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Invited Editorial: Eugenics and Genetic Discrimination

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Three recent events—and the national attention given them—suggest that eugenics and genetic discrimination could still flourish in the United States. The first concerned a Los Angeles talk show on which the host expressed disapproval of a television newswoman, Bree Walker, for taking the chance of having a child with ectrodactyly (absence of some terminal digits), the autosomal dominant condition she had (Seligmann and Foote 1991). The second was the Louisiana gubernatorial campaign. Part of David Duke's popularity came from his excoriation of the poor (interpreted to mean poor blacks) for their drain on society's resources. The third was a recent decision of the United States Court of Appeals for the Fifth Circuit, which held that it was lawful for a self-insured employer to limit health benefits for AIDS after an employee was diagnosed with the disease (*McGann v. H & H Music Co.* [1991]). This decision could apply to people in whom genetic tests indicate a high probability of future disease. Against this backdrop, it is worth being reminded of the "abuse of genetics" in the past (Harper 1992), learning that genetic discrimination exists today (Billings et al. 1992), and considering legal protections against such discrimination (Natowicz et al. 1992).

Recognizing the dominant inheritance of Huntington disease (HD), Charles Davenport, Director of the Cold Spring Harbor Biological Laboratory and Eugenics Record Office in the early 1900s, advocated sterilizing "all those in which chronic chorea has already developed" (quoted in Harper 1992). Harper notes that Davenport missed "the most important point on which any population prevention of HD must rest": the disease is transmitted by individuals at risk who have not yet manifested it. In Davenport's time, presymptomatic individuals could not be identified. Today they can. Recombinant DNA technology and mapping of the human genome provide the technological capability of establishing a much more exacting, comprehensive eugenic policy than was possible in Davenport's time. Although this seems unlikely, especially as the constitutionality of abortion is in grave danger of being overturned, we should remember that the Supreme Court decision upholding the constitutionality of the Virginia sterilization law (*Buck v. Bell* [1927]) has not been overturned and that laws permitting involuntary sterilization are still on the books in a few states (Reilly 1991).

David Duke's campaign is a reminder of the appeal of using scapegoats in times of economic crisis. The poor, the unpopular, and those perceived as disabled have long been the targets of eugenic policies (Ludmerer 1972; Kevles 1985). ("No eugenicist has publicly proposed sterilization as a remedy for defective kingship," Lancelot Hogben wrote in 1938, referring to hemophilia in the royal houses of Europe [Hogben 1938].)

In the absence of low-cost "cures" for those born with disease-causing or susceptibility-conferring genotypes, avoiding the conception of an infant at risk for a genetic disease—or avoiding the birth of a fetus prenatally diagnosed as having one—will often be less expensive than clinical management. Our understanding of most diseases has not progressed to the point at which cures are abundant. In the absence of such cures, third-party payers will be reluctant to insure those at risk for developing potentially costly disorders. In this issue of the *Journal* Billings et al. report 41 incidents of possible discrimination because of genotype, not phenotype. Thirty-two of the incidents involve insurance. Although this number constitutes a very small proportion of all of those known to be at risk for genetic disease, it does not represent such a

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small proportion of the companies that currently sell insurance in the United States. Unfortunately, no data are presented on how many companies were involved. Billings et al. present one case in which a health maintenance organization considered withdrawing coverage of a woman's pregnancy and her future child's pediatric care after prenatal diagnosis revealed a fetus with cystic fibrosis. Although we may not soon reach the stage of compulsory eugenics legislation, denying health care coverage because of genotype could exert pressure on at-risk families to avoid having children with disabilities, despite the families' wishes.

Seven of the incidents reported by Billings et al. involved discrimination in employment. In some of the cases, this discrimination was tied to securing health care benefits. If employers are required to pay for the health care of employees and their families, as some pending legislation proposes, they will have greater impetus to deny employment—or health coverage—to workers who have (or whose dependents have) an increased chance of incurring high health care expenses (Rothstein 1989). Genetic testing is one way of accomplishing such exclusion.

