accompanying text.

106. See *supra* notes 80–83 and accompanying text.

107. See, e.g., Armstrong et al., *supra* note 100, at 1734 (discussing the barrier to healthcare use among African Americans resulting from their distrust of the medical profession); Giselle Corbie-Smith et al., *Distrust, Race, and Research*, 162 ARCHIVES INTERNAL MED. 2458, 2460 (2002) (“Even after controlling for markers of social class, African Americans were less trusting [of medical professionals than whites].”); Abigail Rose et al., *Development and Testing of the Health Care System Distrust Scale*, 19 J. GEN. INTERNAL MED. 57, 61–62 (2004) (finding that “distrust of the health care system was higher among African Americans than whites, even after adjusting for education . . .”); TWEEDY, *supra* note 74, at 237, 244–45 (2015) (noting that “many black people are mistrustful of doctors and medical treatments” and describing various approaches—connecting with patients as individual persons, race-focused competency training for physicians, and quality of care improvements for all patients—to break down the barriers of distrust blacks often have toward doctors and other medical personnel).

108. Armstrong et al., *supra* note 100, at 1734.

109. See *supra* note 88 and accompanying text.

110. See *supra* note 93 and accompanying text.

psychological impacts of termination.<sup>111</sup> But left to their own devices, women seldom anticipate these impacts or consider them in informing their choice. In sum, under this second possible scenario, the most likely result will be an increase in abortions of genetically anomalous fetuses by poor, black women, and with it an increase in the prevalence of pathological grief, depression, and post-traumatic stress within this population.

The third possible scenario is the one with which I am most concerned. Should poor, black women undergo genetic analysis at the same rates as other populations and, upon the discovery of a fetal anomaly, engage with genetic counseling in good faith, there exists the distinct possibility that they will disproportionately receive directive counseling in favor of termination. In its ideal form, prenatal genetic counseling should provide a complete picture of the pros and cons of bringing a genetically anomalous fetus to term. The exchange of information between counselor and patient should seek to achieve bilateral “satisfaction with the information provided,”<sup>112</sup> whatever form it may take. Accomplishing this objective requires that there be an open, iterative dialogue in which the mother’s need for information and assurance is placed at a premium.<sup>113</sup> Only in this way—through the establishment of a close and comfortable relationship with genetic counseling—can mothers make a truly informed choice accurately factoring in the costs and benefits of whatever choice they make.

Unfortunately, the establishment of such a close relationship with medical professionals providing genetic counseling will likely prove difficult for poor, black mothers. In addition to the striking lack of diversity among doctors, nurses, and genetic counselors,<sup>114</sup> the socioeconomic and educational gaps between these patients and their providers,<sup>115</sup> and the historical devaluation of black reproduction by the medical profession,<sup>116</sup> there is now evidence of “moderate to strong pro-White implicit attitudes among genetic counselors.”<sup>117</sup> Among the representative population of genetic counselors sampled in one study, nearly three quarters held some form of pro-white bias.<sup>118</sup> The study found that the greater a genetic counselor’s pro-white bias, the less likely she or he was to engage in rapport-building with minority clients, and the more likely she or he was to be less verbally dominant with (and hence more responsive counselors for) white clients.<sup>119</sup>

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111. Asbury, *supra* note 1 (manuscript at 9-19).

112. See Nina Asplin et al., *Pregnancy Termination Due to Fetal Anomaly: Women’s Reactions, Satisfaction and Experiences of Care*, 30 *MIDWIFERY* 620, 625 (2014).

113. See Asbury, *supra* note 1 (manuscript at 46-51).

114. See *supra* notes 97-98 and accompanying text.

115. See *supra* note 99 and accompanying text.

116. See *supra* notes 63-83 and accompanying text.

117. Schaa et al., *supra* note 98, at 116.

118. *Id.* at 114 (“23.9% of participants held a strong pro-white bias, 25.4% held a moderate bias, [and] 25.4 held a slight bias . . .”). The study also noted that just 23.9 percent did not hold any pro-white bias, with 11.9 percent “holding a slight-moderate degree of pro-Black bias.” *Id.* This study also noted that its “population’s demographic and geographic characteristics are generally representative of the national population of genetic counselors.” *Id.* at 117.

