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Past as Prologue: Sobering Thoughts on Genetic Enthusiasm

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Racism, prejudice, and genetics have made for a socially combustible and often deadly mix. The mixture has proven so toxic that a strong case can be made that applying knowledge from the realm of human genetics to public policy has led to far more misery, confusion, and suffering in the twentieth century than it has to human betterment.¹

At the beginning of the twentieth century, scientists and lawyers—and the doctrines of science and law—made inappropriate use of genetics. Now, at the dawn of the twenty-first century, genetics has reappeared as a medical and social panacea. Yet the scientific and policy communities have not taken to heart the lessons of the past and are repeating some of the same mistakes. As a century earlier, the science of genetics is being oversold and used for political purposes. Even well-meaning genetics programs are creating unwarranted risks because they are being adopted prematurely, without sufficient concern for their psychological and social impact, and in a way that further disadvantages the least powerful groups in society.

I. HISTORICAL MISUSE OF GENETICS IN THE UNITED STATES

Both science and law have taken a number of false turns in their assessment and use of genetic information. In the late 1800s, a majority of the geneticists in this country believed that one could extend genetic principles to explain human behavior.² Traits such as feeble-mindedness,³

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¹ Arthur L. Caplan, *Handle with Care: Race, Class, and Genetics*, in *JUSTICE AND THE HUMAN GENOME PROJECT* 30-45, 32-33 (Timothy F. Murphy & Marc A. Lappe eds., 1994).

² See generally KENNETH M. LUDMERER, *GENETICS AND AMERICAN SOCIETY* (1972).

³ See Jon Beckwith, *Social and Political Uses of Genetics in the United States: Past and Present*, in *ANNALS N.Y. ACADEMY OF SCIENCES* 46, 47, 265 (1976) (citation omitted).

criminality,⁴ pauperism,⁵ prostitution,⁶ and seafaringness,⁷ were thought to be single gene defects. In fact, seafaringness was thought to be an X-linked trait because it affected only men.⁸ People began to make private choices about whom to marry on genetic grounds, to avoid having a child with a disfavored trait.⁹ In 1910, a Eugenic Records Office was established in Cold Spring Harbor, New York which trained field workers to collect family histories from people around the country.¹⁰ By 1924, data on people had been entered on around three quarters of a million cards and people made inquiries to the office about whether particular proposed marriages would be eugenically appropriate.¹¹

Genetic theories quickly served as the basis for proposals for social and legal reform. The prime thrust of the reforms was to prevent people with presumably undesirable genes from reproducing. The Chairman of the Department of Psychology at Harvard University advocated "the replacement of democracy by a caste system based upon biological capacity with legal restrictions upon breeding by the lower castes and upon intermarriage between the castes."¹² Federal and state legislatures took the teaching of genetics to heart. They passed laws to prevent people with presumably undesirable genes from reproducing,¹³ on the grounds that the care of the unfit (such as the mentally disabled) was draining society's resources.¹⁴

The policy argument in favor of sterilization of the feebleminded and criminals was that those individuals cost the rest of society money. In the 1870s, state governments had provided extensive funding for institutions for the care of the feebleminded, but subsequently they began reassessing this expenditure.¹⁵ In its press for mandatory sterilization laws, the American Eugenics Society pointed out that the descendants of one

⁴ See *id.* at 48; DANIEL KEVLES, *IN THE NAME OF EUGENICS: GENETICS AND THE USES OF HUMAN HEREDITY* 100 (1985).

⁵ See Philip Reilly, *Eugenic Sterilization in the United States*, in *GENETICS AND THE LAW* III 227, 227 (Aubrey Milunsky & George J. Annas eds., 1985).

⁶ See KEVLES, *supra* note 4, at 53, 101.

⁷ See Beckwith, *supra* note 3, at 47; see also KEVLES, *supra* note 4, at 46.

⁸ See Daniel 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 9* (Daniel J. Kevles & Leroy Hood eds., 1992) [hereinafter *THE CODE OF CODES*] (citation omitted).

⁹ See LORI ANDREWS, *MEDICAL GENETICS: A LEGAL FRONTIER* 12 (1987).

¹⁰ See KEVLES, *supra* note 4, at 54.

¹¹ See *id.* at 56.

¹² Beckwith, *supra* note 3, at 48 (citation omitted).

¹³ See ANDREWS, *supra* note 9, at 12.

¹⁴ See *id.* at 13.

¹⁵ See Reilly, *supra* note 5, at 228.

allegedly genetically inferior pauper couple—the Jukes—had cost the State of New York \$2,000,000, but that it would have only cost \$150 to sterilize the original Jukes pair.¹⁶ At a time when attention was focused on gangsters, the American Eugenics Society told the public that crime, a function of hereditary defects, was costing the average family \$500 annually.¹⁷ In the 1920s, county fairs exhibited a display that

revealed with flashing lights that every fifteen seconds a hundred dollars of your money went for the care of persons with bad heredity, that every forty-eight seconds a mentally deficient person was born in the United States, and that only every seven and a half minutes did the United States enjoy the birth of “a high grade person . . . who will have the ability to do creative work and be fit for leadership.”¹⁸

The first eugenics law, enacted in Indiana in 1907, provided for the involuntary sterilization of institutionalized, unimprovable individuals who were idiots, imbeciles, rapists, or habitual criminals.¹⁹ By the end of the next decade, other states had followed suit.²⁰ Over 60,000 people were sterilized under those laws.²¹ In Germany, the Nazis modeled their sterilization law after the American model.²² And the German example was used by some American eugenicists in an attempt to spur on United States lawmakers. In 1934, a doctor tried to get the Virginia legislature to broaden its sterilization law, stating: “The Germans are beating us at our own game.”²³

The Nazi misuse of sterilization did not dampen the American program. In a study of sterilization laws and their implementation, Philip Reilly found that “more than one half of all eugenic sterilizations [in the United States] occurred after the Nazi program was fully operational.”²⁴ These laws had public support. According to a 1937 *Fortune* poll, 66% of the public favored involuntary sterilization of the mentally retarded

¹⁶ See KEVLES, *supra* note 4, at 93.

¹⁷ See *id.* at 72-73.

¹⁸ *Id.* at 62.

¹⁹ See Reilly, *supra* note 5, at 230.

²⁰ See *id.* at 231.

²¹ See PHILIP REILLY, *THE SURGICAL SOLUTION* 94 (1991).

²² In 1923, Boeters, the leading eugenics advocate in Germany, had acknowledged the American influence: “What we racial hygienicists promote is not at all new or unheard of. In a cultured nation of the first order, in the United States of America, that which we strive toward was introduced and tested long ago.” Beckwith, *supra* note 3, at 49. In 1936, Harry Laughlin, the head of the Eugenics Records Office in the United States, enthusiastically accepted an honorary doctorate from Heidelberg University for his critical role in shaping the law that was the model for the Germans. See Garland A. Allen, *The Eugenics Age Revisited*, *TECH. REV.* 23-31, 26 (Aug./Sept. 1996).

²³ Reilly, *supra* note 5, at 228.

²⁴ *Id.* at 227, 235.

and 63% favored sterilization of habitual criminals.²⁵ Upholding a law allowing sterilization of feeble-minded institutionalized individuals, Justice Holmes wrote his famous line: "Three generations of imbeciles are enough."²⁶ Emphasizing the fiscal concerns, Justice Holmes indicated that sterilizing Carrie Buck might mean that if she were returned to society she would not be a "menace," but would be "self-supporting."²⁷

The scientific beliefs in the predictive power of genetics and the dangers caused by creating individuals with poor genes rapidly became woven into the fabric of society. Enlightened political figures such as Theodore Roosevelt²⁸ and feminist Margaret Sanger²⁹ believed in the eugenics effort. Genetic beliefs found support on both ends of the political spectrum—the radicals and conservatives³⁰—as well as with some religious leaders. Protestant ministers and Jewish rabbis preached about eugenics and even entered into a eugenic sermon competition.³¹ The eugenic movement captured the public's imagination and spirit. Between 1910 and 1914, the *Reader's Guide to Periodical Literature* listed 122 popular press magazine articles on eugenics, "making it one of the most referenced subjects in the index."³² There were more magazine articles on eugenics than on slums, tenements, and living standards combined.³³ Best-selling books about eugenics abounded,³⁴ including one that preached: "Do unto both the born and unborn what you would have both the born and unborn do unto you."³⁵ Most colleges offered courses in eugenics or genetics.³⁶ In 1914, F. Scott Fitzgerald, then a Princeton undergraduate, wrote the song "Love or Eugenics."³⁷

Today, we are once again at a point in history where there is a strong individual and public interest in genetics—and where fiscal con-

²⁵ KEVLES, *supra* note 4, at 114.

²⁶ *Buck v. Bell*, 274 U.S. 200, 207 (1927).

²⁷ *Id.*

²⁸ See Reilly, *supra* note 5, at 231.

²⁹ See Beckwith, *supra* note 3, at 48. Sanger wrote "more children for the fit, less from the unfit—that is the chief issue of birth control." *Id.*; see also LINDA GORDON, *WOMAN'S BODY, WOMAN'S RIGHT: A SOCIAL HISTORY OF BIRTH CONTROL IN AMERICA* 281-82 (1976).

