

---

# Genetic Testing and the Future of Disability Insurance: Thinking about Discrimination in the Genetic Age

*Paul Steven Miller*

As we enter the new century, humanity wields increasing power to understand, alter, and control the world in which we live. The mysteries of our genetic code provide remarkable new insights into our unique human characteristics. Rapid developments in information technology provide instant access to limitless data. The information age has taken hold, and the genetic revolution is in full swing. With apologies to Aldous Huxley, we stand at the precipice of a brave new world.

It has been just 50 years since James Watson and Francis Crick's groundbreaking discovery of the double helix.<sup>1</sup> Since then, profound developments in the science of genetics have been staggering. More staggering still are the potential benefits, the boundless horizons, the promised and unimagined applications of their work, and the work of the many scientists involved in the sequencing of the human genome. There can be no doubt that a firm and unwavering commitment to the betterment of humankind has fueled this tireless effort.

And yet, as with most technological advances, there are significant risks of misuse and abuse of a new science. History has taught us that the wonders of science hold unique power to sway and seduce, and too often to corrupt, the course of human nature. James Watson has urged that genetic progress in health can come only with a firm awareness of the potential for abuse.<sup>2</sup> Whether the scientific community is mobilized to deride something as junk science or voodoo genetics may ultimately not matter. Sometimes public opin-

ion and market forces prevail, regardless of whether something is scientifically rational.

As humanity charts a new course, it must do so with an abiding respect and admiration for human potential and the rights of individuals. In short, humans must insist that genetic profiles – in whatever form they take – remain in the control of the individual, and should never be used to violate fundamental human rights. The challenge for scientists, philosophers, ethicists, jurists, and policymakers is how to best balance the rights of the individual against the needs of society in this rapidly changing world.

## Eugenics and Genetics

### *Darwin's Theories*

If history is to remember Watson and Crick as the most important biologists of the 20th century, then it certainly must grant the 19th century to Charles Darwin. Indeed, over a century ago, Darwin's revolutionary theories on natural selection and the evolution of species sparked many wonderful scientific advances and led to a greater understanding of mankind's place in the natural world.<sup>3</sup> Unfortunately, dreadful misapplications of his brilliant concept of "survival of the fittest" also prospered.<sup>4</sup> Plugged into the social, religious, cultural, and historical milieu of the time, Darwin's scientific theories found less scientific and more destructive applications.<sup>5</sup>

Bigoted notions of the underlying causes of class, social, and biological differences attributed "undesirable" characteristics to heredity. This in turn led to the misguided theory that humanity could be perfected by encouraging offspring for "the fit"<sup>6</sup> and discouraging or prohibiting reproduction by "the unfit."<sup>7</sup> This dangerous distortion of Darwin's insights led to the eugenics movement,<sup>8</sup> which legitimized atrocities like the

---

**Paul Steven Miller, J.D.**, is the Henry M. Jackson Professor of Law; Director of the Disability Studies Program at the University of Washington School of Law; and former Commissioner at the U.S. Equal Employment Opportunity Commission.

forced sterilization of convicted felons and the mentally ill<sup>9</sup> and fueled the anti-immigrant sentiments of the early 20th century.<sup>10</sup>

Scientific advances never exist in a vacuum and must always be viewed through a social, ethical, legal, and political prism. Darwin's theories preceded and accompanied an unprecedented wave of immigration to America from Southern and Eastern Europe.<sup>11</sup> Not entirely unlike today, there was a backlash against these new immigrants that manifested itself in a variety of anti-immigrant groups and movements.<sup>12</sup>

### *Buck v. Bell*

The U.S. Supreme Court legitimized state-sponsored sterilization in the name of eugenics in its landmark decision of *Buck v. Bell*.<sup>13</sup> Carrie Buck was sent to the State Colony of Epileptics and the Feeble-Minded in Virginia to have a child conceived when she was raped by the nephew of her foster parents. At that time, Virginia permitted sexual sterilization when it was determined that a patient or "inmate" was afflicted with hereditary forms of insanity or imbecility.<sup>14</sup> The authors of the law designed it to prevent the reproduction of "mentally defective" people in the best interest of the patient and society.<sup>15</sup> Buck was ordered sterilized against her will. Dr. Albert Priddy (Superintendent of the State Colony for Epileptics and Feeble-Minded) and Aubrey Strode (counsel for the State Colony and drafter of Virginia's sterilization law) chose Buck as the test case for the new law. Buck's guardian originally appealed the sterilization order upon the request of both men.<sup>16</sup> In its case, the State of Virginia simply analogized the forced sterilization to compulsory vaccinations.<sup>17</sup>