119. *Id.* at 116. As the study explains, “[v]erbal dominance has been considered to be an

On some level, none of this should be surprising. Given the demographics of genetic counseling, one would expect there to be an overall ingroup preference that inures to the benefit of white clients.<sup>120</sup> But for those who are concerned about the subtle ways that genetic counseling can coerce women into terminating anomalous fetuses and their attendant psychological harms, this sobering, specific evidence of pro-White bias serves as the ultimate proof that, try as they may, black women will be hard-pressed to develop the necessary rapport to have a trust-based and meaningful genetic counseling experience. In this regard, they will be like either the cohort of women who decline to engage substantively with genetic counseling or the large group of women who currently experience genetic counseling, but find it to be impersonal, of little use, and/or directive.<sup>121</sup>

Black women who are poor and carrying a genetically anomalous fetus will likely fare worst of all, due to the combination of genetic counseling's pro-white bias and the public's begrudging attitude toward the "meager increase in benefits for one more child" and the general "depletion of public resources for general health care and for supporting people with disabilities."<sup>122</sup> While it is possible that genetic counseling providers will be able to shield themselves from these considerations, it is unlikely given the subjective, selective nature of genetic counseling and the socioeconomic and cultural factors that inevitably play a role in shaping the patient-counselor relationship.

Taken together, these three possibilities paint a grim picture of the future of poor, black pregnancy. While it is possible that the expanded availability of prenatal genetic analysis will produce no meaningful increase in the detection of fetal anomalies among this population, there will likely be a significant rise. Should these women decline to engage meaningfully with genetic counseling providers upon learning of a fetal abnormality, the vast majority will terminate. Should they enter genetic counseling in good faith reliance upon their provider's expertise, pro-white and anti-poor biases will inevitably seep in, resulting in encounters that are generic (rather than intimate) at best or directive toward uninformed terminations at worst. The dystopian gloss on either of these latter possibilities would be a two-tiered genetic counseling regime in which the increasing sensitivity to disability rights results in an increase anomalous births among the privileged, while poor, black fetuses with genetic abnormalities are routinely, through the neglect or indifference of genetic counseling, deemed not worthy of life.

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important indicator of patient-centeredness . . . Lower verbal dominance has been linked empirically to greater patient-centered care in primary care contexts, which . . . is associated with better health outcomes." *Id.*

120. See *id.* (noting that the study's findings are not "unexpected, given that the majority of the sample was White and nearly 80% of White Americans show an ingroup preference . . .").

121. See *supra* notes 85–87 and accompanying text; PETER D. TURNPENNY & SIAN ELLARD, EMERY'S ELEMENTS OF MEDICAL GENETICS 268 (14th ed. 2012) (noting that of couples who attend genetic counseling, "approximately 50% have been influenced to some extent").

122. Roberts, *supra* note 102, at 784, 798. Roberts wonders whether the objective of state support of genetic testing programs might not be to provide women with reproductive choices "but to escape public responsibility for disability-related needs" by fostering the termination of fetuses who will or might be born with disabilities. DOROTHY ROBERTS, FATAL INVENTION: HOW SCIENCE, POLITICS, AND BIG BUSINESS RE-CREATE RACE IN THE TWENTY-FIRST CENTURY 221 (2011).

## III. EUGENICS BY THE BACK DOOR?

The foregoing Parts have sought to show that there is reason to be concerned that the introduction of prenatal genetic analysis to underserved populations, particularly poor blacks, has the potential to result in the widespread and disproportionate termination of poor, black fetuses. This concern is buttressed by both the historical ties among eugenics, genetic counseling, and notions of black inferiority and the persistent marginalization of black reproduction throughout the twentieth century. Because the widespread rejection of readily available and affordable prenatal genetic analysis is an unlikely means of addressing this concern, this Part addresses itself toward ensuring that poor, black women take advantage of the counseling available to them upon learning of a fetal abnormality and reducing the likelihood of bias in the counseling they receive.