³⁰ See KEVLES, *supra* note 4, at 63.

³¹ See *id.* at 61. One rabbi told his congregation, "May we do nothing to permit our blood to be adulterated by infusion of blood of inferior grade." *Id.*

³² Reilly, *supra* note 5, at 228.

³³ See KEVLES, *supra* note 4, at 312 n.5 (citing JOHN HIGHAM, *STRANGERS IN THE LAND: PATTERNS OF AMERICAN NATIVISM—1860-1925* 150-51 (1963)).

³⁴ See *id.* at 58.

³⁵ *Id.* at 59 (citing ALBERT E. WIGGAM, *THE NEW DECALOGUE OF SCIENCE* (1923)).

³⁶ See *id.* at 69.

³⁷ *Id.* at 58.

cerns are ruling medicine. To a great extent, it will be the law that will be the caretaker of our values as we decide upon the proper uses of genetic technologies. To determine the role that law should play in this endeavor, it is useful to analyze the parallels between the earlier uses of genetics and those of today.

II. GENETIC HUCKSTERISM—THEN AND NOW

A century ago, scientists purported to find a genetic basis for a vast array of social conditions such as pauperism, prostitution, criminality and certain forms of industrial sabotage.³⁸ They were so convinced of the explanatory power of genetics that, in some instances, they misrepresented their data to underscore their beliefs.³⁹ H.H. Goddard, the director of research at the Vineland Training School for Feeble-Minded Girls and Boys in New Jersey, argued that IQ was the chief determinant of moral conduct⁴⁰ and that people with mental ages between eight and twelve should be institutionalized and prevented from breeding.⁴¹ He supported his argument by publishing a "study" of a family that he gave the fictionalized name of Kallikaks, from the Greek word for beauty (kallos) and bad (kakos).⁴² Goddard's book described the descendants of Martin Kallikak. Martin's liaison with a purportedly feeble-minded tavern wench supposedly led to descendants who were feeble-minded paupers and vagrants living in the pine woods,⁴³ while the same man's descendants with his worthy Quakeress wife purportedly produced descendants who were upstanding citizens.⁴⁴ How did Goddard determine the relative traits of the two families? The assistant he sent to interview the branch of the family in the pine woods looked at the strong, healthy father and classified him as sitting helplessly in the corner, saw the children in their scanty clothes and worn-out shoes and found them to have the "unmistakable look of the feeble-minded."⁴⁵ To persuade readers of the study of the accuracy of these conclusions, Goddard's book included photos of the pine woods relatives that were doctored by inserting heavy dark lines to give their eyes and mouths a more retarded, evil look.⁴⁶

³⁸ See Allen, *supra* note 22, at 25.

³⁹ For example, Cyril Burt fabricated intelligence testing data in identical twins. See STEPHEN JAY GOULD, *THE MISMEASURE OF MAN* 27 (1981).

⁴⁰ Like other eugenicists, H.H. Goddard believed that morality was linked to intelligence. See *id.* at 160.

⁴¹ See *id.*

⁴² See *id.* at 168.

⁴³ See *id.*

⁴⁴ See GOULD, *supra* note 39, at 168.

⁴⁵ *Id.* at 169.

⁴⁶ See *id.* at 171, 173.

Today's geneticists reject the earlier genetic assessments as due to poor science, and insist that their own analysis is credible. But the incentives today (obtaining scientific prizes and funding, legitimating the social status quo) are much the same as before, and the results look strikingly similar. Genetics is again being oversold, as an explanation for everything from infidelity to homelessness. As an article in *Science* pointed out, "Today the *Archives of Genetic Psychiatry* is filled with the claims that heredity plays a role in everything from gregariousness and general cognitive ability to alcoholism and manic-depression."⁴⁷ Yet the "sighting" of genes for complex traits such as manic-depression, schizophrenia, and alcoholism have often been followed by retractions.⁴⁸ Just one week before this conference, the claim that there is a gene for novelty-seeking was dealt a blow when a subsequent study failed to replicate the finding. And, as has happened in the past, there have been contemporary examples of fraud in genetic claims.⁴⁹ Also, a week before the conference, researchers at the National Institutes of Health (NIH)—National Center for Human Genome Research (NCHGR) had to retract substantial portions of five published articles about the genetics of leukemia because a researcher had falsified the data.⁵⁰

The Human Genome Project itself has been oversold. It is a federally-funded \$3 billion, fifteen-year effort to map (that is, determine the location of) and sequence (analyze the constituent parts of) each of the 50,000 to 100,000 genes in the human cell. Congress was convinced to fund it on the promise that it would lead to diagnosis and cure of genetic disease. But, even if completed on time and as promised, mapping and sequencing will not provide information about diseases and their cures. The director of NCHGR himself has noted, "We will then face the chal-

⁴⁷ Charles C. Mann, *Behavioral Genetics in Transition*, 264 SCI. 1686, 1686 (1994). Recent research claims to have found a genetic disposition for pathological gambling. See Ted Gregory, *Researcher's Theory Criticized: Doctor Proposes Genetic Link to Gambling*, CHI. TRIB., Sept. 4, 1996, § 2, at 8.

⁴⁸ For a discussion of the numerous failures to replicate researchers' genetic linkage of common neuropsychiatric disorders (such as schizophrenia, manic-depression, and Alzheimer's disease), see Neil Risch, *Genetic Linkage and Complex Diseases, with Special Reference to Psychiatric Disorders*, 7 GENETIC EPIDEMIOLOGY 3-16 (1990). Risch points out that "there are fundamental differences between the rare, Mendelian disorders and the common 'complex' familial disorders, both in terms of conceptualizing and approaches to analysis, that need to be addressed before significant progress can be made in understanding the 'complex' diseases." *Id.* at 4; see also Eliot Marshall, *Highs and Lows on the Research Roller Coaster*, 264 SCI. 1693-95 (1994); Steven Rose, *The Rise of Neurogenetic Determinism*, 373 NATURE 380-82 (1995).

⁴⁹ See, e.g., Natalie Angier, *Maybe It's Not a Gene Behind a Person's Thrill-Seeking Ways*, N.Y. TIMES, Nov. 1, 1996, at A22.

⁵⁰ See Lawrence K. Altman, *Falsified Data Found in Gene Studies*, N.Y. TIMES, Oct. 30, 1996, at A12.

lenge of understanding what the 'instructions' encoded in human DNA mean; in other words, how the genes function."⁵¹ Even once further efforts are undertaken to determine which genes are linked to which diseases, genes will explain far less about human disease than the fanfare about genetics would have one believe. For example, only 5 to 10% of women with breast cancer have a hereditary form of the disease.⁵² Evelyn Fox Keller points out, "Even though, in actuality, genetics remains of quite limited practical relevance to the healing arts, the concept of disease—now extended throughout the domain of human behavior—has increasingly come to be understood by health scientists in terms of genetics."⁵³

Geneticist Benno Müller-Hill challenges the hubris with which contemporary geneticists approach the genetic underpinnings of disease:

Let us assume that a gene is isolated that predisposes for schizophrenia. . . . Does this mean that we will understand schizophrenia if we know that it often occurs in people with a certain ion channel or a certain enzyme is damaged? Many scientists would answer in the affirmative, but I would like to say, emphatically, that the answer is no. Understanding a biochemical defect brings us no nearer to the thoughts and actions of the schizophrenic.⁵⁴

In addition, a defect at the genetic level does not necessarily translate to a disease at the level of the person. Even if a genetic mutation is predictive of a disease, it does not indicate when the person will get the disease or how severe the symptoms will be. When the gene for cystic fibrosis was identified, some geneticists advocated screening couples who were planning to have children, and undertaking amniocentesis on the fetuses of carrier-carrier couples, so that the couples could avoid the birth of children who had cystic fibrosis.⁵⁵ It was subsequently learned the

⁵¹ *Technological Advances in Genetic Testing: Implications for the Future Before the Subcomm. on Technology*, Sept. 17, 1996, available in LEXIS, News Library, CURNWS File (statement of Francis Collins before the House Science Committee).

⁵² *See generally Scientists Report New Lead in the Genetics of Breast Cancer*, NIH NEWS, Sept. 28, 1995.

⁵³ Evelyn Fox Keller, *Nature, Nurture and the Human Genome Project*, in *THE CODE OF CODES*, *supra* note 8, at 292.

⁵⁴ Benno Müller-Hill, *The Shadow of Genetic Injustice*, 362 NATURE 491, 492 (1993). Müller-Hill additionally points out:

Although the molecular-genetic approach will certainly lead to a frenzy of new drugs on the market, in the end the suffering of patients will be helped only partially. . . . It is so much easier to prescribe a pill than to change the social conditions that may be responsible for the severity of symptoms.

Id.

⁵⁵ *See* D. Brock, *Population Screening for Cystic Fibrosis*, 47 AM. J. HUM. GENET. 164-65 (1990); P.N. Goodfellow, *Steady Steps Lead to the Gene*, 341 NATURE 102-03

disease has a range of severity, and that some people with the mutated gene have no symptoms.