In 1927, the U.S. Supreme Court in *Buck v. Bell*<sup>18</sup> dismissed Buck's concerns. An employee of the Eugenics Record Office,<sup>19</sup> Harry Laughlin,<sup>20</sup> studied Buck's medical records and concluded that she exemplified the "shiftless, ignorant, and worthless class of anti-social whites in the South."<sup>21</sup> Despite her appeals to the highest court in the land, Carrie Buck could not be spared from the cruelest corruption of Darwin's theories.

The Court emphasized that Carrie Buck was the daughter of a "feeble-minded" mother and the mother of an "illegitimate" feeble-minded daughter. Justice Oliver Wendell Holmes wrote in the opinion,

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>22</sup>

Years later in 1979, researchers determined that Carrie Buck, her sister, Doris, who was also sterilized, and her daughter, Vivian, all possessed standard intelligence.<sup>23</sup> According to one report, this brand of pseudoscience permitted the forcible sterilization of 60,000 Americans in the 40 years after *Buck v. Bell*.<sup>24</sup>

### **Genetic Discrimination in the Workplace**

As the science of genetics explodes and the technology becomes more accessible, the issue of how society protects its workers from the misuse of genetic information becomes more important. Those poised to profit from the profound and estimable benefits of the genetic revolution must be keenly aware of the myriad ethical and policy concerns accompanying this new scientific frontier. Many share the fear that employers will attempt to exclude qualified workers from employment due to real or perceived genetic predispositions.<sup>25</sup>

Broadly, the policy questions follow. Should an employer have access to this genetic information? Should the employer know a person's genetic information even if that person chooses not to know it? Where should the line be drawn between legitimate concerns about occupational safety and an individual's fundamental rights of privacy and self-determination? Should an employer be able to participate in, or influence these most personal questions and issues? What protections do employees have to ensure that their genetic information will not be misused?

The potential for genetic discrimination is real and no longer just the stuff of science fiction.<sup>26</sup> For purposes of this article, genetic discrimination is defined as an employer taking an adverse employment action based upon an asymptomatic, genetic predisposition to a disease or medical condition; essentially, the increasing ability, due to advances in genetics, of predicting who may become ill in the future. Most genetic markers cannot predict that an individual will get sick, only that there is a greater likelihood that he or she will actually fall ill.<sup>27</sup> It is important to keep in mind that our genes are only one part of our destiny. While employers can learn an employee's genetic information through genetic testing, disclosure can also be made through company medical exams, family medical history information, and medical records.<sup>28</sup> The problem is not simply one of the genetic testing procedures; rather, it is the use of asymptomatic, predictive genetic information.

It is difficult to know precisely how prevalent is the use of genetic testing in the workplace. Studies and arti-

cles provide anecdotal evidence of instances of genetic discrimination.<sup>29</sup> However, there is a lack of empirical evidence measuring the extent to which, or for what purposes, employers presently seek genetic information about their employees or applicants. Empirical research is needed to document the type of genetic testing that is currently being conducted, if any; the ways in which predictive, genetic information may be collected by employers; and to furnish a better understanding of the actual scope of the genetic discrimination problem. Even if the evidence does not point to a widespread problem today, as the cost of genetic testing decreases and the practice becomes more commonplace, the potential for real discrimination dramatically increases. Thus, concerns about genetic discrimination are not unwarranted or alarmist.