Because genetic counseling in its ideal form can provide a complete picture of the implications (positive and negative) of both terminating and carrying a genetically anomalous fetus to term—and, accordingly, foster informed choice—it is essential first and foremost that the field be drastically reshaped. Improvements in genetic counseling are most likely to be achieved through a combination of legislative and practice-based solutions. Whether state or federal, legislation aimed at providing women with adequate information and support upon learning of a fetal abnormality should cover a broad array of conditions, not just Down syndrome, as a number of states currently do.<sup>123</sup> It should also require that women (not just their caregivers) be provided with information regarding the range of potential outcomes for their fetuses, as well as access to support services such as peer support and available adoption options.<sup>124</sup> No current legislation requires that women learning of a fetal abnormality be provided with all of this information and support.

The effective implementation of comprehensive pro-information legislation will require radical changes in the practices of most caregivers who provide genetic counseling. To foster truly informed choice, counselors should candidly discuss not only the challenges of bringing a genetically anomalous fetus to term and raising a potentially disabled child, but the psychological and emotional downsides of terminating on genetic grounds. The channels of communication between patient and provider should be open during the decision making process to promote the mutually satisfactory exchange of specific (rather than generic) information. Those who choose to terminate should receive some form of post-pregnancy counseling (in addition to the customary medical follow up) shaped by reassurance, empathy, care, support and understanding, as well as access to group therapy with others who have terminated for a fetal abnormality and psychological treatment.<sup>125</sup> Again, few women currently have access to this range of services as a matter of course.

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123. See, e.g., OHIO REV. CODE ANN. § 3701.69 (West 2014); 35 PA. CONS. STAT. ANN. § 6244 (2014); MD. CODE ANN., HEALTH-GEN. § 20-1502 (West 2014); LA. STAT. ANN. § 40:1300.392 (2014); KY. REV. STAT. ANN. § 211.192 (West 2013); DEL. CODE ANN. tit. 16, § 801B (West 2014); MASS. GEN. LAWS ANN. ch. 111, § 70H (West 2012).

124. Asbury, *supra* note 1 (manuscript at 44–46).

125. Asbury, *supra* note 1 (manuscript at 48–51).

Beyond these general, though far-reaching, changes in genetic counseling, there are a number of steps that could specifically improve the experience of poor, black women carrying genetically anomalous fetuses. In recognition of genetic counseling’s evidenced pro-white bias, policymakers should endeavor to increase counselor awareness through interventions targeted at improving racially discordant counseling sessions and reducing racial disparities in the delivery of counseling services.<sup>126</sup> These interventions should focus on both the causal source of the pro-white bias and the impact it can have on how counselors behave toward, and communicate with, black patients, driven by the overall aim of increasing mindfulness, sensitivity, patient-centeredness, and attentiveness to personhood.<sup>127</sup> Though successful interventions of this kind may prove difficult to design and execute—one recent nine-week intervention seeking to increase awareness of personal racial attitudes toward blacks increased bias in as many participants as it decreased it<sup>128</sup>—acknowledging and beginning to address the pro-white bias of genetic counseling is an important first step, regardless of its initial rate of success.

Because it impairs the formation of a close relationship with genetic counseling providers, black patient mistrust of the medical profession (and of medical genetics in particular) should also be dealt with head-on. Providers should understand from the outset that they are likely to be met with skepticism by many black patients and address these concerns openly<sup>129</sup> by explicitly disavowing any eugenic intent. One manner of doing so would be for counselors to refocus their attention on nondirectiveness, emphasizing to their black patients the benefits of genetic testing and counseling rather than just the risks and potential challenges of raising a child with a genetic condition.<sup>130</sup> And given how common it is for non-black counselors to trigger mistrust and trepidation in black clients,<sup>131</sup> they should also acknowledge and seek to bridge any cultural gaps as soon as possible, ideally during the first counseling session.<sup>132</sup> This more balanced and particularized approach should be paired with efforts aimed at increasing the racial and ethnic diversity of genetic counselors,<sup>133</sup> more than ninety percent of whom remain white.

At the organizational level, healthcare administrators should take steps to ensure that genetics-related service environments are culturally sensitive so that

126. See Schaa et al., *supra* note 98, at 117.

127. *Id.*

128. Robin Steed, *The Effects of an Instructional Intervention on Racial Attitude Formation in Occupational Therapy Students*, 25 J. TRANSCULTURAL NURSING 403, 405 (2014) (“[A]pproximately 25% of the students’ scores actually increased (indicating increased bias toward Blacks) whereas 25% of the scores decreased (indicating decreased bias toward Blacks).”).