Moreover, learning to diagnose genetic disease does not necessarily mean we will readily be able to treat it. The gene responsible for sickle cell anemia was discovered in 1949,⁵⁶ yet there is still no gene therapy for the syndrome. Consequently, the term "prevention" in the genetics context generally means abortion of an affected fetus.⁵⁷

Rather than face that fact, scientists make excessive claims about the benefits of gene therapy. Dr. W. French Anderson, the leading researcher on gene therapy, predicts a time when doctors will diagnose a patient's genetic disease and, paraphrases one reporter, "give them the proper snippets of molecular thread and send them home."⁵⁸

As in the past, the enthusiasm about genetics has reached even the highest governmental officials. President Clinton, at a November 1996 fundraiser in Houston, described how NIH scientists would make it possible for all infants to be genetically screened and treated shortly after birth. In his Inaugural Address, the President said, "Scientists are now decoding the blueprint of human life. Cures for our most feared illnesses seem close at hand."⁵⁹ The public, too, is sold on genetics. In one poll, 88% of Americans surveyed said they would be willing to give gene therapy to their children to correct a serious disease.⁶⁰ Many parents would seek gene therapy to enhance certain traits in otherwise healthy children, including 43% who approve of using gene therapy to improve their children's physical characteristics and 42% who approve of gene therapy to improve their children's intelligence level.⁶¹

Since Anderson undertook the first authorized gene therapy on humans in 1990,⁶² hundreds of ailing volunteers have been given gene therapy as part of research protocols. Extensive public attention has focused

(1980); M. Super et al., *CF Screening*, 344 NATURE 113-14 (1990); G. Vassart et al., *CF Screening*, 348 NATURE 586 (1990).

⁵⁶ See Barton Childs, *The Clinical Detection of the Genetic Carriers of Inherited Disease*, 71 MED. 102 (Mar. 1992); C.J. Houtchens, *The Humanity in Human Genetics*, USA WEEKEND, Jan. 9, 1994, at 20.

⁵⁷ "[E]stimates of arrival times for therapeutic benefits run, optimistically, as long as fifty years hence. Thus 'treatment' is at best a long-term goal, and 'prevention' means preventing the births of individuals diagnosed as genetic aberrant—in a word, it means abortion." Keller, *supra* note 53, at 295-96.

⁵⁸ Philip Elmer-Dewitt, *The Genetic Revolution*, TIME, Jan. 17, 1994, at 46.

⁵⁹ Clinton's Inaugural Address, BALTIMORE SUN, Jan. 21, 1997, at 8A.

⁶⁰ See Results of Public Survey on Human Genetics Released, CANCER WKLY., Dec. 21, 1992, at 9; see also Richard Liebmann-Smith, *It's a (Blond-Haired, Blue-Eyed, Even-Tempered, Ivy-Bound) Boy!*, N.Y. TIMES, Feb. 7, 1993, § 6, at 21.

⁶¹ See *id.*

⁶² See Barbara J. Culliton, *Gene Therapy Begins*, 249 SCI. 1372, 1372 (1990); Richard Saltus, *4-Year-Old Gets Historic Gene Implant*, BOSTON GLOBE, Sept. 15, 1990, at 1.

on a study in which children with severe combined immune deficiency (SCID) received gene therapy and improved. However, when the media⁶³ and scientists (including Bernadine Healy when she was the director of the NIH)⁶⁴ describe the experiment, they fail to point out that in addition to receiving gene therapy, that the children were also receiving standard medical treatments for the disease (administration of enzymes), so it is hard to pinpoint which treatment made the difference. Geneticist Michael Conneally points out that the SCID children were getting 50% of their enzymes through standard treatments. "You never hear that," he says. "That is never said to you."⁶⁵

Last year, the new NIH director Harold Varmus concluded that, even though 567 Americans had undergone gene therapy in approximately one hundred different experiments, "there is still little or no evidence of therapeutic benefit [of gene therapy] in patients, or even animal models."⁶⁶ A federally-appointed committee investigating gene therapy condemned most of the efforts as "pure hype."

Nonetheless, belief in genetics is so strong that some physicians coerce people to learn their genetic status and take action upon it. In some instances, physicians surreptitiously test pregnant women's blood for carrier status for genetic disease.⁶⁷ In other instances, physicians mislead pregnant women into undergoing genetic testing.⁶⁸ Some physicians co-

⁶³ See Elmer-Dewitt, *supra* note 58, at 50.

⁶⁴ See Dr. Bernadine Healy, Director, National Institutes of Health, *Testimony at Hearing on the Possible Uses and Misuse of Genetic Information Before the Subcommittee on Government Information, Justice and Agriculture*, 3 HUMAN GENE THERAPY 51-56, (Oct. 17, 1991).

⁶⁵ Presentation of Michael Conneally at Symposium on Culture and Biology, Galveston, Texas, Nov. 1996.

⁶⁶ Laurie Garrett, *The Dots are Almost Connected. . . . Then What?*, L.A. TIMES MAG., Mar. 3, 1996, at 22.

⁶⁷ See P.T. Rowley et al., *Do Pregnant Women Benefit from Hemoglobinopathy Carrier Detection?* 565 ANN. N.Y. ACAD. SCI. 152-60 (1989).

⁶⁸ In an innovative anthropological study, Nancy Press and Carol Browner observed physician visits in which physicians offered the maternal serum alphafetoprotein (MSAFP) test to pregnant women. A California regulation requires physicians to offer women the blood test that measures the level of a fetus's alphafetoprotein that is circulating in a woman's blood. See CAL. CODE REGS. tit. 17, § 6527 (1996). Press and Browner identified factors that caused physicians to exert pressure on women to participate in so-called voluntary MSAFP programs. See Nancy Press & Carol Browner, *Collective Fictions: Similarities in the Reasons for Accepting MSAFP Screening Among Women of Diverse Ethnic and Social Class Backgrounds*, 8 FETAL DIAGNOSIS & THERAPY 97-106 (1993). The authors also note, as does Michael J. Malinowski, *Coming into Being: Law, Ethics, and the Practice of Prenatal Screening*, 45 HASTINGS L.J. 1435, 1493 (1994), that health care professionals may push women into prenatal tests due to fear of malpractice liability. They found that the physicians did not obtain true informed consent. Physicians offering the testing to women did not reveal the significance of the testing to the women—that it might show that a fetus had spina bifida or anencephaly and

erce women into aborting fetuses with genetic anomalies.⁶⁹ According to Judy Norsigian of the Boston Women's Health Book Collective, "when it comes to something like Down's syndrome, most physicians have been extremely directive and even obnoxious. They will even say, 'we'll be scheduling an abortion for you.' This happens even when the extent of the disability is very mild."⁷⁰

There are no standards indicating which genetic tests should be offered. Some physicians want to test fetuses for mutations of the breast cancer gene even though there is professional disagreement about whether this is appropriate. Some physicians want to test elderly people for a gene potentially predictive of Alzheimer's disease, even though there is scientific debate over the validity of the test, and its predictive value in different racial groups. The lack of consensus about what type of screening should be offered means there is no clear guidance for state policymakers adopting mandatory screening plans either. Along those lines, state newborn genetic screening programs vary in the disorders for which they mandate testing. In some instances, states have mandated genetic testing of newborns for certain disorders even when national panels of medical experts recommend against testing for those disorders.⁷¹

III. PREMATURE ADOPTION OF GENETIC PROGRAMS

In the past, well-meaning genetics programs were adopted prematurely, causing harm. In the late 1960s, state public health departments began mandatory screening of all infants for phenylketonuria (PKU), a genetic disorder that can cause mental retardation if the child is not put on a special low phenylalanine diet shortly after birth. Because the program was implemented without adequate previous research or monitoring of the treated children, some infants who did not have PKU died or suffered irreversible damage when put on the special diet.⁷²

The social and psychological aspects of the use of genetic technologies have been ignored as well. In the early 1970s, many states passed

that they would be faced with a decision about whether or not to abort. Instead, the test was routinely described as "a simple blood test" or as a test to show "how your baby was developing." While testing was supposed to be voluntary, those women who refused testing were hounded by the physician until some consented to testing.

⁶⁹ See Malinowski, *supra* note 68, at 1468.

⁷⁰ Charlotte Allen, *Boys Only: Pennsylvania's Anti-Abortion Law*, 206 NEW REPUBLIC 16, 18 (1992).

⁷¹ See *Assessing Genetic Risks: Implications for Health and Social Policy* 66-67 (Lori B. Andrews et al. eds., 1994) (Committee on Assessing Genetic Risks, Division of Health Sciences Policy, Institute of Medicine, National Academy of Sciences, Washington, D.C.) (discussing reasons why newborn screening should not be undertaken for cystic fibrosis).

