The Human Genome Project

The proposed benefits for society of the Human Genome Project (HGP) include the identification, treatment, and eradication of certain diseases, and cleaner and more efficient manufacturing processes (Human Genome Project Information, 2003), and human motivational traits (Brock, 1994). While no one would disagree with such benefits, there is a growing body of literature, based on the impact of the HGP, which debates the use of information gained through genetic testing. The identification of genes or disease locations could lead to a reductionism approach to complex behaviors including those of specific concern to our field. If society believes that inappropriate employee behavior can be reduced to genetic causes, the ways individuals are selected, trained or evaluated could radically change.

Genetic Discrimination

Asch (1996) states that, “people who carry genes for disabilities or illnesses, and people who themselves are affected by those
conditions, are likely to experience employment problems that the civil-rights laws are not designed to solve” (p. 159). Other authors (Gostin, 1991; Hubbard & Henifin, 1985; Natowicz, Alper & Alper, 1992; Nelkin & Lindee, 1995; Nelkin & Tancredi, 1994) have also become increasingly concerned that advances in genetic testing techniques will lead to discriminatory employment practices despite legislation such as the Americans with Disabilities Act of 1990, and state-specific legislation. This concern has recently led the Senate to pass the Genetic Non-Discrimination Bill. The legislation bars insurance companies from denying coverage or raising premiums and prevents employers from making employment decisions based on an individual’s genetic information. House action is unclear at this point, so it is unknown whether this bill will ever become law.

To understand how genetic discrimination could occur, one must consider the two different forms of genetic testing currently in use. Genetic monitoring, involves testing specific current employees for genetic changes that occur as a result of workplace exposure to chemicals or radiation. Monitoring is designed to find actual harm (Diamond, 1983). In genetic screening, individuals, regardless of job, are tested to identify any existing aberrations from the normal human genotype. Diamond (1983) described this as the “ascertainment of susceptibility to future harm” (p. 232). In genetic monitoring, organizations may have an obligation under the Occupational Safety and Health Administration (OSHA) to conduct such monitoring to provide a safe work environment. Through genetic screening, the organization receives information which may not be job-related, but which could lead to higher insurance costs. This information, even with limited dissemination, could lead to subtle discrimination. That is, an individual diagnosed with a condition may find that they are excluded from important work or career-related information or opportunities. The individual would not be told that their condition was precluding advancement or training. Slowly the person would be put at a competitive disadvantage.

A recent article in the Wall Street Journal (Lublin, 2004)
indicated that job applicants were not disclosing chronic illnesses because they believed that they would be screened out of a job because the employer would perceive higher costs associated with such a hire. These applicants believed that the employer would find other “reasons” to not hire them. This type of dynamic could occur for those with genetic markers. This is of increasing concern. According to the American Civil Liberties Union, genetic testing in workplaces is on the rise. In 1982, the results of a federal government survey reported that 1.6% of companies responding were using genetic testing for employment purposes. In a similar survey conducted by the American Management Association in 1997, 6–10% of employers were found to be conducting genetic testing (American Civil Liberties Union, 2000).

The passage of the National Sickle Cell Anemia Control Act of 1972 provides an example of how genetic screening can be misused. Sickle Cell Anemia is a genetically transmitted disease. It primarily affects those of African descent; however, there are other groups that are also affected, e.g., Arabs, Greeks, Italians, Latin Americans, and those from India (Sickle Cell Information Center, 2003). An individual possessing two sickle cell genes, or one from each parent, has Sickle-Cell Anemia (SCA) which can lead to health problems and a shorter life span. An individual who has only one sickle cell gene is labeled as having Sickle-Cell Trait (SCT). These individuals do not have the disease and do not exhibit clinical symptoms (Hubbard & Henfin, 1985). According to Reilly (1978), the original intent of the National Sickle Cell Anemia Control Act of 1972 was to both authorize funding for genetic services to assist individuals in making childbearing decisions (rather than to provide treatment) and to provide guidelines to specifically reduce stigmatization. However, despite this, a number of negative outcomes occurred, some related to employment.

Suzuki and Knudtson (1989) point out that there have been cases where employees have been screened for SCT even though there is no “reliable evidence that blacks diagnosed with sickle-cell trait are more likely to suffer under hazardous
work conditions than those without the trait” (p. 162). For example, black employees at the Lawrence Berkeley Laboratory had preemployment sickle cell testing. The United States Court of Appeals, Ninth Circuit decided on February 3, 1998 that the Laboratory had violated these employees rights under Title VII of the Civil Rights Act by singling them out for non-consensual testing on which their employment was contingent (Washington State Department of Health, 2003). Originally, the employees claimed violation under the ADA. They stated that the company was conducting tests that were neither job-related nor necessary for business. However, their claim was denied on those grounds.

The case of the U.S. Air Force Academy is another example of the misuse of genetic screening with SCT. The Academy prevented blacks with SCT from attending flight school for more than ten years (Suzuki & Knudtson, 1989). The belief was that the presence of even one copy of the gene could lead to problems with low-oxygen conditions such as those experienced at high altitudes. In 1981, after legal action and no evidence that supported the Academy’s concerns, the policy was changed (Suzuki & Knudtson, 1989). According to the authors, private employers continue to screen for SCT and apply this test only to one protected population despite evidence that other groups possess it. The last example of the inappropriate use of genetic screening, not involving SCT, is the case involving the Burlington Northern Santa Fe Corporation (Porter, 2001).

It is interesting to note that the insurance industry, which faces many similar issues concerning the use of genetic mapping/testing, has made some progress in this area. For example, the Health Insurance Portability and Accountability Act of 1996 (HIPAA) prohibits a group health insurance plan from using genetic information to establish rules for eligibility or continued eligibility and goes on to stipulate that genetic information shall not be treated as a pre-existing condition in the absence of a diagnosis of the disease (Greengard, 1997). However, HIPAA does nothing to prohibit an insurer from raising rates or excluding all coverage for a particular condition.
Public policy is vague in determining whether genetic discrimination should be treated under the laws that address mistreatment of certain groups. Executive Order 13145, signed by President Clinton on February 8, 2000, prohibits discrimination in federal employment based on genetic information. This order defines such discrimination as well as defines how genetic information shall be treated (e.g., confidentiality and disclosure standards) in the federal government. At least twenty-four states have adopted similar legislation for state government employees (Miller, 2000). Some previous court rulings have stated that individuals with genetic imperfections are not protected under the ADA, the most likely legal option. Therefore, it appears that genetic discrimination differs from other forms of disability discrimination and must be treated as such by future research. This is challenging especially because the genetic problem may not be readily visible. Additionally, genetic testing may impact employee experiences through self-stigmatization and not just the adverse impact of discrimination.

REFERENCES


