3

Genetic Commerce: The Challenges for Human Resource Management*

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Purpose of this Chapter

The American Civil Liberties Union reports that genetic testing in the workplace is on the rise. Genetic testing is the ability to determine the presence of a genetic marker for a specific disease or condition. In 1982, a federal government survey reported that 1.6% of responding companies were using genetic testing. In a 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). With the completion of the Human Genome Project (HGP), scientists have the ability to define individual genetic composition. In turn, other scientists are now working on new ways to test for genetic conditions that may indicate individual predisposition to known diseases such as cancer. While this research is noble in its cause, it could have a negative impact on society in terms of how this information is (mis)used. Organizations, in particular, must be cautious in their use of genetic testing for current or potential employees.

There are two main uses of genetic testing for organizations: screening and monitoring. Genetic screening is used in the selection process to determine if a potential employee is genetically fit for employment. Diamond (1983) described this as the "ascertainment of susceptibility to future harm" (p. 232). Genetic monitoring is used to examine if the organization's current workforce may have a certain genetic predisposition that may inhibit their ability to perform a specific job (e.g., hazardous work environment). Monitoring is designed to find actual harm (Diamond, 1983). These applications of genetic testing will be discussed throughout this chapter. In particular, we will examine the ethical, political, strategic, and practical concerns for human resource

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management (HRM) responsibilities within organizations as they pertain to the various forms of genetic testing. A prescription for how HR professionals will need to address these concerns is also proposed.

The Challenges for Human Resource Management

Ethical

HR managers may become the boundary spanners between society and the organization in terms of the ethical treatment of employees with regards to genetic testing. Organizations will no doubt consider using the information collected through genetic testing for the purposes of employee recruitment, promotion, and retention. Organizations generally use testing of many types to protect their human capital and their investment in that capital. Potential employees may be tested as part of the screening process, or even for internal promotions or retention if specific job environments change. Therefore, it is natural to assume that organizations might consider genetic testing as a new protocol as genetic tests validity increases.

As previously mentioned, organizations have two primary uses for genetic testing: screening and monitoring. However, unlike many currently used personnel tests, individuals may argue as to the timeliness of genetic testing for organizational purposes. For example, if the testing results merely indicate the presence of a genetic marker for a disease, but the disease itself has not occurred, there is an issue as to how the organization might use this information. The case of Huntington's disease (Huntington's) illustrates our point. Huntington's is a degenerative condition of the central nervous system that usually develops at around age 30 or 40. Affected individuals become severely debilitated and require extensive assistance until an often premature death. Should an organization make an employment decision based on this knowledge? There is no guarantee that any employee will remain employed or healthy over time. In addition, through genetic testing, an individual may be identified as a carrier for a particular condition. Just because an individual might be a carrier for the disease (only has one of the necessary two genes), does not indicate that the affected individual will develop the disease. Therefore, if a current or potential employee tests positively as a carrier, the organization might now consider the new increased insurance liability they may take on; however, while this individual will not develop the disease, his or her children might. The ethical issue arises because this could be an area where these individuals may be discriminated against. Is the risk of future cost (e.g., an employee's child manifesting the disease) warranting the exclusion of a healthy individual? In such a case it is not unreasonable to suggest that some organizations would exclude

the individual for other "stated" reasons. In fact, 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.

Of additional concern here, is whether an organization's practice of genetic testing may be subject to tests of adverse impact. Human resource professionals will have to determine whether a program of genetic testing (un)intentionally discriminates against individuals of protected groups with certain genetic imperfections. Genetic markers may have ethnic group links.

HR managers will also have to determine if the genetic testing is truly job related; a very subjective area. It may be relatively clear cut if an organization is trying to determine whether an individual may have a predisposition to developing a problem in a potentially hazardous environment. For example, in *Echazabal v. Chevron* (reported in Little & Makee, 2002–2003), Echazabal was denied employment because he had hepatitis C. The job he wanted could have worsened his condition. The Supreme Court in a 9-0 ruling said, "by hiring employees whom they know will be injured by the job, employers could be complicit in injury" (p. 302). Although this case was not related to genetic makeup per se, it suggests that employers may increasingly avail themselves of genetic (medical testing) technology to reduce risk exposure.