⁷² See Neil A. Holtzman, *Dietary Treatment for Inborn Errors of Metabolism*, 21 ANN. REV. OF MED. 335-56 (1970).

laws mandating sickle cell anemia screening of African-American individuals.⁷³ The laws established programs that did not provide adequate counseling or protections of confidentiality. Moreover, some people identified through testing as having genetic mutations were stigmatized and discriminated against in both insurance and employment.⁷⁴

Today, once again, genetic testing is being undertaken for a wide range of conditions—carrier status, genetic anomalies in fetuses, and late-onset disorders such as breast cancer—without sufficient attention to its psychological impact nor sufficient protections from genetic discrimination. Law professor Karen Rothenberg and NCHGR staff member Elizabeth Thomson point out that there is substantial literature on the biological safety of prenatal genetic technologies, but only minimal literature on “the psychological, sociocultural, ethical, legal or political impact of their application on women and their pregnancy experience.”⁷⁵ In addition to the potential benefits of genetic information, learning one’s genetic status can have negative effects on one’s emotional well-being, self-concept, relationship with family members and other individuals, and insurability and employability.⁷⁶ People have been denied health care insurance or benefits due to their genetic status,⁷⁷ and few states have legal protections against this practice.⁷⁸ Employment discrimination based on genetics has also occurred,⁷⁹ with only somewhat more legal protections.⁸⁰

⁷³ See ANDREWS, *supra* note 9, at 18.

⁷⁴ See PHILIP REILLY, *GENETICS, LAW, AND SOCIAL POLICY* 62-86 (1977).

⁷⁵ Karen H. Rothenberg & Elizabeth J. Thomson, *Women and Prenatal Testing: An Introduction to the Issues*, in *WOMEN AND PRENATAL TESTING: FACING THE CHALLENGES OF GENETIC TECHNOLOGY* 1, 3 (Karen H. Rothenberg & Elizabeth J. Thomson eds., 1994).

⁷⁶ See Lori B. Andrews, *Prenatal Screening and the Culture of Motherhood*, 47 *HASTINGS L.J.* 967, 973-88 (1996).

⁷⁷ See, e.g., NEIL A. HOLTZMAN, *PROCEED WITH CAUTION* (1989); Office of Technology Assessment, *Cystic Fibrosis and DNA Tests: Implications of Carrier Screening*, Washington, D.C.: U.S. Government Printing Office (1992); P.R. Billings et al., *Discrimination as a Consequence of Genetic Testing*, 50 *AM. J. HUM. GENET.* 476-82 (1992); Lawrence Gostin, *Genetic Discrimination: The Use of Genetically Based Diagnostic and Prognostic Tests by Employers and Insurers*, 17 *AM. J. LAW MED.* 109-44 (1991).

⁷⁸ For example, 12 states prohibit the use of genetic test results in insurance decisions. See CA. HEALTH & SAFETY CODE § 1374.7 (West 1996 supp.); COL. REV. STAT. § 10-3-1104.7 (Supp. 1996); GA. CODE ANN. § 33-54-3 (West Supp. 1997); 1997 ILL. ALS 25; MD. ANN CODE art. 48A, § 223.1 (1994); MINN. STAT. § 72A.139 (1995); N.H. REV. STAT. ANN. § 141-H:4 (1995); 1996 N.J. ADV. LEGIS. SERV. 126; OHIO REV. CODE ANN. § 3901.49 (Anderson 1996); OR. REV. STAT. § 746.135 (Michie Supp. 1996); VA. CODE ANN. § 38.2-508.4 (Michie 1996); WIS. STAT. § 631.89 (West 1995).

⁷⁹ In the early 1970s, employers discriminated against African-American employees and job applicants who were carriers of sickle cell anemia even though carrier status had

Because of the potential for discrimination, bioethicist Arthur Caplan has suggested that there be a moratorium on genetic testing until laws providing sufficient protection against genetic discrimination are adopted.⁸¹ Yet, insurers and some policymakers argue that continued discrimination is justified. Their fiscal logic is similar to that used in the earlier eugenics movement—that healthy people (that is, people with “good genes”) should not have to support people who have or may develop genetic diseases (people with “bad genes”).

Because the medical benefits of genetic testing are in many instances unproven and there are potential psychological and social risks in genetic testing, the need to assure that patients make voluntary and informed decisions about whether to participate in testing is particularly profound. Currently, however, informed consent is often compromised in the clinical setting, with people being tested without their knowledge or consent or receiving inadequate information about the nature or purpose of genetic testing or the use to which the results can be put.⁸²

Unauthorized testing has particularly affected individuals of color. African-American women are often tested for the sickle cell anemia gene during pregnancy without their knowledge or consent. In 1995, African-American employees of the Lawrence Berkeley Laboratory filed suit claiming that during routine physicals they had been tested without their knowledge for the sickle cell gene and that the results of the tests had been entered into their employment files.⁸³ Their case was dismissed be-

no relation to the individuals' health or ability to perform their jobs. See ANDREWS, *supra* note 9, at 18. More recently, a healthy carrier of Gaucher's Disease was denied a government job based on his carrier status. See generally Billings et al., *supra* note 77. Another man was given restricted benefits and denied a promotion and job transfer because he and his son carry the gene for neurofibromatosis.

⁸⁰ For example, the EEOC has interpreted the Americans with Disabilities Act, 42 U.S.C.A. § 1201 *et seq.* (West Supp. 1995), to prohibit employment discrimination against people with genetic mutations that predispose them to late-onset disorders. See EEOC Compliance Manual (BNA) § 902, at 47 (1995). In addition, seven states prohibit employers, labor organizations or licensing agencies from seeking to obtain, obtaining or using any genetic information to discriminate. See IOWA CODE § 729.6 (1995); N.H. REV. STAT. ANN. § 141-H:3 (1995); 1996 N.J. ADV. LEGIS. SERV. 126; N.Y. CIV. RIGHTS LAW § 48-a (Consol. 1996); OR. REV. STAT. § 659.036 (1995); R.I. GEN. LAWS § 28-6.7-1 (1995); WIS. STAT. § 111.372 (1994).

⁸¹ See Arthur Caplan, *Ethical Issues, Symposium on Genetic Testing for Breast Cancer Susceptibility: The Science, the Ethics, the Future*, Nov. 22, 1996, San Francisco, California. Similarly, Congressman Obey suggested that it might be appropriate not to give grants under the Human Genome Project to scientific researchers in states that do not have protections for genetic privacy. See Lori B. Andrews, *Genetic Privacy: From the Laboratory to the Legislature*, 1 GENOME RES. 1 (Oct. 1995).

⁸² See Lori B. Andrews, *Compromised Consent: Deficiencies in the Consent Process for Genetic Testing*, 32 J. AM. MED. WOMEN'S ASS'N 39 (1997).

⁸³ See *Norman-Bloodsaw v. Lawrence Berkeley Nat'l Lab.*, No. C95-03220 (N.D. Cal. filed Sept. 12, 1995).

cause no laws protected against such genetic intrusions. Only three states have specific statutes prohibiting genetic testing without consent.⁸⁴

The practice of unconsented-to testing is likely to grow. Multiplex tests are being developed where fifty or one hundred different genes can be assessed at the same time—such as the genes related to breast cancer, Huntington's disease, and cystic fibrosis carrier status. Physicians claim they cannot possibly ask for informed consent before each test, so they plan to inform people after the fact if they have a deleterious gene. Given that many people do not want genetic information—particularly for untreatable disorders—such a policy seems totally inappropriate. For example, less than 15% of people at risk for Huntington's disease decide to undergo the test.⁸⁵

Moreover, when benefits do accrue from genetic testing and treatment, it is unclear how the most disadvantaged in society will be able to benefit. Daniel Koshland, the editor of *Science*, described why money should go to the genome project rather than to the homeless: "[T]he homeless are impaired. . . . Indeed, no group will benefit more from the application of human genetics."⁸⁶ In the near term, how the homeless, with little or no access to health care, will reap the "benefits" of genomics is hard to fathom. And if Koshland is looking to a more distant future, he is making precisely the claims of the earlier era. Money that goes to the poor is a waste, for they are poor because of factors that are natural, even inevitable. The future promise of genetics is an excuse for present social policy.

IV. USE OF GENETICS FOR POLITICAL PURPOSES

In the earlier eugenics movement, genetic explanations were used for political purposes. They were based on prejudice⁸⁷ and used to try to maintain the economic positions and values of those in power in society.⁸⁸ Anyone who did not share those values—or who represented an economic threat—was categorized as having bad genes. This effort consequently had a disproportionate impact on the least powerful and most disadvantaged in society—women and minorities.

⁸⁴ See FLA. STAT. ANN. § 760.40 (West 1995); 1996 N.Y. ADV. LEGIS SERV. 497; OR. REV. STAT. § 659.715 (1995).

⁸⁵ See M. Bloch et al., *Predictive Testing for Huntington Disease: II. Demographic Characteristics, Life-Style Patterns, Attitudes, and Psychological Assessments for the First Fifty-One Test Candidates*, 32 AM. J. MED. GENETICS 217, 222 (1989).

⁸⁶ Keller, *supra* note 53, at 282.

⁸⁷ Historian Daniel Kevles points out that "[c]lass and race prejudice were pervasive in eugenics." Daniel Kevles, *Out of Eugenics: The Historical Politics of the Human Genome Project*, in THE CODE OF CODES, *supra* note 8, at 9.