That said, the mere fear of discrimination may cause reluctance in taking advantage of the growing array of genetic tests that can identify vulnerability to specific diseases. Craig Venter, the pioneering genetic scientist, has said that the fear of the misuse of genetic information by employers and insurers is the most significant barrier to genetic advances – greater than the inherent pitfalls that mark the journey to scientific discovery.<sup>30</sup>

Legal protections are essential so that scientific breakthroughs are realized, privacy is preserved, and the workplace remains free from discrimination. Moreover, the law provides a uniform standard of conduct regarding the use of genetic information in the workplace. Genetic discrimination is a new application of an old violation of the law. The entire body of American workplace anti-discrimination law is built upon the premise that applicants and employees must be selected and evaluated based upon their ability to do the job, and not upon the myths, fears, and stereotypes about a person due to his or her race,<sup>31</sup> ethnicity,<sup>32</sup> gender,<sup>33</sup> age,<sup>34</sup> religion,<sup>35</sup> or disability.<sup>36</sup> Society now faces the question of whether employers should be able to consider genetic predisposition information in making employment decisions, and if so, how the law should protect workers from the misuse of such information.

### The Civil Rights Model

The Americans with Disabilities Act (ADA),<sup>37</sup> which prohibits disability discrimination in employment, defines a protected disabled individual as a person (1) with a physical or mental impairment that substantially limits one or more major life activities, such as walking, eating, seeing, or working; (2) with a record of having such an impairment; or (3) who is regarded as having such an impairment. Nowhere does the Act explicitly address the issue of genetic discrimination.

Even so, the ADA covers individuals with a manifested genetically-related illness or disability, assuming it substantially limits a major life activity.<sup>38</sup> Similarly, the ADA covers individuals with a prior record of a genetically-related disability such as a cancer survivor.<sup>39</sup> The more challenging question is whether the ADA prohibits discrimination based on a diagnosed, but asymptomatic, genetic condition that does not substantially limit a major life activity.

In 1995, the U.S. Equal Employment Opportunity Commission (EEOC), the federal agency charged with enforcing the employment title of the ADA, adopted the view that the ADA prohibits discrimination against workers based on their genetic makeup.<sup>40</sup> Though lacking the force of law, the EEOC's policy explicitly states that discrimination on the basis of genetic information is covered under the third prong of the definition of the term "disability," which covers individuals regarded as having impairments.<sup>41</sup> This part of the statute is designed to protect against prejudices and misconceptions about disability and reflects a recognition by Congress that the reactions of others to an impairment or a perceived impairment can be just as disabling as the limitations caused by an actual and substantially limiting impairment. Genetic predisposition discrimination is exactly the kind of situation Congress must have intended to be covered by the "regarded as" prong of the definition of disability.

### Pending Genetic Discrimination Legislation

The EEOC's legal theory has never been tested in the courts. Notwithstanding the EEOC's legal arguments for ADA coverage of asymptomatic genetic conditions, some are concerned that courts will find that the ADA does not cover genetic predisposition discrimination.<sup>42</sup> Others believe that genetic discrimination is so different from traditional disability discrimination that the ADA does not provide a satisfactory framework.<sup>43</sup> However, the principle of genetic non-discrimination in employment enjoys wide bipartisan support.<sup>44</sup>

Legislation which specifically prohibits discrimination on the basis of genetic information by employers has been introduced in Congress both by Republican and Democratic members.<sup>45</sup> The Senate approved a bill in February 2005 which prohibits discrimination based on genetic information regarding both health insurance and employment.<sup>46</sup> Moreover, President Bush has expressed his support for genetic discrimination legislation.<sup>47</sup>

In addition to federal law, 34 states have enacted laws that, in one form or another, prohibit the use of genetic information in the workplace.<sup>48</sup> These laws vary widely in form and breadth.<sup>49</sup>

It is important to note that no genetic employment discrimination case has ever been decided, either in federal or state court. Indeed, there have only been a few charges of discrimination filed with the EEOC or the companion state agencies alleging genetic discrimination.<sup>50</sup> However, in 2002, the EEOC filed a lawsuit against the Burlington Northern and Santa Fe Railroad, alleging genetic employment discrimination.<sup>51</sup> The theory of the EEOC's suit was that the alleged genetic discrimination violated the ADA.<sup>52</sup> As it was settled without a trial on the merits, no court ruled on the applicability of the theory.

The facts of the case are simple.<sup>53</sup> The EEOC alleged that Burlington Northern, or BNSF, subjected its employees to surreptitious genetic testing. BNSF was testing to identify a genetic marker for carpal tunnel syndrome to address a high incidence of repetitive stress injuries among its employees. The EEOC further alleged that at least one employee was threatened with discipline and possible termination for refusing to take the genetic test once it was discovered.