However, this issue becomes less clear when genetic testing may be used to screen for psychological or behavioral traits, which genetic tests may reveal. For example, Brock (1994) states, "the Human Genome Project [this has mapped the human genome structure] will eventually enable us to understand human motivational and character traits as having important genetic determinants" (p. 26). Such identification of genes or disease locations could lead to a reductionism approach. If society believes that inappropriate employee behavior can be reduced to genetic causes, the ways individuals are selected, trained, or evaluated could radically change without input from those in our field.

Based on the above discussion, do employees have a right to refuse to provide genetic information or submit to this testing? As discussed in the next section of this chapter, it is still unclear where the legal environment stands on this issue, but many potential or current employees are likely to refuse to provide this information unless a clear connection to their jobs and possibly a rationale for its intended use and protection are provided. There seems to be a trend on the part of employees to be cautious in sharing health information with their employers either due to fear of future opportunities or possible rising employer health care costs. The Health Insurance Portability and Accountability Act of 1996 (HIPAA) addresses some issues of privacy regarding health care information, the details are discussed in the next section.

However, employers can still require genetic testing; the dilemma surrounds both how to use that information and who should have access to it. For example, if employers request employees' genetic information does the employer have the appropriate means to correctly interpret the findings? Genetic test results are likely to be relatively complex in their findings, and organizations will need to ensure that their human resource staff has the capabilities to draw the appropriate conclusions as they are relevant to that organization. Also, not all individuals may want to know whether they may be genetically predisposed for a disease. Therefore, HR professionals will have to develop protocols for both disseminating this information within the organization and to the individual employee tested. At some point in time legislation may also detail the appropriate use of such information within the workplace.

Does the level of privacy of genetic test results depend on the impact this individual has on the organization? For example, if an organization is negotiating a large executive compensation package for a new member of top management, is knowledge of their genetic information more critical than for a lower-level employee? While organizational policies are supposed to be equally applied throughout the organization, there is some evidence that one's organizational level can impact policy application. Stone and Colella (1996) suggest that when employees suffer from disabilities beyond their control, supervisors may act leniently toward them (p. 363); however, would a person in an executive position receive such deferential treatment? Human Resource practitioners will need to address this issue to mitigate any potentially discriminatory practices in relation to which employees are tested and how the information is used across the organization.

The issue of whether employer insurance will bear the costs of genetic testing for individual use is likely to be the responsibility of employee benefits managers. If employers use these tests as part of an occupational safety (e.g., monitoring) or recruitment (e.g., screening) program, the organization must bear all costs. However, individuals may want to have their own genetic tests conducted for their own use as part of their own health care coverage. Gibons (2004) indicates that health plan managers need more information about genetic services. Similarly, Human Resource Managers also need such information in order to consider negotiating such benefits. This already is an issue with regard to whether insurance policies cover genetic testing of unborn children. Therefore, human resource professionals will have to assess not only whether to provide coverage for these tests, but also at what cost to employees. Also, can organization mandate genetic counseling or genetic testing of (unborn) children or spouses in an effort to minimize health care costs? Although this seems somewhat farfetched, one should recall that in the 1950s and 1960s candidates for high-level executive positions often had their wives subjected to "screening" for appropriateness.

Political

Asch (1996) states , "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 (Hubbard & Henifin, 1985; Gostin, 1991; Natowicz et al., 1992; Nelkin & Tancredi, 1994; Nelkin & Lindee, 1995) 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 (ADA) and state-specific legislation. Human Resource professionals need to be concerned with the relevant legislation and case law surrounding genetic testing to know what recourse their (potential) employees may have if they feel discriminated against based on the test results and develop employment practices to minimize this risk. There is likely a new legislation to address how genetic testing information can be used and how to disseminate, however, neither legislation nor case law has yet to address these problems. Below is a discussion of the existing legislation and case law that illustrate the issues of concern for Human Resource professionals in this area.