⁸⁸ See Beckwith, *supra* note 3, at 50.

The first American eugenics efforts—the institutionalization of the “feeble-minded”—concentrated mostly on women.⁸⁹ In an extensive analysis of the early eugenics movement and its writings, Nicole Rafter demonstrates how geneticists and policymakers labeled promiscuous women as a social problem and developed institutionalization and sterilization programs to deal with them.⁹⁰ An 1879 study asserted “one of the most important and dangerous causes in the increase of crime, pauperism, and insanity is the unrestrained liberty allowed to vagrant and degraded women.”⁹¹ Rafter argues that this approach was actually a mechanism to force women to behave in a socially acceptable way by not allowing them to create children outside of marriage.⁹² Even women who were not feeble-minded or promiscuous were targets of legal rules to attempt to assure the health of the next generation. A 1908 United States Supreme Court case, *Muller v. Oregon*, upheld a law limiting the number of hours a woman could work, reasoning that “as healthy mothers are essential to vigorous offspring, the physical well being of women becomes an object of public interest and care in order to preserve the strength and vigor of the race.”⁹³ Women’s challenges to male dominance brought repressive social policies legitimated by theories available in science.

In a stunning research project, Paul Lombardo showed in 1985 that Carrie Buck, the famous target of Holmes’s “three generations of imbeciles,” was not an imbecile.⁹⁴ She had done well in school, as did her daughter. Rather than being institutionalized because she was feeble-

⁸⁹ See Nicole H. Rafter, *Claims-Making and Socio-Cultural Context in the First U.S. Eugenics Campaign*, 39 SOC. PROBS. 17-34 (Feb. 1993).

⁹⁰ Rafter notes that Richard Dugdale’s 1877 study, *The Jukes*, described poor women as dwelling in “hot beds where human maggots are spawned.” *Id.* at 21 (citing RICHARD L. DUGDALE, *THE JUKES: A STUDY IN CRIME, PAUPERISM, DISEASE, AND HEREDITY* 54 (1877)).

⁹¹ *Id.* (citing Josephine Shaw Lowell et al., *Report of the Committee on a Reformatory for Women*, in NEW YORK STATE BOARD OF CHARITIES, 12TH ANNUAL REPORT, New York Senate Doc. 13, at 189 (1879)).

⁹² “The very possibility that poor women might use their bodies unconventionally threatened the biological understanding of gender as fixed and immutable.” *Id.* at 25. The eugenic movement to institutionalize dependent, allegedly feeble-minded fertile women can be seen in part as “the punitive reaction to changes in women’s social position.” *Id.* at 29. Similarly, non-feeble-minded women who got pregnant were punished by being forced to go to term under stricter abortion laws, such as the one adopted in Connecticut in 1860, which prohibited post-quickening abortion. See *Roe v. Wade*, 410 U.S. 113, 139 (1973).

⁹³ *Muller v. Oregon*, 208 U.S. 412, 421 (1908). There is evidence, however, that the laws were not designed to protect women, but to protect men’s jobs. Women in low-paying traditionally female jobs like nursing were exempted from the laws. See Lori B. Andrews, *A Delicate Condition*, 13 STUD. LAW. 21, 30-36 (May 1985).

⁹⁴ See Paul A. Lombardo, *Three Generations, No Imbeciles: New Light on Buck v. Bell*, 60 N.Y.U. L. REV. 30, 52 (1985).

minded, she had been institutionalized because she was considered to be "immoral" for having a child out of wedlock.⁹⁵ Yet that pregnancy was the result of being raped by the nephew of the foster parents with whom she lived—the very people who committed her to the institution! The doctor who sterilized her was "obsessed with placing checks on sexuality and propagation"⁹⁶ and Buck received appallingly poor legal representation. Her lawyer, who had been part of the institution's board that authorized her sterilization,⁹⁷ did not call any witnesses or introduce any facts to challenge the characterization of his clients as feeble-minded.⁹⁸ Her attorney obviously was in a conflict of interest and should not have represented her.⁹⁹

In addition to its application to women, the early eugenics movement also provided a way for those with means in society to avoid meeting the civil rights demands of the poor and the working class. Slaves were freed, but one of their basic civil rights was curtailed in the name of eugenics. African-American citizens were thought to be so inferior that interracial marriage was prohibited to prevent the birth of defective offspring.¹⁰⁰ Starting in 1895, thirty-four states forbade such marriages by statute.¹⁰¹

Also in the latter part of the nineteenth century, there was growing labor unrest culminating in the 1866 Haymarket bombing and riots.¹⁰² The demonstrations were blamed on immigrant workers who had lesser genes.¹⁰³ This led to the passage of a series of immigration laws to keep

⁹⁵ See *id.* at 53.

⁹⁶ *Id.* at 62.

⁹⁷ See *id.* at 55.

⁹⁸ See *id.* at 42 n.8

⁹⁹ Despite the pervasive acceptance of eugenic ideals, particularly among the well-educated, another lawyer might have done a better job. In six lower courts that heard challenges to laws authorizing sterilization of the feeble-minded or insane, three declared them unconstitutional on equal protection grounds because they applied only to institutionalized persons and three declared them unconstitutional on due process grounds because they did not provide adequate procedural safeguards. See Reilly, *supra* note 5, at 232.

¹⁰⁰ See ANDREWS, *supra* note 9, at 12. In the early twentieth century, "a number of scientists and social scientists applied Darwinian analysis to various 'racial' groups and decided that some 'races' were more advanced than others on the evolutionary scale." MARK H. HALLER, *EUGENICS: HEREDITARIAN ATTITUDES IN AMERICAN THOUGHT* x (1984).

¹⁰¹ See Beckwith, *supra* note 3, at 49.

¹⁰² See *id.* at 47.

¹⁰³ The respectable *New York Times* asserted at the time that "demonstrations were always mobs composed of foreign scum, beer-smelling Germans, ignorant Bohemians, uncouth Poles and wild-eyed Russians." *Id.* (citation omitted). Jon Beckwith points out: "The eugenics movement served mainly as an ideological weapon against the poorer classes in society that were seeking a greater share in wealth and power." *Id.* at 50.

people thought to be genetically undesirable from entering the country. In 1882, a law was adopted to prohibit the immigration of people who were lunatics or idiots or who were likely to become public charges.¹⁰⁴ Later, in 1924, the United States Congress passed an immigration act setting quotas on the number of immigrants from various countries. This law was influenced by testimony that the United States gene pool was endangered by a large influx of people from southern and eastern European nations.¹⁰⁵ The inadequate genes of the people trying to gain entry to the United States was "demonstrated" by H.H. Goddard (the author of the Kallikak study) who administered pen and paper intelligence tests to exhausted, frightened individuals who had just landed on Ellis Island. The results—87% of the Russians, 83% of the Jews, 80% of the Hungarians, and 79% of the Italians were found to be feebleminded.¹⁰⁶ Immigration was criticized as potentially making the American population "darker in pigmentation, smaller in stature, more mercurial . . . more given to crimes of larceny, kidnapping, assault, murder, rape and sex-immorality."¹⁰⁷ As Vice-President of the United States, Calvin Coolidge publicly declared: "America must be kept American. Biological law shows . . . that Nordics deteriorate when mixed with other races."¹⁰⁸

Whether the focus was women, African-American citizens, or immigrants, genetic arguments were part of the Social Darwinism that insisted that those on the bottom of the social ladder belonged there—indeed should affirmatively be kept there if they claimed a higher place. Today, biological explanations are again given for the inferiority of the least powerful. And, again, women and minority groups are the targets of much of the concern raised about the demise of the gene pool. They are also the groups most likely to have their individual decisions overridden sometimes on the grounds that it is for their own good, other times for the supposed good of society.

As earlier, biological explanations are now being set forth for why women are not suited to become full functioning members of society.¹⁰⁹ In addition, the concern that poor women are producing inferior offspring

¹⁰⁴ Reilly, *supra* note 5, at 229.

¹⁰⁵ Beckwith, *supra* note 3, at 49.

¹⁰⁶ GOULD, *supra* note 39, at 166.

¹⁰⁷ KEVLES, *supra* note 4, at 49 (quoting CHARLES DAVENPORT, *HEREDITY IN RELATION TO EUGENICS* (1911)).

¹⁰⁸ *Id.* at 97 (footnotes omitted).