129. Sheppard et al., *supra* note 100, at 21.

130. *Id.*

131. DERALD WING SUE & DAVID SUE, COUNSELING THE CULTURALLY DIFFERENT: THEORY AND PRACTICE 247 (3d. ed. 1999).

132. WANDA M.L. LEE, ET AL., INTRODUCTION TO MULTICULTURAL COUNSELING FOR HELPING PROFESSIONALS 132 (2nd ed. 2007).

133. Schaa et al., *supra* note 98, at 117 (noting that “race-concordance in health-care interactions has been associated with more positive communication markers, including higher patient ratings of satisfaction, more positive judgments of physicians’ participatory decision-making, and more patient positive affect.”) (internal citations omitted).

they are more welcoming for black patients.<sup>134</sup> In a similar vein, community-level outreach programs aimed at raising the level of “genetic health literacy” among black women would also serve to soften the image of genetic medicine.<sup>135</sup> Because black patients overall see a disproportionately small group of physicians—who on average face greater difficulties providing their patients access to high-quality subspecialists<sup>136</sup>—direct outreach to underserved black populations regarding the highly specialized and ever-evolving field of genetics has the potential to be particularly impactful.

This multi-pronged approach incorporating elements aimed at educating both providers and black patients would do much to alleviate concerns that the advent of normalized prenatal genetic analysis could usher in an era of “eugenics by the back door”<sup>137</sup> targeting anomalous black fetuses. While it is both reasonable and appropriate to assign blame to the culturally-imbedded marginalization of poor, black reproduction and the pro-white bias of genetic counselors as primary culprits, it would be shortsighted to ignore the role that black women can play in pushing back against the racial and economic biases of prenatal genetic counseling. Only through persistent engagement can poor, black women begin to receive the kind of prenatal genetic counseling and subsequent support all women deserve. The alternative—disengagement—is ultimately self-defeating, as it carries with it an elevated risk of unanticipated and long-standing psychological harms. To combat the potential eugenic erasure of the next generation of genetically anomalous black fetuses, advocates should embrace prenatal genetic counseling for poor, black women and strive to fix it from the inside. This is not to exculpate the racist, eugenic attitudes and behaviors that continue to haunt the field, but to shine a light on them and demand something better.

#### CONCLUSION

This brief article has sought to raise awareness of the cultural complexity and potential pitfalls of prenatal genetic counseling for poor, black women. It takes for granted that individual experiences with prenatal genetic counseling are and will remain widely varied, regardless of race and socioeconomic status. Nonetheless, in light of persistent efforts to limit the reproductive freedoms of the poor and people of color, the uneasy relationship many blacks have with medical professionals, evidence of pro-white bias in genetic counseling, and the historical relationship between medical genetics and eugenics, there is a strong case for treating poor, black women in need of prenatal genetic counseling as a class meriting special consideration. The deeply personal decision whether to bring a genetically anomalous fetus to term has psychological, economic, and

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134. See Sheppard et al., *supra* note 100, at 21 Olufunmilayo I. Olopade et al., *Breast Cancer Genetics in African Americans*, 97 *CANCER* 236, 243–44 (2003) (describing the importance of developing the sensitivity of genetic counselors to cultural issues and the importance of providing testing in a “culturally sensitive research setting”).

135. See Sheppard et al., *supra* note 100, at 21.

136. Peter B. Bach et al., *Primary Care Physicians Who Treat Blacks and Whites*, 351 *N. ENG. J. MED.* 575, 579 (2004); see also Armstrong et al., *supra* note 100, at 1735.

137. I borrow the term from Troy Duster. See *supra* note 2 and accompanying text.

social ramifications that can last a lifetime—this is why prenatal genetic counseling is so crucial. But where counseling is racially or economically biased, it undermines rather than promotes reproductive freedom. The suggestions offered above are intended to empower poor, black women more effectively to exercise this freedom, one that continues to be questioned and subjugated in many quarters to this day.