The Legislation

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 24 states have adopted similar legislation for state government employees (Miller, 2000). The Genetic Non-Discrimination bill passed in the Senate and under review by the House of Representatives is the first attempt to clarify these issues and provide protection in this area in the private sector. These laws are clearly meant to protect individuals against discrimination based on their genetic information, however, much of the case law argues protection under the ADA.

The ADA was established to prohibit discrimination against qualified individuals with a disability, those with a record of a disability and those perceived as having a disability. For example, employers must provide reasonable accommodation of the workplace to make their ability to work a smooth process (e.g., a magnifying glass on a computer monitor, accessibility to the building). Employers must also offer benefits to disabled workers on the same basis as those offered to able-bodied employees. Because this law is relatively new, it has been subject to much interpretation in the court system. Its use to support an individual's discrimination claim (based on genetic information) has begun to be tested and is discussed in more detail below. Although individuals

have sued their employers with claims of discrimination based on a genetic disability using the ADA, the courts not granted these individuals protection under this law. The existing case law is discussed in the next section.

Organizations are also responsible for adhering to both the federal Occupational Safety and Health Administration (OSHA) and comparable state agency guidelines that require organizations to provide a safe working environment. This may mean through genetic screening or monitoring as the situation dictates. As new genetic tests are developed, HR managers will need to monitor the development of protocols for using these tests in their industries.

The last relevant piece of legislation that HR managers need to understand is the HIPAA prohibits group health insurance plans from using genetic information to establish rules for eligibility or continued eligibility. HIPAA also states 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. It is interesting to note that both OSHA and HIPAA may drive the future of how genetic testing may be used and its results disseminated, unless new legislation is passed specifically for genetic testing. Currently OSHA (and its state counterparts) has protocols in place for when genetic testing (most often monitoring) is conducted for certain jobs that may expose affected individuals to higher predispositions to various conditions. HIPAA also handles confidentiality of medical information, which genetic test results are likely to be considered.

Case Law

There are several examples of how individuals are beginning to file discrimination claims on the basis of genetic makeup. Although individuals with genetic defects are not a protected class under the Title VII of the Civil Rights Act of 1964, they may receive protection through legal action. The following examples illustrate how cases involving genetic screening have been argued and decided.

In a case examining the use of genetic testing for employee screening, the Burlington Northern Santa Fe Corporation (Porter, 2001) was found to have illegally tested employees for genetic defects. In an interim settlement reached with the Equal Employment Opportunity Commission through mediation, the company agreed to pay $2.2 million to 36 workers. The company, which was found in violation of the ADA (United States Equal Employment Opportunity Commission, 1999), took blood samples from employees to ascertain whether they were genetically predisposed to carpal tunnel syndrome. The company did not use the information to move workers to different jobs. However, the violation was related to gathering of DNA information because the employees had not given consent.

The National Sickle Cell Anemia (SCA) Control Act of 1972 provides another example of genetic screening misuse. SCA is a genetically transmitted disease. It primarily affects those of African descent; however, there are other groups that can also be affected, for example Arabs, Greeks, Italians, Latin Americans, and those from India (Sickle Cell Information Center, 2003). An individual possessing two sickle cell genes has SCA. A person with SCA experiences episodes of severe pain, develops organ damage related to circulation problems, and generally has a shorter life span. An individual who has 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 & Henifin, 1985). The original intent of the National SCA 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 (Reilly, 1978). However, despite this, a number of negative outcomes occurred, some related to employment. The U.S. Air Force Academy prevented blacks with SCT from attending flight school for more than 10 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).

More recently, black employees at the Lawrence Berkeley Laboratory had pre-employment 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. However, their claim was denied on those grounds.