¹⁰⁹ See, e.g., Jason Geitzen, *She's in the Army Now and Her Higher Injury Rates Concern Pentagon*, OMAHA WORLD HERALD, Apr. 28, 1996, at A1, in which military officials make the argument that women's greater susceptibility to stress fractures and inability "to urinate while standing in the corner of a truck bed" make them unfit for certain higher prestige military jobs. See *id.*

out of wedlock is a common refrain today in the media and in policy discussions.¹¹⁰ An astonishing 97% of obstetricians favor sterilizing unmarried welfare mothers.¹¹¹ Several states have proposed legislation providing incentives for women on welfare not to have additional children. These include offering welfare benefits to women who implant the long-acting contraceptive Norplant (proposed in Connecticut, Florida, Kansas, Louisiana, Mississippi, Ohio, South Carolina, Tennessee, Washington, and West Virginia),¹¹² or offering women on welfare cash bonuses for undergoing sterilization (proposed in Ohio and Washington).¹¹³ The language used in the current debate on preventing pregnancies in women on welfare sounds like language used in the earlier eugenics movement. West Virginia Supreme Court Justice Richard Neely advocates creating incentives for such women to use Norplant: "I am speaking for the Heartland of America, where the underclass is growing by leaps and bounds."¹¹⁴

Minority women are treated differently with respect to genetic testing. While genetic testing of pregnant white women for the cystic fibrosis mutation (which is of high prevalence among Whites) is undertaken with elaborate consent procedures,¹¹⁵ pregnant African-American women

¹¹⁰ See Lisa C. Ikemoto, *The Racialization of Genomic Knowledge*, 27 SETON HALL L. REV. 937 (1997).

¹¹¹ See Beverly Horsburgh, *Schrodinger's Cat, Eugenics, and the Compulsory Sterilization of Welfare Mothers: Deconstructing the Old/New Rhetoric and Constructing the Reproductive Rights of Natality for Low-Income Women of Color*, 17 CARDOZO L. REV. 531, 535 (1996).

¹¹² See John Robert Hand, *Buying Fertility: The Constitutionality of Welfare Bonuses for Welfare Moms Who Submit to Norplant Insertion*, 46 VAND. L. REV. 715, 718 (1993). Kathleen Megan, *Proposal Offers Money for Contraceptive Use . . .*, HARTFORD COURANT, Feb. 17, 1994, § A, at 1; Peter Mitchell, *Lawmaker Puts Money on Birth Control Idea*, ORLANDO SENTINEL, Feb. 16, 1994, at D5; see also III REPROD. FREEDOM NEWS, Mar. 11, 1994, at 5. The use of Norplant is being urged despite the fact that several thousand women have filed suit against the manufacturer with products liability complaints. See Melynda G. Broomfield, *Controlling the Reproductive Rights of Impoverished Women: Is This the Way to 'Reform' Welfare?* 16 B.C. THIRD WORLD L.J. 217, 234 n.151 (1996).

¹¹³ In Washington, women on welfare would receive \$10,000 for having a tubal ligation after one child was born. See Hand, *supra* note 112, at 718.

¹¹⁴ *Paying Teenagers Not to Have Babies?*, CHRISTIAN SCI. MONITOR, Jan. 14, 1993, (People Section), at 14. Most of the proponents of Norplant use make the fiscal argument, reminiscent of the early advocacy by the American Eugenics Movement, that the rest of society should not have to support paupers whose birth could have been avoided. Some proponents use eugenic arguments as well. When David Duke, a former Ku Klux Klan Grand Wizard, proposed a Norplant bonus in Louisiana, he suggested that social problems could be averted by preventing the birth of "undesirables." See Broomfield, *supra* note 112, at 233 (citation omitted).

¹¹⁵ See B.A. Barnhardt et al., *Educating Patients About Cystic Fibrosis Carrier Screening in a Primary Care Setting*, 5 ARCHIVE FAM. MED. 336-40 (1996).

are tested for the sickle cell mutation (which is of high prevalence among African-Americans) without their advance knowledge or consent.¹¹⁶

Even white women, though, are disproportionately targeted for genetic interventions when compared to men. When the cystic fibrosis gene was identified, some geneticists indicated that it might be useful for couples considering having children to be tested because if both individuals had a mutation of the gene, there was a 25% chance that any child they had would receive two copies of the mutated gene and thus have cystic fibrosis.¹¹⁷ If one individual was tested, though, and was not found to have an identifiable mutation, then the chance was much lower that the couple would have an affected child. The American Society of Human Genetics and NIH Workshop emphasized the need to screen *couples* pre-conceptually.¹¹⁸ Either the man or woman would have the test first and, if their test showed the genetic mutation, their partner would be tested as well. Most clinicians, however, are not offering the test to couples, but rather to pregnant women.¹¹⁹ The woman is tested first and only if she has a mutation is her partner tested. Because one in twenty-five Whites have the mutation, twenty-five women are tested for every man, even though men and women are equally likely to pass on a mutation to the child. Such an approach disproportionately affects women and may make it seem that genetics is a woman's responsibility rather than a shared choice.

Moreover, the extensive use of prenatal testing (with some obstetricians refusing to treat pregnant women unless they agree to undergo such testing) sends the message that once again, it is women who are expected to be guarantors of their children's health. When pregnant women do not undergo available prenatal testing, health care professionals blame them for the resulting genetic conditions of their children.¹²⁰ Further blame is placed on women when genetic testing reveals a son to have a condition that was passed on from the woman via the X chromosome—such as Fragile X, Duchenne's muscular dystrophy, or even homosexuality.

¹¹⁶ See generally Rowley, *supra* note 67.

¹¹⁷ See *supra* note 55.

¹¹⁸ See *Statement from the National Institutes of Health Workshop on Population Screening for the Cystic Fibrosis Gene*, 323 NEW ENG. J. MED. 70-71, 71 (1990); *Statement of the American Society of Human Genetics on Cystic Fibrosis Carrier Screening*, 51 AM. J. HUM. GENET. 1443-44 (1992).

¹¹⁹ See Peter T. Rowley et al., *Cystic Fibrosis Carrier Screening: Knowledge and Attitudes of Prenatal Care Providers*, 9 AM. J. PREV. MED. 261-63 (1993); M.A. Fox et al., *Consent to Cystic Fibrosis Carrier Screening in an Ethnically Diverse Population*, Abstract No. 50 (1993) (American Society of Human Genetics Annual Meeting) (on file with author).

¹²⁰ See Theresa M. Marteau & Harriet Drake, *Attributions for Disability: The Influence of Genetic Screening*, 40 SOC. SCI. MED. 1127-32 (1995).

Rabbi Elliot N. Dorff has advocated that "women with the defective BRCA1 have a duty to inform their prospective mates of the fact"¹²¹—apparently so that the men could choose to marry someone else with "better genes."

As with women, the biological limitations on African-Americans are underscored today. *The Bell Curve*¹²² asserts that African-American individuals, as a group, have lesser mental capacities than White individuals.¹²³ Inner city youths are thought to have genetic differences that cause them to be violent, and pharmacological intervention or gene therapy is proposed to change their behavior.¹²⁴

There is reason to be skeptical of such assertions, which, as a century ago, fit so comfortably with our current social ideologies. Sociologist Dorothy Nelkin notes, "Behavioral genetics is in vogue these days—just as eugenics was in the 1920's—in part because it suits the political context, providing justification for prevailing social policies."¹²⁵ Genetics researcher Alan Tobin adds, "Predestination (of whatever sort) means that no one is responsible for inequalities in the society, for the success of some and the failures of others."¹²⁶

In fact, the best-selling *Bell Curve* presents a contemporary perspective that is almost identical to a speech that H.H. Goddard gave to Princeton undergraduates in 1919, in which he said:

¹²¹ B.D. Cohen, *Proceedings of the Workshop on Inherited Breast Cancer in Jewish Women: Ethical, Legal, and Social Implications*, 10 CENTER VIEWS 7-10 (Spring 1996).

¹²² RICHARD J. HERRNSTEIN & CHARLES MURRAY, *THE BELL CURVE: INTELLIGENCE AND CLASS STRUCTURE IN AMERICAN LIFE* (1996).

¹²³ See *id.* at 269-340. *The Bell Curve*'s assertion that some individuals do not have the cognitive skill sufficient to make it in today's society is similar to the assertion by Francis Galton (who coined the term "eugenics") that certain people in his day did not have the refined capacities to be a proper Englishman. See *id.* at 25-115.

¹²⁴ For an extensive discussion of the legal and social issues raised by purported propensities to crime, see Lori Andrews, *Predicting and Punishing Anti-Social Acts: How Courts Might Use Behavioral Genetics*, in *BIOLOGY AND CULTURE* (Mark Rothstein ed., forthcoming 1998).

¹²⁵ Dorothy Nelkin, *Genetics and Dismantling the Welfare State*, in *BIOLOGY AND CULTURE* 135 (Mark Rothstein ed., forthcoming 1998). Nelkin and Lindee point out why such explanations are readily accepted by the public and policymakers: "they can relieve personal guilt by implying compulsion, an inborn inability to resist specific behavior" and they can relieve societal guilt and give society an excuse to cut out social services by deflecting attention away from social and economic influences on behavior. See generally DOROTHY NELKIN & SUSAN LINDEE, *THE DNA MYSTIQUE* (1995).