Natowicz et al. point out that the Americans with Disabilities Act (ADA), passed in 1990, does not explicitly prohibit genetic testing or discrimination by employers. Yet, by concluding that "genetic discrimination in employment is already covered adequately by the ADA, the Rehabilitation Act, and similar state laws," they give a misleading impression of the protection provided by the ADA. According to the Equal Employment Opportunity Commission (EEOC), the agency charged with enforcing the ADA, an individual is not covered under the law until he or she is symptomatic (Blumenthal 1991). Consequently, presymptomatic individuals with late-onset disorders, such as HD and adult polycystic kidney disease, are not covered. Carriers of recessive disorders, such as cystic fibrosis, and carriers of X-linked disorders, such as DMD, are not covered and could be denied employment. The EEOC also has specifically rejected efforts by the National Institutes of Health–Department of Energy Joint Working Group on Ethical, Legal and Social Issues to interpret the ADA as prohibiting genetic discrimination and as proscribing mandatory genetic testing at employees' preplacement examinations (Juengst 1991).

The limitations of the ADA, combined with a lack of federal regulation of employee health benefits programs, raise the real possibility of genetic discrimination in employment and health benefits. Five of the six states that have enacted laws prohibiting genetic discrimination limit them to carriers of a few disorders. A more comprehensive bill to prohibit discrimination in employment and insurance was vetoed by California Governor Pete Wilson in 1991, as Natowicz et al. point out.

Both Billings et al. and Natowicz et al. call for drastic reform of health care to overcome genetic discrimination. A universal entitlement to health care could eliminate the potential for denying (whether for genetic or other reasons) people and their children access to health care. The danger exists, however, that a national insurance program could exert pressure on people to take a certain course of action, such as avoiding the birth of potentially disabled offspring. That this could happen is consistent with Harper's claim that there is a conflict between public health and individual rights. The validity of the claim depends on the goals of public health. The public's health would be better served by assuring access to care for everyone, rather than by compelling the relatively small number of people who would choose to have children with serious disabilities not to do so. The transmission of genetic diseases cannot be compared to that of infectious disease, which can devastate large segments of the population in a few months or years.

The past history of eugenics and the current evidence of genetic discrimination emphasize the importance of increasing professional and lay educational programs in genetics, assuring patient autonomy through nondirective counseling, and protecting the confidentiality of genetic information. New laws may be needed to protect reproductive decision making, regulate access to genetic data banks, and prohibit genetic discrimination. The threat of eugenics and genetic discrimination comes not only from meddlesome social commentators and political demagogues but from the increasing economic pressures on our employment system that remains largely responsible for access to private health insurance and health care.

References

Billings PR, Kohn MA, de Cuevas M, Beckwith J, Alper JS, Natowicz MR (1992) Discrimination as a consequence of genetic testing. Am J Hum Genet 50:476–482

Blumenthal R (1991) Letter from Acting Director of Communications and Legislative Affairs, EEOC, to Representative Bob Wise, Chairman, House Subcommittee on Government Information, Justice and Agriculture, Washington, DC, November 22

Buck v. Bell, 274, U.S. Supreme Court 200 (1927)

Harper PS (1992) Huntington's disease and the abuse of genetics. Am J Hum Genet 50:460–464

Hogben L (1938) Science for the citizen. Alfred A Knopf, New York

Juengst E (1991) Priorities in professional ethics and social policy for human genetics. JAMA 266:1835

Kevles DJ (1985) In the name of eugenics: genetics and the uses of human heredity. Alfred A Knopf, New York

Ludmerer KM (1972) Genetics and American society: a historical appraisal. The Johns Hopkins University Press, Baltimore

McGann v. H & H Music Company, 946 F2d 401 (5th Cir, 1991)

Natowicz MR, Alper JK, Alper JS (1992) Genetic discrimination and the law. Am J Hum Genet 50:465–475

Reilly PR (1991) The surgical solution: a history of involuntary sterilization in the United States. The Johns Hopkins University Press, Baltimore

Rothstein MA (1989) Medical screening and the employee health cost crisis. BNA, Washington DC

Seligmann J, Foote D (1991) Whose baby is it, anyway? *Newsweek,* October 28, p 73