Public policy is vague in determining whether genetic discrimination should be treated under current laws that address discrimination. Some court rulings have stated that individuals with genetic imperfections are not protected under the ADA, the most likely legal option. It appears that genetic discrimination differs from other forms of disability discrimination. This is challenging because the genetic problem may not be readily visible or immediate. Therefore, human resource professionals need to be proactive in handling this information in an impartial and professional manner. Recommendations are detailed in the last section of this chapter.

Strategic

These cases and existing legislation illustrate the conundrum organizations face in deciding whether to determine the genetic risks of their employees as

well as what potential actions to take based on this information. There are no clear legal guidelines for either gathering genetic information or what human resource actions are appropriate. Diamond (1983) states, "caution must be taken that genetic testing does not become a form of discrimination disguised as science" (p. 242). While it is clear that all organizations must adopt an approach toward genetic testing, the extent and nature of this protocol is likely to vary by the industry, role of human capital, and accompanying approach to risk management.

The need for genetic testing is going to vary between organizations both within and among industries. For example, organizations in a more clearly hazardous work environment (e.g., handling toxic substances) are going to have to employ genetic testing as part of their overall approach to employee safety and as mandated by governmental safety organizations. However, as many organizations are increasing their reliance on human capital, this role of genetic testing becomes less clear. Some organizations may choose to employ genetic screening to not only test for genetic disease but also personality "defects." Human resource professionals will have to determine the role of genetic testing in their overall screening procedures.

Conventionally, corporate risk management has centered on conducting a financial assessment of some type of organizational change that may expose a company to increased liability or loss. Examples of such assessment would be a bank assessing the profit/loss probabilities associated with a new service, a manufacturing organization determining if a change in the pricing structure of a product would reduce market share, or an organization considering the costs associated with the closing or relocation of a plant. In spite of this focus, Pyne and McDonald (2001) state that [financial] organizations' "people risk" is the top risk facing enterprises. Erven (2004) further suggests that risk management has not paid sufficient attention to HRM risks. Pyne and McDonald's (2001) report identifies risk areas related to people such as poor decisions, poor leadership, outdated reward strategies, and untrained staff. The issues surrounding genetic testing for organizations touch upon several of these "people" areas. Organizations will have to develop specific protocols for their human resource managers to handle the issues with genetic testing. There will have to be a clear connection between what genetic tests to administer and specific job duties. There will have to be a rationale for using these tests and also specific measure to ensure that all organizational members who may be privy to this information are trained in handling the communication issues that accompany such personal employee information. Specific recommendations for the various functions of HRM are detailed in the next section of this chapter.

There has been some research about the use of genetic information in risk assessment or insurance underwriting (Pokorski, 1997; Peters, 1998; Steinberg,

2000). Pokorski (1997) has made cogent arguments for the use of genetic information in insurance underwriting. Stone (1996) indicates that from the health insurance perspective, adverse selection (people with identified genetic aberrations who know of them will be more likely to seek insurance than those who do not have genetic problems) will occur unless the company itself has access to this medical information. Human resource managers will need to address the use of genetic screening with the employer's insurers. Although the insurance industry has begun thinking about how to use genetic information, human resource managers have yet to address the potential increased exposure to higher insurance costs related to genetic conditions that could necessitate expensive medical treatment.Also, if employers' risks of genetic mutations are because of workplace conditions (e.g., chemical handling), organizations will have to determine the impact on both the employees and the organization's rate of worker's compensation claims, which in turn may influence rates for this type of insurance.

Recommendations

Human resource responsibilities typically include all activities that pertain to the recruitment, development, administration, and retention of human capital for organizations. Increasingly these responsibilities are often tied to each organization's strategic position that will likely guide the development of goals within each HR activity. The organizational strategy will drive the HR strategy both with respect to the industry and competitive direction. For example, if an organization needs to recruit individuals that are resilient to certain hazardous work conditions, they will need to make goals to that effect; genetic screening will likely support that goal. Table 3.1 details the specific HR responsibilities and the accompanying genetic testing considerations that these professionals must address. We outline recommendations for organizations in how their HR professionals might address these considerations. Together these recommendations provide a starting point for HR to establish its own protocol of action for the inclusion or exclusion of genetic testing.