¹²⁶ Alan J. Tobin, *Amazing Grace: Sources of Phenotype Variations in Genetic Boosterism* 8 (Nov. 1996) (paper for Conference on Culture and Biology, Galveston, Texas) (on file with author). Tobin points out that there is a sense in which genes preordain success: "We may reasonably question why so many 40-60 year old male academics have been arguing so intensely about the excellence of their own genes?" *Id.*

Now the fact is, that workmen may have a 10 year intelligence while you have a 20. To demand for him such a home as you enjoy is as absurd as it would be to insist that every laborer should receive a graduate fellowship. How can there be such a thing as social equality with the wide range of mental capacity?¹²⁷

Already, genetic rationales are being appropriated by certain groups as rationales for social policies. Recently, an organization that seeks to reduce school taxes argued against special education programs on the grounds that, because such disabilities are genetic "responsibility should fall to the medical system, not to the schools."¹²⁸ Philanthropic organizations are also beginning to make predictions based on genetics. A recent article in a philanthropy journal, relying on the book *The Bell Curve*, indicated that some people are genetically predestined to be low achievers, so that it is probably not worth using foundation money to try to enhance their opportunities.¹²⁹ And, Rebecca Pentz has pointed out that tobacco companies "claim that smoking only causes cancer in those with a genetic susceptibility—implying that if we just fix the genes there is no need to stop buying and using their product."¹³⁰

The latest social arena in which genetics is taking hold is criminal justice. The current view of crime as due to genetic defects is parallel to what occurred a century ago. The popular sentiment fueling it is similar as well. A British reporter described it this way: "Americans, weary with liberal quests for social and economic causes of spiraling crime, are intrigued by the simple notion that some people are born to be bad."¹³¹ Violence is being approached as a medical matter that is financially draining public funds. The Centers for Disease Control and Prevention has declared violence a pressing public health problem.¹³² The *Los Ange-*

¹²⁷ GOULD, *supra* note 39, at 16.

¹²⁸ *Id.* at 10.

¹²⁹ Geneticist Benno Müller-Hill points out:

The scientific prediction of a person's limitations, and thus his possible fate, has a very dangerous component in that it may lead an individual to inaction and despair. It may also lead the population to believe that, as there is no real chance, money should not be wasted to counteract genetic limitations. It could be forgotten that these limitations are also set by environmental factors.

Benno Müller-Hill, *The Shadow of Genetic Injustice*, 362 NATURE 491, 492 (1993).

¹³⁰ Rebecca D. Pentz, Commentary on 'Ethical Issues in Genetic Engineering, Screening and Testing,' by P. Michael Conneally 1-2 (Nov. 1996) (paper for Conference on Culture and Biology, Galveston, Texas) (on file with author).

¹³¹ Sarah Boseley, *Second Front: Genes in the Dock*, GUARDIAN, Mar. 13, 1995, at T2.

¹³² Such an approach has allowed CDC to enhance its budget. President Clinton endorsed a special CDC line item to fund violence prevention programs. See Sheryl Stolberg, *Fear Clouds Search for Genetic Roots of Violence*, L.A. TIMES, Dec. 31, 1993, at

les Times ran an article about "the high cost" of violence, noting that "[e]ach year, more than 2 million Americans suffer injuries as a result of violence, and more than 500,000 are treated in emergency rooms." The newspaper estimated that it costs \$18 billion annually to care for victims of violence, as compared to \$10 billion for victims of AIDS.¹³³

This data has led to attempts to find ways to "cure" people with "criminal" genes through medical means.¹³⁴ The type of treatment envisioned might be extremely interventionist. In 1993, a group of scientists identified a genetic mutation that, in a large Dutch family, was associated with males having borderline mental retardation and abnormal behavior including impulsive aggression, arson, attempted rape, and exhibitionism.¹³⁵ The scientists reported that "isolated complete MAOA [monamine oxidase A] deficiency in this family is associated with a recognizable behavioral phenotype that includes disturbed regulation of impulsive aggression."¹³⁶ After the publication of the findings on MAOA (dubbed the "mean" gene by one journalist), talk radio hosts suggested sterilizing people with the gene.¹³⁷ In the future, people thought to have genetic predisposition to crime might be subject to gene therapy if it becomes usable. Jon Beckwith points out that, "Pacification genes may then be added to drug therapy and psychosurgery as tools of social control."¹³⁸ Harold Green notes that society might also try to restrict marriages when the couple might produce a child with a genetic propensity to anti-social acts or abortion might be made mandatory if the condition were diagnosed in a fetus.¹³⁹

It is likely that any medical intervention to curtail the manifestation of alleged criminal genes would be applied in a discriminatory fashion. African-American individuals are more likely to be prosecuted than white

A1. John Douard describes how turning a social problem into a public health problem is done as an "institutionalized distraction." When a society throws up its hands about doing anything about racism or poverty, it can appease itself by moving to a new type of expert, a public health expert. See John Douard, presentation at conference on Biology and Culture, Galveston, Texas, Nov. 1996.

¹³³ See generally Stolberg, *supra* note 132.

¹³⁴ See Sheryl Stolberg, *Fear Clouds Search for Genetic Roots of Violence*, L.A. TIMES, Dec. 30, 1993, at A1.

¹³⁵ See H.G. Brunner et al., *Abnormal Behavior Associated with a Point Mutation in the Structural Gene for Monoamine Oxidase A*, 262 SCI. 578 (1993).

¹³⁶ *Id.*

¹³⁷ See Mann, *supra* note 47, at 1689.

¹³⁸ Beckwith, *supra* note 3, at 54. There seems to be a current societal willingness to find medical solutions to criminal acts. In California, on August 31, 1996, the legislature passed a bill permitting chemical castration of child molesters. See Dan Morain & Max Vanzi, *Senate Oks Access to Sex Offenders Database*, L.A. TIMES, Sept. 1, 1996, at A3.

¹³⁹ See Harold P. Green, *Genetic Technology: Law and Policy for the Brave New World*, 48 IND. L.J. 559, 571 (1973).

individuals and African-American individuals receive harsher sentences than Whites for similar crimes.¹⁴⁰ "Let's just assume we find a genetic link (to violence)," said Ronald Walters, a political scientist at Howard University in Washington, D.C. "The question I have always raised is how will this finding be used? There is a good case, on the basis of history, that it could be used in a racially oppressive way, which is to say you could mount drug programs in inner-city communities based upon this identification of so-called genetic markers."¹⁴¹

The trend toward finding genetic explanations for social problems is achieving legitimacy, based on the fact that some of the most influential scientists today are urging a genetically-determined view of humans.¹⁴² "We look upon ourselves as having infinite potential," writes the Nobel Prize winner, Harvard molecular biologist Walter Gilbert. "To recognize that we are determined, in a certain sense, by a finite collection of information that is knowable will change our view of ourselves. It is the closing of an intellectual frontier, with which we have to come to terms."¹⁴³ Harvard zoologist Edward O. Wilson asserts that the human brain is not *tabula rasa* later filled in by experience but, "an exposed negative waiting to be slipped into developer fluid."¹⁴⁴ And James Watson, co-discoverer of deoxyribonucleic acid (DNA) and the first director

¹⁴⁰ See Ericka L. Johnson, *A Menace to Society: The Use of Criminal Profiles and Its Effect on Black Males*, 38 HOW. L.J. 629, 664 (1995). For example, white pregnant women are slightly more likely to abuse drugs than African-American pregnant women, but African-American pregnant women are 9.58 times as likely to be reported for substance abuse during pregnancy. See Kary Moss, *Substance Abuse During Pregnancy*, 13 HARV. WOMEN'S L.J. 278-99, 294 (1990) (citation omitted). Moreover, offenses that are seen as primarily African-American are punished more harshly than white offenses—for example, the use of crack cocaine is subject by statute to longer prison sentences than is the use of powder cocaine. See Johnson, *supra*, at 644. More generally, surveillance has been used discriminatorily against men of color, to the point where it has been found justifiable to detain African-American men or Hispanic men and search them if they are found in primarily white neighborhoods. See *id.* at 630-31.

¹⁴¹ *Id.*

¹⁴² Beverly Horsburgh points out:

Intellectuals who participate within a discipline become both subjects and objects, acted upon by the very body of knowledge they create. As part of a hierarchal structure, some scientists are thereby inevitably drawn to eugenics. By its nature, science demands reductionist thinking, examining only isolated parts of the world or of human beings. Individuals all too easily can be reduced to the purported worth of their genes.

Horsburgh, *supra* note 111, at 534. Steven Rose puts it this way: "The core issue is reducibility, which as Medavan once remarked, comes not as second but as first nature to natural scientists." Steven Rose, *The Rise of Neurogenetic Determinism*, 372 NATURE 380-82, 390 (1995).

¹⁴³ Walter Gilbert, *A Vision to the Grail*, in THE CODE OF CODES, *supra* note 8, at 83-87.

