

# Genetic Testing, Nature, and Trust

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## I.

The United States Human Genome Project is a billion-dollar commitment to "analyzing the structure of human DNA and determining the location of the estimated 100,000 human genes."<sup>1</sup> The genome project aims to decode the complex sequence of hereditary instructions contained within DNA to determine which genes are responsible for what physiological functions throughout the human lifespan. Part of an international genome initiative, the United States' initiative is expected to cost an estimated \$200 million per year for fifteen years.<sup>2</sup> Officials at the National Institutes of Health predict that scientists will complete the sequencing of the human genome early in the first decade of the twenty-first century.<sup>3</sup>

The timely progress of the genome project has intensified the need for careful discussion of its applications. Genetic science has already produced reliable techniques of prenatal diagnosis, paternity testing, and forensic identification. A paramount aspiration for gene science is that its medical applications will dramatically improve the ability to prevent, predict, treat, and cure serious disease and disorders.

Science inspires hope, but also fear.<sup>4</sup> Developments in gene science have prompted predictions that human beings increasingly will "play God," interfering with nature by genetically reengineering the natural world. Although few people object to the goal of reducing the risk of early onset debilitating diseases, many object to genetic manipulation seemingly aimed at cleansing the human race of medically and socially imperfect people. Gene science has led to fears that the future, like the

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<sup>1</sup> NAT'L INST. OF HEALTH, U.S. DEP'T OF HEALTH & HUMAN SERVICES & U.S. DEP'T OF ENERGY, PUB. NO. 90-1590, UNDERSTANDING OUR GENETIC INHERITANCE—THE U.S. HUMAN GENOME PROJECT: THE FIRST FIVE YEARS FY1991-1995 (April 1996).

<sup>2</sup> See *id.* at 7.

<sup>3</sup> See *id.* at 1.

<sup>4</sup> See generally Anita L. Allen, *Genetic Privacy: Emerging Concepts and Values*, in 1 GENETIC SECRETS (Mark Rothstein ed., Yale Univ. Press 1997).

past, will be marked by eugenics and intolerance.

Another major fear prompted by human genetics is fear of lost privacy.<sup>5</sup> Genetics science indeed augurs diminished privacy. In the wake of privacy losses, comes the potential for social stigma, discrimination in employment, barriers to health insurance, and other problems.<sup>6</sup> For people and communities of color, privacy loss is particularly worrisome, because stigma, discrimination, and barriers to health insurance are ubiquitous anyway. My greatest philosophical concern is that novel applications of gene science, including genetic testing, could become pervasive before appropriate ethical and legal safeguards are in place to protect valued forms of privacy. Moreover, the splendid benefits of science could blind society to some of its social costs, lowering expectations of privacy below levels philosophers describe as just and ethical.

The fate of privacy in our age of science is mainly, but not solely, a

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<sup>5</sup> See *id.*

<sup>6</sup> See generally Nancy E. Kass, *Insurance for the Insurers: the Use Of Genetic Tests*, 22 HASTINGS CENTER REP. 6 (1992) (discussing genetic testing and its effect on health insurance applicants/claimants); Regina H. Kenen & Robert Schmidt, *Stigmatization of Carrier Status: Social Implications of Heterozygote Genetic Screening Programs*, 68 AM. J. PUB. HEALTH 1116 (1978) (discussing latent psychological and social questions surrounding genetic screening programs that must be answered before national genetic screening program plans progress); Joseph Kupfer, *The Ethics of Genetic Screening in the Workplace*, 3 BUS. ETHICS Q. 17 (1993); Jennifer Landes, *Genetic Testing Thorny for Insurers: Privacy Issues vs. Value of New Information*, in NAT'L UNDERWRITER—LIFE AND HEALTH INSURANCE EDITION 3 (1992) (outlining how genetic testing advances while informative may be cost and public outcry prohibitive); Marc Lappé, *Ethical Issues in Testing for Differential Sensitivity to Occupational Hazards*, 25 J. OCCUPATIONAL MED. 797 (1983); J.A. Lowden, *Genetic Discrimination and Insurance Underwriting*, 51 AM. J. HUM. GENETICS 901 (1992); Naomi Obinata, *Genetic Screening and Insurance: Too Valuable an Underwriting Tool to Be Banned from the System*, 8 SANTA CLARA COMPUTER AND & HIGH TECH. L.J. 145 (1992) (discussing policy and ethical considerations of insurers use of genetic testing); Susan O'Hara, *The Use of Genetic Tests in the Health Insurance Industry: The Creation of a Biologic Underclass*, 22 SW. U. L. REV. 1211 (1993) (noting perceived probable health insurance industry discrimination of applicants based on genetic testing); Judy D. Olian, *Genetic Screening for Employment Purposes*, 37 PERSONNEL PSYCHOL. 423 (1984) (noting genetic screening in employment placement and policy considerations surrounding such practice); Gilbert Omenn, *Genetic Testing and Screening: Predictive and Workplace Testing*, in ENCYCLOPEDIA OF BIOETHICS (Warren T. Reich ed., Simon & Schuster 1995); David Orentlicher, *Genetic Screening by Employers*, 263 JAMA 1005 (1990) (caution warranted in the use of the "human genome project" results in employment placement); Harry Ostrer, *Insurance and Genetic Testing: Where Are We Now?*, 52 AM. J. HUM. GENETICS 565 (1993) (discussing the impact of the abuse of genetic information by the insurance industry); Mark A. Rothstein, *Genetic Screening in Employment: Some Legal, Ethical, and Societal Issues*, 1 INT'L J. BIOETHICS 244 (1990) (discussing policy and ethical considerations surrounding genetic screening in the workplace); Mark A. Rothstein, *The Genome Project and Employment Law*, in LEGAL AND ETHICAL ISSUES RAISED BY THE HUMAN GENOME PROJECT 366 (Houston Health Law & Policy Institute 1991) (noting genetic discrimination in employee placement).