In order for HR to establish a both legally defensible and effective program for incorporating genetic testing into its activities, the following considerations should be taken into account. In order for recruitment and selection procedures to be judged effective, they should be both reliable and valid. If genetic testing works toward this effectiveness, the program will likely be legally defensible as well. For example, if genetic testing is used to confirm a condition that could harm a job candidate if they work in a hazardous environment, and that individual is then screened out of employment, the organization will be able to argue that the genetic test was used both to protect the individual from harm

Table 3.1 Genetic Testing Considerations for HRM

Human resource responsibility	Considerations
Recruitment	Genetic screening Hazardous work environment
Selection	Genetic screening and monitoring
Training and development	Confidentiality Dissemination of test results
Compensation and benefits	Job relatedness Adverse impact Insurance
Labor relations	Treatment specified within collective bargaining agreement

as well as the organization from liability. Caution must be made that the test must be used for all workers applying for these jobs, not just those in certain groups (e.g., Lawrence Berkeley Laboratory case).

To this effect, the protocol for handling any inclusion of genetic testing will need to address how this information will be disseminated as well as communicated to any individuals tested. Individuals within organizations will need to be trained with appropriate procedures for handling this very personal and confidential information. Organizations may even want a third party provider to handle this type of testing to both reduce corporate liability and leave the matter in expert hands. Also, this may help individuals feel that the information will be handled in a more confidential manner; similar to Employee Assistance Plans.

Any program of genetic testing needs to be able to be justified as job related. Therefore, organizations must be able to argue effectively that any employees or job applicants tested are being screened uniformly and for current job specific capabilities. An interesting example that illustrates this importance is the case involving Target Stores. In an effort to improve hiring procedures, Target identified emotional characteristics that are problematic in security guards. On the recommendation of psychological consultants, Target began to administer pre-employment psychological screening tests. Applicants (who were denied employment) sued Target (*Soroka v. Dayton Hudson Corp*., dba Target Stores) on the basis that some questions that dealt with religion and sexual orientation violated their rights to privacy. Although the plaintiffs lost on the grounds of rights to privacy (a third party vendor was used to score the examinations), the court held that questions that violate privacy must be directly and narrowly related to the nature of the employees duties (American Psychological Association, 2005). Also, the program must be tested to ensure that the program of genetic testing does not inadvertently create adverse

impact. The program must not systematically screen certain groups while not screening others, a discriminatory environment.

Insurance is a relatively complicated organizational issue with regards to genetic testing. Organizations must consider how legislation affects their ability to limit coverage for pre-existing genetic conditions as well as their own approach to minimizing their overall insurance liability. This must all be assessed in relation to the various insurance packages offered. For example, does the company not only provide coverage for the employee but also for the employee's family? The issue then arises as to the appropriateness of testing these insured individuals, although they do not directly work for the organization but may increase its insurance costs.

Unions are likely going to drive how genetic testing can be used by organizations, aside from legal constraints. In most unionized workplaces, seniority is used as the means whereby job promotions and rewards are allocated, so testing is not likely to be used for these human resource decisions, however, organizations may want to start screening new employees with these tests as they become available. Just as unions are now increasingly accepted a two-tier wage structure, they may be forced to accept a two-tier benefit/screening structure, especially if the organization can argue for its use to limit insurance liability and overall benefit costs. The use of genetic testing is likely to become a new bargaining issue.

Conclusion

While genetic testing may not impact many Human Resource Managers in the immediate future, as the technology develops, individuals not trained in the sciences will be confronted with complicated technical data. The ethical code of the Society for Human Resource management (SHRM, 2005) states that we are socially responsible. This suggests that we, as HR professionals, consider genetic testing in a larger social framework. The ethical, political, strategic, and practical issues discussed in this chapter and the accompanying recommendations proposed provide a clear rationale that the issues surrounding genetic testing will become something all HR professionals must address.

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