¹⁴⁴ Tom Wolfe, *Sorry, but Your Soul Just Died*, FORBES ASAP, Dec. 2, 1996, at 212.

of the Human Genome Project has stated, "We used to think our fate was in the stars. Now we know, in large measure, our fate is in our genes."¹⁴⁵

Yet, as Kenneth Schaffner points out, "*purely* genetic explanations do not exist—even for very simple organisms."¹⁴⁶ The environment can have a profound effect on the expression of disorders. Prior to World War II, certain behaviors were thought to be part of the syndrome of schizophrenia that were actually due to the nature of the large regimented asylums in which patients with schizophrenia were housed. Changes in institutional policies led to changes in what was considered to be the nature of the disease.¹⁴⁷ Moreover, prognosis for patients with schizophrenia is better in undeveloped than industrialized countries,¹⁴⁸ which is also suggestive of environmental influences. And studies have found that people with higher levels of schooling are less likely to suffer from Alzheimer's disease after age sixty-five.¹⁴⁹

The intense focus on genetics may cause researchers to make spurious connections. Researchers may mistake correlations (or even effects) for causes. In aggressive encounters, there are physical changes in a person's hormones, neurotransmitters, and so forth, some of which may permanently change a variety of brain and body markers. If in individuals who have been exposed to high levels of violence, such markers are taken as proof of a genetic cause of violence, researchers would be confusing effects with causes.¹⁵⁰

Genetic blinders can also avert researchers' attention from social causes. Biracial children in the United Kingdom are diagnosed as schizophrenic at a much higher rate than either black individuals or white individuals.¹⁵¹ Those researchers who characterize schizophrenia as a genetic disorder fail to provide an explanation for this epidemiological finding.¹⁵²

Even if accurate genetic predictions were possible, medical interventions might still be inappropriate. Dr. Sarnoff Mednick, a psychologist at the University of Southern California, who published the most

¹⁴⁵ Leon Jaroff, *The Gene Hunt*, TIME, Mar. 20, 1989, at 63.

¹⁴⁶ Kenneth F. Schaffner, Complexity and Research Strategies in Behavioral and Psychiatric Genetics, at 13 (paper for Conference on Culture and Biology, Galveston, Texas, Nov. 1996).

¹⁴⁷ See Leon Eisenberg, *The Social Construction of the Human Brain*, 152 AM. J. PSYCHIATRY 1563, 1569 (Nov. 1995).

¹⁴⁸ See *id.*

¹⁴⁹ See *id.* at 1571.

¹⁵⁰ See Rose, *supra* note 142, at 381.

¹⁵¹ See *id.* at 382.

¹⁵² See *id.*

commonly-cited study linking genetics and crime,¹⁵³ argues that even if it could be shown that a gene impaired moral learning by making the autonomic nervous system less responsive, scientists should not try to suppress the genetic trait. "You might also suppress other more positive qualities like creativity," he says.¹⁵⁴

V. COMMERCIALISM AND GENETICS—A TROUBLING COMBINATION

There are enough social parallels to the earlier genetic movement to raise concern about modern uses of genetics. Such concern should be heightened when we consider another factor that encourages genetic hucksterism today—the rampant commercialization of genetic technologies and services.¹⁵⁵ It is not just that the incentives of scientific awards and funding promote genetic solutions, but also the fact that the economic rewards can be quite substantial.

The expanding interest in the use of genetic technologies is driven in part by commercial incentives fostered by legal developments in the 1980s. A landmark United States Supreme Court case in 1980 granted a patent on a life form—a bacteria—setting the stage for the patenting of human genes.¹⁵⁶ Initially, researchers assumed that people's genes were not patentable because patent law covers "inventions" and prohibits patenting the "products of nature." But in the mid-1980s, the patent office began granting patent rights for human genes, allowing the researcher who identifies a gene to earn royalties on any test or therapy created with that gene.¹⁵⁷ A second radical change was a 1980 federal law allowing universities to reap the profits from their government-supported research.¹⁵⁸ This encouraged collaborations between researchers and biotechnology companies—and a growing interest in the economic value of genetic technologies.

In the context of advances in biotechnology, the 1980s legislation led to important changes in the goals and practices of science and medicine. Leon Rosenberg, when he was Dean of the Yale University School

¹⁵³ The study compared 14,427 adopted Danish men with their biological fathers and found no direct inherited tendency, but a correlation between biological fathers and sons in the commission of property crimes.

¹⁵⁴ Daniel Goleman, *New Storm Brews on Whether Crime Has Roots in Genes*, N.Y. TIMES, Sept. 15, 1992, at C1.

¹⁵⁵ See, e.g., ANDREW KIMBRELL, *THE HUMAN BODY SHOP: THE ENGINEERING AND MARKETING OF LIFE* (1993).

¹⁵⁶ *Diamond v. Chakabarty*, 447 U.S. 303 (1980).

¹⁵⁷ See, e.g., Rebecca S. Eisenberg, *Patenting the Human Genome*, 39 EMORY L.J. 721 (1990).

¹⁵⁸ See 15 U.S.C.S. § 3701 *et seq.* (1996). See generally SHELDON KRIMSKY, *BIOTECHNICS AND SOCIETY* (1991); PAUL RABINOW, *MAKING PCR* (1996).

of Medicine, described the influence of the biotechnology revolution on scientific research: "It has moved us, literally or figuratively, from the class room to the board room and from the *New England Journal* to the *Wall Street Journal*."¹⁵⁹

Biotechnology companies and physicians heavily market genetic services and products, and the supposedly neutral scientists developing them often share a cut of the profits as patent holders or members of biotechnology boards. This commercialized setting makes it more likely that tests will be implemented prematurely, that they will be performed without appropriate concern for informed consent, and that the poor and disadvantaged will be least likely to share in any benefits.

Within six months of the discovery of a genetic mutation predisposing to breast cancer and melanoma, commercial testing for the mutation was being offered. Oncor Med., Inc., a biotechnology company, had signed an agreement with Preferred Oncology Network, a nationwide group of hundreds of private carrier specialists, to offer the test. Oncor Med had also developed a computer program to determine which patients were at a higher than average cancer risk to target them for testing.¹⁶⁰ In an analysis of a biotechnology company's informational brochure given to patients deciding on breast cancer testing, geneticist Neil A. Holtzman found that it overestimated the chance of women getting cancer,¹⁶¹ perhaps frightening people into testing.

VI. CONCLUSION

As historian Daniel Kevles and genetics researcher Leroy Hood have emphasized, "In its ongoing fascination with questions of behavior, human genetics will undoubtedly yield information that may be wrong, or socially volatile, or, if the history of eugenics is a guide, both."¹⁶² A recent article in the *Houston Chronicle* pointed out that the excessive claims about genetics have not turned out to be true, leading to a backlash against "genetic hucksterism," including the formation of a California Biotech Action Coalition.¹⁶³ As we attempt to develop legal policies

¹⁵⁹ Leon Rosenberg, *Using Patient Materials for Production Development: A Dean's Perspective*, 33 CLINICAL RES. 412-54 (Oct. 1985).

¹⁶⁰ Gina Kolata, *Tests to Assess Risk for Cancer Raising Questions*, N.Y. TIMES, Mar. 27, 1995, at A1.

¹⁶¹ Neil A. Holtzman, Symposium, Genetic Testing for Breast Cancer Susceptibility: The Science, Ethics, the Future, San Francisco, California (Nov. 1996) (on file with author).

¹⁶² Daniel J. Kevles & Leroy Hood, *Reflections*, in THE CODE OF CODES, *supra* note 8, at 300-28, 326.

¹⁶³ Keay Davidson, *High Hopes or Just Hype?*, HOUSTON CHRON., Sept. 29, 1996, at 2.

to deal with genetics, we should not only learn from our history, but from what I will call our future history: How will later generations judge our actions?

It is useful to realize that the turn-of-the-century purveyors of genetic ideas did not consider themselves evil. They saw themselves on a laudable quest for human betterment. Their ideas were widely accepted and implemented. The inappropriateness of these ideas and their discriminatory impact was not recognized for many decades.

When Mark Haller wrote a 1984 introduction to the reissuing of his 1964 book, *Eugenics: Hereditarian Attitudes in American Thought*, he indicated that one of the failures of the first edition was not to recognize the way broad societal value systems shaped the movement:

In the largely White Anglo-Saxon Protestant dominated intellectual life of the late nineteenth and early twentieth centuries, it was possible to speak or write in stereotypical and derogatory ways about Blacks, or Irish, or Italians to an extent that grates strangely today. Similarly, there was sufficient social distance between successful and less successful members of society, so that those of the educated elite could refer to segments of the poor as 'the dangerous classes' and, in some ways, conceive the poor to be biologically different from themselves.¹⁶⁴

In their quest to do good with genetic tools, geneticists and their enablers (biotechnology companies, patients, the media, and others) may again be oblivious to the way current social values and the distribution of political power lead to inappropriate claims and uses of genetics. Yet a close examination of the parallels between the earlier era and the contemporary use of genetics demonstrates that science is again being used to legitimate those who would like to defend their privileges as natural and inevitable, and to condemn the underprivileged as occupants only of a place where they naturally belong. In this setting, the law can play an important role in assuring we do not repeat our mistakes. At a minimum, the law should guarantee that individuals can refuse genetic testing and other genetic interventions, that they receive accurate information upon which to base their decisions about using genetic technologies, that they control access to their genetic test results, and that they are protected from discrimination based on their genotype.

¹⁶⁴ MARK H. HALLER, *EUGENICS: HEREDITARIAN ATTITUDES IN AMERICAN THOUGHT* x (1984).