Shortly after filing the case, the EEOC and Burlington Northern announced a mediated settlement in the amount of \$2.2 million.<sup>54</sup> The railroad also agreed to halt any genetic testing that may have been occurring at the company. While the result was overwhelmingly positive in that the EEOC achieved everything it sought in its lawsuit, by resolving the lawsuit informally, it was never necessary for the court to rule on the applicability of the ADA to the circumstances underlying the workers' complaints.

What was particularly interesting about the Burlington Northern case was that no one, not the business community, the employer groups, the scientists, the press, the politicians, nor even the talking heads on cable news programs thought that the surreptitious genetic testing of employees and adverse actions against those who had the "wrong genetic marker" should have been allowed.

## Conclusion

With advances in genetic technology, we will soon realize that everyone has genetic predispositions for one genetic condition or another. Mapping the human genome changes the way we understand who is "normal" and who is "disabled." If we all have genetic misspellings, how do we define who is healthy and who is not? If we all have genetic conditions that are just waiting to express themselves in the future, aren't we all truly disabled? As we will all have knowledge of the potential genetic disorder that we each harbor, disabled people may no longer remain stigmatized as "the other" in society.

It is important to note that genetic mutations are not themselves all bad – even those that cause a disorder. The same genetic code that causes sickle cell anemia when inherited from both parents also confers immunity to malaria when inherited from only one.<sup>55</sup> In the past, biological imperatives determined the importance of particular genetic mutations. People either survived to pass on their genes to their children or they did not. Because of advances in medical care and in our understanding of the mechanics of heredity, biological imperatives are less important. It is society that imparts value to genetic diversity, and until now, society has generally assigned a negative value to those mutations which in their expression diverge from the norm, however defined. What about those hidden markers that we will now learn each of us harbors? Are we going to be willing to allow employers to assign a negative value to such genetic markers even if they have no effect on one's ability to do a job? Such actions should be called illegal discrimination.

## References

1. J. D. Watson and F. H. C. Crick, "Molecular Structure of Nucleic Acids: A Structure for Deoxyribose Nucleic Acid," *Nature* 171 (1953): 737-738.
2. N. Wade, "DNA, the Keeper of Life's Secrets, Starts to Talk," *New York Times*, February 3, 2003.
3. See C. Darwin, *The Origin of Species by Natural Selection; or, the Preservation of Favored Races in the Struggle for Life* (London: John Murray, 1859); C. Darwin, *The Descent of Man, and Selection in Relation to Sex* (London: John Murray, 1871).
4. See *infra* notes 6 and 7.
5. *Id.*
6. Francis Galton, an English scientist, advocated the theory that the best and brightest people would produce the best and brightest offspring. He coined the term "eugenics" (meaning well-born), and his views on heredity and breeding became known as "positive eugenics." E. Carlson, "Scientific Origins of Eugenics," *Eugenics Archive*, available at <<http://www.eugenicsarchive.org/eugenics/list3.pl>> (follow "Scientific Origins" hyperlink) (last visited March 5, 2007).
7. In the United States, "negative eugenics" took root. Negative eugenics assumed that by preventing people with "undesirable" traits from breeding, the human gene pool would be enhanced because these traits could be purged from human stock. *Id.*
8. Francis Galton was Charles Darwin's cousin. He believed that Darwin's theories could help create a better race of people, stating, "what Nature does blindly, slowly, and ruthlessly, man may do providently, quickly, and kindly." D. Kevles, *In the Name of Eugenics* (New York: Alfred A. Knopf, 1985): at 12.
9. See generally P. Lombardo, "Eugenic Sterilization Laws," *Eugenics Archive*, available at <<http://www.eugenicsarchive.org/eugenics/list3.pl>> (follow "Sterilization Laws" hyperlink) (last visited March 5, 2007).
10. In 1920, Congress began working on a bill to restrict immigration of eastern European immigrants. The chairman of the House Committee on Immigration and Naturalization appointed an employee of the Eugenics Record Office to study recent immigrants who were confined in state institutions. The employee, Harry Laughlin, later testified falsely that most inmates were recent immigrants or the children of immigrants and concluded that these people threatened the eugenic health of the nation. In 1924, Congress passed an immigration law which limited the number of immigrants from European coun-