worry of ethicists, health-care providers, and lawyers. Public awareness of genetic policy problems is limited. But opinion polls suggest that the general public views threats to privacy as significant issues. Because of what Dorothy Nelkin calls the "social power" of information,<sup>7</sup> personal privacy merits protection from employers, insurers, researchers, health-care providers, schools, businesses, and government.

## II.

The delivery of genetic services to members of racial minority groups raises important questions. I would like to highlight two such questions. First, in view of the past mistakes of the scientific and medical communities,<sup>8</sup> can anyone fully trust scientists to study non-white Americans without racial bias? Second, can health-care providers adequately serve non-white Americans, knowing that many are uneasy about science, formal medicine, and explorations of human health and intellect?<sup>9</sup> Recent service as a member of the National Institutes of Health's National Human Genome Research Institute's National Advisory Council for Human Genome Research (NCHGR) brought these questions into sharp relief. As a member of the Council, I frequently reflected on the implications for minority groups of the nation's portfolio of scientific, social scientific, and humanistic research relating to genetics. A number of leading experts agree that a policy emphasis on genetic testing should be closely examined for its warrant and risks.

## III.

What are we really like? What are our biological natures? How are we different from one another? Questions of this ilk have their origins in wonder about "God's creation." Yet knowledge of the answers that scientists and scholars once gave to questions like these may make some people of color less anxious to listen to current experts and quite unable to trust them.

The history of human achievement has been marred by the dissemination of a good deal of scholarly and scientific nonsense about inherited

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<sup>7</sup> Dorothy Nelkin, *The Social Power of Genetic Information*, in *THE CODE OF CODES: SCIENTIFIC AND SOCIAL ISSUES IN THE HUMAN GENOME PROJECT* 170, 170-90 (Daniel H. Kevles & Leroy Hood eds., Harvard Univ. Press 1992).

<sup>8</sup> See generally JAMES JONES, *BAD BLOOD: THE TUSKEGEE SYPHILIS EXPERIMENT* (Maxwell Macmillian 1993); EDWARD J. LARSON, *SEX, RACE, AND SCIENCE: EUGENICS IN THE DEEP SOUTH* (John Hopkins Univ. Press 1995).

<sup>9</sup> See generally *THE BELL CURVE WARS: RACE, INTELLIGENCE, AND THE FUTURE OF AMERICA* (Steven Fraser ed., 1995); RICHARD J. HERRNSTEIN & CHARLES MURRAY, *THE BELL CURVE: INTELLIGENCE AND CLASS STRUCTURE IN AMERICAN LIFE* (1994).

traits. A case in point is the set of texts purporting to report on the biological characteristics of the disparate races of humanity. One such text, selected at random, is an article on the "Negro" published early in the present century in the thirteenth edition of the *Encyclopaedia Britannica*.<sup>10</sup> Citing learned authorities the article asserted that: "Mentally the negro is inferior to the white."<sup>11</sup> The Negro is subject to "indolence" and "lethargy" perhaps due to "premature closing of the cranial sutures and lateral pressure of the frontal bone" or because, "[a]fter puberty sexual matters take the first place in the negro's life."<sup>12</sup> Negroes "far surpass white men in acuteness of vision, hearing, direction and topography."<sup>13</sup> But the Negro is like "a child, normally good-natured and cheerful, but subject to sudden fits of emotion and passion during which he is capable of performing acts of singular atrocity . . . ."<sup>14</sup> When it comes to hair, the Negro is like neither the white man nor the higher ape; for those two have true hair, whereas the Negro head is capped by a kind of wool, a "woolly" or "frizzly" pile capable of being felted.<sup>15</sup> Finally, "[t]he recognized leaders of the [Negro] race are almost invariably persons of mixed blood, and the qualities which have made them leaders are derived certainly in part and perhaps mainly from their white ancestry."<sup>16</sup>