- tries to "a small percentage of the foreign-born of the same national origin recorded in the census of 1890." Congressman Robert Allen, Democrat from West Virginia, stated, "The primary reason for the restriction of the alien stream...is the necessity for purifying and keeping pure the blood of America." It should also be noted that former President Calvin Coolidge, who signed the bill into law, stated when he was vice president that "America must be kept American. Biological laws show...that Nordics deteriorate when mixed with other races." See Kevles, *supra* note 8, at 97-103.
11. C. J. Ogltree, Jr., "America's Schizophrenic Immigration Policy: Race, Class, and Reason," *Boston College Law Review* 41 (2000): 755-770, at 759.
  12. See generally I. Scharf, "Tired of Your Masses: A History of and Judicial Responses to Early 20th Century Anti-Immigrant Legislation," *University of Hawaii Law Review* 21 (1999): 131-167.
  13. *Buck v. Bell*, 274 U.S. 200 (1927).
  14. Virginia Sterilization Act, 1924 Va. Acts ch. 394.
  15. *Id.*
  16. R. J. Cynkar, "Buck v. Bell: 'Felt Necessities' v. Fundamental Values?" *Columbia Law Review* 81 (1981): 1418-1461, at 1457.
  17. S. Polirstok, "Buck v. Bell: A Case Study," *Binghamton Journal of History*, available at <<http://history.binghamton.edu/resources/bjoh/BuckvsBell.htm>> (last visited March 5, 2007).
  18. *Buck v. Bell*, 274 U.S. 200 (1927).
  19. The Eugenics Record Office (ERO) was the brainchild of Charles B. Davenport, a leading eugenics advocate in the early 20th century. Initially, Mrs. E. H. Harriman, who managed her late husband's railroad fortune, bankrolled the project. After Harriman founded the ERO, Davenport wrote to her, "What a fire you have kindled! It is going to be a purifying conflagration some day!" (emphasis in original). Later, the Carnegie Institute of Washington financially supported the ERO. Students of the ERO catalogued the backgrounds of various groups, such as albinos, the feeble-minded, and the insane. Their reports were used for such things as reports to legislative committees. See Kevles, *supra* note 8, at 54-56.
  20. Harry Laughlin was superintendent of the Eugenics Record Office. After dabbling in eugenics studies, he went on to receive a doctorate of science from Princeton University. Laughlin worked on such eugenic projects as attempting to prove that the number of immigrants in institutions for the feeble-minded and insane were recent immigrants. See Kevles, *supra* note 8, at 102-103.
  21. This quotation has been variously attributed to both Harry Laughlin (see S. J. Gould, "Carrie Buck's Daughter: A Popular Quasi-Scientific Idea Can Be a Powerful Tool for Injustice (This View of Life)," *Natural History*, July-August, available at <[http://www.findarticles.com/p/article/mi\\_m1134/is\\_6\\_111/ai\\_87854861](http://www.findarticles.com/p/article/mi_m1134/is_6_111/ai_87854861)> [last visited January 9, 2007]) and Dr. Albert Priddy, Superintendent of the Virginia Colony for Epileptics and Feeble Minded (see D. Micklos, "None Without Hope: Buck vs. Bell at 75," *Gene Almanac*, available at <<http://karmak.org/archive/2004/06/buckvbell.html>> [last visited March 5, 2007]). As both men were supporters of eugenics practices, it is not surprising that either man would make that statement.
  22. *Buck v. Bell*, 274 U.S. 200, 207 (1927).
  23. See Gould, *supra* note 21.
  24. P. Quinn, "Race Cleansing in America," *American Heritage* magazine, February-March 2003: 34-43, at 35, available at <<http://www.libarts.ucok.edu/history/faculty/roberson/course/1493/readings/1493.Race%20Cleansing%20in%20America.%202003.htm>> (last visited March 5, 2007).
  25. See K. M. Gatter, "Genetic Information and the Importance of Context: Implications for the Social Meaning of Genetic Information and Individual Identity," *St. Louis University Law Journal* 47 (2003): 423-462, at 427; R. A. Curley, Jr., and L. M. Caperna, "The Brave New World Is Here: Privacy Issues and the Human Genome Project," *Defense Counsel Journal* 70 (2003): 22-35, at 29.
  26. See D. Stipp, "The Prince of Nucleotides," *Fortune*, October 27, 2002.
  27. See *infra* notes 51-55.
  28. See generally J. Husted and J. Goldman, "Medical and Genetic Privacy in the Workplace: The Gaps in Existing Laws," *The Health Privacy Project*, March 2002.
  29. See P. R. Billings et al., "Discrimination as a Consequence of Genetic Testing," *American Journal of Human Genetics* 50 (1992): 476-482, at 476 (describing anecdotal evidence of discrimination against individuals based on "apparent or perceived" genetic abnormalities).
  30. See Prepared Witness Testimony, available at <<http://energycommerce.house.gov/107/hearings/07112001Hearing322/Venter520.htm>> (last visited January 9, 2007).
  31. Civil Rights Act of 1991, Pub. L. No. 102-166, 105 Stat. 1071.
  32. *Id.*
  33. *Id.*
  34. Age Discrimination in Employment Act of 1967, 29 U.S.C. § 621.
  35. See Civil Rights Act of 1991, *supra* note 31.
  36. Americans with Disabilities Act of 1990, Pub. L. No. 101-336, 104 Stat. 327.
  37. *Id.*
  38. See *Berk v. Bates Broadcasting USA*, 1997 WL 749386, at \*5 (S.D.N.Y. Dec. 3, 1997).
  39. *Id.*
  40. See 2 U.S. EEOC, Compliance Manual, Order 915.022, at 902-45 (1995). In these guidelines, the EEOC provides an example of how genetic discrimination may occur. "CP's (Charging Party's) genetic profile reveals an increased susceptibility to colon cancer. CP is currently asymptomatic and may never in fact develop colon cancer. After making CP a conditional offer of employment, R (Respondent) learns about CP's increased susceptibility to colon cancer. R then withdraws the job offer because of concerns about matters such as CP's productivity, insurance costs, and attendance. R is treating CP as having an impairment that substantially limits a major life activity. Accordingly, CP is covered by the third part of the definition of 'disability.'"
  41. *Id.*
  42. See J. Weems, "A Proposal for a Federal Genetic Privacy Act," *Journal of Legal Medicine* 24 (2003): 109-126, at 114; Curley and Caperna, *supra* note 25, at 30.
  43. See Senator Enzi's Remarks on Genetic Information Amendment, available at <<http://enzi.senate.gov/genetic.htm>> (last visited March 5, 2007).
  44. F. Johnson, "Bipartisan Genetic Bias Bill Clears Committee on Voice Vote," *Daily Labor Report*, May 22, 2003, at AA-1.
  45. Genetic Information Non-Discrimination Act of 2005, H.R. 1227, 109th Cong. 2005 and Genetic Information Non-Discrimination Act of 2005, S. 306, 109th Cong. (2005).
  46. Genetic Information Non-Discrimination Act of 2005, S. 306, 109th Cong. (2005).
  47. G. W. Bush, Radio Address by the President to the Nation, available at <<http://www.whitehouse.gov/news/releases/2001/06/20010623.html>> (last visited March 5, 2007).
  48. See "State Genetics Employment Laws Database," *National Conference of State Legislators*, available at <<http://www.ncsl.org/programs/health/genetics/ndiscrim.htm>> (last visited March 5, 2007).
  49. *Id.*
  50. See S. Jones, "The DNA Dilemma," *The News and Observer*, October 22, 2000, at E1 (discussing the case of *Seargent v. Hanover Excess & Surplus*, in which a woman alleged she was fired because of a genetic lung condition).
  51. Agreed Order, *Equal Employment Opportunity Comm'n v. The Burlington Northern and Santa Fe Ry. Co.*, (No.02-C-0456).
  52. Complaint, *Equal Employment Opportunity Comm'n v. The Burlington Northern and Santa Fe Ry. Co.*, (No. 02-C-0456).
  53. *Id.*
  54. See Agreed Order, *supra* note 51.
  55. A. Flynn, "Racial Disparities in the Allocation of Stem Cells," *DePaul Journal of Health Care Law* 6 (2002): 179-200, at 187.