Have the "scientific" images of persons of African descent contained in the quoted passages been utterly eradicated from science, from scholarship, health-care, from popular culture, and from ordinary belief? Geneticists now know that there is no race blood and no single race gene. But there are people on the lookout for evidence that Blacks are genetically inferior to Whites in intellect and that Blacks have criminal proclivities fixed in their genetic make-ups.<sup>17</sup> My impression is that many people of color do not trust science or scientists. When it comes to genetics, one impediment to trust may be the cultural gap between the creators of gene science and the consumers of gene science. Regardless of race and sex, we are all potential consumers of genetic information. But the creators of genetic information, the researchers, are mainly men, and mainly White. The people with the largest labs, who receive the

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<sup>10</sup> 19 ENCYCLOPAEDIA BRITANNICA 344 (13th ed. 1926).

<sup>11</sup> 19 *Id.* at 344.

<sup>12</sup> 19 *Id.*

<sup>13</sup> 19 *Id.* at 345.

<sup>14</sup> 19 *Id.*

<sup>15</sup> 19 ENCYCLOPAEDIA BRITANNICA 344, 344 (13th ed. 1926).

<sup>16</sup> 19 *Id.* at 346.

<sup>17</sup> Joseph S. Alper & Jonathan Beckwith, *Genetic Fatalism and Social Policy: The Implication of Behavior Research*, 66 YALE J. BIOLOGY & MED. 511 (1994); Dorothy E. Roberts, *Crime, Race, and Reproduction*, 67 TUL. L. REV. 1945, 1948 (1993).

largest federal grants, who hire and train the young scientists and doctors are mainly men and mainly White. Heath-care is multicultural, science is less so.<sup>18</sup>

Closing the demographic gap between scientists and consumers could make a difference in the willingness of the public to trust scientists and their products. So, too, could a greater voice in public issues. I experienced keen disappointment when I learned a few years ago how few top gene scientists had bothered to speak out against claims that science showed that reproduction by poor minority women was lowering the average IQ.<sup>19</sup> I heard some scientists explain their silence by saying that they were not interested in popular politics and that they thought the distortion of research by popularizers was too obvious for comment. But those responses left me feeling betrayed and abandoned.

The history of racism in science and scholarship demands that researchers react vocally to claims about the implications and uses of their pure research. Science is the interpretation of nature. I believe many African Americans are understandably ambivalent about nature, their place in it, and the enterprise of its interpretation. Blacks of my generation spent our childhoods hearing mostly from Whites that we are lazy by nature, less intelligent by nature, more prone to moral corruption and criminality than Whites by nature, more impulsive, more dependent, promiscuous, and more prone to noxious diseases than Whites by nature. We grew up afraid of ourselves, secretly ashamed of ourselves, but suspicious and resentful of scientific and clinical interpretations of our natures.

Scientists can make mistakes. We know that what is deemed knowledge in one generation can look like superstition and prejudice in another. This Symposium contains a great deal of information about the misuses of science and scientific information relating to genetics, about the potential for clinical abuses, and about government complicity. In a positive, forward-looking vein, the Symposium contains ideas about how health-care professionals and researchers can serve people of color in good faith.

Some kinds of genetic testing, evaluation, and screening can be useful. For example, when a child is born with multiple abnormalities, genetic testing can confirm a diagnosed syndrome and thereby secure more appropriate health-care. But as the Symposium demonstrates, at least four key issues surround the evaluation of genetic testing: (1) whether genetic testing practices are based on accurate information and research, rather

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<sup>18</sup> See DANIEL SAREWITZ, *SCIENCE, TECHNOLOGY, AND THE POLITICS OF PROGRESS* (Temple Univ. Press 1996).

<sup>19</sup> See generally JONES *supra* note 8.

than on myth, stereotype and prejudiced interpretations; (2) whether society provides equity in access to genetic testing with clear health benefits; (3) whether the delivery of genetic testing and other services is voluntary and appropriately respects the dignity, privacy, and confidentiality of individuals and families; and (4) whether there can be equal respect for the choices people of color make on the basis of genetic information, especially if those choices are different from the choices whites make. I have listed four multifaceted issues. This excellent symposium promises to identify and develop even more.